

Stigma-AIDS

**Summary of electronic discussion forum on
stigma and HIV/AIDS in Africa
February – June 2001**

Background Document
Consultation on Stigma and HIV/AIDS in Africa:
Setting the operational research agenda

4 - 6 June 2001
Dar-es-Salaam
Tanzania



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Introduction

In March 2001, Health & Development Networks (HDN), in collaboration with the UNAIDS Inter-country Team for Eastern and Southern Africa, launched a new e-mail discussion forum focusing on stigma and HIV/AIDS in Africa – “Stigma-AIDS.” This forum was conceived as part of a strategy intended to facilitate the development of an African operational research agenda on stigma. Other elements in this strategy included group and key informant interviews in Botswana, South Africa and Tanzania and the development of a review paper on stigma-related issues and responses in the African region, based on the e-mail forum and the interviews.

The Stigma-AIDS forum was set up as a time-limited, moderated and structured e-mail discussion, with a membership of 1200. As a result of targeted advertising and sustained efforts to identify appropriate members, 85-90% of members come from the African region.

This document attempts to summarise the main points outlined in the 150 substantial contributions received on the e-mail forum. Each discussion theme is summarised separately. It was developed as a background document to inform and feed into the consultation meeting “Stigma and HIV/AIDS in Africa: Setting the operational research agenda, 4-6 June 2001, Dar-es-Salaam, Tanzania.

The full discussion is archived at:

<http://www.hdnet.org>

"AIDS-related stigma is one of the key obstacles in accessing care for persons and families affected by this pandemic. Many people who are infected do not know their status either due to lack of facilities, lack of appropriate information or due to fear of stigma. That AIDS related stigma continues on our continent is a big shame!"

- Noerine Kaleeba, Keynote Address

Stigma-AIDS e-mail discussion forum

Underpinning the debate on the Stigma-AIDS forum, were four ideas that represent the major axes of discussion that have taken place on forum:

- ▶ Establishing a concise definition of stigma;
- ▶ Exploring the contexts within which stigma arises and is experienced most acutely;
- ▶ Identifying strategies to facilitate the reduction of stigma at the individual and the societal levels, within all of the contexts identified; and
- ▶ Developing a social research agenda to address clear questions about the causes and effects of stigma.

Based on the preliminary literature review, focus group discussions and key informant interviews, a discussion framework was developed according to clearly defined themes. A schedule was drawn up for each theme and a key resource person was invited to launch each new discussion theme. A new theme was introduced every week. The moderation team introduced each new theme with a set of clearly designed questions, aimed to guide and focus the discussion. The themes identified were:

- ▶ Define stigma and theoretical context for stigma
- ▶ Stigma and health care providers
- ▶ Stigma and the religious sector
- ▶ Stigma and the media
- ▶ Stigma and politicians
- ▶ Stigma and people living with HIV/AIDS
- ▶ Stigma and discrimination
- ▶ Operational research methodological issues

Contributions came from many countries including Burundi, Cameroon, Ethiopia, Eritrea, South Africa, Swaziland, Botswana, Zimbabwe, Zambia, Tanzania, Ethiopia, Uganda, Malawi, Lesotho, India, Taiwan and some from Europe and the US. The quality of input into the forum has been among the highest ever seen on an e-mail discussion forum related to HIV/AIDS. This discussion was remarkable not only because of the scope of issues that arose, but also because of the depth and intensity of the exchange of ideas, both on theoretical and practical levels.

This e-mail discussion forum engaged many key stakeholders from diverse sectors such as the health care sector, including doctors, nurses, counsellors, traditional healers, people living with HIV/AIDS, the media sector, the religious sector and academic organisations from within the region. The forum has succeeded in raising awareness and education of the importance of stigma as a barrier to HIV/AIDS prevention and care.

The interactive, carefully planned and well researched approach to facilitating discussion has engaged people and challenged their thinking. The list has proven a critical tool in the development of a research agenda on the complex issue of stigma associated with HIV/AIDS. In and of itself, facilitating open discussion in this way is an intervention – the challenge is how to measure the impact and modify the approach accordingly.

It cannot be denied that an e-mail forum such as this one faces fundamental limitations. Most obviously, this list is restricted to those contributors who are able to access computers and able to communicate effectively in English. In addition, information overload is a problem. However, despite such limitations, this email list has created a unique electronic space in which diverse voices have shared experiences and points of view. It has facilitated a high-quality, action-oriented debate on stigma and HIV/AIDS. A formal evaluation of the forum was conducted during June and July 2001 and will be available on the HDN website <http://www.hdnet.org>

Keynote Address: stigma and HIV/AIDS in Africa

Launch of Stigma-AIDS, the e-mail discussion forum for HIV/AIDS-related stigma in Africa

Noerine Kaleeba PhD H.L (Hon. Causa) Keynote Address - 27 March 2001

The issue of HIV/AIDS-related stigma is one of the key obstacles in accessing care for people and families affected by this pandemic. Many people who are infected do not know their status either due to lack of facilities, lack of appropriate information or due to fear of stigma. Stigma is preventing people from seeking early care for TB and other opportunistic infections, seeking counselling and testing services, accessing and receiving good quality care and also preventing people from adhering to treatments where they are available such as mother-to-child transmission. These examples, and there are many more, mean that unless we address HIV/AIDS-related stigma, we cannot hope to succeed in our efforts.

During the 1st Regional Conference on Community Home Based Care in Botswana two weeks ago, I heard some disturbing views about people living with HIV. These are the views that we must keep in mind and challenge when we are talking about combating stigma.

Findings from a study involving 731 people in 70 focus groups in Chobe District Northern Botswana in 1999, reported the attitudes that focus group members expressed towards people living with HIV. Many stated that they felt that HIV positive people should be killed in order to stop the spread of HIV. When asked how, or who by, it was suggested that people living with HIV should be burnt or that nurses could kill them. It was also suggested and supported by many people, that HIV positive people should be marked on the body, such as a tattoo under the armpit so that sexual partners could recognise them when they take off their clothes. Some participants felt that people living with HIV should be cared for but in isolation wards in hospitals. This raised many issues: some thought that hospitals were too congested and should not accommodate people living with HIV. Others felt that people living with HIV were not treated well in hospital and had heard that nurses kill patients when their condition becomes hopeless. Nurses were criticised for being rude and uncaring. One old man who tired of the whole discussion said 'the hospitals discovered this thing so let them deal with it'.

Stigma is particularly complex as it operates at many different levels and has both social and psychological aspects. Stigma has been talked about since the beginning of the HIV/AIDS epidemic but has not been adequately investigated in programmes or policies. There are many factors surrounding stigma including denial, shame, blame, fear, rejection and discrimination. So far, much of the attention has focused on the important subject of discrimination using a human rights approach. However, this has ignored the root causes of stigma and failed to inform our understanding of this complex issue.

Stigma in response to illness is not a new issue in some parts of the world. Stigma has long been associated with mental illness, physical disability, leprosy, cancer and TB. However, HIV-related stigma is particularly severe as AIDS is both a life-threatening illness and also firmly linked in people's minds to sexual behaviour. In this respect HIV-related stigma can be traced back to the early discourse on HIV, which served to further reinforce notions about deviant behaviour by focusing firmly on groups, such as sex workers, drug users and gay men.

One of the key elements that determines the level of stigma in a given community is the "Response Wave" sweeping through that community. The community response to the HIV/AIDS pandemic has been described as happening in "Waves", and stigma is one of these waves:

Wave 1: Denial

Wave 2: Fear, stigma, isolation, rejection of those known or suspected to be HIV+;

Wave 3: Awareness leading to knowledge about modes of transmission and personal risk assessment,

leading to family acceptance; ·

Wave 4: Community tolerance, leading to eventual acceptance, leading to community support, solidarity and enhancement of community care.

Many countries in Africa are still riding on the wave of fear, stigma, isolation and rejection while others are moving slowly into the wave of awareness. It is only few, such as Uganda, that have moved into the wave of tolerance, solidarity and acceptance. It is this that we must strive for.

Everyone has a role to play to combat stigma. However there are a few groups that are particularly key to engage. We need to acknowledge that many of us are playing a role in stigmatising people living with HIV, whether it is conscious or unconscious. The response of civil society to HIV/AIDS has so far been individual and more lately a family response. However, it is time to move towards a more social and community response where responsibility is shared because we are all living with HIV, whether we are infected or affected. It is only by working together and taking collective responsibility that we can truly have an impact.

In many societies, the religious sector has reinforced stigma and denial among HIV-positive people based on moralistic judgements about inappropriate behaviour related to sex etc. In some countries, the church is still denying the burial rights of people suspected to have died from HIV. However, once sensitised and engaged, we know that the religious sector plays a key role in prevention, care and support and can contribute significantly to reducing stigma and creating a supportive environment for people affected by HIV/AIDS.

The media have a particular responsibility to provide appropriate messages when reporting on HIV. AIDS reportage has the power to help minimize the epidemic or, to do harm and worsen the problem. We have all seen the sensationalist reporting that victimises HIV-positive people and can even contribute to putting them at risk, not just of stigma but also of violence.

The lack of political will and commitment to do something about HIV is a significant factor in contributing to stigma. If political and social leaders show no concern for HIV then why should their people? By discussing HIV openly, sensitively and rationally, leaders can make people sit up and listen.

Fear of HIV-related stigmatization by care providers, including doctors, counsellors, nurses, home-based carers and traditional healers, combined with fear of stigma from society means that many people living with HIV do not feel able to access care and support services. Why do health care providers stigmatise – is it because of fear of infection or is because of judgmental attitudes?

We should not forget that care providers may be stigmatised themselves for working with HIV positive people or that they may be experiencing stigma of their own because they are HIV positive.

Stigma is a powerful and discrediting social label that radically changes the way individuals view themselves and are viewed as people. Self-stigmatisation after diagnosis is common, positive people may initially feel guilty and apart from the rest of society.

Many initiatives encourage people living with HIV to be publicly open about their HIV status in an attempt to raise awareness and change behaviour. But do we really know that openness and disclosure reduce stigma? These are important questions which will hopefully be addressed by a new research agenda on stigma.

When we speak of openness it is important to recognise that this operates on different levels.

- ▶ The first level is disclosure on an intimate level, disclosing to one's partner and children. This is very important and strategies such as shared confidentiality are vital.

- ▶ The second is disclosure in order to access support or care. This requires some openness but is usually provided in a safe space where others are also HIV positive. Peer support groups are a key strategy in this.
- ▶ The third is public disclosure, where people living with HIV are asked to give their personal testimonies and discuss publicly the impact of HIV on their lives.

We must also acknowledge the impact of HIV-related stigma on the lives of children. We urgently need to work in partnership with schools, churches and families to reduce the stigma that children are experiencing.

There is much work to be done and it is going to require a lot of commitment, energy, patience and a true spirit of working together.

I believe that this e-mail discussion forum will help to begin this collective responsibility to challenge HIV-related stigma in Africa – as one member said so well when asking to join the forum:

“It is always better to light one candle than to curse the darkness.”

This on-line consultation gives us all a space to share our knowledge, experiences and ideas about stigma, to highlight examples of where we have failed in the past and to suggest ways to reduce stigma in the future. It means that our views can be represented in the operational research agenda that will be presented at the Consultation meeting in June. However, this can only happen if you all make a commitment to actively participate.

I wish you good luck with this challenging but exciting task and encourage you all to gain from each other a renewed sense of hope and encouragement.

Noerine Kaleeba

Dicsussion 1: Stigma, definition and context

To guide the first discussion, the following questions were posed to forum members:

- ▶ What does stigma mean to you? – please tell us how you would define stigma?
- ▶ In what contexts and at what levels does stigma occur – please illustrate with examples?

At the most fundamental level, a standard definition of “stigma” must be established to create a common understanding among researchers, programme planners, and individuals regarding the nature of the issue itself. Without this common understanding, the HIV community cannot confront the issue of stigma in an organized, effective manner. Yet establishing a definition of “stigma” is a challenging endeavour. Stigma is not a concrete intellectual idea; rather, it is a complex emotional process. “Stigma” refers to a set of attitudes and beliefs, at individual and societal levels, that are based on contemporary social norms and values, and which result in discrimination, marginalisation, and outright prejudice against individuals and groups in a given society.

Contributors to the Stigma-AIDS list identified both static and dynamic definitions of stigma, both of which will be critical to a larger understanding of the motor and effects of stigma on people living with or affected by HIV/AIDS. The static definition of stigma is the description we find standardised in the Concise Oxford Dictionary:

- a) a mark or sign of disgrace or discredit
- b) a distinguishing mark or characteristic
- c) a visible sign or characteristic of a disease

Yet stigma does not exist in a vacuum; and any such “marks” or “characteristics” can only be distinguished as disgraceful or undesirable within a moral context that society attributes to them. As one contributor noted, “[Stigma] is a brand, a mark on an individual based on something [his or her] society perceives as morally wrong. Stigma occurs on the societal level and affects individuals and communities.”(Shawna Brown)

Because an understanding of social context is inextricable from a meaningful definition of “stigma,” a truly comprehensive definition of the term requires a dynamic, process-oriented definition. This idea was stated clearly by Peter Aggleton and Richard Parker, who noted that “stigma is not a thing but a process [...] of devaluation”:

“Stigma is linked to power and domination in the community as a whole. It plays a key role in producing and reproducing relations of power and control ... Ultimately stigma creates and is reinforced by social inequality...[and] reinforces social exclusion”.

Such an understanding of stigma enlarges its definition to include the social contexts in which stigma occurs. In all cases, these contexts originate with the individual members of society who create and perpetuate these conditions. As one contributor noted, stigma is ubiquitous in nature. It is not “a set of occasional occurrences,” but rather, the perpetuation of stigma in society includes “nearly all of us for at least some of the time.” (Ken Richards-Down, Tanzania)

Once we accept our own individual roles in perpetuating stigma, we can more easily recognize the contexts upon which stigma is based. Contributors identified a number of levels upon which stigma operates and from which stigma derives its meaning. Some of these contexts were at the micro- or individual level; others function on the macro- or societal level and all stigma occurs within a historical context.

Macro-level environmental contexts. Individual and community behaviours can never be separated from the macro-level environments in which they operate. The institutional, social, and

political mores of a given society dictate community-level responses to almost all social phenomena. For instance, contributors to Stigma-AIDS noted that in countries that have made national political commitments to fighting HIV, such as Uganda, individuals with HIV are much less stigmatised than individuals with HIV in countries that continue to deny the importance of the HIV epidemic within their borders.

Micro-level environmental contexts. No environment is free from manifestations of stigma. The family, the workplace, the medical/health care setting, and interpersonal relationships all provide fertile ground for the perpetuation and reinforcement of stigma. If HIV is the “strongly felt mark given to a person that makes him or her feel different than others,” then these environments provide the context within which that mark is given meaning. (Eric van Praag, US) The medical/health care setting is a particularly important context in this respect, because health care workers are held in high esteem by the community. Doctors, nurses, and community health workers serve as community role models, especially with respect to the social inclusion or exclusion of people affected by disease. If health care workers treat people living with HIV poorly, the community will follow their lead.

Historical contexts. Traditional gender roles, concepts of ethnicity and race, sexual identities, and socio-economic class all exert influence upon the meanings of stigma for different individuals. With respect to HIV, traditional power relations and means of control that are grounded in fabricated concepts of social superiority have resulted in the further subjugation of traditionally oppressed peoples, including people of colour, gays and lesbians, women, and the physically disabled.

Within these diverse contexts, how can we create strategies to facilitate the reduction of stigma? Contributors to the Stigma-AIDS identified the roots of stigma, and suggested strategies to dispel – or, at least, dilute – the effects of stigma upon all of these levels of interaction.

The most commonly cited root cause of stigma was ignorance about HIV/AIDS at the individual level, coupled with the lack of sufficient information disseminated at the societal level. Many contributors also identified the lack of treatment for HIV as the single most stigmatising aspect of the disease, and this second reason seems to function as a corollary of the first. Ignorance regarding HIV transmission and prevention information renders people fearful of anyone who has already contracted the virus, which is seen as a debilitating, deadly disease that has no cure. These fears then provide a basis for the growth of ignorance, which pervades all contexts, from the political sphere, to the family environment, to the health care setting.

Contributors also cited the association of HIV with perceived immoral behaviours as a root cause of stigma. Social mores which label sex as an immoral behaviour, and the subsequent labeling of “high” and “low” risk groups of people based upon social values, has created an extremely stigmatizing environment for the newly infected. “Good” people (i.e., low-risk groups) were infected with HIV by blood transfusions; “bad” people (i.e., high-risk groups) were infected through unprotected sexual intercourse or through injecting drug use. An underlying premise for this idea itself is that the “bad” people are responsible for the infections of the “good” people, and should be blamed for the spread of HIV in society. Thus, even the route through which someone is infected with HIV provides basis for stigma. There is even such a thing as “courtesy stigma:” stigma cloaked in love and pity for someone who is HIV-positive and viewed as a victim, such as AIDS orphans.

Finally, people living with HIV “remind us about our own vulnerability.” (Florence Mhonie, Botswana) This vulnerability translates into fear of HIV throughout society and forms a fourth root cause of stigma. The members of a positive person’s family may feel vulnerable to the disease just as the health workers who treat positive patients feel vulnerable when they confront HIV in their clinics or wards. This sense of vulnerability is based upon our sense of mortality, but more fundamentally, it is rooted in ignorance.

Clearly, stigma can only be reduced by fighting the pervasive misinformed beliefs upon which it is based. However, fighting strongly held beliefs and ignorance is not an easy proposition. Individual perceptions must be changed in order to affect stigma in society as a whole. Yet, at the same time, society must also affect individuals' perceptions of stigma before they can change their personal prejudices.

Contributors suggested many different methods through which stigma can be dispelled. Prominent members of society must come out in support of HIV testing, and those leaders who are HIV-positive must come out openly in society as people living with HIV/AIDS. Similarly, HIV-positive people who are willing to provide testimonials and talk to others about their status are critical elements in the fight against stigma. At the individual level, their experiences will prove more meaningful than any lesson in the science of HIV.

Home-based care workers should also be supported in their work, as these people play a large role in reducing stigma through their own examples in the homes of the patients they treat. In the same vein, traditional healers should also be used as teachers for the community in support of people living with HIV. Most importantly, health care workers in the medical setting have a crucial role to play in reducing stigma in society at large. As one contributor noted, health workers' "behaviour with patients is keenly watched and used to justify stigma by others, because as professionals, 'they ought to know better.'" (Shalini Bharat, India) Their role in reducing stigma cannot be underestimated.

Further research on the nature, manifestations, and destruction of stigma is critically important. The HIV community must support research at the academic/theoretical level that is practical and grounded in reality, and which can be easily operationalised. The discussion that took place on the Stigma-AIDS list provides only a first step in developing new strategies to combat stigma. Now, the academic community must work in conjunction with NGOs and others to create meaningful research endeavours that serve our needs as activists and scientists alike.

Some research questions that arose from the discussion include the following:

- 1) 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? By exploring this question, we will begin to understand how stigma is overcome on the individual level through acceptance of the reality of living with HIV.
- 2) 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? A number of questions arose throughout the list discussion about "real" vs. "perceived" stigma, but neither phenomenon can be defined without a better understanding of the power dynamics involved in the contexts and behaviours raised previously.
- 3) What have been the most effective educational campaigns to reduce stigma on a societal level? We must better explore national HIV "success stories," so that we may better understand the elements of their policies that have created their success. Rather than simply recognizing the importance of political will in support of HIV as a motor for change, how have countries actually modified the political culture to produce the supportive environment and to actualize pro-HIV policies?
- 4) Now that we have a better understanding of the roots of stigma, how do we attack those roots in a programmatic fashion and actually implement constructive programmes and policies to combat stigma?

All of these questions are only first steps in a much larger process of combating stigma that must be carried out at diverse levels within each society. Throughout all of our work, we must remember that "if stigma and denial is really a functional part of society (functioning to produce and reproduce

relations of power and domination), then we all are working to perpetuate it, unless we are very consciously working to undo it." (Lucy Slater).

Indeed, every sector has a role to play in the fight against stigma and HIV. The scientific community must research and develop effective, affordable vaccines and drugs to treat AIDS. The social research community must help us to better define our challenges, and to structure programmes tailored to meet our needs. The NGO community must address stigma while interacting with individuals through community-based efforts. Political leaders must address HIV as a national priority through all ministries of their governments, not only as a health issue. People living with HIV and AIDS should come out openly and provide testimony to positive living in society, with appropriate support. Individuals must accept their roles in perpetuating stigma and work actively to modify their own behaviour in their personal spheres. Only when we effectively address stigma and AIDS in this manner and in all of these contexts can we hope to reduce it.

Discussion 2: Stigma and health care workers

This discussion focused on the following questions:

- ▶ How does stigma manifest itself among health care providers (e.g. doctors, nurses, counsellors, home-based care providers, traditional healers)?
- ▶ What are the reasons for this stigma?
- ▶ Give examples of stigma-reducing interventions in relation to health care providers – either examples of interventions/research currently underway or ideas you may have for interventions or research?

Health care workers fulfill societal roles that place them in uniquely important positions to promote or dissipate AIDS-related stigma. As individuals who have chosen to pursue a path of service to society, health care workers have a special obligation to protect and assist people living with HIV/AIDS. They have a critical role to play in educating the public about AIDS through their own behaviour with their patients.

However, health care workers are also members of the societies in which they live. Thus, like others in their communities, health care workers may accept and promote AIDS-related stigma, either consciously or unconsciously. Indeed, health care workers' tendencies to engender and promote AIDS-related stigma is widespread throughout the African continent and across the world.

These factors rendered the discussion of stigma among health care workers a crucial element in the Stigma-AIDS exchanges. Because of the importance given to health care professionals in society, these individuals must be tapped as sources of positive education in the fight against stigma. To accomplish this goal, we must begin to face the hesitation and fear that exists among all types of health service providers – doctors, nurses, home care providers, and traditional healers alike.

Contributors noted that stigma perpetuated by the health care establishment is especially damaging to the well-being of people living with HIV for two principal reasons. First, because of the special status that society accords to health care workers, societies tend to hold the actions of health care workers to be model behaviours in dealing with the sick. Second, health care workers of all types play important roles in the lives of the ill. An example of this importance is that a doctor or nurse may provide a single critical link between a person newly diagnosed with HIV and the health care system. If that health care professional treats the newly diagnosed patient in a disrespectful manner, the patient may be lost to the system permanently. He or she may be traumatized by this experience at the hands of the health care provider, and subsequently fear further contact with health care workers. Should the patient flee the system entirely, his or her health is likely to decline rapidly.

Why do health care workers promote AIDS-related stigma? If we can discover the sources of health workers' concerns, we will understand the basis upon which interventions can be built to lessen this stigma. Contributors outlined three principal axes upon which this stigma rests:

1. Morality

Health care workers tend to moralize patients' behaviours. One contributor noted that "health care workers tend to be moralistic just like others in the society and blame the patient for the disease." (Bitra George, India) A second contributor explained that health care workers demonstrate:

"a judgmental reaction to what is perceived by many societies as taboos: sex, in the sense of socially disapproved sexual relations, and death [...] two aspects of life many people are often silent about, [and] even more [silent] when these two are linked, as it is felt about HIV/AIDS." (Eric van Praag, US)

These observations are hardly surprising, considering the moralizing behaviours that exist among others in society: religious institutions, the media, and the general public. Yet, while such behaviours by individuals in society are not shocking, they are disappointing. By legitimizing moralistic stances with respect to people living with HIV/AIDS, health care workers deny these patients the proper care they deserve and do an injustice to their calling as service providers.

2. Helplessness in the face of HIV/AIDS

In many cases, the most important element driving health care workers' reactions to people living with AIDS is their sense of clinical helplessness in facing the disease. This helplessness operates on several levels. First, not only are health care workers powerless to cure AIDS, but they are often unable to alleviate the pain of a suffering patient. Second, many health care professionals are not trained to provide the emotional support that HIV patients need in order to maintain an optimistic outlook in the face of an HIV-positive diagnosis.

3. Perceived personal vulnerability

Fear is another critical factor driving health care workers' stigmatizing behaviours. Contributors highlighted two levels upon which fear may operate: 1) fear of infection, and 2) fear of discovering one's own serostatus.

Health care workers' fears of infection are often founded. Shalini Bharat, (India) noted that AIDS-related stigma was more pronounced among health workers in countries with weak health infrastructure. In such settings, health care workers have inadequate access to universal precautions, such as gloves, post-exposure prophylaxis (PEP) and safe blood collection kits. Because of inadequate protective measures, health care workers' fears of contagion are fueled by "unsafe" contact with positive patients. A number of other contributors agreed, including Masimba Biriwasha (Zimbabwe) who noted that "fear of contagion and assessment of risk can result in a sense of helplessness and loss of control."

Regarding the fear of discovering one's own serostatus, contributors noted that often health care workers have not come to terms with their own vulnerability to infection, and therefore they refuse to test themselves for HIV. This refusal to test is based on fear; and this fear is consequently projected toward the patient, and manifested as intolerance and unwillingness to treat him or her.

If these three elements are the driving forces behind stigma among health workers, what interventions can be put in place to address them and dissipate notions of stigma? Contributors identified interventions/areas for research on all levels to ameliorate the situation of AIDS-related stigma in the health care setting. Some of these ideas include:

- ▶ promoting universal precautions;
- ▶ ensuring availability of supplies (gloves, etc);
- ▶ involving people living with HIV/AIDS in their care;
- ▶ recruiting older nurses who dealt with pre-HIV deadly epidemics;
- ▶ assessing PLWA-friendly services;
- ▶ instituting retraining programmes; and
- ▶ assuring social openness about HIV while maintaining individual confidentiality assured.

Discussion 3: Stigma and the religious sector

In discussion 3 the moderator questions were:

- ▶ How does stigma manifest itself among religious leaders and religious organisations?
- ▶ What are the reasons for this stigma?
- ▶ Give examples of stigma-reducing interventions in relation to the religious sector – either examples of interventions/research currently underway or ideas you may have for interventions or research?

The role of the religious sector in creating, reinforcing, and/or dissipating the stigma surrounding HIV constituted a third area of concentration in list discussions. Most contributors concurred that the religious sector is associated with an extremely negative response to the HIV pandemic, irrespective of denomination. Yet contributors also highlighted the great potential that exists within the religious sector to provide care, comfort, and spiritual support to HIV-infected and –affected communities. Moreover, because the religious sector has such far-reaching influence throughout Africa, contributors emphasized the potential of religious leaders to play an active role in promoting healthy preventive messages about HIV, and in leading the fight against stigma in diverse settings across the continent.

As one contributor noted, in numerous rural communities, “there are only two communal buildings: a school and a church building.” The impact of Christianity on many parts of Africa has been significant, and contributors to this list discussion largely limited their comments to the capacities, achievements, and failings of the Church in facing the HIV crisis in Africa. Contributors also identified concerns and recommendations for future action among the religious community, and outlined research questions that must be addressed in order to explore and respond to this topic more effectively in the years to come.

1. The religious response to date: achievements and shortfalls

The origins of stigma in the religious sector are based upon stringent concepts of sexuality and morality. Whereas the principles of Christianity promote respect for neighbours and concern for others, rigid concepts of morality within the religious community impede non-judgmental care for people living with HIV or AIDS. As one contributor noted, “sexual morality is strict and for many of the clergy it is not easy to talk about it, especially when they are celibates.” As a consequence of the discomfort they feel, the clergy tend to ostracize people living with HIV or AIDS, whom they consider to have deviated from sexual mores. In consequence, “[m]any HIV-positive people do not yet feel welcome in the congregation of the faithful. They are afraid to be blemished, to be labeled as sinners among ‘justified’”. (Raphaela Handler, Namibia).

Failings of the religious sector to date center around the ostracization and marginalization of people living with HIV/AIDS, and the refusal by the clergy to turn inward and confront their own attitudes toward the epidemic and toward the social behaviours that are associated with the spread of HIV. The religious sector has not yet comprehensively addressed the ambivalent and often negative interpretation of sexuality that is common in Church dogma, and this ambivalence has been transformed into widespread fear of people living with HIV and cruelty towards them.

Yet, even as many churches across Africa continue to insist that HIV is a well-deserved punishment for sinful behaviour, church leaders are finding ways to adapt their ministries to current social conditions. Catholic AIDS Action, founded in 1998, represents one such movement. At the inauguration of this movement, the Archbishop of Windhoek, Bonifatius Haushiku, noted that “AIDS is a disease, not a sin – although sometimes sinful behaviour might lead to the disease.” While still emphasizing the role of sin in the spread of HIV, the Archbishop carefully liberated the status of a person with HIV from a moral deviant to that of a person who is ill with a common disease. The importance of such public statements and recognition of the nature of HIV cannot be understated.

In many communities, the Church has been instrumental in providing care and support to people living with HIV/AIDS, both through faith-based support groups and via home care for the very ill. These communities attest to the important role played by religious groups in de-stigmatizing HIV and in providing services for those who are affected by the disease. Often, at the inception of such services, faith-based care providers have faced great resistance within their institutions. However, great strides have been made toward providing more comprehensive care for HIV-affected parishioners.

The Salvation Army is an exemplary Christian institution in this respect. Throughout 12 countries in Africa, the Salvation Army has developed dynamic responses to the epidemic, integrating a menu of services into the community setting. Some of the principal elements in these programmes include home-based care for people living with HIV/AIDS, income generation projects for positive people and their families, and community counseling.

One contributor outlined the elements of this strategy and encouraged other faith-based organizations to take up this mantle. He noted that "congregations are only now learning to utilize their culture of compassionate care and voluntarism in dealing with this epidemic," and emphasized that "congregations are worth investing in ... [because] they are strategically placed to provide care, support and prevention services in our communities, especially our rural communities." (Ian Campbell, UK)

2. How can the religious community help to reduce stigma in the future?

If congregations are able to effectively serve people living with HIV and AIDS in the future, their efforts will make huge strides toward reducing stigma against positive people across Africa in the future. This sentiment was echoed in the words of numerous contributors. Because stigma in the Catholic Church manifests itself through the "moralizing" lectures and actions of the clergy, the reduction of stigma can only occur if religious leaders make conscious efforts to change their own behaviour and promote integrated care programmes for people living with HIV/AIDS.

Contributors outlined specific stigma-reducing interventions that faith communities must pursue if they are indeed serious about changing the negative culture surrounding AIDS in the religious sector. These interventions included the following:

- ▶ Religious leaders must take a public stand in support of people living with AIDS. Public statements like the one delivered by the Archbishop of Windhoek (cited above) are critical to changing public perceptions of HIV/AIDS.
- ▶ Religious institutions must support their own responses to the HIV epidemic, like the Salvation Army and Catholic AIDS Action examples cited above. By creating its own response mechanisms, the religious community will institutionalize a positive approach to HIV/AIDS. This institutionalisation will encourage other non-sectarian organisations to support and care for people living with HIV, just as it will encourage individual members of the religious community to provide assistance and compassion to people living with HIV.
- ▶ Congregations should introduce faith-based support groups for people living with HIV/AIDS and families affected by the epidemic. In communities where such groups are already functioning, the results have been excellent. Faith provides a strong pillar of support for people living with the disease, and people living with AIDS have expressed relief and happiness at being able to find solace and expression within the folds of their religious communities.
- ▶ Individual initiative to provide care and support to people living with HIV should be encouraged within the structure of the religious community. Personal faith is often the strongest force that drives individuals to work in support of people living with HIV, and should be valued as such at the institutional level.

- ▶ More generally, the Church must confront prejudices and negative attitudes that pervade its parishes. One contributor outlined the most outstanding areas for improvement as follows:
 1. Homophobia: the fear of people who are different;
 2. Scapegoating those who seem to do the things we fear most in ourselves;
 3. Sexuality as something taboo, not to be talked about;
 4. Using culture and religion as a smoke-screen or a red-herring rather than attempting to deal with the issue at hand;
 5. Viewing the use of condoms as a [simple] solution to the problem.

(Sr. Alison Munro, South Africa)

If religious communities are willing to seriously and comprehensively address these different areas for action, then a more positive response to the HIV epidemic will develop within the folds of faith communities. Institutional commitment is required to support the positive contributions that have been pursued by individuals within faith communities.

As one contributor summarized, "It is [the] wonderful values of our religions such as love, compassion, unconditional support and hope that we need to capitalise on. We need to get rid of the judgmental attitudes that perpetuate stigma [...]" through moralizing and prejudice. (David Patient, South Africa)

3. Research questions

Toward this end, there are many different areas that demand further operational research. Of the many areas that were indicated by list participants, the following seven research questions were echoed in the comments of several contributors. In the following list, these ideas are defined by Raphaela Handler, of Catholic AIDS Action, and Ian Campbell, of the Salvation Army. An important and recurring theme among these diverse ideas is the notion that faith and religious doctrine must be respected within the context of any HIV-related intervention. That notion, in and of itself, requires serious exploration.

- ▶ 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, such as Christianity and Islam?
- ▶ 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 destigmatisation?
- ▶ 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?

Discussion 4: Stigma and people living with HIV/AIDS

An exploration the effects of stigma – and more specifically, self-stigma – on people living with AIDS comprised the fourth component in the discussion of stigma on this email list. Contributors addressed three principal aspects of this topic:

- ▶ What is self-stigma, and what are some examples of self-stigmatisation?
- ▶ What is the role of disclosure in combating stigma?
- ▶ What are the most pressing research questions that we face to better understand the situation of stigma among people living with HIV or AIDS?

Self-stigma was operationally defined as an individual's internalisation of the societal attitudes s/he perceives or experiences in society. Contributors referred repeatedly to a vicious cycle that is unleashed by stigma. This process follows a pattern within which an individual internalizes his or her social stigmatisation and comes to believe that she or he truly is inferior to others in society. As a consequence of this belief, the individual separates him or herself from society and thereby reinforces his or her own stigmatisation and social exclusion.

One contributor noted the important role that HIV-positive people play in the perpetuation of their own stigmatisation as follows:

It has been argued that for stigma to exist and be effective, targeted individuals must also accept the devaluation and discrediting that accompanies stigma. In other words, stigmatised people must perceive themselves as guilty of moral transgression and accept the blame put on them. (Shalini Bharat, India)

If an HIV-positive person accepts a societal judgment that he or she has behaved in a morally reprehensible or sinful fashion, then that individual will believe that he or she is responsible for his or her illness. This belief is at the heart of self-stigmatisation; and once this belief is established, the vicious cycle of stigmatisation gains momentum.

Many examples exist to illustrate the ways in which HIV-positive people stigmatise and separate themselves from society. Perhaps the simplest example of this behaviour occurs within the household setting, wherein an HIV-positive individual may choose to keep his or her utensils and personal belongings separate from his or her family members, fearing that he or she might become the source of "contamination." Conversely, a family which fears such "contamination" may separate a positive individual's personal belongings from those of the rest of the family; and the positive person may justify such action, based upon his or her own guilt and fear of spreading the disease.

Such intense feelings of guilt inevitably lead to depression and an accompanying decline in physical health. For this reason, self-stigmatisation cannot be ignored. Each individual must face his or her internal battle with stigma and cut it down at its root. Indeed, one contributor noted that "self-stigma is as terrifying as it is internal," indicating the morass into which an HIV-positive person may sink if self-stigmatisation is allowed to run its course. (Joanne Manchester, Ireland)

Within this context, how can the insidious cycle of external and internal stigmatisation be stopped?

While there is no easy answer to this critical question, contributors were able to identify important areas for exploration. Most significantly, contributors focussed upon disclosure as a tool to combat stigma. Yet contributors did not advocate full and unconditional disclosure for all people living with HIV/AIDS. On the contrary, the list discussion weighed the benefits and challenges of disclosure and highlighted the importance of individual decision-making therein.

In order for self-disclosure to work as an effective tool against both internal and external stigma, HIV-positive individuals must carefully examine the mental stages through which they have passed since diagnosis. Psychological preparedness for disclosure is critical. Several contributors noted the importance of support groups in helping individuals prepare for disclosure. Support groups help to crush feelings of self-stigma by exposing positive individuals to others like themselves; shame and guilt dissipate within the group setting. Once these negative feelings have diminished, individuals can begin to understand their HIV-positive diagnosis, and move ahead with their lives. As this process moves forward, disclosure at different levels of personal and professional interaction comes as a natural "next step."

Joanne Manchester, co-founder of ICW, highlighted the importance of coming to terms with an HIV-positive diagnosis in one's personal sphere before "sharing the message" with others. She noted from her experience that many HIV-positive African women indicated that they found public disclosure of their status to unknown groups of people much easier than personal disclosure of their status to loved ones.

This point is an important one to consider as we address disclosure as a tool for the empowerment of people living with HIV/AIDS. If an individual can disclose his or her status in an anonymous setting, but cannot do so in closer quarters, has self-stigmatisation actually been reduced, or merely reinforced?

This question leads to a number of other queries that require structured investigation.

- ▶ 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?
- ▶ 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?
- ▶ Given the fact that stigma exists on various levels within all of us, how can we face this reality collectively by developing strategies for working through stigma, rather than attempting to abolish it?

Discussion 5: Stigma and communication

The following questions guided this discussion:

- ▶ How are HIV positive people generally portrayed in the media – radio,TV, print media, drama, etc?
- ▶ How does the media perpetuate HIV/AIDS-related stigma?
- ▶ How can the media decrease HIV/AIDS-related stigma?
- ▶ Give examples of stigma-reducing interventions in relation to the media - either examples of interventions/research currently underway or ideas you may have for interventions or research?

The role of the media in perpetuating and dispelling stigma was discussed as the fifth theme area of Stigma-AIDS. Although most authors – within and out of the media – pointed to the damage that the media has caused which has directly influenced the propagation of stigma, there were a number of constructive contributions related to how we can change this phenomenon. A number of contributors addressed the issue of how tap into the powerful role the media can play in changing perceptions and hence fighting stigma.

1. Role of the media

The first key resource presentation encapsulated the importance of looking at the role of the media:

"... [I]n the absence of an effective medical cure for AIDS, education, information and communication have become a critical component of what can be done overall, particularly in breaking down myths, beliefs and practices that fuel the spread of HIV as well as challenging irrational ideas and behaviours prompted by HIV/AIDS such as stigma." (Masimba Biriwasha, Zimbabwe)

Because journalists play a powerful role in defining the problem of AIDS for the general population, they play a critical role in framing the approaches that society uses to address AIDS. Contributors to this list pointed to this pivotal role played by the media by using words to describe the media and its role such as *double-edged sword, sharp cutlass, or weapon*. Such terminology pointed to widespread perceptions among list members that the media has the power either 1) to aid society, by assisting efforts to stem the negative effects of the epidemic, or 2) to harm society, by hampering efforts to inform the public in a conscious and non-judgmental manner.

As outlined in earlier discussions, a necessary precursor to the promotion of stigma in society is the existence of widespread silence/denial around issues related to HIV. Evidence suggests that media can effectively address silence/denial on HIV/AIDS through a variety of channels, including: conducting public advocacy, providing accurate and culturally sensitive information, stimulating public debate, encouraging critical awareness, facilitating informed decision-making, and generating active involvement of individuals and groups in this process throughout the different levels of society. In this context, the role of the media is essential to any structured HIV/AIDS IEC campaign and in the fight to reduce stigma. As such, the media *"can be moulded into a powerful tool for social action."*(Bitra George, India)

One contributor commented that in relation to a larger discussion about the media, *"stigma is not the only AIDS issue that requires attention."* However, this discussion has highlighted that the issue of AIDS stigma cannot be addressed in a vacuum, as it rests, insidiously, in every media story or image on HIV. Stigma can be tackled by focusing on the way the media handles HIV/AIDS information in general.

Perhaps one of the most relevant issues cited by contributors is the idea that the media are themselves products of society. Media reportage is limited by the socio-cultural, political and economic constraints that a certain country, or locality, is facing. As one contributor noted, *"in essence, the media is a direct reflection of the level of development and consciousness of a certain society."* (A.Birke, Ethiopia) Lucky Mazibuko pointed to South Africa as an example of a nation in which historical circumstances affect who controls media, who are members of the media, and which

public audiences that media choose to target. For example, AIDS was mentioned only twice in thirteen years prior to the post-apartheid era, and when it was mentioned "...it was portrayed as a black disease."

In contrast, contributors also highlighted many positive examples of good HIV media coverage. Some examples included ongoing coverage in newspapers such as *MMEGI* (Botswana), *Mail & Guardian* in (South Africa), *The Herald* (Zimbabwe), and TV dramas in the US and South Africa. Henry Akinsola cited a successful universal child immunization campaign in Nigeria where the Ministry of Health worked closely with mass media to raise public awareness regarding primary health care. Yet in order for more positive coverage to be possible, there are a number of challenges to effective media reporting that must be addressed in a serious and systematic way by all stakeholders.

2. Language and images

Stigma is a complex issue, requiring extreme attention to images and words. Many contributors commented on the importance of using 'responsible language' in communicating information about HIV. A number of terms were identified as problematic, including 'victims,' 'sufferers,' 'AIDS patients.' Contributors also noted that AIDS is often used as an adjective such as 'AIDS orphans' or 'AIDS experts.' Many discussants took special issue with 'AIDS orphans' as opposed to 'accident orphans,' especially because this term creates misinformation – that is, most of the so-called *AIDS orphans* are themselves HIV-negative.

Also, the term 'people living with HIV/AIDS' was seen as homogenising the experiences of people from all walks of life and adding to their stigmatisation. Martina Clark wrote that: "...media (and everyone else) can do more damage with one word than can any lack of a cure." She suggested a list of words and terms that should and should not be used in AIDS-related coverage, noting that many terms assign blame and shame, and set moral tones that guide public thinking toward a division between those people who deserve care and compassion, and those who do not.

With regards to images used, some media have a reputation of manipulating the visual impact of a situation, especially in the early years of the epidemic. Often people living with HIV are portrayed as "... a picture of a hunger victim in Somalia! I asked why [the journalist] had used [the image] and she told me it was meant to scare people from AIDS." (Florence Mhonie, Botswana) These frightening photos have been burned into our impressions of HIV. Charlene Smith, a journalist from South Africa, commented that this phenomenon symbolised "the vulture journalism we see around AIDS." In addition, although we tend to criticise our local media most strongly for its use of such negative images, we must not ignore the fact that Newsweek, Time and other big media use such images constantly.

Discussants recounted many cases in which the media "outed" HIV-positive individuals and their families without their consent. In describing one such situation, Bitra George (India) wrote the following:

"Only sensational aspects like [the] occupation of the patient, method of acquiring the infection and social activists' [quotes] were reported ... The real issues of stigmatisation ... were conveniently forgotten. The denial of right of confidentiality of the patient was also not acknowledged by any of the newspapers when confronted with the reports."

These types of stories have led to widespread suspicion of the media among NGOs and other community groups working to alleviate the suffering of PLWA. Many of these groups now prohibit media coverage of their meetings and campaigns. As one journalist noted, "apologies later don't count ." This phenomenon represents a terrible lost opportunity for media contribution to the field.

3. Entertainment industry

The entertainment industry did not escape scrutiny in this discussion of media's social responsibility. Hollywood, and in particular, American soap operas, were addressed extensively by contributors. It was noted that despite the fact that the entertainment industry has lost countless people to AIDS, popular films and TV dramas still glamorise promiscuity and sexual indiscretion. Occasionally, the

industry creates and promotes films dealing with HIV, but these films are few in number. One contributor asked cryptically whether anyone had ever counted the numbers of sex partners of the characters on the American soap, *The Bold and the Beautiful*, intimating that the show is unrealistic and harmful in its promotion of casual sex.

Discussants noted that these shows, as well as music videos, reach millions of adults and youth worldwide, perpetuating gender stereotypes and sexual mores which have long been noted as barriers to safer sex negotiation. Within this context, Brown (USA) asked whether raising HIV issues in films help people deal with day-to-day realities of AIDS, or whether the contextual association of HIV with these films might instead romanticise the disease, and thereby add to stigma.

Despite many negative examples that were raised, some contributors noted that the powerful medium of drama has been used effectively to tackle issues of HIV. Examples cited included the American TV dramas *St. Elsewhere* and *ER*, and the South African dramas *Soul City* and *Yizo Yizo*. Some of the better shows even link humour to HIV/AIDS, a relatively new strategy that could also help to reduce stigma.

4. Commercial interests

One major challenge to sensitive reporting is the need to "*sell the paper*." Contributors noted that most stories are printed or aired only if they are regarded as newsworthy by media gatekeepers, such as newspaper editors and television executives. These gatekeepers promote stories that are controversial and new; and as a result, stories and images of people living courageously with HIV are not as popular as more dramatic pieces highlighting sick, emaciated people. Thus, serious issues related to HIV are often transformed into tabloid news. As one contributor noted, we "*go for the scandal and for the jugular... [S]eldom does the life of an ordinary HIV positive person, living a drama-free life warrant attention. It should.*" (Brown, USA)

Not only do media gatekeepers rarely prioritise HIV/AIDS reporting, but they also neglect to develop editorial policies for HIV/AIDS reporting. Such neglect of these basic foundations may result from either the profit-making motives of the media as an industry, or from the ideological biases of editors. However, it should be noted that in many African countries, the media gatekeepers are not the final authority determining which stories will be published or aired. Media freedom is also curtailed by excessive political control, which might transcend any efforts made by media to report HIV/AIDS stories in a balanced way.

Some contributors suggested that journalists who support this kind of positive reporting should join with AIDS activists to lobby media gatekeepers. Editors and executives should be encouraged to develop and adopt policies that will ensure consistent and appropriate HIV reporting. Measures that could support these policies would include the allocation of resources to HIV-related news, such as devoting full-time journalists with dedicated transportation budgets to the reporting of HIV-related news. Additionally, consistent time and space could be devoted to HIV/AIDS reports in regularly printed HIV/AIDS columns or supplements, and in regularly scheduled radio or television shows.

Contributors perceived that the most significant challenge to the successful realisation of any of these strategies is the fact that media gatekeepers' priorities are driven by profit. Commercial interests drive the sensational reporting which has come to define media, and even serious journalists must face the challenge of "selling" a paper, or a story. Yet this difficult piece of the puzzle can also be addressed. For instance, in countries hardest hit by the AIDS pandemic, positive reporting about HIV may in fact help the tourist industries of these countries. In such cases, one discussant noted, working against stigmatisation, "*is logically good for the economy.*" (G. Kararach, Zimbabwe) This argument represents only one creative response to the conundrum; journalists and activists working together can certainly identify further strategies.

Media limitations

Contributors agreed that HIV/AIDS-related information must be disseminated through all types of media, and that often the most sensible channels for distribution important information are vastly under-utilised. Instead of print media and television, we must explore alternative – and often, more

basic – channels for information dissemination. In Zimbabwe, for instance, although UNICEF reported in 1999 that only 36% of households own radios, Felicity Hatendi noted that people in that nation often listen to radio programmes in buses and other group/social situations, thus rendering the radio an extremely effective means of communication. In addition, mobile film units in Zimbabwe have screened locally produced HIV/AIDS films and videos that have reached about 2.5 million rural Zimbabweans in the last year.

Unfortunately, these types of examples are not as common as they might be. Moreover, media messages must be constructed carefully. In order to appeal to the audience of interest, creators of media messages must be careful to employ appropriate local languages and cultural contexts.

Another limitation to the dissemination of information via the media is the fact that media messages are not interactive. In large part, audiences cannot react to messages or question information. If individuals wish to pursue further clarification or information about a topic, they may not have been given any referrals or resources by the media. Keeping this limitation in mind, we must incorporate efforts to address this problem in future strategies to use more channels more creatively. Coupling our efforts with the development and strengthening of channels of feedback to the media and to resource people will be critical.

More basic media limitations were also cited. Journalists in Africa are constrained by limited or non-existent access to simple technical tools, such as e-mail, fax, Internet, telephone, and postal service. In many countries, the lack of good transport prevents widespread national or provincial coverage of HIV/AIDS, and results in the dominance of urban-based HIV/AIDS stories and reports. Even rural-focused stories often must rely upon urban-based resources, and tend to over-emphasise the statements about HIV made by government, rather than the work done around HIV by medical practitioners, social scientists, and development workers. Such reporting alternatively promotes 1) a fallacious impression that HIV is an “urban problem,” and/or 2) a proliferation of poorly-informed articles on the effects of HIV on rural communities.

Often, adequate libraries and resource centres for research are also unavailable. In many countries, even conscientious journalists are hard-pressed to produce well-informed reports on HIV because access to accurate information is severely curtailed. Research often produces conflicting messages, and IEC materials are not always clear and appropriate. Without a reliable filter for this research and these materials, journalists are left to do the guesswork of sorting the “good” from the “bad” on their own. They may easily misinterpret HIV-related data, and, consequently, their stories may misrepresent that information to the public.

Strengthening HIV communication

In most cases, journalists who report on HIV are not full-time HIV journalists. At best, journalists may be health reporters who occasionally turn their eyes to HIV. For this reason, few journalists have the experience or skills necessary to effectively communicate an HIV-related public health message.

Governmental and other donor support is urgently needed to address skills training for journalists and their editors in HIV-related reporting, interviewing HIV-positive people, and in the correct use of appropriate and non-stigmatising language and images in their stories. As one contributor reflected, *“The issue is: how can we take advantage of this strong pen of the journalist and his good command of the language to achieve the objective of destigmatising HIV/AIDS?”* (Akinsola, Nigeria).

Material support from these sources must also be dedicated to the creation of national-level HIV/AIDS information banks for journalists. These banks would house regularly updated and researched, accessible HIV/AIDS-related information geared toward a media audience. Going a step further, contributors suggested that one mechanism to encourage and motivate local media to address HIV/AIDS and health issues in a comprehensive way could be the establishment of awards to recognise excellence in HIV/AIDS and health reporting. Journalists should also be encouraged to use existing e-mail discussion forums to ensure full understanding of issues related to HIV/AIDS.

In addition to all of these suggestions, contributors noted that "*all of us have a role to play in shaping the media,*" and thus, everyone involved in AIDS work has a responsibility to make full use of the media. Bitra George (India) gave concrete suggestions to organizations on how to work with the media. One of his most interesting suggestions was to cultivate journalists empathetic to the cause by keeping a list of journalists who have reported on HIV-related issues in an appropriate and positive manner. Once this list is compiled, these journalists should be included in events and trainings by AIDS-related organizations. Bitra George also suggested that organizations produce guidelines for interaction with the media which would include lists of media contacts and how to approach them. He further suggested that organizations avoid telephonic interviews to minimise the potential for misquotes, and that agencies be pro-active in distributing concise media briefs at events or press conferences, and in being transparent in dealing with journalists.

Finally, media messages are often limited to audio/visual communication channels such as radio, television, newspapers, posters, films, Internet, theatre, slides, cassette and product labels. Often we forget to utilise more traditional media to reach people. Examples of these channels to explore include interpersonal networks, oral narratives, community drama/theatre, story telling, music, drums, churches and even town criers. These vehicles should be mobilised to communicate with the rural majority of affected and infected populations who may not have access to mainstream media.

Some of the key areas for operational research identified are:

- ▶ 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?
- ▶ 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?

Discussion 6: Stigma and discrimination

'Stigma' and 'discrimination' are often used interchangeably. The sixth discussion on the list looked closer at this issue.

Two questions were offered as the entry point into the discussion:

- ▶ What are the differences between stigma and discrimination?
- ▶ Given these differences, is it appropriate to adopt the same approach to understand and decrease stigma and to reduce discrimination?

Unfortunately there was little discussion on this very important issue. However, there was one interesting interjection to this issue from Florence Mhonie (Botswana) who, in response to the opening discussion piece, that perhaps there are two very different discussions we should be having – one on stigma and the other on discrimination as they each require special focus.

She also discussed the very real risks of discrimination people weigh when considering to seek health care and hence disclosing their status to family, community and health workers. Disclosure is deemed necessary mainly because concerns of care providers about protecting themselves and others in the home from HIV infection. *"While these concerns are understandable, disclosure of a person's HIV status to colleagues, residents or members of the community does not necessarily address these concerns but are in effect discriminatory."* Added to this is that infected and affected people have very little knowledge of and access to legal help. "They are afraid to seek and use legal assistance even where this is free because it will expose them. Employers and those who practice stigma including the church take advantage of this unfortunate situation and perpetuate discrimination knowing that the person with HIV will not report or complain."

Below, is an excerpt from the opening piece of the key resource person to this topic, Miriam Maluwa (Malawi).

Any research agenda addressing stigma must aim to change the way people think and consequently behave. This will be an arduous task, as changing deep seated thoughts and behaviours may be long-term process.

In the short-term people, however, may be persuaded to see the moral, ethical basis for treating others fairly. After all, all societies, for religious, moral or cultural grounds, acknowledge the concept of fairness and justice. On the other hand, persuasion may fall on deaf ears and people may persist in holding prejudiced viewpoints or positions. These may lead them to take actions that negatively impact on the rights and entitlements of others. When individuals take these actions, they discriminate against others. Stigma and discrimination are therefore fundamentally linked.

There are two important things to note up front however. First, a focus on reducing stigma per se need not necessarily be based upon respect for human rights. It could also derive from religious, moral or cultural considerations.

Second, so long as issues remain at the level of negative thought, thus stigma, no harm is done to others. However, once a person's prejudiced thought/s lead them to doing something, or omit to do something, that then harms or denies services or entitlements to another person, the act that harms is a discriminatory act. Discrimination ensues when a distinction is made against a person which results in their being treated unfairly and unjustly on the basis of their belonging, or being perceived to belong, to a particular group.

What then is the relevance of discrimination to the discussion on stigma?

Firstly, linking stigma and discrimination is conceptually more enriching. Freedom from discrimination is a fundamental human right founded on principles of natural justice that are universal

and perpetual. The basic characteristics of human rights are that they in here in individuals because they are human, and that they apply to people everywhere in the world. Principles of non-discrimination are central to human rights thinking and practice. All international human rights instruments and the African Charter¹ prohibit discrimination based race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, fortune, birth or other status.

Moreover, recent UN Commission on Human Rights resolutions², have unequivocally stated that "the term 'or other status' in non-discrimination provisions in international human rights texts should be interpreted to cover health status, including HIV/AIDS", and has confirmed that "discrimination on the basis of HIV/AIDS status, actual or presumed, is prohibited by existing human rights standards." Discrimination against people living with HIV/AIDS, or those thought to be infected, is a clear violation of their human rights.

Beyond this, a focus on discrimination and its inter-relationship to stigma has practical significance in at least two ways:

First, since freedom from discrimination is a human right, there is an existing framework for responsibility and accountability of action. Human rights are principally concerned with the relationship between the individual and the Government or state. They derive from a legal obligation of Government to regulate the relationship between its citizens. Thus, Governments are responsible and accountable not only for not directly violating rights, but also for ensuring the conditions that enable individuals to realize their rights as fully as possible. States have obligations to respect protect and fulfil human rights.

Second, human rights provides access to existing procedural, institutional and other monitoring mechanisms for the enforcing the rights of People Living With HIV/AIDS, countering and for redressing discriminatory action. Since discrimination leads to legal offences being committed, persons who discriminate can be made accountable by law and redress can be provided, where appropriate.

Of course this is not to suggest that a focus on discrimination will inevitably lead to a better situation. We know that gaps still exists in people's awareness of the fact that discrimination is unlawful, gaps exist in accessibility of services or places where people can lodge their complaints when they are discriminated against, and gaps exist in the redress of infringement of rights. These services are normally neither affordable nor close to the most vulnerable communities.

Given the symbiosis between stigma and discrimination, it is important that as we elaborate the research agenda relating to stigma, we bear in mind the development of two kinds of alleviation strategies:(i) strategies that prevent stigma or prejudicial thoughts being formed and (ii) strategies that address or redress the situation when stigma persists and is acted on through discriminatory action that leads to negative consequences or denial of entitlements or services of others.

Clearly, law and human rights are an important tool in addressing both stigma and discrimination. However law is not an end in itself. Any law remains a dead letter unless supported by the values and expectations of a society as a whole, and these expectations and values are exactly what can also lead to stigma. For society to embrace a law, its members have to be participants in its development: they have to understand it and be able to enforce it. Thus, unless there is an interaction between law and the cultural and social values that closely govern peoples lives and behaviour, the fundamental changes required to change the epidemic remain unattainable

Suggestions for an operational research agenda relating to stigma and discrimination

- ▶ What is the capacity of law and human rights to deal with both stigma and discrimination?

- ▶ What enforcement mechanisms can be put in place to address stigma? How can we redress stigma?
- ▶ How do we make existing enforcement mechanisms more accessible to the most vulnerable and stigmatised?
- ▶ What new enforcement mechanisms are needed?

1 The Right to Non discrimination is contained in Article 2 of the Universal Declaration on Human Rights; International Covenant on Civil and Political Rights; International Covenant on Economic Social and Cultural Rights; Convention on Elimination of All Forms of Discrimination Against Women; Convention on the Rights on the Child; the African Charter)

2 Commission on Human Right Resolution 1999/49 and 2001/51

3 For example, adopting of legislation to ensure the equal access to health care and health related services provided by third parties; to control the marketing of medicines and medical equipment and to ensure that medical practitioners and other health professionals meet appropriate standards of education, skill and ethical codes of conduct.

Discussion 7: Stigma: measurement and indicators

For the final discussion, which was unfortunately very short, the following questions were posed:

- ▶ How can we measure HIV/AIDS-related stigma?
- ▶ What indicators can be used to measure this stigma?
- ▶ What are the methodological and ethical considerations when researching stigma in relation to HIV/AIDS?

Developing ways to measure levels of stigma is difficult because stigma is an abstract and social phenomenon. However, indicators are needed to measure stigma and to be able to demonstrate impact of interventions in reducing it.

Global indicators would be invaluable in comparing programs cross-nationally and in applying lessons learned in new settings. However, we know that the manifestations of stigma vary considerably, from one context to another. Globally applicable indicators or blueprint questionnaires may be difficult to develop. It may be easier to develop global "dimensions" or aspects of stigma (Brown, Gilborn, Pulerwitz, US).

To understand prevailing stigma in a specific community, setting or culture, learning about the practices and beliefs of that context is vital. Cultural practices that may be perceived as stigmatizing in one culture might not necessarily be viewed as stigmatizing in another. This is why qualitative research will provide unique insights. More specifically, contributors to this discussion indicated that research should be participatory action research (PAR). PAR provides a "way of creating knowledge that involves learning from investigation and applying what is learned to collective problems through social action". That is, the people experiencing the problem are directly involved in the research process; from formulation of the research question, to methods of inquiry, and to creating social change (Liz Lindsey, Canada).

It is important to obtain information from many perspectives, including those who may stigmatize others, and HIV positive individuals or those who know HIV positive individuals. Establishment of global domains could lead to the over-arching topics of guidelines for conducting qualitative research, such as in-depth interviews and focus group discussions.

Lisanne Brown, Laelia Gilborn and Julie Pulerwitz, key resource people for this discussion, identified the following gaps that are common 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.

All citations refer to the Stigma-AIDS discussion forum archives of postings and can be found at: <http://www.hdnet.org>