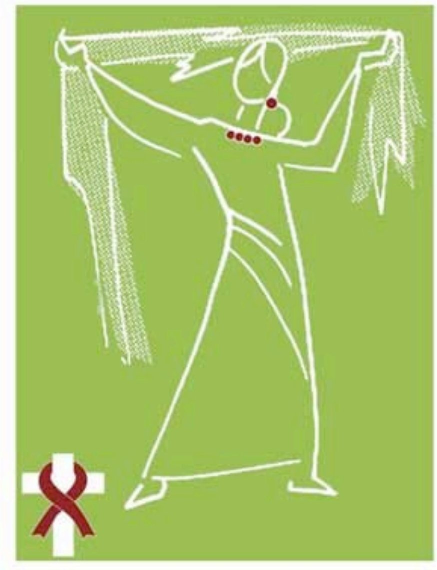
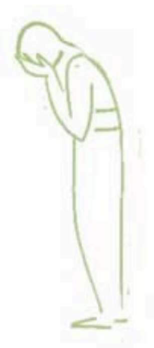
# HIV/AIDS, Stigma and Faith-based Organisations

*A review*





**Developed by**

Centre for AIDS Development, Research and Evaluation (CADRE) on behalf of Futures Group, management consultants to the UK Department for International Development (DFID), HIV and AIDS Multisectoral Support Programme.

**Compiled for**

DFID-funded Christian Aid HIV and AIDS programme of the Anglican Church of Southern Africa: '*Isiseko Sokomeleza*'

DFID/Futures Group MSP ©2005

**Written by**

Warren Parker and Karen Birdsall

**Acknowledgements**

We gratefully acknowledge the contributions of Penny Morrell and Niko Knigge for the identification of literature, as well as related discussion in the preparation of this report.

Disclaimer: Viewpoints expressed in this report are those of the authors and should not be taken to represent the views of DFID, the Futures Group, Christian Aid or the Anglican Church of Southern Africa.

## CONTENTS

Introduction ... 4
Theorising stigma and discrimination ... 4
Factors underlying HIV/AIDS stigma ... 5
HIV/AIDS stigma and blame ... 7
HIV/AIDS stigma in perspective ... 8
Responses to HIV/AIDS stigma ... 9
Grassroots responses ... 10
Broader responses ... 11
HIV/AIDS stigma in the context of religious communities and FBOs ... 11
From ‘part of the problem’ to ‘part of the solution’ ... 12
Challenges posed by HIV/AIDS in faith settings ... 14
De-stigmatising HIV/AIDS: FBO Responses to the Epidemic ... 16
Continuing challenges ... 20
Researching stigma ... 21
Methods and approaches ... 22
Areas of focus relevant to FBOs ... 24
Research questions ... 25
Research as a tool for guiding interventions ... 26
Conclusions ... 26
References ... 28

## Introduction

Stigma and discrimination have often been identified as primary barriers to effective HIV prevention, as well as the provision of treatment, care and support. Such viewpoints tend to employ stigma and discrimination as a catch-all for the multiplicity of negative beliefs, attitudes and actions related to the disease. There is, however, a need to be cautious. As Bond notes, 'it is easy to fall into a trap of labeling attitudes or acts as an example of stigma without examining other possible motives', there is a need to 'look at the wider context… Stigma is not the whole picture, but one important part of the wider picture'.[1]

The weighting given to stigma and discrimination as primary and ultimate barriers impeding HIV/AIDS response is problematic as such weighting often implies that stigma and discrimination are pervasive throughout society. This has the effect of stigmatising many communities as being uncaring and inhumane – a process that can perpetuate existing marginalisation. Stigma and discrimination therefore need to be carefully defined, cautiously analysed and critically reviewed if we are to understand impacts and develop appropriate responses.

This review explores theoretical and definitional aspects of stigma and discrimination in relation to HIV/AIDS. It then reviews faith-based organization (FBO) responses to HIV/AIDS, considering factors that contribute to stigma and discrimination, as well as those which mitigate against them. This is followed by reflections on research processes for exploring stigma and discrimination.

## Theorising stigma and discrimination

Individual identity is the product of how we think of ourselves and of others. This includes our attitudes, beliefs and values about our commonalities and differences in relation to others:

> *Identity gives us a location in the world and presents the link between us and the society in which we live… [it] gives us an idea of who we are and how we relate to others and to the world in which we live… [it] is most clearly defined by difference, that is, by what it is not.*[2]

This subjective sense of identity incorporates both positive and negative, rational and irrational thoughts and emotions that define how we see ourselves in relation to

---

[1] Bond, V. (2002). The dimensions and wider context of HIV/AIDS stigma resulting discrimination in Southern Africa. In: M. Heywood, V. Bond, T. Barfod, H. Ullum, W. Silomba, G. Foster, A. Whiteside, M. O'Grady, M. Fuglesang, P. Dover, M. Hammarskjöld, B. Egerö, J. Collins & B. Rau. *How can we increase and broaden our responses to HIV/AIDS*? Stockholm: Swedish International Development Cooperation Agency (SIDA). p. 34.

[2] Woodward, K. (2002). *Identity and difference*. London: Sage. p. 1.

others. Our sense of identity is intertwined with social and cultural ideas that allow us to understand ourselves in relation to others, including social differences linked to gender, age, class, religion, race, ethnicity, nationality, sexual orientation and physical attributes.

Stigma is that part of identity that has to do with prejudice – the setting apart of individuals or groups through the attachment of heightened negative perceptions and values. Stigma is a process that may occur at the individual level, but it is also influenced by social processes related to assumptions, stereotypes, generalisations and labeling of people as falling into a particular category on the basis of association. Stigma involves the social expression of negative attitudes and beliefs that contribute to processes of rejection, isolation, marginalisation and harm of others.[3]

It is useful to distinguish between stigma and discrimination. Stigma is largely related to ideas about others, whilst discrimination involves some form of direct enactment of stigma which may be verbal or physical, and which is likely to be hurtful and/or harmful to the person to whom it is addressed. Many authors, however, refer to stigma as encompassing both ideas and action.

Most countries and societies have recognised that forms of stigma and discrimination are antagonistic to concepts of human rights and equality. Constitutions, bills of rights and various pieces of legislation have been enacted with a view to addressing and limiting such practices. South Africa, in general, and in relation to HIV/AIDS, has a wide range of constitutional and legal provisions that set out to address inequalities, and which provide protection from discrimination on various grounds.

Whilst discrimination involves overt practices (some of which may be considered illegal), stigma is more subtle and less readily defined. Processes of enshrining non-stigmatising and non-discriminatory practices are therefore complex and gradual. Many inequalities are perpetuated in social practices that are well established and embedded such as in the use of language. In the case of HIV/AIDS, for example, the naming of people as 'victims' and 'sufferers' contributes to their stigmatization, and extended discourse processes are necessary to address these constructions.

### *Factors underlying HIV/AIDS stigma*

There have been shifting processes of meaning related to how HIV/AIDS has been situated within society, how it has been addressed, and how people have been directly, indirectly and disproportionately affected. The particular causal pathways of the epidemic have contributed to negative perceptions of people living with

---

[3] Link, B. & Phelan, J. (2001). Conceptualising stigma. *Annual Review of Sociology*, 27. 363-385.

HIV/AIDS (PLHA) – for example, associations with sexual immorality and promiscuity are linked to the primarily sexual mode of HIV transmission.

HIV/AIDS is a complex disease that includes a long phase of infection without any outward symptoms, followed by severe illness and death. At the same time, there is a narrow subset of modes of infection – through sex, from mother to child, and through exposure to blood or other fluids. The absence of outward symptoms, in combination with intimate forms of transmission and the long latency period of infection, has set HIV/AIDS apart from many other diseases. Such aspects, however, are not readily integrated into common-sense understandings of disease. People are accustomed to being cautious about disease contagion in general, and this natural fear of infection is thus readily applied to HIV/AIDS.

In a review of HIV/AIDS stigma in four countries, Ogden and Nyblade (2005) explored the root causes of individual perceptions of stigma. They found fundamental similarities in the development and expression of stigmatising ideas in all contexts. These included fear of contagion through everyday contact, a preoccupation with unlikely modes of transmission, and an association of the disease with immorality. The multi-country study found that, although knowledge of ways HIV could be transmitted was high in general, there was a lack of understanding about how HIV could *not* be transmitted. This was found to be exacerbated by fear-based public messages and sensationalism. Perceptions of morality were linked to promiscuity, moral transgression, choosing to engage in 'bad' behaviour, and punishment from God. This is contrasted with social values to do with what is considered normative, appropriate or 'good' behaviour. Gender was found to be a cross-cutting issue whereby women were 'expected to be sexually faithful, chaste and morally upstanding' and thus, when infected with HIV, there was a greater attribution of blame. Perceptions of relative guilt or innocence in relation to HIV infection were also referred to – for example, babies who were infected maternally, or health-workers who were infected with HIV during the course of their work were seen as 'innocent victims', whereas people who were infected through sexual intercourse were perceived as being 'guilty' as a product of having brought the disease upon themselves.[4]

It was found that the enactment of stigma through discriminatory practices included physical isolation (for example, separating eating utensils and living quarters); social isolation (for example, isolation from social events, loss of social networks, and diminished standing as a productive member of the community); verbal discrimination and abuse (for example, gossip, taunting, blaming and labeling); and

[4] Ogden, J. & Nyblade, L. (2005). *Common at its core: HIV-related stigma*. Washington DC: International Centre for Research on Women. p. 23.

institutional discrimination (for example, loss of employment, customers, housing, financial opportunity/protection, poorer health care, refusal of services, fear-based representation). Researchers note that although physical violence is rare, practices of discrimination as a whole coalesce in the form of an undercurrent of structural violence against PLHA.

### *HIV/AIDS stigma and blame*

HIV prevention campaigns emphasise individual choice – for example, promoting abstinence, faithfulness and condom use. Such emphases imply that people who become HIV positive have been irresponsible through their own actions and omissions as a product of not adopting appropriate HIV prevention behaviours. These constructions are exacerbated by western notions of health that are embedded paradigms which emphasise individual responsibility and volitional determination of health and wellbeing. Emphasis on individual agency masks many of the underlying conditions that influence and exacerbate HIV risk – for example, economic conditions such as labour migration brought about by economic disparity foster the break-up of families and fragmentation of communities. Additionally, vulnerability to HIV infection is influenced by disparities in power that are a product of gender imbalances, age differentials, abuse of authority, physical power and violence, and economic power, all affect individual agency and thereby influence how and when sex occurs.[5]

PLHA are the objects of stigma and are thus vulnerable to fear of being stigmatised or discriminated against. Such 'felt' stigma/discrimination may be expressed through feelings of denial, fear, guilt, depression, withdrawal, loss of hope, and worthlessness, and sometimes extend to suicidal thoughts and actions. 'Felt' stigma and discrimination is not necessarily directly related to actual or pervasive levels of stigma and discrimination in the broader community.

Fear of stigma amongst PLHA, or people who believe they are HIV positive, has been found to be a barrier to accessing Voluntary Counselling and Testing (VCT) and other HIV/AIDS-related support services.[6] This may include fears of disclosure, fears of judgmental attitudes of health workers, and fears of confidentiality. It should also be noted that fear of stigma intersects with other psychological processes to do with HIV infection, including guilt at potentially having infected others, fear of illness and death, feelings of inadequacy, and denial. PLHA are also subject to identity processes

---

[5] Parker, W. (2004). Rethinking conceptual approaches to behaviour change: The importance of context. Johannesburg: CADRE.

[6] See Malcolm, A., Aggleton, P., Bronfman, M., Galvao, J., Mane, P. & Verral, J. (1998). HIV-related stigmatisation and discrimination: Its forms and contents. *Critical Public Health*, 8(4). 347-371; Bond, V. (2002).

that include negative and positive constructions of 'the other', and therefore PLHA may themselves stigmatise others living with the virus.

### *HIV/AIDS stigma in perspective*

It is important not to exceptionalise HIV/AIDS stigma and discrimination, nor to over-elaborate it. Stigma and discrimination occur on the basis of many factors, and these wide-ranging forms need to be recognised. It makes little sense to attempt to address HIV/AIDS-specific stigma and discrimination without problematising other forms of discrimination (for example, those that are directed towards women, people who are obese, people of other races, cultures, religions, or nationalities). This suggests that responses to stigma and discrimination should be framed by broader concepts of equality and rights and principles of non-discrimination.

In addition to over-elaborating HIV/AIDS stigma and discrimination, there has also been a tendency to suggest that such beliefs and practices are pervasive and predominant throughout communities. In South Africa, for example, isolated incidents such as the murder of Gugu Dlamini, which was linked to her public disclosure of her HIV status, have been widely portrayed as symbolic of generalised and extreme levels of stigma pervading the country as a whole – something that is not borne out in reality. Such constructions mask the complex of positive responses by individuals and communities to HIV/AIDS – many of which occur informally and at local level and which are in direct response to the immediate exigencies of the disease.

Examples of such responses include involvement in prevention activities, provision of care and support to the dying and their families, the provision of care and support to orphans, associates, neighbours, friends and family members who are affected by, or are living with HIV/AIDS. In a survey of public transport commuters in South Africa in 2002, it was found that 26% of respondents had helped to care for a person with AIDS, 16% were members of an AIDS club, 48% had worn an item of clothing with an AIDS message or worn a red ribbon, and 90% were interested in talking about HIV/AIDS with an HIV-positive person.[7] Similar levels of non-discriminatory attitudes were found in a national survey in 2002.[8] A study of three South African communities also found high numbers of community-based organisations providing HIV/AIDS services across a wide spectrum of activities including prevention, VCT, treatment, care and rights.[9]

---

[7] Parker, W., Oyosi, S., Kelly, K. & Fox, S. (2002). *On the move: The response of public transport commuters to HIV/AIDS in South Africa*. Pretoria: Department of Health.

[8] Shisana, O. et al. (2002). *Nelson Mandela/HSRC study of HIV/AIDS: South African national HIV prevalence, behavioural risks and mass media. Household survey 2002*. Cape Town: HSRC.

[9] Birdsall, K. & Kelly, K. (2005). Community responses to HIV/AIDS in South Africa: Findings from a multi-community survey. Johannesburg: CADRE.

Such findings run counter to global discourses that suggest that stigma and discrimination are pervasive, that individuals and communities are overwhelmingly antagonistic to HIV/AIDS and PLHA, and that the epidemic is not readily addressed at community level. Rather, such findings open the door to understanding that stigma and discrimination exist in varying degrees, but are not necessarily pervasive. It is important to consider particular instances of stigma and discrimination, rather than making assumptions about generalised forms. For example, stigma and discrimination exercised by persons whose opinions and leadership are valued, or forms that are combined with physical harm, may have more severe impacts even if they involve only isolated instances.[10]

### Responses to HIV/AIDS stigma

HIV/AIDS stigma reduction and mitigation should be thought of as long-term processes that include giving direct attention to the contexts within which they occur. Whilst degrees of stigma may vary, interventions should be oriented towards the goal of reducing stigma and mitigating its effects, rather than attempting complete eradication.

Responses to HIV/AIDS stigma involve a range of strategies including knowledge-oriented activities (such as providing factual information about HIV transmission as well as stigma), legal and rights-oriented strategies, leadership approaches, and community-level initiatives. These strategies are not mutually exclusive, and are more likely to succeed if there is some level of integration.

A regional consultation on stigma and HIV/AIDS in Africa[11] noted that responses should focus on the following groups and areas:

- Families;
- Children (who face different challenges to adults);
- Community involvement through participatory approaches (rather than communities as passive recipients);
- People living with HIV/AIDS (recognising their relative social disempowerment, and potential to participate in stigma reduction activities);
- Research (to ensure that stigma and discrimination are adequately understood).

It is worth noting that some of the strongest responses to non-stigmatising and non-discriminatory practices in relation to HIV/AIDS have been led within communities

[10] Parker, R. & Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: A conceptual framework and implications for action. *Social Science and Medicine*, 57. 13-24.

[11] Health Development Networks (HDN). (2001). *Stigma and HIV/AIDS in Africa: Setting the operational research agenda*. Pretoria: Health Development Networks.

and groups affected by the disease – for example, initiatives in gay, sex worker and drug-user communities; within grassroots community organisations in many countries (including South Africa); and PLHA support groups.[12]

### *Grassroots responses*

In a participatory development process exploring community-level responses to HIV/AIDS in 2001, it was noted that social capital, defined as 'a process embracing clear but culturally nuanced mechanisms for enabling people and organisations to work together in trust for mutual social benefit', is useful in breaking down stigma.[13] In Amatole, a small rural community in the Eastern Cape, participatory activities related to addressing HIV/AIDS gave rise to the development of a community declaration in response, which included non-stigmatising commitments such as 'encouraging people affected by this disease to disclose' and 'supporting and loving those known to have HIV/AIDS'.[14] The declaration read in part as follows:

> *We resolve to discuss the issue in community gatherings;*
>
> *We agree to disclose our HIV status with the knowledge that we will have support from our community;*
>
> *We encourage all and their families to disclose HIV status when one has AIDS;*
>
> *We pledge to support, and never to gossip about or humiliate in any way, those who are known to have HIV/AIDS;*
>
> *We pledge to draw PWAs close and to encourage them to live positively;*
>
> *The community will deal severely with anyone seen to discriminate against them;*
>
> *We will preach and pray about AIDS at church, in schools and in concerts;*
>
> *We have started holding inter-faith AIDS prayer services and will continue doing this;*
>
> *We commit to use AIDS symbols in our workplaces as a visual sign of our unity and commitment (for example, on our clothes for work and church and school);*

---

12 Malcolm, A. et al. (1998); Low-Beer, D. & Stoneburner, R. L. (2004). *Social communications and AIDS population behaviour changes in Uganda compared to other countries*. Johannesburg: CADRE; Birdsall, K. & Kelly, K. (2005). *Community responses to HIV/AIDS in South Africa: Findings from a multi-community survey*. Johannesburg: CADRE.

13 Kelly, K., Ntlabati, P., Oyosi, S., van der Riet, M. & Parker, W. (2002). *Making HIV/AIDS our problem: Young people and the development challenge in South Africa*. Pretoria: Save the Children.

14 Ibid, p. 59.

*We commit ourselves to maintaining and building upon this initiative.*

This declaration provides insight into forms that community-level responses to stigma might take, but also the potentials for bottom-up approaches in comparison to externally led top-down interventions.

### *Broader responses*

Strategies and potential interventions for reducing HIV/AIDS-related stigma identified through an African regional consultation[15] include:

- Involvement of FBOs;
- Partnerships between non-governmental organisations (NGOs), FBOs, government and the private sector;
- Training of service providers and professions, including health workers, social workers, media workers, educators, religious leaders and police, amongst others;
- Provision of strong political and sectoral leadership;
- Promotion of solidarity as communities respond to HIV/AIDS;
- An emphasis on human rights and legal reform; and
- Involvement in treatment and care.

Emphasis was placed on communication processes that view people and communities as agents for change (rather than as objects to be changed), and that prioritise dialogue and debate at community level.

### HIV/AIDS stigma in the context of religious communities and FBOs

It has long been recognised that FBOs play a pivotal role in relation to the HIV/AIDS epidemic. Elements include doctrinal positions and religious teachings on the meaning of HIV infection, the degree of openness with which religious figures address HIV/AIDS, and HIV prevention and HIV/AIDS mitigation efforts undertaken by religious institutions in the communities and societies within which they work. In the discussion below we make reference to the body of work that has explored issues of religion and faith in relation to HIV/AIDS. We use the term FBO broadly to encompass any religions, religious communities, religious institutions, faiths and denominations. However, much of the available literature focuses on formally organised religion and predominantly Christian responses, and thus our analysis largely reflects this predominance.

---

15 Health Development Networks, (2001).

### *From 'part of the problem' to 'part of the solution'*

A key area of interest is the extent to which the world's religions have contributed to or mitigated HIV/AIDS-related stigma and discrimination over the course of the epidemic. Observers are largely in agreement that early on in the epidemic FBOs constituted 'part of the problem' rather than 'part of the solution'. FBOs have been faulted, for example, for their delayed responses, for their failure to acknowledge the scope and implications of rising HIV infection rates, and for moralistic, judgmental and socially conservative stances towards HIV/AIDS which have contributed to silence and secrecy.[16]

The association of HIV infection with immoral behaviour and the failure to openly discuss the root causes underpinning HIV transmission – particularly differentials of power – have contributed to stigmatisation and discrimination of PLHA within the church. Cochrane (2005, p. 2) notes how religion feeds into the problem of stigma through the 'taboos, sanctions, and silences [about sexuality], much of it authorised by religious legitimations'. This extends to the patriarchal aspects of religion, to prejudices about same sex relationships, and to racial and class differences.

Current literature makes reference to the challenges of eradicating HIV-related stigma and discrimination within FBOs,[17] and whilst some analyses suggest that HIV-related stigma and discrimination are pervasive within FBOs, there is also a body of documented HIV/AIDS-response activities that takes place within and via FBOs that are currently growing rapidly. This includes supporting families and orphans, providing medical care, resourcing HIV-positive support groups, and providing counseling and pastoral care. In South Africa, a review of FBOs listed in the national HIV/AIDS database found that FBOs that had AIDS activities at local level predominantly worked with PLHAs (33%) and orphans and vulnerable children (27%).[18]

The direct and concerted support to PLHA and persons affected by HIV/AIDS suggests that the central tenets of compassion and shared humanity within FBOs are frequently applied to the epidemic, and that these in turn contribute to mitigating stigma and discrimination. Clearly situations vary: in some instances stigma and discrimination are perpetuated by FBOs, whilst in others, responses contribute to their

---

[16] See, for example, discussions in: Liebowitz, J. (2002). *The impact of faith-based organizations on HIV/AIDS prevention and mitigation in Africa*. Durban: Health Economics and HIV/AIDS Research Division (HEARD), University of KwaZulu-Natal; Green, E. (2003). *Faith-based organizations: Contributions to HIV prevention*. Washington: The Synergy Project; Lewis in Friedman, S. (2003). *Building partnerships for life: The role of religions in caring for children affected by HIV/AIDS*. New York: World Conference on Religion and Peace; Clifford, P. (2004). *Theology and the HIV/AIDS epidemic*. London: Christian Aid; Tiendrebeogo, G., Buykx, M. & van Beelen, N. (2004). Faith-based responses and opportunities for a multisectoral approach. *Sexual Health Exchange,* 1. 1-3.

[17] See, for example: Paterson, G. (n.d.). *Church, AIDS and stigma*. Geneva: Ecumenical Advocacy Alliance.

[18] Birdsall, K. (2005). *Faith-based responses to HIV/AIDS in South Africa: An analysis of the activities of faith-based organisations (FBOs) in the national HIV/AIDS database*. Johannesburg: CADRE.

mitigation. It also appears that, in some instances, these contradictions may co-exist within the same settings.

A number of factors combine to explain the powerful role played by FBOs in relation to HIV/AIDS.[19] FBOs are influential institutions as a product of:

- the respect and trust they enjoy from the communities in which they operate and their moral authority within society as a whole;
- their nature as value-based institutions with direct 'jurisdiction' over issues of personal behaviour, morality, family life and belief;
- their regular involvement with members and followers, including direct contact with people at key life events (birth, coming of age, marriage, death); and
- their position as a spiritual home for members and as a source of strength, support and hope for people who are ill or in need.

The diverse, inconsistent and sometimes contradictory roles of FBOs in relation to HIV/AIDS needs to be understood as contingent upon a range of contextual factors that operate at both a micro- and macro-level. These factors are synthesised in Table 1 under three broad headings:

- **Attitudinal/conceptual** factors which relate to official or unofficial stances of religious bodies on the question of HIV/AIDS;
- **Societal** factors which involve the position occupied by a faith group or religion within a community or society as a whole; and
- **Political/structural** factors which relate to the frameworks, partnerships and other relationships in which religious groups are embedded, and their capacity to affect change.

[19] Byamugisha, G., Steinitz, L., Williams, G. & Zondi, P. (2002). Journeys of faith: Church-based responses to HIV and AIDS in three southern African countries. St. Albans, UK: TALC; Green, E. (2003); Huggins, J., Baggaley, R. & Nunn, M. (2004). God's children are dying of AIDS: Interfaith dialogue and HIV. London: Christian Aid; Liebowitz, J. (2002); Woldehanna, S., Ringheim, K., Murphy, C., Gibson, J., Odyniec, B., Clérismé, C., Uttekar, B.P., Nyamongo, I.K., Savosnick, P., Keikelame, M.J., Im-em, W., Tanga, E.O., Atuyambe, L. & Perry, T. (2005). *Faith in action: Examining the role of faith-based organizations in addressing HIV/AIDS*. Washington: Global Health Council.

### Table 1. Factors that shape role of FBOs in relation to HIV/AIDS

| | Macro-environment (society) | Micro-environment (local religious community) |
|---|---|---|
| **Factors**<br><br>*Attitudinal and conceptual* | • Doctrinal positions of dominant religions in relation to disease causality, sexuality, gender<br>• Openness of major religions in discussing/confronting AIDS<br>• Attitude towards openly positive religious leaders/figures<br>• Relationship between major religions and other belief systems (e.g. traditional healers) | • Degree of conformity with official doctrine<br>• Knowledge, attitudes and behaviours of local religious figures in relation to HIV/AIDS<br>• Internal dynamic between clergy and laity within religious community<br>• Openness in discussing/confronting AIDS<br>• Openly positive religious leaders/figures |
| *Societal* | • Relative importance of religion within society<br>• Moral authority of religious leaders<br>• (Historical) role of religious group(s) in providing social services, health care etc. | • Embeddedness of local religious group within larger community<br>• Community setting (rural, urban) |
| *Political and structural* | • National AIDS response framework<br>• Nature of relationship / degree of collaboration between major religions, governments & other actors in national AIDS response<br>• Donor framework and priorities in relation to FBOs | • Ability to mobilise resources (financial, in-kind, human)<br>• Leadership: presence/absence of 'change agents' or activists<br>• Relationship with other local actors (NGOs, government) and cultural belief systems<br>• Extent of existing networks and associations (e.g. Mother's Union) |

### *Challenges posed by HIV/AIDS in faith settings*

FBOs are ideally placed to deal with the realities of HIV/AIDS and the intersections between faith, care and hope have been noted further above.[20] FBOs promote values of compassion, tolerance and care for the needy; they are embedded within communities and understand local needs and conditions; and they have long histories of delivering health care and other social services in poor and underdeveloped areas. Yet some FBOs have been involved in denouncing or rejecting PLHA – including their own clergy. Negative sanctions have included forcing HIV-positive clergy and members out of parishes, compelling them to confess the 'sins' that led to their infection, and leading congregations in special prayers for HIV-positive followers who may be 'punished' for their status.[21]

Studies of HIV-related stigma within FBOs point to interlinked factors that are related to such occurrences, including:

- Reduction of HIV infection to issues of individual morality and sin;[22]

---

20 Health Development Networks, (2001).

21 Paterson, G. (n.d.); Aggleton, P., Wood, K., Malcolm, A. & Parker, R. (2005). *HIV-related stigma, discrimination and human rights violations: case studies of successful programmes*. Geneva: UNAIDS.

22 Dube, M. (2001). *HIV/AIDS and the curriculum: Methods of integrating HIV/AIDS in theological programmes*. Geneva: World Council of Churches.

- The failure of many FBOs to engage openly with topics fundamental to HIV/AIDS prevention, including human sexuality and women's empowerment;[23] and
- Denial that HIV/AIDS is a problem within one's faith.[24]

Such factors are related to the relative power of institutionalised religion.[25] Given that HIV is transmitted largely through sexual contact, the disease introduces the realities of human sexual behaviour into the public domain. The inter-relation of HIV infection with assumptions of promiscuity and immorality poses a threat to the moral authority and respectability of churches and religious institutions and may thus be seen as provoking the denunciations, rejections and dismissals of those deemed to have committed such 'moral transgressions'. Specifically, committing such perceived moral transgressions is seen as a failure to observe the tenets required of membership to a particular faith and expulsion is therefore considered an appropriate sanction.

HIV/AIDS also raises vexing theological questions. For example, the deep and widespread suffering brought about by the disease is a challenge to many religious frameworks and systems of belief – even those, such as Christianity, which encompass a theology of suffering.[26] As Maluleke observes:[27]

> *AIDS represents the frightening world of chaos, disorder and non-meaning from which we hoped our faith had delivered us… The AIDS pandemic recreates for us the frightening world of the earlier church where we do not control the elements….*

Other factors which have contributed to HIV stigmatisation in religious settings are not theologically based, but are instead linked to fundamental misunderstandings about the nature of the epidemic and an accompanying lack of knowledge upon which to act. These include:

- Emphasis on HIV/AIDS as a biomedical (rather than social) issue;
- Stereotypical beliefs about who is at risk of HIV infection;
- Lack of knowledge and awareness of the modes of HIV transmission; and
- Lack of understanding of underlying factors that contribute to vulnerability to HIV infection.

A 2003 review of HIV/AIDS-related stigma in faith-based organisations in South Africa, which included interviews and focus groups with both Christian and Muslim

---

[23] Paterson, G. (n.d.).
[24] POLICY Project (2003). *Siyam'kela. Tackling HIV/AIDS stigma: Guidelines for faith-based organisations*. Cape Town: POLICY Project, Centre for the Study of AIDS, USAID, & Department of Health.
[25] Parker, R. & Aggleton, P. (2003).
[26] Clifford, P. (2004).
[27] In Clifford, P. (2004). p. 65.

religious leaders, identified a number of practical issues and challenges which remain barriers to reducing stigma and discrimination within religious communities.[28] These included:

- Views of human sexuality as sinful;
- Inadequate training of religious leaders in the basics of HIV transmission;
- Failure to incorporate issues related to HIV/AIDS into theological training and curricula;
- A lack of specially-developed materials and resources for use in addressing HIV/AIDS in religious settings – e.g. interpretations of religious scriptures and readings through an HIV 'lens';
- Problems with confidentiality in relation to individuals' HIV status and lack of guidelines for clergy in how to deal with disclosure; and
- Denial on the part of some religious leaders that AIDS is present within their faith or congregation.

### De-stigmatising HIV/AIDS: FBO Responses to the Epidemic

Without discounting documented instances of stigma and discrimination in faith-settings, and acknowledging continued concern about their negative effects, it is important to note the multi-faceted responses to HIV/AIDS being mounted by religious communities and faith-based organisations worldwide.[29] The main areas of response are outlined in Table 2 below. These include both internally and externally oriented activities carried out in individual religious communities as well as at a denominational level.

---

[28] POLICY Project (2003); POLICY Project (2004). *Siyam'kela. Promising practice of stigma-mitigation efforts from across South Africa: Reflections from faith-based organisations, the workplace and people living with HIV/AIDS who interact with the media*. Cape Town: POLICY Project, Centre for the Study of AIDS, USAID, & Department of Health.

[29] See, for example: Byamugisha, G. et al. (2002); Liebowitz, J. (2002); Liebowitz, J. (2004). *Faith-based organisations and HIV/AIDS in Uganda and KwaZulu-Natal*. Durban: Health Economics and HIV/AIDS Research Division (HEARD), University of KwaZulu-Natal; Parry, S. (2002). *Responses of the churches to HIV/AIDS: Three southern African countries*. Harare: World Council of Churches, Ecumenical HIV/AIDS Initiative in Africa, Southern Africa Regional Office; Mulonzya, M. (2003). *The churches confronted with the problem of HIV/AIDS: Analysis of the situation in six countries of Eastern Africa*. Geneva: World Council of Churches, Ecumenical HIV/AIDS Initiative in Africa, Eastern Africa Regional Research Team; Foster, G. (2004). *Study of the response by faith-based organizations to orphans and vulnerable children*. New York and Nairobi: World Conference of Religions for Peace and UNICEF; Tiendrebeogo, G. & Buykx. M. (2004). *Faith-based organizations and HIV/AIDS prevention and impact mitigation in Africa*. Amsterdam: KIT Publishers; Aggleton, P. et al. (2005); Woldehanna, S. et all. (2005).

### Table 2. FBO Responses to HIV/AIDS

| | Macro-environment (society) | Micro-environment (local religious community) |
|---|---|---|
| **Responses**<br><br>*Internal* | • Establishment of AIDS desks and official response programmes<br>• Integration of AIDS into religious/theological training<br>• Development of training and educational materials<br>• Involvement of people living with AIDS | • Direct service provision (VCT, health care, care & support, support groups, support to OVC, day care centres, treatment, food/material support, income generation)<br>• Education & outreach/destigmatisation (awareness)<br>• Behaviour change: promote delayed sexual debut, fidelity, partner reduction, abstinence<br>• Spiritual support and pastoral care |
| *Internal and external* | • Linkages with secular organisations<br>• Interfaith initiatives | • Local level interfaith and inter-organisational collaboration |
| *External* | • Engagement with national policy framework<br>• Advocacy/lobbying<br>• Conducting situational analysis | • Local situational analysis<br>• Networking/referrals<br>• Collaboration with other local actors |

Although FBOs have been involved with AIDS-related activities for a decade or longer, attention to their contributions has increased in recent years as FBOs, churches and other religious groups have come to be seen as key actors in many aspects of AIDS response. Liebowitz (2002) suggests that belated consideration of the 'comparative advantages' of FBOs may be linked to the fact that religion is relatively less important in many developed countries where AIDS research and policy agendas are driven – in comparison to the developing world where the highest HIV prevalence rates are to be found. The widely held notion that many religious communities maintain conservative moral stances on HIV/AIDS may also have dissuaded engagement with FBOs on AIDS-related issues.

Currently many international donors are channeling HIV/AIDS funding to FBOs in the belief that their proximity to affected communities and relative cost-effectiveness make them logical conduits for assistance. This emphasis has increased more recently in the case of large-scale funding programmes such as the United States' PEPFAR initiative – although elements of the programme have been critiqued for following an explicit moral agenda. Increased involvement with FBOs as partners and service deliverers may also be linked to the emergence of a more nuanced understanding of how FBOs are engaging with the epidemic.

The case of Uganda, which saw a dramatic decline in HIV prevalence and incidence during the 1990s, has contributed to better understandings of the potential role of FBOs in AIDS response. The broad-based social mobilisation that took place in that country included the active involvement of churches and mosques running on

'parallel tracks' with that of non-governmental organisations, community networks and government structures.[30] Religious leaders adapted Uganda's AIDS prevention messages to their own belief systems: those that could not condone or promote prevention through condom use for religious reasons focused on abstinence, partner reduction and monogamy. Religious groups also became active in care and support activities which helped to de-stigmatise the epidemic and promote inclusiveness of PLHA.

Existing analyses of FBO responses to HIV/AIDS are largely descriptive and there is a distinct lack of literature that has attempted to evaluate the impact and effectiveness of FBOs in relation to AIDS, with the exception of Liebowitz's (2004) comparative assessment of FBO responses in South Africa and Uganda. Many of the reviews have been conducted by religious institutions (e.g. the World Council of Churches) or faith-based NGOs (e.g. Christian Aid), or by donors or multi-lateral agencies wanting to better understand the core strengths of FBOs in relation to AIDS response. Because the existing literature is diverse and uneven in focus, findings are not readily summarised. Broadly speaking, however, the following can be noted:

- **Care and support activities** are regarded as the 'traditional strength' of FBOs, particularly Christian groups that were among the first to openly treat and embrace individuals with AIDS. Even in settings where AIDS is not dealt with openly, many religious communities still have a 'logic that can encourage acceptance of and care for people with AIDS'.[31] Activities aimed at mitigating the impact of HIV/AIDS include provision of clinical care (e.g. Tuberculosis, STI treatment, and ARVs in some settings), home-based care, spiritual and pastoral support, psychological care, counseling and VCT, nutrition support, food and material support, income generation activities, support groups, medicine banks and collecting alms. While many care and support activities happen locally and on a small scale, there are also examples of large-scale interventions, such as the integrated care programme run by the Catholic Diocese of Ndola, in Zambia, which uses a network of 750 volunteers to serve a population of 350,000-400,000 people in 26 low-income townships.[32]
- FBOs have traditionally been less involved with **HIV prevention** work in comparison to care and support activities, although the picture is not uniform.[33] Liebowitz (2004), for example, found that FBOs in Uganda and in KwaZulu-Natal

---

[30] Liebowitz, J. (2002); Thornton, R. (2003). *The Uganda HIV/AIDS success story examined: The role of civil society and linkage to social and economic development*. AIDS Mark/USAID; Jamil, I. & Muriisa, R. (2004). *Building social capital in Uganda: The role of NGOs in mitigating HIV/AIDS challenges*. Paper presented at the conference of the International Society for Third Sector Research (ISTR), Toronto.

[31] Liebowitz, J. (2002). p. 28.

[32] Aggleton, P. et al. (2005).

[33] Green, E. (2003); Woldehanna, S. et al. (2005).

Province in South Africa place a heavy emphasis on HIV awareness and education. In general however, approaches to HIV prevention have been highly contested within religious circles and debates over 'realistic' vs. 'moralistic' approaches to HIV prevention – i.e. emphasising condom use and treatment of STIs vs. faithfulness and abstinence have, in some cases, overshadowed other areas of response and have deadlocked efforts at ecumenical and/or interfaith cooperation.[34] In some cases where FBOs have worked to promote behaviour change (e.g. Senegal, Uganda) their efforts have been deemed successful,[35] but this may be attributed in part to 'agreements to disagree' on the most appropriate prevention approaches.[36]

- **Orphan support** has emerged as a major focus of FBO activity. In a study conducted in six southern African countries for UNICEF and the World Conference of Religions for Peace, Foster (2004) found close to 350 faith-based initiatives supporting more than 150,000 orphans and vulnerable children. It is suggested that this represents only a tiny proportion of such work. More than 80% of these initiatives are occurring at community level through projects supporting less than 100 children. Most do not receive any outside support. The main activities undertaken are material support, medical care, income generation schemes, day care centres, and home-based care. He concludes that local-level work with orphans and vulnerable children (OVC) is flourishing and expanding rapidly, that it is well-organised, and that the cumulative impact is significant.
- A number of authors note that **HIV advocacy and rights** are under-emphasised areas among FBOs. Involvement in public policy dialogue differed strongly across the six countries studied by Woldhanna et al. (2005): while FBOs in Uganda were heavily involved with political processes and frameworks, in countries like Thailand FBOs are removed from 'worldly' work such as policy. Parry (2002) notes that the voices of FBOs are 'muted' in relation to key issues such as access to treatment and care, human rights, and other factors that underpin HIV transmission, such as gender discrimination and domestic violence.
- Another area of AIDS response concerns **internal 'de-stigmatisation'** efforts within FBOs. A growing body of practical resources, training manuals, discussion guides, theological reflections, resource manuals for incorporating AIDS themes into sermons and liturgies, and curricula for training theologians are being

[34] Parry, S. (2002); Tiendrebeogo, G. & Buykx, M. (2004).
[35] Green, E. (2003); Liebowitz, J. (2002); Tiendrebeogo, G. & Buykx, M. (2004).
[36] Tiendrebeogo, G., Buykx, M. & van Beelen, N. (2004).

produced by religious institutions to assist their own leadership and clergy to better understand and respond to HIV/AIDS.[37]

### *Continuing challenges*

The Siyam'kela initiative, led by the POLICY Project to explore aspects of HIV/AIDS-related stigma in South Africa, produced a set of guidelines for faith-based organisations wishing to develop stigma-mitigation interventions (2003). Based in part on focus groups and interviews with faith leaders, faith community members and PLHAs who are part of faith groups, the following recommendations were made:

- Guidelines should be developed to assist faith leaders and religious communities to deal with HIV/AIDS in faith settings, including managing disclosure and protecting the confidentiality of HIV-positive people who have chosen to disclose;
- Anti-discrimination and stigma mitigation approaches should be mainstreamed into various aspects of religious practice through policy;
- Faith leaders should be trained to contribute effectively to anti-stigmatisation activities, including greater sensitisation to how stigma develops and is experienced within faith communities;
- HIV/AIDS stigma mitigation interventions should be driven and monitored by faith leaders who should also ideally be the 'face' of anti-stigma campaigns and be actively and directly involved in interventions;
- PLHA should be appointed to positions of leadership within FBOs and should be involved to a greater degree in policy development, programme delivery and monitoring;
- Anti-stigma interventions should be built upon local-level stigma assessments that gauge the extent of the problem, identify local barriers to stigma mitigation, and recognise factors contributing to stigma reduction;
- Anti-stigma messages should emphasise tolerance and acceptance, should involve non-stereotypical images and concepts of PLHAs (i.e. not focus on images of frail

[37] See for example Rubenson, B. (1989). *Learning about AIDS: A manual for pastors and teachers*. Geneva: World Council of Churches, Ecumenical HIV/AIDS Initiative in Africa; Dube, M. (2003). *Africa praying: A handbook on HIV/AIDS sensitive sermons guidelines and liturgy*. Geneva: World Council of Churches; Dube, M. (2001); Judge, M. & Schaay, N. (2001). *Planning our response to HIV/AIDS: A step by step guide to HIV/AIDS planning for the Anglican communion*. Cape Town: The POLICY Project; Cucuzza, L. & Moch, L. (2003). *Faith community responses to HIV/AIDS: Integrating reproductive health and HIV/AIDS for non-governmental organizations, faith-based organizations and community-based organizations (vol 2)*. Washington: The Center for Development and Population Activities (CEDPA); Positive Muslims (2004). *HIV, AIDS and Islam: Reflections based on compassion, responsibility and justice*. Observatory, South Africa: Positive Muslims.

or ill people or high-risk groups only), should employ positive and inclusive language, and should focus on risk behaviours rather than risk groups;

- Faith communities need greater sensitisation to HIV/AIDS stigma, but interventions should move beyond simply providing information and attempt to address underlying beliefs or assumptions which can contribute to behaviour change; and
- Partnerships between FBOs and other institutions should be enhanced, including with NGOs, hospices and others, and better use should be made of existing services and referral networks which assist and support PLHAs.

### Researching stigma

The concepts of stigma and discrimination readily lend themselves to anecdotal accounts, and this contributes to generalisations and stereotypes that are inaccurate and may themselves be stigmatising – for example, suggesting that particular communities or groups overwhelmingly stigmatise PLHA implies that uncaring and inhumane attitudes are deeply embedded in that culture, community or group.

Whilst research into the occurrence of stigma and discrimination is relevant, it is important that such research be contextualised by understanding existing and proactive responses to HIV/AIDS, given that it is these responses that provide the foundation for addressing stigma in the long run. Additionally, existing proactive and positive responses to HIV/AIDS are likely to have the spin-off benefit of reducing stigma. Such responses may have occurred informally and organically, or may be the product of formal strategies, policies and interventions.

At the broad social level, factors influencing stigma and discrimination may be linked the following structural and institutional elements:[38]

- Leadership emanating from government, traditional and community structures;
- Legal provisions including statutes, laws and systems of legal support;
- Programmes and leadership within workplaces (including management and unions);
- Programmes and leadership within FBOs (including church leadership and congregations);

---

[38] See Herek, G.M. & Mitnick, L. (1996). *AIDS and stigma: A conceptual framework and a research agenda*. Final report from a research workshop sponsored by the National Institute of Mental Health; Policy Project (2004). *Siyam'kela: Tackling HIV/AIDS stigma: Guidelines for the workplace*. Cape Town: POLICY Project, Centre for the Study of AIDS, USAID, & Department of Health. Policy Project (2004). *Siyam'kela: Examining HIV/AIDS Stigma in selected South African media: January to March 2003, a summary*. Cape Town: POLICY Project, Centre for the Study of AIDS, USAID, & Department of Health.

- Programmes and systems within the health care and social service provision sectors;
- Systematic approaches within the news and entertainment media; and
- Multisectoral approaches.

Such approaches would seek to measure the extent to which stigma and discrimination are being identified, prioritised and addressed. In relation to FBOs, it follows that research would set out to examine the degree to which stigma is understood by leaders and others within FBO hierarchies, the extent to which stigma and discrimination are articulated as focal points to be addressed, and the extent to which HIV/AIDS is addressed programmatically (including specifically in relation to stigma and discrimination).

Related to this would be research conducted on attitudes and practices directed towards PLHA and affected persons on the one hand, and the experiences of PLHA and affected persons. At the individual level, there is relevance in understanding experiences of PLHA and affected persons in relation to actual and 'felt' stigma and discrimination, as well as approaches to coping with and/or addressing the same. Researchers should remain open to concepts of existing response and their impacts, rather than uniformly assuming that stigma and discrimination can only be addressed through top-down interventions, or that persons on the receiving end of stigma and discrimination are uniformly disempowered 'victims'.

### *Methods and approaches*

The complex nature of stigma and discrimination makes it difficult to study and quantify. Quantitative research on its own is unable to capture the layered nature of stigma, nor the complexities that exist in relation to specific contexts. Qualitative approaches are therefore extremely important. The following are some examples of research approaches:

- **Stigma and discrimination at the structural level:** Such studies would attempt to assess political leadership as well as legislative and rights frameworks. This would include reviews of policies, laws and systems of support.[39]
- **Stigma and discrimination at social level:** Many cross-sectional HIV/AIDS studies utilising random sampling approaches and have been conducted incorporating questionnaire-based stigma 'measures and indicators'. Questions are generally confined to small modules within larger studies and include, for example, measures of whether people would share eating utensils or accept PLHA

[39] See UNAIDS. (2000). *Protocol for the identification of discrimination against people living with HIV.* Geneva: UNAIDS

in their communities. Such questions provide a broad sense of attitudes and potential stigma, but provide little evidence of actual enactment of stigma.

- **Stigma and discrimination at institutional level:** Both quantitative and qualitative approaches incorporating various methods have been applied to such studies. These would include reviews of policies and strategies as well as attitudes, behaviours, practices and responses in the specific context.
- **Experiences of PLHA, interaction with other forms of stigma, and relation to gender**: These objectives framed a study conducted in two cities in Vietnam (Ogden & Nyblade, 2005). The study sample included PLHA, family members of PLHA and community members. In-depth interviews and focus group methods were used. Local leaders, health workers, community members and teachers were also interviewed.
- **Disentangling factors underlying stigma, documenting the influence of context, experiences of PLHA, and impacts on access to support services**: These objectives framed a study conducted in three countries (Ogden & Nyblade, 2005). One urban and one rural area were selected in each country. The study samples included PLHA, HIV-positive VCT clients, households and children. Diary methods, repeated rounds of in-depth interviews, and workshops were used. Additionally, in Tanzania, linguists, HIV/AIDS experts, historians and theologians reflected on stigma in relation to language and media communication, and a group of researchers also explored stigma and discrimination in health care settings.

A recent working report of research conducted in Tanzania provides a comprehensive overview of how HIV/AIDS stigma and discrimination can be measured quantitatively.[40] Specific emphasis was placed on developing indicators that were valid and reliable and many existing measures and indicators were reviewed and tested. Through this process a revised set of indicators has been developed.

The Siyam'kela project[41] conducted a range of research activities within the faith sector, national government and PLHAs, and through this process developed indicators for measuring HIV/AIDS stigma. These included two broad categories – external stigma and internal stigma – with various themes. Themes related to external stigma included avoidance, rejection, moral judgment, stigma by association, unwillingness to invest in PLHAs, discrimination and abuse. Internal stigma included themes such as self-exclusion from services and opportunities, perception of self, social withdrawal, overcompensation, and fear of disclosure. Each of these themes

---

40 Nyblade, L., MacQuarrie, K., Phillip, F., Kwesigabo, G., Mbawambo, J., Ndega, J., Katende, C., Yuan, E., Brown, L. & Stangle, A. (2005). *Working report measuring HIV stigma: Results of a field test in Tanzania*. Synergy Project.

41 Policy Project (2003). *Siyam'kela: HIV/AIDS stigma indicators. Tool for measuring the progress of HIV/AIDS stigma mitigation*. Cape Town: POLICY Project, Centre for the Study of AIDS, USAID, & Department of Health

have been operationalised for measurement, with definitions as well as consideration of means and conditions of verification.

In summary, quantitative methods to review stigma and discrimination include survey questionnaires, psychometric testing and psychological experiments, whilst qualitative methods include focus groups, interviews, in-depth interviews, psychological case studies, diary studies, participant observation, ethnographic approaches and participatory techniques.[42] In addition, theoretical reviews are important for informing methodologies to understand particular elements of stigma, for example, the relation between language and stigma, political ideology and stigma, and history and stigma. It is beneficial to adopt multiple methodologies with a view to triangulating findings.

### *Areas of focus relevant to FBOs*

The following areas are relevant for assessing stigma and discrimination within FBOs:[43]

- The way that HIV/AIDS and PLHA are spoken about by FBO leaders;
- The way language is used to talk about HIV/AIDS and how it is used in relation to PLHA and affected persons;
- The way religious texts are employed towards PHLAs and affected persons;
- The way HIV status is managed in relation to privacy and disclosure;
- The way HIV/AIDS has been integrated into religious practices and ceremonies;
- The way constructions of sexuality and sexual morality are employed by religious leadership in relation to HIV/AIDS;
- The involvement of PLHA in faith-based activities;
- The utilisation of processes of reconciliation where stigma and discrimination have occurred; and
- The existence of partnerships with external faith-based and secular groups to provide support to PLHAs.

Additionally, FBOs may be considered to be workplaces, so it is relevant to consider internal policies, strategies and practices in relation to HIV/AIDS. Key elements of workplace programmes include:

---

[42] See Deacon, H., Stepney, I. & Prosalendis, S. (2004) *Understanding HIV/AIDS stigma: A theoretical and methodological analysis*. Cape Town: HSRC

[43] See Policy Project. (2004). S*iyam'kela: Promising practice of stigma-mitigation efforts from across South Africa. Reflections from faith-based organisations, the workplace, and people living with HIV/AIDS who interact with the media.* Cape Town: POLICY Project, Centre for the Study of AIDS, USAID, & Department of Health.

- Leadership on HIV/AIDS response within the workplace;
- Workplace HIV/AIDS policy;
- Human resources management systems for supporting PLHA within the workplace;
- Inclusion of employees living with HIV/AIDS in workplace response;
- Non-stigmatising and non-discriminatory practices in relation to employees living with HIV/AIDS; and
- Provision of relevant training.

### *Research questions*

It is beyond the scope of this review to develop a detailed reflection on specific methodologies for conducting research on stigma and discrimination within FBOs. The following areas may, however, be considered when framing research questions:[44]

- **Assumed HIV status:** Privacy and confidentiality of personal health matters, including HIV status, have been established as a right, and HIV disclosure occurs within the context of public-private domains. Assumptions about HIV status may flow from assumed signs and symptoms of HIV/AIDS such as weight loss, changes in appearance, and presence of opportunistic infections. Stigma and discrimination are not necessarily confined to persons whose status is known, therefore selecting only known PLHA for interviews may overlook this dimension;
- **Stigma by association:** Association with PLHA including through friendship, care and support provision, and family relationships may expose individuals to stigma and discrimination;
- **Attribution of blame:** Blame attribution is directly linked to constructions of guilt and innocence – for example, seeing babies as innocent, adults as guilty or married women as innocent, married men as guilty;
- **Felt stigma:** Whilst PLHA may feel and fear the oppressive weight of stigma, it does not necessarily follow that stigma pervades the person's broader environment. Research therefore needs to explore specific examples, although the existence of felt stigma as a phenomenon also requires investigation in relation to systems of support that might reduce it.
- **Relation to other forms of stigma and discrimination:** As outlined in the theoretical discussion, HIV/AIDS stigma and discrimination occur in the context of other forms of stigma, including in relation to gender, income, ethnicity, visual

[44] See Bond, V. (2002).

appearance and the like. The relation of HIV/AIDS stigma to stigma per se is relevant for review, as is the potential for other attributions of stigma to exacerbate HIV/AIDS stigma.

- **Situational stigma:** Stigma may vary by setting – for example, a person may express compassion and support for PLHA in the context of an HIV/AIDS intervention, but privately hold and express stigmatising beliefs and attitudes;
- **Fear:** The fear of becoming infected with HIV is associated with the natural fear of disease contagion. Whilst HIV is transmitted mainly through intimate contact, it is not unreasonable for people also to fear the opportunistic infections that occur alongside HIV infection, and which are more readily transmitted (eg. tuberculosis);
- **Discrimination:** Acts of discrimination that have infringed rights and laws may need to be addressed in formal ways, and researchers need to consider whether research will inform processes of legal recourse.

### *Research as a tool for guiding interventions*

Whilst research offers an opportunity for describing and understanding the prevalence, processes and experiences of HIV/AIDS stigma and discrimination, it is important for research approaches to additionally consider processes of support and intervention for mitigation. This includes considering what approaches might usefully build upon existing responses to HIV/AIDS. This review has provided an overview of the broad spectrum of responses occurring in FBOs, as well as policies, strategies and guidelines that have been suggested for the mitigation of stigma and discrimination. In addition, research is a valuable tool for monitoring and evaluating both informal and formal responses, and for consolidating and guiding overall response. Researchers should therefore consider the potential integration of monitoring and evaluation processes into interventions.

## Conclusions

Stigma and discrimination are complex concepts that are often over-simplified, over-generalised and incorrectly utilised as a catch-all for understanding negative responses to HIV/AIDS and PLHA. Theoretical explorations help to contextualise stigma and inform the design of research that can identify the form of the problem in a given setting.

Whilst there is much reference to the FBOs as settings where stigma and discrimination prevail, there are few research findings that document specific instances and manifestations of the problem. Examples given in the broader literature are largely anecdotal. There do not appear to be any systematic investigations of

stigma and its forms within FBOs. Rather, it is assumptions about the moral underpinnings of faith, in conjunction with conservatism about sexuality, that forms the basis for such attribution. We have found a predominance of literature that has identified a growing trend in positive and proactive responses within FBOs, and these contradict accounts of FBOs as contexts where stigma is widespread. This is not to say that stigma and discrimination are not problems in FBO settings, but rather that they may coexist alongside proactive positive responses to HIV/AIDS. It is this interaction that is important to understand.

Investigations into stigma and discrimination in FBO settings need to adopt a broad approach incorporating multiple methods which are appropriate for 'disentangling' the complex layers of the phenomenon.

## References


ACORD. (2004). Unravelling the dynamics of HIV/AIDS-related stigma and discrimination: The role of community-based research. Case studies of Northern Uganda and Burundi. London: ACORD.

Ackermann, D. (n.d.). *Engaging stigma: An embodied theological response to HIV and AIDS.* Stellenbosch: University of Stellenbosch.

Aggleton, P., Wood, K., Malcolm, A. & Parker, R. (2005). *HIV-related stigma, discrimination and human rights violations: Case studies of successful programmes*. Geneva: UNAIDS.

Birdsall, K. (2005). *Faith-based responses to HIV/AIDS in South Africa: An analysis of the activities of faith-based organisations (FBOs) in the national HIV/AIDS database*. Johannesburg: CADRE.

Birdsall, K. & Kelly, K. (2005). *Community responses to HIV/AIDS in South Africa: Findings from a multi-community survey*. Johannesburg: CADRE.

Bond, V. (2002). The dimensions and wider context of HIV/AIDS stigma resulting discrimination in Southern Africa. In: M. Heywood, V. Bond, T. Barfod, H. Ullum, W. Silomba, G. Foster, A. Whiteside, M. O'Grady, M. Fuglesang, P. Dover, M. Hammarskjöld, B. Egerö, J. Collins & B. Rau. *How can we increase and broaden our responses to HIV/AIDS*? Stockholm: Swedish International Development Cooperation Agency (SIDA).

Brown, L., Trujillo, L. & Macintyre, K. (2001). *Interventions to reduce HIV/AIDS stigma: What have we learned?* New York: Population Council.

Byamugisha, G., Steinits, L., Williams, G. & Zondi, P. (2002). *Journeys of faith: Church-based responses to HIV and AIDS in three southern African countries*. St. Albans, UK: TALC.

Campbell, C., Foulis, C. A., Maimane, S. & Sibiya, Z. (2005). "I have an evil child at my house": Stigma and HIV/AIDS management in a South African community. *Public Health Matters*, 98(5). 808-815.

Castro, A. & Farmer, P. (2005) Understanding and addressing AIDS-related stigma: From anthropological theory to clinical practice in Haiti. American Journal of Public Health. 95(1). 53-59.

Clifford, P. (2004). *Theology and the HIV/AIDS epidemic*. London: Christian Aid.

Cochrane, J. (2005) *Reconceptualising religion and public health.* Opening address to the African Religious Health Assets Programme Colloquium, Johannesburg.

Cochrane, J., Olivier, J. & Schmid, B. (2005). *Importance of religious health assets in Africa.* Unpublished paper.

Cucuzza, L. & Moch, L. (2003). *Faith community responses to HIV/AIDS: Integrating reproductive health and HIV/AIDS for non-governmental organisations, faith-based organisations and community-based organisations (vol 2).* Washington: The Center for Development and Population Activities (CEDPA).

Deacon, H., Stephney, I. & Prosalendis, S. (2005). *Understanding HIV/AIDS stigma: A theoretical and methodological analysis.* Cape Town: Human Sciences Research Council.

Dube, M. (2003). *Africa praying: A handbook on HIV/AIDS sensitive sermons guidelines and liturgy*. Geneva: World Council of Churches.

Dube, M. (2001). *HIV/AIDS and the curriculum: Methods of integrating HIV/AIDS in theological programmes*. Geneva: World Council of Churches.

Family Health International. (2003) *HIV/AIDS prevention, care and support across faith-based communities: An annotated bibliography of resources*. Washington, DC: Family Health International.

Foster, G. (2004). *Study of the response by faith-based organisations to orphans and vulnerable children*. New York and Nairobi: World Conference of Religions for Peace and UNICEF.

Friedman, S. (2003). *Building partnerships for life: The role of religions in caring for children affected by HIV/AIDS*. New York: World Conference on Religion and Peace.

Green, E. (2003). *Faith-based organisations: Contributions to HIV prevention*. Washington: The Synergy Project.

Green, K., Frey, L. & Derlega, V. (2002). Interpersonalizing AIDS: Attending to the personal and social relationships of individuals living with HIV and/or AIDS. *Journal of Social and Personal Relationships*. 19(1). 5-17.

Gregory, R. & Satterfield, T. (2002). Beyond perception: The experience of risk and stigma in community contexts. *Risk Analysis*, 22(2). 347-358.

Health Development Networks (HDN). (2001). *Stigma and HIV/AIDS in Africa: Setting the operational research agenda*. Pretoria: Health Development Networks.

Herek, G. (2002). Thinking about AIDS and stigma: A psychologist's perspective. *Journal of Law, Medicine and Ethics*, 30. 594-607.

Herek, G. & Mitnick, L. (1996). *AIDS and stigma: A conceptual framework and a research agenda*. Final report from a research workshop sponsored by the National Institute of Mental Health.

Holzemer, W. & Uys, L. (2004). Managing AIDS stigma. *Journal of Social Aspects of HIV/AIDS*, 1(3). 165-174.

Huggins, J., Baggaley, R. & Nunn, M. (2004). *God's children are dying of AIDS: Interfaith dialogue and HIV*. London: Christian Aid.

Jamil, I. & Muriisa, R. (2004). *Building social capital in Uganda: The role of NGOs in mitigating HIV/AIDS challenges*. Paper presented at the conference of the International Society for Third Sector Research (ISTR), Toronto.

Josephine, S. (2001). *Churches and the HIV/AIDS pandemic: Analysis of the situation in ten West African countries*. Geneva: World Council of Churches and World Alliance of YMCAs.

Judge, M. & Schaay, N. (2001). *Planning our response to HIV/AIDS: A step by step guide to HIV/AIDS planning for the Anglican communion*. Cape Town: The POLICY Project.

Kelly, K., Ntlabati, P., Oyosi, S., van der Riet, M. & Parker, W. (2002). *Making HIV/AIDS our problem: Young people and the development challenge in South Africa*. Pretoria: Save the Children.

Klein, S., Karchner, W. & O'Connell, D. (2002). Interventions to prevent HIV-related stigma and discrimination: Findings and recommendations for public health practice. *Journal of Public Health Management Practice*. 8(6). 44-53.

Liebowitz, J. (2004). *Faith-based organisations and HIV/AIDS in Uganda and KwaZulu-Natal*. Durban: Health Economics and HIV/AIDS Research Division (HEARD), University of KwaZulu-Natal.

Liebowitz, J. (2002). *The impact of faith-based organizations on HIV/AIDS prevention and mitigation in Africa*. Durban: Health Economics and HIV/AIDS Research Division (HEARD), University of KwaZulu-Natal.

Link, B. & Phelan, J. (2001). Conceptualising stigma. *Annual Review of Sociology*, 27. 363-385.

Low-Beer, D. & Stoneburner, R. L. (2004). *Social communications and AIDS population behaviour changes in Uganda compared to other countries*. Johannesburg: CADRE.

Malcolm, A., Aggleton, P., Bronfman, M., Galvao, J., Mane, P. & Verral, J. (1998). HIV-related stigmatisation and discrimination: Its forms and contents. *Critical Public Health*, 8(4). 347-371.

Maldanado, J. (1990). *Guide to HIV/AIDS pastoral counselling*. Geneva: World Council of Churches.

Maluleke, T. (2003). Towards an HIV/AIDS-sensitive curriculum. In M. W. Dube (ed.), *HIV/AIDS and the curriculum: Methods of integrating HIV/AIDS in theological programmes*. Geneva: World Council of Churches.

Manet+ (2003). *Voices for equality and dignity: Qualitative research on stigma and discrimination issues as they affect PLWHA in Malawi.* Lilongwe: MANET+

Marshall, P. (2005) Towards a theology of HIV/AIDS. *ERT*. 29(2). 131-148.

Miller, R. (2005). An appointment with God: AIDS, place and spirituality. *The Journal of Sex Research*. 42(1). 35-45.

Mulonzya, M. (2003). *The churches confronted with the problem of HIV/AIDS: Analysis of the situation in six countries of Eastern Africa*. Geneva: World Council of Churches, Ecumenical HIV/AIDS Initiative in Africa, Eastern Africa Regional Research Team.

Nyblade, L., MacQuarrie, K., Phillip, F., Kwesigabo, G., Mbawambo, J., Ndega, J., Katende, C., Yuan, E., Brown, L. & Stangle, A. (2005). Working report measuring HIV stigma: Results of a field test in Tanzania. Synergy Project

Ogden, J. & Nyblade, L. (2005). *Common at its core: HIV-related stigma*. Washington DC: International Centre for Research on Women.

Parker, R. & Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: A conceptual framework and implications for action. *Social Science and Medicine*, 57. 13-24.

Parker, W., Oyosi, S., Kelly, K. & Fox, S. (2002). *On the move: The response of public transport commuters to HIV/AIDS in South Africa*. Pretoria: Department of Health.

Parker, W. (2004). *Rethinking conceptual approaches to behaviour change: The importance of context.* Johannesburg: CADRE.

Parker, W (2002). *Research in stigma and discrimination. Consideration for evidence-based interventions.* Johannesburg: CADRE.

Parry, S. (2002). *Responses of the churches to HIV/AIDS: Three southern African countries*. Harare: World Council of Churches, Ecumenical HIV/AIDS Initiative in Africa, Southern Africa Regional Office.

Parry, S. (n.d.). *Responses of the faith-based organisations to HIV/AIDS in sub-Saharan Africa*. Harare: World Council of Churches, Ecumenical HIV/AIDS Initiative in Africa (EHAIA).

Paterson, G. (n.d.). *Church, AIDS and stigma*. Geneva: Ecumenical Advocacy Alliance.

Policy Project (2003). *Siyam'kela: HIV/AIDS stigma indicators. Tool for measuring the progress of HIV/AIDS stigma mitigation.* Cape Town: POLICY Project, Centre for the Study of AIDS, USAID, & Department of Health

Policy Project (2003). *Siyam'kela. Tackling HIV/AIDS stigma: Guidelines for faith-based organisations*. Cape Town: POLICY Project, Centre for the Study of AIDS, USAID, & Department of Health.

Policy Project (2004). *Siyam'kela. Promising practice of stigma-mitigation efforts from across South Africa: Reflections from faith-based organisations, the workplace and people living with HIV/AIDS who interact with the media*. Cape Town: POLICY Project, Centre for the Study of AIDS, USAID, & Department of Health.

Policy Project (2004). *Siyam'kela: Tackling HIV/AIDS stigma: Guidelines for the workplace.* Cape Town: POLICY Project, Centre for the Study of AIDS, USAID, & Department of Health.

Policy Project (2004). *Siyam'kela: Examining HIV/AIDS Stigma in selected South African media*. Cape Town: January to March 2003, a summary. POLICY Project, Centre for the Study of AIDS, USAID, & Department of Health.

Positive Muslims (2004). *HIV, AIDS and Islam: Reflections based on compassion, responsibility and justice*. Observatory, South Africa: Positive Muslims.

Reidpath, D. & Chan, K. (2005). A method for the quantitative analysis of the layering of HIV-related stigma. *AIDS Care*, 17(4). 425-432.

Rethink. (2003). *Reducing stigma and discrimination: What works? Showcasing examples of best practice of anti-discrimination projects in mental health*. Conference proceedings of the Rethink/Institute of Psychiatry conference, Birmingham, June 2003.

Rubenson, B. (1989). *Learning about AIDS: A manual for pastors and teachers*. Geneva: World Council of Churches, Ecumenical HIV/AIDS Initiative in Africa.

Shisana, O. et al. (2002). *Nelson Mandela/HSRC study of HIV/AIDS: South African national HIV prevalence, behavioural risks and mass media. Household survey 2002*. Cape Town: HSRC.

Stein, J. (2002) HIV/AIDS: The latest dirty secret. *African Journal of AIDS Research*. 2(2). 95-101.

Synergy Project. (2004). *Big issues in brief: Scaling up responses to HIV/AIDS. Stigma and HIV/AIDS-A pervasive issue.* Washington: The Synergy Project.

Thornton, R. (2003). *The Uganda HIV/AIDS success story examined: The role of civil society and linkage to social and economic development*. AIDS Mark/USAID.

Tiendrebeogo, G., Buykx, M. & van Beelen, N. (2004). Faith-based responses and opportunities for a multisectoral approach. *Sexual Health Exchange,* 1. 1-3.

Tiendrebeogo, G. & Buykx. M. (2004). *Faith-based organisations and HIV/AIDS prevention and impact mitigation in Africa*. Amsterdam: KIT Publishers.

UNAIDS. (2000). *Protocol for the identification of discrimination against people living with HIV*. Geneva: UNAIDS

UNAIDS (2003). *A report of a theological workshop focusing on HIV and AIDS related stigma*. Geneva: UNAIDS.

Valdiserii, R. (2002). HIV/AIDS stigma: An impediment to public health. *American Journal of Public Health*. 92(3). 341-342.

Weaver, R. (2004). *Reaching out? Donor approaches to faith-based organisations in the response to HIV/AIDS.* Middlesex: Tearfund.

Woldehanna, S., Ringheim, K., Murphy, C., Gibson, J., Odyniec, B., Clérismé, C., Uttekar, B.P., Nyamongo, I.K., Savosnick, P., Keikelame, M.J., Im-em, W., Tanga, E.O., Atuyambe, L. & Perry, T. (2005). *Faith in action: Examining the role of faith-based organisations in addressing HIV/AIDS*. Washington: Global Health Council.

Woodward, K. (2002). *Identity and difference*. London: Sage.

World Council of Churches (1997). *Facing AIDS: The challenge, the churches' response*. Geneva: WCC Publications.

A Constella Company

**U.S. Office**

*Suite 200*
*One Thomas Circle, NW*
*Washington, DC 20005*
*USA*
TEL: 202.775.9680
FAX: 202.775.9694

**U.K. Office**

*Edgar Buildings*
*17 George Street*
*Bath BA1 2EN*
*United Kingdom*
TEL: +44 (0) 1225.321.840
FAX: +44 (0) 1225.443.856

*info@futuresgroup.com*
*www.futuresgroup.com*