

# AIDS RELATED STIGMA

Thinking Outside the Box: The Theological Challenge

GILLIAN PATERSON



For the churches, the most powerful contribution we can make to combating HIV transmission is the eradication of stigma and discrimination... Given the extreme urgency of the situation, and the conviction that the churches do have a distinctive role to play in the response to the epidemic, what is needed is a rethinking of our mission, and the transformation of our structures and ways of working.

*The Ecumenical Response to HIV/AIDS in Africa,  
World Council of Churches 2001*



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Front cover photograph from the 2004 International AIDS Conference in Bangkok  
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## Background

*In November 2001, the World Council of Churches convened a meeting of African church leaders, in Nairobi, to draw up an ecumenical plan of action for responding to the AIDS epidemic. It was unanimously agreed that, for churches, the eradication of HIV and AIDS-related stigma must be a priority: a resolution that has since been endorsed, regionally and internationally, by individual denominations. The plan of action itself gave birth to a range of international initiatives, including the Council's Ecumenical HIV and AIDS Initiative in Africa; the UNAIDS-sponsored theologians' workshop on AIDS-related stigma in Namibia in 2003; the EAA's ecumenical and interfaith programme for the International AIDS Conference in Bangkok, 2004; and the thematic focus on HIV and AIDS at the WCC Assembly in Brazil, 2006. This article is a reflection on some of the challenges encountered, in relation to HIV and AIDS, by churches and individual Christians who are grappling with the theological implications of their concern to eradicate stigma.*

Silence kills, stigma kills. We should not want those living with HIV to be the modern equivalent of the biblical leper who had to carry a bell and a sign saying, 'I am unclean'.

*Archbishop Desmond Tutu, July 2004*

## Preamble: an unsettling experience

At the International AIDS Conference in Bangkok, religions had had a much higher profile than in previous international conferences. Progress was being made. Nonetheless, faith-based organizations still found themselves castigated, and in the closing sessions alone the words 'rigid,' 'fossilised,' 'judgemental,' 'patriarchal' and 'exclusive' were all applied to them. As Nelson Mandela put it, no institution will succeed in meeting the challenges of this epidemic until it learns to 'think outside the box.'

I do not need to convince the reader that AIDS-related stigma is a problem: if you are reading this article, you already know this. The challenge is to disturb the silence that often surrounds it. For stigma is engraved on people's identity at the deepest level. Stigmatized and stigmatizers: both groups are complicit in what James Alison (though not in the context of AIDS) describes as 'the profound "do not be" which the social and ecclesiastical voice speaks to us' (Alison 2001). This makes the experience of 'thinking outside the box' as unsettling as it is potentially liberating.

This article is the fruit of ten years of conversations, correspondence, research, meetings, writing, study and reading about AIDS-related stigma. Its purpose is to suggest some possible approaches for Christian institutions charged with developing theologically-based approaches to the stigmatization and discrimination experienced by people living with or affected by HIV or AIDS. It does not seek to deny the subjective nature of the experience of stigmatization, nor the fact that there are other possible entry points to this particular task. But by placing theory at the service of praxis,



**EXPERIENCE**

A starting point for reflection is the experience of AIDS-related stigma, recounted by those who have been on the receiving end of it. For stigma is not a theoretical concept. On the contrary, it is a highly subjective experience (for stigmatizers as well as stigmatized), arousing profound emotions, and engraved on people's identity at the deepest level. It is through the experience of stigmatized individuals, groups and institutions that we can take the first steps towards understanding the problem we seek to address.

worship and theological reflection, it aims to contribute to a deeper understanding of the phenomenon of stigma and its challenges, and to suggest a basis and a possible framework for further theological, ethical and ecclesiological reflection.

In order to do this, the article suggests ten possible lenses for looking at stigma and its effects, each suggesting a theological, philosophical, moral or ecclesiological way of thinking about AIDS-related stigma. The boxes offer some brief pointers for group or personal reflection. However, it should also be stressed that this whole exercise is a provisional one. The real hope is that those who read it will be inspired to contribute their own thinking and views to the ongoing process of addressing the theological issues raised by the stigmatization of those living with or affected by HIV or AIDS, and of developing frameworks of reflection that will contribute to the unsettling but liberating process of ‘thinking outside the box.’

## 1 ] Church, world and Christian mission

The story of church responses to AIDS has been a gradual process of moving ‘out of the box.’ It mirrors movements that have taken place in missiological thinking over the past half century. We might take this in three phases. Phase 1 began when the epidemic first came out of the shadows. Many churches, particularly (but not only) in Africa, responded with great compassion by opening their mission hospitals to patients whom other hospitals rejected, by adapting community based care programmes or by finding ways of assisting orphaned children and their carers. Here the ‘model’ or ‘paradigm’ of mission was ‘the Church’ going out into ‘the World’ to heal and save: ‘Church’ and ‘World’ being viewed, broadly, as separate theatres of activity.

Phase 2 saw ‘the World’ invading ‘the Church’, and ‘the Church’ struggling to come to terms with the fact. There was an appalled realisation that Christians themselves (even Christian clergy) were not immune from infection, and churches were being forced to acknowledge that that they, too, are deeply affected by HIV or AIDS. The slogan that best characterises this stage is the statement that ‘the Body of Christ has AIDS.’

Phase 3 was triggered by the current focus on the eradication of stigma. Statements like the Nairobi declaration (WCC 2001) reveal a growing realisation that churches have contributed to the spread of the virus by their judgemental and moralistic attitudes, by their approach to sex and sexuality, and by the non-inclusive character of many Christian communities. This forces us to ask questions about what Christians believe, and what their churches think and teach (UNAIDS 2005).

In the crisis precipitated by this epidemic, the Church

cannot serve the world without asking searching questions about its own missiological, ethical and ecclesiological teachings, and about the theological assumptions that it uses to support those teachings. Thus Phase 3 shows God calling the Church, through the HIV epidemic, to a process of transformation. Landmark events have included the WCC-sponsored meeting of African church leaders, held in Nairobi in 2001; the UNAIDS-sponsored theologians’ workshop on stigma, held in Namibia in 2003;

### HOLINESS, HEALING AND GOSPEL



Historically, purity codes established external boundaries that delineated the holy from the unholy, the clean from the ‘unclean.’ “Jesus redefined the meaning and activities of holiness,” says Zambian theologian Japhet Ndhlovu (FOCCISA-Nordic 2006). “In Jesus, holiness became an act of engagement, not a state of separation. In Jesus, holiness’ healing touch was the touch of inclusion and participation; the touch that said ‘you belong’...Jesus brought an image of holiness defined not by its *distance* from what was considered to be unclean, but by its *proximity* to it. Into a world so divided and separated within itself came Jesus, who, with the touch of a hand, restored human community.” What light does this throw on our current approaches to healing, in the context of the HIV epidemic?

Pope John Paul II's frequent meetings with people living with HIV and AIDS during the course of his pastoral visits to various countries; the historic gathering of top church leaders organized by the All Africa Conference of Churches in 2004; and the profound understandings of stigma and of stigma-reduction that have flowed from the creation of ANERELA+ (the African Network for Religious Leaders Living with or Affected by HIV or AIDS).

We raise our voices to call for an end to silence about this disease – the silence of stigma, the silence of denial, the silence of fear. We confess that the Church herself has been complicit in this silence. When we have raised our voices in the past, it has been too often a voice of condemnation. We now wish to make it clear that HIV/AIDS is not a punishment from God. Our Christian faith compels us to accept that all persons, including those who are living with HIV/AIDS, are made in the image of God and are children of God.

*Statement of Anglican Primates on AIDS, Canterbury, April 2002*

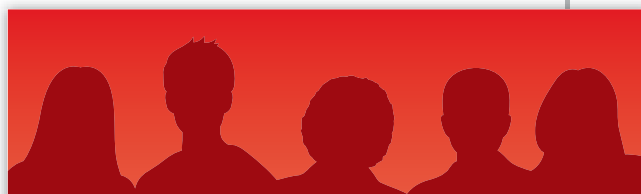
## 2 ] What is stigma?

'Both organizations and individuals have taken various actions to address stigma; however these actions have often not been grounded in a broad biosocial understanding of stigma and AIDS-related discrimination. The Joint United Nations Programme on HIV/AIDS (UNAIDS) often refers to the need to fight stigma in order to combat HIV/AIDS, but the definition of stigma remains unclear' (Castro and Farmer 2005).


Despite the international priority being given, currently, to stigma reduction, it is frequently said that we lack a really satisfactory definition. Consequently, stigma becomes a kind of catch-all concept, blamed for any of a multitude of factors that can sabotage effective testing, treatment or prevention. From a South African context, Deacon *et al* describe this as 'conceptual inflation' (Deacon 2005). This section proposes ten broad principles on which a definition might be based.

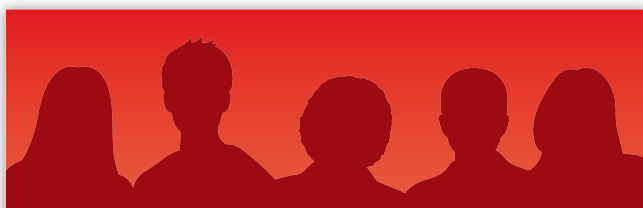
**Principle 1** Stigma is contextual, and it is social. It is recognized not because of the stigmatized characteristic a person carries, but because of social or political response it attracts from others. For example my ethnic background, gender or age can be stigmatizing in one environment, but constitute the norm in another. It is by the way that others treat me that you form the judgement that I carry a stigma.

**Principle 2** Stigma is different from discrimination. Stigma is connected with deeply held attitudes




**PHENOMENOLOGY**

 Both the experiential and the phenomenological are crucial preliminaries to theological reflection. It is therefore helpful to gain a wider perspective on the phenomenon of stigma: an account of what stigma is, in the light of different disciplines through which it is addressed.



**CREATION-CENTRED OR REDEMPTION-CENTRED?**

 For a contextual theologian, says Stephen Bevens, two basic theological orientations or perspectives are available: the creation-centered and the redemption-centered. 'A creation-centered orientation,' says Bevens, 'sees the world as sacramental, the place where God reveals God's self. It is characterized by the conviction that culture and human experience are generally good. Grace builds on nature, but only because nature is capable of being built on.'

A redemption-centered theology, by contrast, 'is characterized by a conviction that culture and human experience are either in need of radical transformation or in need of total replacement. In this context, grace cannot build on or replace nature, because nature is corrupt. Rather than being a vehicle for God's presence, the world distorts God's reality and rebels against it. Rather than a culture being already holy with the presence of God, Christ must be brought to that culture for that culture to have any saving meaning whatsoever.' (Bevens 1992 p.16). How might this distinction affect the way we think theologically about AIDS?

and communal norms; discrimination is a dynamic process that can (but need not) occur as a result of stigma. It is sometimes possible to resist or legislate against the more obvious forms of discrimination, but more difficult to alter the (stigmatizing) attitudes that produced them.

**Principle 3** Some discrimination is based on a rational assessment of risk, and is therefore legitimate. This should not be described as stigma. For example, it is discrimination (but justified discrimination) for people living with HIV or AIDS to be considered ineligible for blood donor programmes, or for an HIV negative person to expect an HIV positive sexual partner to use a condom. It is unrealistic not to worry about the effects on a family's budget of the discovery that one of its members has HIV, and to realise that hard choices may need to be made regarding the allocation of resources.

**Principle 4** Much stigma is to do with fear, and with ignorance. We fear the unknown and mysterious; we fear things we do not understand; and we fear untreatable or incurable disease. In South India, the single most effective strategy in the war against leprosy-related stigma was a long-running poster campaign that read 'LEPROSY CAN BE CURED!' Both accurate information and access to treatment are therefore important elements in combating disease-related stigma.

**Principle 5** Deacon *et al* distinguish between instrumental and symbolic stigma. Instrumental stigma is 'intended discrimination based on risk perceptions and resource concerns' (see Principle 3 above). Symbolic stigma, which relates to cultural or religious 'meanings,' may be expressed in religious or moral judgements, or in emotional responses. Instrumental and symbolic stigma do not originate from the same social, cognitive or emotional processes, nor would the same interventions be appropriate (Deacon 2005).

**Principle 6** Religion, as defender of the moral and social norms of a culture, often functions in such a way as to reinforce and ritualise symbolic stigma. For it is symbolic stigma that carries the weight of the religious, moral, cultural and social baggage associated with particular diseases, imbuing them with negative meanings that go far beyond the instrumental concerns over risk assessment and resource constraint. In the language of religion, the infringement of cultural and social norms may be re-conceptualized as 'sin.'

**Principle 7** Self-stigma can be a major element in the cocktail of stigmatization. When stigma is internalised, it can result in shame or self-disgust that permeates the whole identity. Thus the stigmatized individual comes to collaborate in his or her own stigmatization.

**Principle 8** Levels of stigmatization can change and modify over time, making stigma-reduction an achievable goal. For example, in the West, the stigmatization of divorced people and unmarried mothers has reduced dramatically in the past 30 years. Some people fear, though, that reducing stigmatization may have unintended (and less desirable) consequences. For example, there is a concern that stigma-

reduction (especially when it is combined with greater access to treatment) will result in an increase in extra-marital and pre-marital sexual activity.

**Principle 9** Stigma can play a useful role in reinforcing moral or cultural norms. Thus religious institutions are able, with a clear conscience, to stigmatize and exclude members who are discovered to have ‘sinned’: they are doing so, they believe, on the grounds that fear of exclusion is necessary for the preservation of their institutional identity and the protection of the moral welfare of the majority of their members.

**Principle 10** Stigma exacerbates existing inequalities. It is members of existing ‘out groups’ who tend to get the blame for disease or other calamity. An example is the so-called 4-H group originally promoted in the US as being responsible for HIV: namely, ‘homosexuals, haemophiliacs, heroin-addicts and Haitians.’ The identification of scapegoats distances the ‘moral majority’ from a sense that they themselves may be at risk, and therefore reduces anxiety in ‘the general population.’

Facing the serious threat of AIDS...we are committed to promote changes of mentality, attitude and behaviour necessary for confronting the challenge of the pandemic; work tirelessly to eradicate stigma and discrimination and to challenge any social, religious, cultural and political norms and practices which perpetuate such stigma and discrimination; (and) play a major role in eradicating the damaging myths of stigma and discrimination.

*Symposium of Episcopal Conferences of Africa and Madagascar, December 2003*

### **3 ] So what kind of an issue is stigma?**

For a European, approaching the issue of stigma, the overriding attitude must be one of humility. Writers from the developing world repeatedly draw attention to the dominance, within the international dialogue about AIDS, of Western bio-medical, cultural and sociological paradigms (see Mugambi 1989; Magesa 2002). In relation to AIDS, in particular, it has been convincingly argued that European and North American economic and media hegemony results in the stifling of non-Western meanings and understandings (Downing 2005). The following observations are made in the hope that this will not continue, for ever, to be the case.

Goffman’s often-quoted definition of stigma as an issue of ‘spoiled identity’ suggests ways in which the individual bearer of the stigma learns to come to terms with his or her condition and to ‘manage’ it in terms of his or her relationships with others and with society (Goffman 1963). Other voices, particularly from the developing world, have described Goffman’s work as individualistic and Western. A more anthropologically sensitive description would suggest that stigma is communally generated, and that it arises from shared values, prejudices and taboos. By this second analysis, although the empowerment of individuals is (of course) important, it is at the level of community that genuine stigma reduction takes place (Weiss and Ramakrishna 2001; Das 2001).

For epidemiologists, on the other hand, stigma is an integral part of society’s response to disease. Epidemiological history tells us that ‘framing and blaming’ is a universal stage in the progress of all

epidemics. Because epidemics are generally unanticipated, this is a stage that cannot be bypassed, because it is generated by fear, by ignorance of the unknown and by the accompanying urge to find scapegoats to blame for the disaster.

These scapegoats are most likely to belong to groups whom a particular culture or institution already stigmatizes. There are many examples of this. During the Ugandan-Tanzanian war, each side held the other responsible for the spread of the epidemic in the border areas. Urban people blame rural people, and rural people urban. Difference in terms of ethnic origin, disability or sexual orientation may attract stigmatization. And in all cultures, it is women who are most likely to be blamed. Stigma, therefore, is magnified by the marginalisation and prejudice that already exists in society.

Stigma is, pre-eminently, to do with power. Gender, class, education, race and economic status become part of the ideology of difference attaching itself to the disease (Deacon 2005). Discrimination occurs when members of the so-called 'normative' group seek to bolster their own symbolic status through the exclusion or marginalisation of members of the 'out-group.' Thus interventions will never be effective unless they are targeted at the power base from which the stigmatizing behaviour is coming: the church congregation, the playground bullies or the bureaucratic administration. To be effective, interventions must either change the hearts of the powerful or (if that fails) forcibly remove from them the ability to wield that power.

#### 4 ] In search of a theological method


This reflection was triggered (i) by acknowledgements from church leaders that AIDS-related stigma causes suffering and has damaging effects on testing, treatment and prevention programmes, and (ii) by their growing realisation that their churches, by stigmatizing those who are living with or affected by HIV or AIDS, have frequently contributed to the problem. The challenge, now, is to suggest how we might move 'outside the box,' in theological terms, in our response to stigma. And to do this we need to relate the idea to the theological categories which we bring to bear on issues of faith, and within which it is generally taught and discussed in our churches, institutions of theological education.

For theology, stigma is first and foremost an ethical issue: it is about truth; and it connects with our broad understanding of what it means to be a human being. AIDS-related stigma also invites reflection from the sub-disciplines of ecclesiology, missiology and public theology: it has implications for the Church as community or communities, its mission in the world, and its role in relation to the rest of civil society. It has implications for church history and for biblical studies, in that it relates to attitudes that stem from the tradition of the Church, and also to the way Scriptures and other texts have been transmitted and interpreted. Stigma is also a Christological question, raising issues about incarnation, salvation, and about what it means for the Church to be 'the Body of Christ'.

Methodologically, though, it may be found more helpful to start by treating stigma as discrimination as contextual issues. For some contextual theologians,



**IMAGES OF GOD**

 How do we see God? In Norway, at a workshop organized by and for people living with or affected by HIV or AIDS, many participants said their dominant childhood image was that of a strict and exacting God: judge, lawgiver, stern and angry teacher, the one who punishes wrongdoing and has favourites; a God who is incomprehensibly 'angry even when I try to do my best' (FOCCISA-Nordic 2006). When God is communicated as patriarchal and judgemental, and experienced as angry, rejecting and unfair, then it is a serious challenge to the church.

How many of us have such images? Do they throw light on the experience of stigma? And how do they compare with the gospel image of the prodigal's father, running to meet the beloved child when still far off?

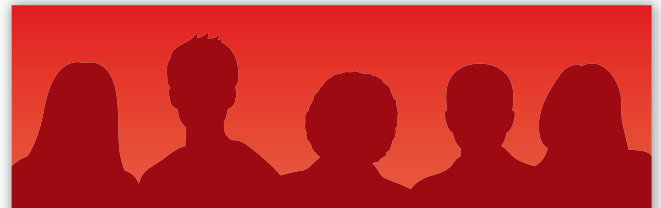
this means locating it (synchronically) at the interface between (i) an interdisciplinary understanding of the phenomenon (which involves a recognition that theological discourses must operate in dialogue with medical, cultural, sociological and political discourses); (ii) the reality of the present (which is embodied in the specific social context we are addressing, and involves individual human experience, local cultural, historical and economic realities, and the need for change); and (iii) the heritage of the past (which is embodied in scriptures, ethics, the particular theological tradition we inhabit, and the way we understand church authority).

Christian churches and theological traditions differ in the relative weight they attach to (i) the phenomenology; (ii) the reality of the present and (iii) the heritage of the past. This methodology is therefore extremely helpful as an objective tool for analysing the chasms that sometimes open up between participants in theological dialogue on contextual issues, especially when this dialogue strays into areas of human experience that are protected by cultural or religious taboo. (See Bevans 1992 and 2002 for more about this).


Another possible entry point to dialogue is through the idea of narrative (Williams 2000). Examples of this come from Asian and Latin American women who have reclaimed paradigm biblical themes on behalf of poor people (Gebara 2002). We understand what is happening to us (diachronically) through the ongoing story (or 'plot') of our communal, institutional and individual lives. The idea of narrative enables us to think about change by reading the story through the eyes of other actors, and by engaging with future possibilities as well as with the heritage of the past and the reality of the present. By introducing an eschatological, yet-to-come dimension into the discourse, we are offered a way out of the no-win struggle between the heritage (on the one hand) and on the other, the existential reality of the present crisis. For this reason, narrative methodologies may make a particularly useful contribution to the exercise of 'thinking outside the box.'

## 5 ] Stigma and taboo

One reason why stigma is so difficult to address is that it is woven, at the very deepest level, into the fabric of society, and into the subconscious patterns by which its members order their lives. Challenge stigma, and you arouse passions that are profound, but may not be consciously understood. For stigma is the servant of taboo. And it is through their taboos, deeply embedded as they are in the communal and individual consciousness, that societies, institutions or social groups protect themselves from harm, danger, and the destructive influence of 'the different' or 'the other' (Douglas 1966). Of all elements in a culture, the ones that are most prone to taboo-thinking are sex and sexuality, gender, disease, race, sin and death. Taken in conjunction with the particular stigmas associated with AIDS, it may be found that most of the difficulties that arise during our conversations on stigma are connected with one or other of these elements. For example, depending on one's class perspective,



### MAPPING THE TERRITORY

 Christian thought and action have, in all ages and cultures, been shaped by the way in which certain defining concepts have been interpreted. For the purposes of this reflection, we suggest that theological territory to be explored should include five theological 'horizons' (creation, incarnation, salvation, eschatology and community) defined by the twin theological 'pillars' of Christology and ecclesiology. In each case, fresh challenges have led to a deeper exploration of those principles, leading in turn to new understandings of their significance in a particular time and context. (See Gonzalez 1999; Bevans and Schroeder 2004; S lle 1990.)

It will be observed, of course, that these are precisely the issues on which theologians often disagree. This is why it is so important that the dialogue starts from the relatively solid ground of experience and phenomenology. When there are disagreements, it may also be found helpful to explore them in the light of the creation-centred / redemption-centred axis described above. The interface may not produce agreement, but at least it may bring about a clearer understanding of difference!

AIDS may be seen as a disease either of the rich or the poor; depending on one's gender perspective, it may be seen as a women's disease, or a disease caused by men; depending on one's race perspective, it becomes a black disease or a white issue. And so on.

The social function of taboo is primarily the preservation of society's most prized attribute, regarded as the basis for its continued flourishing, namely order. It is no accident that our scriptures open with the 'founding' story of God making order out of chaos. Accordingly, every society and institution has, encoded into its cultural identity, an 'ordered' (though not identical) system of values, beliefs and relationships that govern life, death, sex, reproduction, family, the creation of categories and the meaning of events. Universally, the social or institutional 'order' is safeguarded by laws (or taboos) that protect it from hostile influences and preserve its purity: Indian caste rules are a well-known example. To ignore these rules puts the individual and their family outside the system and exposes the whole society or institution to danger and possible destruction. The reason why the struggle to eradicate stigma is such a painful one is that we are, in effect, grappling with the taboos that support the fabric of our respective societies and institutions, with which our identity as human beings is inextricably connected.

Religion plays a crucial role in sanctifying the social order, and in meeting the need of society for rituals in which its corporate life can find expression. This gives religion great authority. Therefore World Council of Churches initiatives, such as *Africa Praying*, target prayer, liturgy and preaching as potentially powerful ways in which the church can challenge the stigmatizing elements in society (Dube 2003). When norms of behaviour are contradictory, though, the situation gets complicated. Instead of engaging with or resisting social culture, the Church cushions itself with fictions of one kind or another. For example, let us say that it is generally assumed, in your peer group or culture, that a man will have multiple sexual partners or more than one wife. This is the Real Code. This is what it means to belong. Even if you choose not to follow the 'code', you know that it is somehow connected with being judged a 'real man' in your society or your peer group. On the other hand, as a Christian, it may be assumed that you obey the Official Code, which says that Christian men abstain, sexually, until marriage and remain monogamous thereafter (Douglas 1966, Setel 1999).

## SEX, SEXUALITY AND SIN



The stigmatization of people with HIV or AIDS is connected with the mistaken link that Christian thinking has often made between sexuality and sin. In most countries, this is exacerbated by the taboos that surround homosexuality.

Is there a place for God in sexuality? Many religious people would say 'no': that sex belongs to the dark and secretive side of human nature, hemmed in with guilt, shame and taboo. By contrast, the media (especially in the West) are full of sex, which appears to be so freely available and openly discussed that it has become difficult to admit that one doesn't want it or finds it difficult. Both positions imply denial.

Zambian theologian Japhet Ndhlovu, reflecting on his own churches' mission in the face of AIDS, argues the need for Christian theology to engage openly with the damaging alliance between culture and Christian teaching, particularly in relation to sexuality and gender (FOCCISA-Nordic 2006). Silence and denial provide a safety zone for sexual abuse, and they prevent young people and women from learning to negotiate the terms of sexual encounters. Both *denial* and sexuality and the *glorification* of sexuality imply that sex has somehow lost its connection with human relationships. And to be in God is 'to be in relationship.' What are the theological implications of this?

When HIV appears among members of a particular church or parish, it exposes the truth, which is the likelihood that a good many people, clergy included, are not following this Official Code. The only thing that will be achieved by stigmatizing or excluding them, or publicly proclaiming their sinfulness, is to produce denial and to prevent adults and children from being tested or coming for treatment. At the same time, prevention programmes can't be built on fictions. Therefore a process of theological reflection must allow space for negotiation between the Real Code (which reigns in the marketplace and

the bar, the classroom, the hospital and the village square) and the Official Code (which takes precedence in the Church). For the virus makes no distinction between the two: if you're living with HIV in the bar, then you're living with it in the church as well.

We must banish the stigma that so often makes society harsh in relation to the AIDS victim, and dissipate the prejudices of those who fear the proximity of AIDS victims because they want to avoid contagion.

*Cardinal Javier Lozano Barragan,  
President of the Pontifical Council for the Pastoral Care of Health Workers and the Sick, Vatican  
November 2004*

## **6 ] The body as taboo**

HIV and AIDS are linked, in people's minds, with sex, sexuality and sexual orientation: all of which are associated, in Christian tradition, with sin. This, it is often said, is why AIDS is so heavily stigmatized. But difficulties with sex and sexuality are just one aspect of a more general history, within Christian tradition, of highly ambivalent attitudes to the human body itself. This particularly applies to the bodies of women, but also to sexually active bodies, diseased bodies, disabled bodies, dying bodies, out-of-control bodies, and bodies whose ethnic origin or skin-colour differs visibly from the communal norm. For most of us, it is hard to find the words to talk about our bodies without becoming embarrassed or being considered immodest or offensive. It is on this basis that we would describe the body as 'taboo.'

Transmission being mainly sexual, and AIDS itself being associated with sickness and death, AIDS has acted as a magnet for all the negative meanings that Western Christian tradition attached to the body: meanings which underpinned its ethics and ecclesiology, and which influenced the culture of Christian churches. These in turn became part of the heritage of the churches of the global South, where (as African feminist theologians have pointed out) they allied themselves with existing cultural approaches, and in turn helped to shape the culture of churches in Africa, Asia and Latin America (Oduyoye in Njroge & Dube, 2000). But the fact is that we all have bodies. We are all born and die and bleed; and whether we are sexually active or not, we are still sexual beings. We are all vulnerable, all (to some extent) disabled. For the real, lived body is not perfect: it is human.

Embracing an incarnational faith, whose founding sacrament is the Eucharist, it would be logical to assume that Christians would celebrate the human body, however broken and disabled it might be. However, most people are so conditioned by anti-body messages that they find it impossible to hear or to articulate a conviction that their own bodies are 'God's temple' (1 Cor.3:16-17). Therefore, theological reflection on HIV and AIDS-related stigma needs to face up honestly to the effects of Christian constructions of the body. It should do so in the light of the gospel promise that, in the birth, life, death and resurrection of Christ, we have the assurance that 'to be human' is not just OK but God's greatest gift.

## **7 ] Talking across cultural divides**

'Doing contextual theology' is difficult even when participants share a particular local or institutional context, and can engage with what it means to be part of the culture of that context. For without necessarily realising it, people experience their cultures differently. Male participants will make assump-

tions about what it feels like to be a woman, white participants about what it feels like to be black, lay people about what it feels like to be clergy, HIV negative people about what feels like to be HIV positive, and so on. And in order to unravel such assumptions, especially in relation to the subject of stigma, it will (of course) be necessary to address some of the power relations that exist between these groups. It would therefore be false to assume that 'we are all alike,' even if we live in the same street.

The process of 'contextualising' the conversation is doubly difficult when it is taking place across cultural and regional divides (as it does within the World Council of Churches and other international networks and organizations). Consider, for example, the issue of taboo. Although all cultures have taboos, the objects of taboo will vary from culture to culture, or even within the same culture. This means that cross-cultural, cross-regional conversations on AIDS are particularly prone to difficulties and misunderstandings, most notably in relation to those areas of culture that carry the highest taboo-ratings, namely (as we have said before) sex and sexuality, gender, disease, race, sin and death. For it is relatively easy to identify the taboos of others, but almost impossible to own up to our own.

None of us thinks of ourselves as stigmatizers. One's own (or one's group's) attitudes are never 'stigmatizing': they are just 'the way things are'; they are, if you like, 'default.' It is the nature of the stigmatizing process that the negative judgements it contains appear natural and unquestionably right to those

who share them. On the other hand, the stigmatizing attitudes of others (which one does not share) are often all too obvious. Thus well-meaning attempts to question the (apparently irrational) taboos of others may be met with outraged resistance, and the whole encounter end in confused denial and retreat.

One such situation emerged from a collaborative theological reflection being carried out between the Nordic churches and the Fellowship of Councils of Churches in Southern Africa. In the Nordic countries, there is a strong connection between HIV transmission and homosexuality. Although homosexual relationships are still stigmatized in these cultures, it is generally possible to live openly as a gay person, and not normally impossible to discuss the issue. In Southern African countries, however, the idea of homosexuality was judged to be taboo, especially in religious circles; and this gave rise to a deep-seated discomfort in engaging with the Nordic experience.

Participants also struggled with different cultural approaches to sin. In Southern African contributions to the project, the idea of sin was of great importance, the association between AIDS and sin making the virus a major source of culture-related stigma. In Nordic countries, though, liberal approaches to sex and sexuality have resulted, in some circles, in a virtual denial of the existence of sin, at least as the churches have traditionally understood it, and especially in relation to sex (FOCCISA-Nordic 2006). Thus Nordic participants found themselves deeply uneasy in engaging with the Southern African experience.

## EUCHARIST, BODY AND COMMUNITY



In the Eucharist, we celebrate the memory and the presence of the 'Christ-event': that is, the incarnation, which is the womb-life, birth, life, death and resurrection of Jesus, and the gift to the world of His spirit. Eucharistic symbolism has a highly physical character. In our own bodies, we are brought into relationship with Christ's life, divine and human. When the celebrant says, 'this is my body,' the 'this' in that statement means the bread; but 'this' also becomes my own body; and 'this' becomes, too, the sacrament of the gathered community, which is the body of Christ. To spiritualise the Eucharist, says Sri Lankan theologian Aloysius Pieris, is to deny its embodied reality, for the Eucharist combines the horizontal and the vertical, linking salvation (which is personal and spiritual) with liberation (which is holistic, corporate and social). The Eucharistic bread and the feeding of the poor are one and the same thing: if we genuinely engage with the meaning of the Eucharist, we cannot fail to be empowered to bring Christ's 'real presence' to the needy (Pieris 1999).

Does the theology of Eucharist have anything to contribute to the conversation about AIDS-related stigma? Are there aspects of Eucharistic celebration that contribute to the fear of AIDS-related stigmatization and exclusion? For example, does it have implications for gender-based stigma, if only men are allowed to celebrate the Eucharist?

Cross-regional encounters like the FOCCISA –Nordic process are of great value in helping us to understand other cultures. Perhaps, though, the greatest value of cross-cultural theological dialogue lies not in what it teaches us about others but in its potential for propelling us into a greater understanding of our selves. Here is an unsettling but powerful way of breaking the silence which protects ‘the box’ of our own cultural and institutional identities.

Churches should fight stigmatization of AIDS, which has proved to be the biggest impediment in the war against the disease.

*Revd Dr Melaku Kifle, when Acting General Secretary,  
All Africa Conference of Churches, March 2003*


## 8 ] What is the sin?

A further challenge is the need for Christians to find a language of truth and a moral framework for talking about AIDS. AIDS-related stigma is a denial of human worth. It is also an obstacle to HIV prevention and treatment, and has therefore been labelled a sin, a human rights issue, even a crime against humanity. Arguably, most church leaders would agree with this view (although it would be interesting to know how many do not). The problem is that the languages of human rights and of science, which dominate the discourse about AIDS, do not translate readily into the language of Christian ethics. As a result, the rules (‘thou shalt not ...’) which have provided the moral foundations of our churches as communities can easily come to look judgemental and exclusive.


On the other hand, the human rights position (born out of an altogether laudable resistance to prejudice or injustice) can easily harden into the ‘politically correct’ position, thus producing taboos of its own: taboos that can result in the silencing of truths, and also a level of intolerance towards alternative worldviews that makes real dialogue very difficult. For the reality is that what is often being secretly thought, during conversations about AIDS-related stigma, is that it is not the stigmatization of people living with or affected by HIV or AIDS that is the sin, it is the circumstances in which transmission occurred in the first place. HIV or AIDS then becomes evidence of immorality. And in that case (goes the secret line of thought) then a positive diagnosis is only what the ‘guilty’ person deserved.

What then is the moral issue? Is it adultery, or is it the religious, societal response to adultery? Is it homosexuality, or is it the outlawing of homosexuality?


These questions are crucial ones for church leaders, for they raise other fundamental questions about the church as institution: questions that leaders, if they are responsible stewards, are bound to ask. For example, what does the church community stand for, if not for certain moral standards? To sinners, Christ promised




**INTERPRETING THE BIBLE**

 The Bible, of course, is a foundational resource. Nevertheless, until recent years it has been communicated and interpreted exclusively by white, Western male scholars. It has often been used to support stigmatizing attitudes and practices within the church, and to increase the stigmatization of the vulnerable and marginalised. But in the birth, the life, the healing ministry, the death and the resurrection of Christ, we find the ultimate rejection of stigmatization.

AIDS-related stigma summons us to ‘read’ the Bible in the same way as it summons us to ‘read’ the context, namely from the standpoint of the excluded. It summons us to approach our Scriptures with eyes that are willing to see and identify with the poor, the women, the disabled, the foreigners, the widows and orphans, the slaves, the colonised, and those who have been cast out of community on account of disease or mental illness. It summons us to ensure that the Bible is freed to function as a liberating and healing text, not a tool of exclusion and oppression.



**THE SELF-EMPTYING OF CHRIST**

 Asian theologians, in particular, have explored the ecclesiological idea of kenosis: the model of the self-emptying God who – in Christ – chooses to put away power in order to identify with the powerless and marginalised. On the face of it, the principle of kenosis seems an attractive one for those who simply want the churches to ‘put down’ the stigma-creating baggage of moralisation, exclusion, patriarchy and prejudice.

It is interesting to apply this thinking to the kinds of situations that arise in Sections 8, 9 and 10 of this publication. Could it be that the kenosis principle here calls for a putting down of the defences we use to protect ourselves from the other person’s truth?

forgiveness, acceptance and freedom to move on; but how can there be forgiveness if there is no admission of having sinned? What if, in campaigning against stigma, one ends up with an anything-goes morality that throws away the moral principles the Church has always taught? Isn’t there a danger that too broad an inclusiveness will shatter the cultural or moral foundations of Christian community and make church membership meaningless?

Simplified it may be: but I suspect that the above scenario will ring bells with readers familiar with the kinds of exchanges that the HIV epidemic has generated within the churches. For what is being experienced here is an interface between two opposing worldviews or ideologies, each one deeply influenced by its own internal taboo system. Where the argument becomes polarised like this, it may sabotage the development of initiatives that are integrated, earthed in reality, and draw on the experi-

ence and resources of all those involved. What is needed is a more open and nuanced dialogue, in an environment where participants are secure in the knowledge that differences may be named and real concerns be heard.

## 9 ] A political and moral chasm

This section seeks to draw attention to a fault line that permeates the discourse on AIDS-related stigma. For the conflicting positions explored in previous sections are symptomatic of a moral and political chasm that runs right the way through the current international discourse on HIV and AIDS. On the one hand, there is the so-called ‘conservative right,’ with its strong religious links. On the other is the ‘liberal left,’ widely associated with secular, scientific and human rights thinking. The ‘liberal left,’ say its critics, encourages adultery, both by its anti-stigma advocacy and by its encouragement of the use of condoms. Its members, they allege, encourage early sexual experience among young people through (i) tolerating early sexual experimentation as inevitable and (ii) insisting on the importance of full and accurate prevention education. On the other hand, ‘conservative right’ (say its critics) increases the stigma attached to AIDS by demonising the ways in which HIV is transmitted. Further, it undermines HIV prevention by refusing (through its abstinence-based approach and stigmatization of the condom) to recognize the reality of people’s lives. And finally (by its resistance to providing full and accurate information) it infringes human rights and causes preventable deaths.

This polarisation is an over-simplification. Nevertheless, it contains a truth that many will recognise, and which throws light on another source of frustration and confusion, namely the catastrophic policy chasm that is widely perceived to divide the United Nations’ Global Fund (associated with ‘liberal left’ thinking) from the US administration’s ‘President’s Emergency Program for AIDS Relief’ (PEPFAR), which is in turn associated with ‘conservative right’ thinking. Because of this clash of the giants (it is said), donor policy unduly influences programme development, in that recipients of financial support report feel obliged to tailor their programmes to the requirements of these funding agencies, rather than to (i) local conditions and (ii) their real beliefs about what is needed in their own contexts. And yet both these approaches have, over the years, made massive contributions to the response to the epidemic, and continue to do so. Neither has a monopoly on ethics or on human rights. Their advo-

cates would all agree that the basic aim is to help those who are affected by the virus, and to bring the epidemic to a close as soon as possible. In this context, a huge gift that a strengthened, ethically- and theologically-coherent global dialogue could offer to the world is a healing, reconciling conversation that addresses this gulf and thinks ‘outside the box’ in which it seems, currently, to be locked.

It is now common knowledge that in HIV/AIDS, it is not the condition itself that hurts most (because many other diseases and conditions lead to serious suffering and death), but the stigma and the possibility of rejection and discrimination, misunderstanding and loss of trust that HIV positive people have to deal with.

*Revd Canon Gideon Byamugisha,  
Anglican Church of Uganda and founder of ANERELA+, November 2001*

## **10 ] Towards a new Creation**

Anyone who is reading this has probably identified at some level with the resolution that appears on the front cover of this publication, suggesting that ‘for the churches, the most powerful contribution we can make to combating HIV transmission is the eradication of stigma and discrimination’. As human beings we build walls to separate us and protect us from each other: walls that become, in time, those very institutional, cultural, political or academic ‘boxes’ that provide the rationale for stigmatizing thinking, because they reinforce the ‘othering’ of what is different. In this paper, therefore, we have been trying to arrive at a deeper, specifically *theological* understanding of stigma, and of AIDS related stigma in particular. What is stigma? How do we think about it? What light can Christian theology throw on its consequences? The questions in the red frames provide an opportunity for exploring that process, and for engaging with some of its moral, political and pastoral consequences. But where do we go from there?

First, let us visit the space between the ‘boxes’. Yes, we are all different; and yes, the specifics of stigma differ from context to context: and yet our bodies are biologically similar and get sick much the same ways. Comparable anthropological patterns may be observed in our social, cultural and institutional lives and the politics that flow from them. Our own emotions and spirituality are capable of giving us insight into the emotional and spiritual responses of others. Therefore informed reflection must, if it is to have any public credibility, engage with (or at least respect) the search for truth going on in the shared (though sometimes contested) disciplines of biology, science, anthropology and psychology.

As Christians, however, we have our own resources to draw on in the struggle to understand and transform stigmatizing structures and beliefs. We have a common heritage and common scriptures, although we may differ in the way we interpret or apply them. We may experience or worship God in different ways, but we do have a shared faith in the Triune God, active in history, revealed in the Word-made-flesh, and deeply involved, now, in our lives as individuals and as institutions. We have a shared commitment to the Church, and to its transforming mission, even where we differ about specific goals and methodologies. And yet stigma – the ideology of ‘othering’ – operates and is experienced in different ways in different cultures and contexts. Often it reflects the patterns of broader power-relations: thus our personal ‘boxed’ thinking may lead us to condone the lock-up cells that turn some

groups or individuals into prisoners of poverty; prisoners of discrimination based on gender, race or disability; prisoners of ignorance, fear or lack of education; prisoners of our own sense of failure or sin, and so on. And all these have been identified as powerful contributors to HIV transmission.

This paper's primary aim has been to explore the kind of cultural and theological beliefs that have served to justify the continued existence of such power relations. It also aims to encourage readers to identify the mechanisms by which institutions draw on those beliefs to justify stigmatisation and exclusion, and to stand in the way of a broad-based, open, flexible and unbureaucratic response to the epidemic. This includes identifying and being willing to change the people and groups who have the power to shape or maintain those cultures and belief systems. For instance, is it just the voices of the articulate that are heard, or those with a position in an existing hierarchy? Do those voices include women, lay people, or people living with HIV or AIDS? For issues of stigma and discrimination have to be confronted 'not just at the level of church organization and practice, but also by Christian theology itself: at the level of what is taught in seminaries, what academic theologians think and write about, what the faithful believe and do, and what values inform the pastoral formation of clergy and lay people' (UNAIDS 2005).

So how do we do it? The first paragraphs of this section contained some suggestions about common ground that exists 'between the boxes', from which a critique of one's own 'box' might be launched. But this is not just an intellectual exercise. For 'thinking outside the box' requires courage, imagination, vision, and the humility to stand in the shoes of others and see what it might feel like to be there. But it is no carping, critical, disapproving God who is calling us to this task. This, rather, is the

re-creating God, moving on the face of the waters with power, with passion and with love. This is the Christ, born, died and risen, reconciling the world to the Creator, and thus making all things new. This is the renewing Spirit who came in fire and wind, at Pentecost, and blew down the doors that divided people. For this is a vulnerable God, deeply and passionately involved in the world. It is in the spirit of this narrative of creation, renewal and recreation that we embark on the daunting, unsettling, but ultimately liberating adventure of 'thinking outside the box'.

And now it is over to you. The blank pages that follow leave space for your own thoughts and conclusions, your own set of goals, your own route map, and your own list of resources for the journey. But before writing that luggage list, we should echo the advice of Jesus, sending first the twelve and then the seventy disciples out into the world: 'travel light!'


## LANGUAGE AND LAMENT




'We are challenged,' says South African theologian Denise Ackermann, 'by the lack of an effective language to deal with HIV and stigma. Stigma is nourished by silence. Internalised trauma, fear of rejection, cultural restraints and wrong understandings of sin and punishment, all rob people of their power to name their reality....The scriptures have given us a language that can deal with suffering. In the ancient language of lament, we have a way of naming the unnameable and crying out to God and naming situations that are unbearable.' (UNAIDS 2005). Lament, says Ackermann, is risky because it names the truth to God, refuses to settle for things the way they are, avoids false optimism and yet confirms that God will help. It is also a powerful tool for dealing with suffering.

If silence and denial contribute to stigma, then our efforts to respond should surely include the search for ways of talking about sex and sexuality, about suffering and about disease. Ackermann's work suggests one approach. What might other approaches be?

## Notes, ideas and questions



### REVELATION AND NARRATIVE

 Rowan Williams stresses the historical context of revelation. Christ is revealed to us in the events of our lives, generating new understandings of the past and new possibilities for the future (Williams 2000). Revelation is Trinitarian in character, because it takes us back to the Word, and forward into the ongoing activity of the Spirit. Revelation therefore becomes a grace-filled invitation to engage with a narrative whose context is the whole story of God's reign, through an entry point that is specifically our own. In this way, it generates new possibilities in terms of the narratives of our own lives and those of our institutions.

Is Christ revealing himself to us in the experience of AIDS-related stigma? If so, how? And what new perspectives and narrative possibilities might this revelation generate for us, or for our churches?

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*Asterisked items and other useful resources are included on the CD-Rom Combating Stigma and Discrimination (2005), published by the Ecumenical Advocacy Alliance ([www.e-alliance.ch](http://www.e-alliance.ch)) and the World Conference of Religions for Peace ([www.religionsforpeace.org](http://www.religionsforpeace.org))*

## About the author

**Gillian Paterson** is a writer, consultant, researcher and theologian who has been working in the field of AIDS since 1995. Her recent research has concerned the relationship between HIV-related stigma and Christian theology. Publications include *Love in a Time of AIDS* (Geneva WCC-Risk 1996, US edition *Women in the Time of AIDS* Orbis 1997); *AIDS and the African Churches* (Christian Aid 2002); *Church, AIDS and Stigma* (EAA and UNAIDS 2003).

This publication suggests a possible, preliminary framework for theological reflection on HIV and AIDS-related stigma. We hope it will prove useful. But we are also aware of the limitations of such a framework, and of the many omissions you will find. This paper should be seen, therefore, as an invitation to take part in a global process of reflection, leading to a further, more comprehensive publication or to other initiatives. If you are interested in participating in such a process, or if you have responses, suggestions, or ideas for future work, please address them to: **beyondthebox@aol.com**.

**For more resources for faith communities on HIV and AIDS, and efforts to overcome stigma and discrimination, visit: [www.e-alliance.ch](http://www.e-alliance.ch)**

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# AIDS RELATED STIGMA

Thinking Outside the Box: The Theological Challenge



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If churches are to engage effectively with local, regional and international responses to the epidemic, then issues of stigma and discrimination have to be confronted not just at the level of church organization and practice, but also by Christian theology itself: at the level of what is taught in seminaries, what academic theologians write and think about, what the faithful believe and do, and what values inform the pastoral formation of pastors and lay people.

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