A Report of a Theological Workshop Focusing on HIV and AIDS Related Stigma

DRAFT

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Background

The Joint United Nations Programme on HIV/AIDS (UNAIDS) recognizes and values the efforts carried out by religious groups in care and treatment of people with HIV infection and AIDS. This is the first of a series, of what UNAIDS hopes will be several documents reporting on the work of leaders from different religions (Christian, Islamic, Hindu and Buddhist) addressing the challenge of HIV and AIDS from their own religious perspective.

There is a need for a broader engagement on issues related to HIV by religious leaders, and theologians, to support those working in the field. One important area is the eradication of stigma and discrimination towards People Living with HIV/AIDS (PLWHA). Stigmatization and discrimination of those who are HIV positive is a violation of human dignity. It also fuels further infections, as fear of the stigma and discrimination associated with HIV and AIDS, undermines willingness to seek out testing.

In order to start this process of collaboration UNAIDS supported a workshop to which 62 leading academic theologians from Christian traditions were invited. It took place in Windhoek, Namibia in December 2003. One result is the framework for theological reflection included in this report. This is a text that solely reflects the views of those who have signed it. The participants were invited in their personal capacities and they acknowledge that in many cases, doctrinal formulation rests with the competent authorities within their respective communions.

Acknowledgements

Thanks are due to all those who gave of their time, energy and creative thinking to this workshop and to the development of the resulting framework for theological reflection.

To the informal advisory group: Musa Dube, Linda Hartke, Musimibi Kanyoro, Rebecca Larson, Gillian Paterson, Birgitta Rubenson, Michael Czerny, Manoj Kurian, Christoph Mann and Robert Vitillo.

To those who extended a warm welcome to all participants during the stay in Namibia. The owners and the staff of the Greiters conference centre in Windhoek, the Namibian Council of Churches, the Namibian Young Women Christian Association YWCA, the Catholic AIDS action in Namibia who all made this workshop possible.

It is with much gratitude that thanks are extended to the persons living with HIV/AIDS who came to the workshop and shared both their good and their bad experiences of churches. Without them, the workshop would not have been grounded in the reality of personal experience.

Thanks too to those who were personally unable to attend, but in order to show their support have asked that their names be added to the list of those endorsing the framework.

Acronyms

3TC	Lamivudine, an Antiviral drug used in the treatment of AIDS
AACC	All African Council of Churches
ABC	Abacavir, an antiviral drug used in the treatment of AIDS
AIDS	Acquired immunodeficiency syndrome
ANERELA	African network of religious leaders living with and affected by HIV/AIDS
ARV	Antiretroviral
AZT	Zidovudine, an Antiviral drug used in the treatment of AIDS
CAFOD	Catholic fund for overseas development
CD	Compact Disc
CD4	Cluster designation 4, T helper cells are responsible for coordinating much of the immune response. HIV`s preferred targets are cells that have a docking molecule called “cluster designation 4” on their cells.
DC	District of Colombia
DIFID	Department for international development
EHAIA	Ecumenical HIV/AIDS initiative in Africa
FBO	Faith based organisations
HIV	Human immunodeficiency virus
ICASA	Independent communications authority of South Africa
PLWH	People living with HIV
PLWHA	People living with HIV and AIDS
TB	Tuberculosis
UEM	United Evangelical Mission
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
USA	United States of America
WCC	World Council of Churches
WHO	World Health Organisation
YWCA	Young Women Christian Association

Framework from the workshop

HIV and AIDS RELATED STIGMA
A Framework for Theological Reflection

BACKGROUND AND PREAMBLE

Churches and faith-based organizations have a key role to play in the struggle against HIV and AIDS. In many communities, worldwide, this moment is one of crisis and kairos. AIDS is increasing its deadly toll. Parents are dying, so that incomes disappear and there are growing numbers of orphans and desperately poor families. Incomes are further eaten away by the cost of caring for the sick. Young people are at greatest risk. In severely affected regions, our priests, pastors and lay leaders are stretched to breaking point by the increased burden of funerals, the support of dying people and their families, the care of orphans and those who look after them, and their efforts to provide a ministry to the sick. They are aware, meanwhile, that what they are seeing is only the tip of the iceberg. In communities, among church congregations, and among clergy themselves, HIV is silently advancing.

When people fear that they are HIV positive, but know that they will not be in a position to access treatment, there is little incentive for them to seek help or change behaviour. If they make such a move, they are risking the stigma attached to those who are known to be living with HIV or AIDS, and which spreads out, in waves, to their families, their survivors, and others who are close to them. Treatment may be available to prevent mother-to-child transmission, but pregnant women may not come forward to ask for it. Rather than risk the stigmatization and discrimination that will follow if they are discovered to have HIV or AIDS, they may prefer to take the risk of giving birth to an HIV positive child.

In this situation, says a South African priest, 'Our theological education and pastoral formation have left us feeling like a cricket team, sent out onto the field only to find that the bats we have been given are broken.'

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 lecture, write and think about, what the faithful believe and do, and what values inform the pastoral formation of clergy and lay people. But this puts great pressure on those who teach in these contexts, who may know little or nothing about HIV or AIDS, and whose own background and training is unlikely to have provided them with the tools for reflecting theologically upon it.

As part of its strategy for meeting this need, UNAIDS organized an international workshop for academic theologians from different Christian traditions. Held at Windhoek, Namibia from 8-11 December 2003, the workshop had two primary objectives: to sharpen the response to HIV and AIDS-related stigma among theological educators and church leaders; and to develop a framework that might provide a useful basis for theological reflection in the contexts of theological education, church councils and synods, and pastoral formation. This document is one result of that process.

The group which produced the present document consisted of leading academic theologians from five continents and many church traditions, people living with HIV or AIDS, and clergy and lay people working at global and community level in the field of HIV and AIDS. The participants in the workshop are listed at the end. The document represents their best efforts to grapple with the serious and complex issues related to stigmatizing and discriminatory reactions to HIV and AIDS, and to discern the values and beliefs that underlie a justice-based response to such negative phenomena. Participants did not attempt to produce a consensus statement. They were similarly aware that, in some churches, doctrinal formulation rests with the competent authorities within their respective communions. They sincerely hope, however, that this framework will guide additional research, reflection and action in relation to the stigma and discrimination that regrettably characterises this stage of the HIV and AIDS pandemic.

HIV and AIDS RELATED STIGMA
A Framework for Theological Reflection

INTRODUCTION

In the context of HIV and AIDS, the most powerful obstacle to effective prevention, treatment and care is proving to be the stigmatization of people living with HIV and AIDS. Christian theology has, sometimes unintentionally, operated in such a way as to reinforce the stigma, and to increase the likelihood of discrimination. However, at other times, Christian theology has also, often, been successful in challenging society's injustices and bringing about change. Examples include the theological bases on which reformers argued for the abolition of slavery, and also the theological process that led to the Kairos document, which played such a notable part in hastening the end of structural apartheid in South Africa.

Stigma is difficult to define. Generally, though, it implies the branding or labelling of a person or a group of persons as being unworthy of inclusion in human community, and it results in discrimination and ostracization. The branding or labelling is usually related to some perceived physical, psychological or moral condition believed to render the individual unworthy of full inclusion in the community. We may stigmatise those we regard as impure, unclean or dangerous, those who are different from ourselves or live in different ways, or those who are simply strangers. In the process we construct damaging stereotypes and perpetuate injustice and discrimination. Stigma often involves a conscious or unconscious exercise of power over the vulnerable and marginalized.

The purpose of the present document is to identify those aspects of Christian theology that endorse or foster stigmatizing attitudes and behaviour towards people living with HIV and AIDS and those around them, and to suggest what resources exist within Christian theology that might enable churches to develop more positive and loving approaches. It is not a theological statement, but rather a framework for theological thinking, and an opportunity, for church leaders, to pursue a deeper Christian reflection on the current crisis.

We have identified the following major theological themes as ones that need to be addressed in any structured reflection on HIV and AIDS related stigma:

- God and Creation
- Interpreting the Bible
- Sin
- Suffering and Lamentation
- Covenantal Justice
- Truth and Truth-telling
- The church as a Healing, Inclusive and Accompanying Community

GOD AND CREATION

At the heart of the stigmatizing attitudes to HIV and AIDS that can be found within the churches lie widely differing understandings of God. Sometimes Christians have presented a model of a vindictive God who inflicts HIV and AIDS as a punishment for human sin. In contrast, we believe that God is a God of compassion, who delights in creation. HIV is a virus (albeit extremely dangerous to human beings), but not a divine punishment for sin.

God created us as unique persons and differentiated beings. God delights in our differences, and invites us to do the same. God created us as sexual human beings in all our differences. This is to be celebrated, enjoyed and treated responsibly. The story of the Garden of Eden is partly the story of human beings' alienation from their sexuality. God's gift to us is the capacity to enjoy one another as sexual beings, and it is we who have squandered that gift. God created us for one another and for God, and wants us to celebrate the gift of sexuality through which God's Creation unfolds.

The embodied human being is the temple of the Lord. The abuse of bodies is therefore an offence, both against God and against God's Creation, as well as being a sinful exercise of power. This includes the abuse, by men, of the bodies of women. Men and women are created equally. In honouring one another as sexual beings, we are honouring life itself. And yet HIV transmission is often linked with the vulnerability and abuse of women or of young boys or girls. Women cannot protect themselves from HIV, and nor can children, if their sexuality is controlled by others.

Images of God have often been used to support patriarchy, while interpretations of the Book of Genesis have led to the stigmatization of women's sexuality. These misreadings of the Scriptures have hampered the church's attempts to engage with the stigmatization of people living with HIV and AIDS and have thus diminished its capacity to help prevent HIV transmission.

God is present with the vulnerable and, in a special way, with stigmatized people.
We need to reclaim (and also to communicate to Christian believers) biblical images of God that are Trinitarian, non-patriarchal and grounded not in punishment but in divine love.

INTERPRETING THE BIBLE

Christian faith, as shown in the Bible, is central to Christianity. The Bible tells the story of God's ongoing concern for creation and humanity, and in doing so it has much to teach us about stigma. Nevertheless, the Bible has often been read and interpreted in such a way as to encourage stigmatizing attitudes and practices within the church, and to increase the stigmatization of the vulnerable and marginalized.

Historically the churches have often used the Bible for purposes of exclusion. In the context of stigmatization, attempts are being made to discover and reclaim texts that foster inclusion. It is not possible to find, in the Bible, an exact parallel to the stigmatization of those living with HIV and AIDS: and yet within Biblical tradition there are many examples that point to the way in which the stigmatized of the day were treated. We need to learn from the manner in which Jesus related to and responded to the stigmatized, for example lepers, Samaritans, a menstruating woman, and those with physical and emotional disabilities. Jesus mixed with them, included them, invited them into his circle of friends, touched them and, in turn, allowed himself to be touched by them. In the end Jesus submitted himself to the ultimate stigmatization of public crucifixion outside the city walls.

In seeking to reclaim these destigmatizing readings of the Bible, the following points may be made.

- The Scriptures themselves were written in particular contexts, at different times and they reflect the social locations of the authors.
- When we choose texts to support stigma, we are often refusing to acknowledge our own social context and the cultural traditions that have shaped our views.
- The two consistent themes of scripture are God's love and God's justice, by which God seeks to redeem creation and humanity.
- Since God's abiding concern is for our well-being or fullness of life, no passage from Scripture should be used to diminish this in any other human being.
- The life, death and resurrection of Jesus Christ offer hope and new life to all of humanity. They deal a deathblow to all stigma. They affirm the human worth shared by all humanity, created as we are in the divine image and sanctified by Christ's sacrifice.

Readings of the Bible must be Christ-centred, and linked to the context in which we find ourselves. We need to acknowledge insights, now available to us, which were not available to the biblical authors and previous generations of people studying or reading the Bible. These include the findings of modern biblical scholarship, and relevant anthropological and sociological research on biblical themes. They also include insights gained from contextual theologies, and from a deepening understanding, within the church, of issues of social justice.

SIN

Biblical faith understands sin relationally, namely as the breaking of our essential relatedness to God, to one another and to the rest of creation. Sin, therefore, is alienation and estrangement, and infects us all. Whether we have HIV or not, we are all sinners. As communities and as individuals, we have fallen short of the glory of God. To stigmatize the other is to deny this truth.

Understandings of sin, therefore, constitute an essential component of HIV- and AIDS-related stigma. Within this relationship, four main strands can be identified.

The sin of stigmatizing

The stigmatization of individuals is a sin against the Creator God, in whose image all human beings are made. To stigmatize an individual is to reject the image of God in the other, and to deny him or her life in all its fullness. This is not just a sin against a neighbour but also a sin against God.

The association between sexuality and sin

The stigmatisation of people living with HIV and AIDS has grown out of the mistaken link, often made in Christian thinking, between sexuality and sin. It includes the widely held assumption that HIV is always contracted as the result of 'sinful' sexual relations, and the additional tendency to regard sexual sin as the gravest of the all sins. So sex may come to carry the stigma of sinfulness, and is also stigmatized among other sins. Consequently, people living with HIV and AIDS are subjected to a deeper stigmatization that sets them apart from the so-called 'lesser' sinners.

It is true that HIV transmission occurs, in the vast majority of cases, as a result of sexual activity. But far from being inherently sinful, the responsible use of sex and human sexuality is part of God's Creation, to be celebrated and enjoyed. Within the context of faith today, there is a need to denounce the identification of sin with sex, as well as the stigmatization and the debased theology of sin that results from it. (It should also be stressed that HIV transmission does not result solely from sexual activity, and that unhygienic methods of collecting blood, failure by governments to screen blood donations, and the use of shared needles for injecting drugs can also cause HIV transmission.)

HIV and AIDS as punishment for sin

It is wrong to interpret HIV and AIDS (or other human catastrophes) as God's punishment for sin. This interpretation is damaging, because the judgmental attitudes that result are highly undermining to the church's efforts at care and prevention. It is also theologically unsustainable, a fact that is demonstrated powerfully in the Book of Job, and also in many of the healing narratives of the gospels. In reflecting on the connections between HIV transmission and sin, it is important to remember that many people who become infected bear no responsibility for their condition: namely babies born with the virus, abused women and children and faithful partners of unfaithful spouses.

Sin as failure to take responsibility

The threat posed by the HIV pandemic requires that human beings should act responsibly. We have a responsibility to be faithful in our sexual relationships. Those with HIV or AIDS have a special responsibility not to risk infecting other people. Those

who screen donated blood have a responsibility to be vigilant. And those taking blood or injecting drugs have a responsibility to ensure that the needles are sterile. A wilful lack of responsibility in any of these areas is dangerous to other people and, on that account, sinful.

In summary, if we are to combat stigma effectively, we need a more positive Christian understanding of sexuality, focused upon faithfulness, kindness and the care and protection of families. If we have HIV or AIDS, we should expect that our churches treat us compassionately and without stigma. The stigmatisation of others is a sin far greater than most of the so-called 'misdeeds' on which HIV infection is often blamed. After all, the sinful attitudes, most frequently identified by Jesus as being incompatible with His Kingdom, were pride, self-righteousness, exclusivity, hypocrisy and the misuse of power: all of them ingredients in the deadly cocktail that causes stigma.

SUFFERING AND LAMENTATION

As embodied and relational people we suffer. However, suffering has sometimes been considered a given, the unavoidable destiny of individuals. On other occasions, it has been regarded as a punishment for sin. Suffering may also be inappropriately exalted as a virtue. These interpretations have no place in Christian theology, which needs, rather, to emphasize the redemptive aspect of suffering, and to challenge those social structures that cause undue suffering and stigma. Jesus, after all, showed compassion for the suffering: a compassion that involved both strong feeling for suffering individuals and a determination to help and empower them. In the Cross of Jesus, God enters the suffering creation to heal it from within. Jesus showed solidarity with us, and compassion. On the Cross Jesus died, stigmatized and outcast, outside the city walls.

In gaining better insights into the nature of suffering and our response to it, we can seek to recover Biblical texts on suffering, and in this context it is helpful to draw on the rich biblical tradition of lament. Lament primarily articulates the cries of the suffering, but it can also give voice to the cries of the guilty seeking forgiveness and reconciliation. Lament offers us language which names the suffering, questions power structures, calls for justice and recounts to God that the human situation should be otherwise. Lament also expresses hope and trust in God's compassion and willingness to deliver us from suffering. It is both an individual and a communal activity. Given circumstances which (in St John Chrysostom's words) are 'grazed thin by death', how can we fail to lament? Thus lament can enrich church liturgies and pastoral care and contribute to a more truthful and intimate relationship with God by naming the 'un-nameable' to God.

COVENANTAL JUSTICE

The biblical concept of Covenant implies a reciprocal, binding relationship between God and human beings, which should be mirrored in the relationships that human beings have

with one another. Just as God has given us the grace to ask for God's friendship, human beings can justly ask certain things of the societies they build. However, the needs of the powerless are easily overlooked, especially if they are carrying the double stigma of poverty and HIV or AIDS.

It is no coincidence that HIV and AIDS are raging in the developing world. Of course impoverishment does not, in itself, cause HIV infection: the virus has manifestly affected both rich and poor in different parts of the world. Nevertheless it does exacerbate the problem. It leaves people economically poor, hungry, illiterate and with inadequate access to health-care services. In this situation, the impact of HIV and AIDS stretches poor nations' already limited resources to breaking point and makes it less likely that prevention strategies and caring programmes will succeed.

It is not enough to tackle the symptoms of poverty, although there are moments when such intervention is appropriate. In the long term, we must identify the root causes of impoverishment, which often lie in deliberately chosen political, social and economic policies. Unfortunately, rulers at local and national levels are often relatively powerless when it comes to taking on the banks and multi-national corporations with whom many of the strategic economic and political decisions lie. Nevertheless, political leadership should be challenged about the misuse of public resources, and this includes the disproportionate use of national budgets to acquire armaments, rather than allocating them to health, education and basic services for the poor. In a world disfigured by AIDS, we need especially to address political corruption.

Churches have tended to engage with the symptoms and condemn the causes, while failing to explore ways of addressing poverty's structural roots. For example, we are sometimes compromised because of our dependence, for support of our ministry, on those who make their wealth in poor nations. As theologians, we have not sufficiently promoted the church's social teaching, or challenged the church to rediscover its prophetic voice and ministry.

While some churches in the Global North have responded to the needs of their sisters and brothers in Christ in the South, there still exists a lack of global solidarity among those who claim unity in the Body of Christ. If we truly believe that HIV and AIDS are in the church, then no part of the Body of Christ is left unaffected, regardless of the separations imposed by geography, culture or tradition. The theological challenge to the churches must therefore be to re-examine their priorities in terms of ministry and of budgets, as they seek to engage with this crisis, this *kairos* moment.

TRUTH AND TRUTH-TELLING

Stigma feeds on silence and denial. Individuals sometimes keep quiet about their fears of being HIV positive because they are too afraid to seek help for themselves or their families. Institutions and communities may fear the stigma that will fall on them if members are found to be carrying a stigmatised condition. Thus the dread of

stigmatisation becomes more powerful than the demands of truth or the longing for wholeness.

This raises a number of theological challenges, for churches as well as for individuals. What should they teach or not teach about HIV, particularly to young people? What should they say or not say about individual members? What should individuals disclose or keep secret about themselves? How can our communities move beyond denial and become more accepting of those who speak the truth?

Jesus taught us that truth sets us free, and gave us the mandate to teach truth. However, churches often find this difficult. The truth sometimes exposes the gap between what their leaders and members preach and what they actually do. This creates a huge problem for individuals, for whom the disclosure of stigmatising information in an unsympathetic, stigmatising environment can be a fearsome and risky undertaking.

In relation to HIV and AIDS, experience has shown that the best form of prevention is truthful education. This applies to 'truths of fact' (what HIV is, how it is transmitted, how it can be prevented, and what will happen if a person becomes infected); but it also applies to 'truth of meaning', which is a theme which churches are well fitted to explore. 'Truth of meaning' relates to the meaning of suffering, the nature of sin, the relationship between life and death, and the search for the mind of God.

There is an urgent need to build communities that are welcoming, supportive and capable of breaking the silence about HIV and AIDS. Many churches are committed, in principle, to doing this. But it is hard to see how they can succeed without some painful soul-searching at the level of the institutions themselves, as well as of their hierarchies, clergy and members. For churches, truth-telling may involve an acknowledgement that they have been party to stigmatisation. They may have advocated 'bad theology' or failed to challenge it. They may have condoned a climate of silence and denial at institutional level, diluted or misrepresented the facts in their educational programmes, failed to provide strong, prophetic leadership, and been responsible for the poor moral example which sometimes exists within the churches themselves. It must be remembered that Jesus was particularly critical of religious people when he caught them out in hypocrisy.

THE CHURCH AS A HEALING, INCLUSIVE AND ACCOMPANYING COMMUNITY

The stigmatisation of people living with HIV and AIDS calls the church to ask itself what it means, in our time, to be the inclusive community that Jesus proclaimed**.** Churches have a fine record in the care of people living with HIV and AIDS and their families, care of orphans, and support for the families of those who have died; while today, in the context of HIV and AIDS, some churches are stretched to breaking point by the burden of funerals and of ministry to the sick and dying. But these efforts have not always been successful in tackling the stigma attached to HIV and AIDS.

As a community of disciples of Jesus Christ, the church should be a sanctuary, a safe place, a refuge, a shelter for the stigmatized and the excluded. The church is called to work towards both the prevention of stigma and the care of the stigmatized. And yet churches have habitually excluded and stigmatized those who were 'different', those who did not conform, and those who have sinned or were thought to have sinned. This challenges our understanding of the church's identity, and calls for deeper reflection on the issue of inclusion and exclusion within our communities. Jesus' ministry was inclusive to the point of scandalizing religious authorities and so-called 'respectable' people. In a time when people living with HIV and AIDS are being stigmatized and discriminated against within our churches, this suggests the need for renewed theological reflection on the nature and identity of the church itself.

If we acknowledge suffering we must be prepared to respond, and many church leaders are realizing the need for help and support at parish level. However, sometimes our ability to accompany suffering people is restricted by our lack of confidence, and by our sense that we do not have the necessary resources. Education is therefore needed for churches trying to accompany those who are carrying the stigma of HIV or AIDS. Also required is much sensitivity to the fears the stigmatized person may have about disclosure or further rejection. Appropriate resources will enable clergy, laity, and in particular young people to respond, so that the church may fulfil its task in a responsible, loving and dialogical way.

This role needs to be explored at the level of theological education, so that clergy and lay leaders go into parishes with some understanding of the dynamics of accompanying stigmatized and suffering people, of praying with them and their families, of 'standing and waiting' alongside them, and of loving them into hope.

In addressing stigma, people living with HIV and AIDS are the churches' most precious resource. They have been described as the 'wounded healers' of our time. Their full inclusion in all aspects of the church's life is the best possible strategy for changing attitudes and removing fear. The experience of living with HIV or AIDS raises profound questions about the meaning of suffering and the nature of God and in sharing these insights, the spirituality of the whole worshipping community may be enriched. People living with HIV or AIDS have commented that the liturgies and rituals of the Church have been a great source of strength, particularly when they are combined with the support of the worshipping community.

In our reflections on a church that says 'no' to stigma, we need constantly to revisit the Christ of the Gospel narratives, who has given us a paradigm for accompaniment, human relationships and Christian healing. We believe that our Scriptures encourage us to move beyond the stigmatisation and exclusion of the crucifixion towards resurrection, hope and redemption. The church must remain a church of hope even in a context of HIV and AIDS.

Workshop participants

This framework was formulated during a workshop held in Windhoek, Namibia from
8 – 11 December 2003, to which 62 Christian academics and theologians were invited. The final number of participants was 37, a further 14 signed up to support the framework later, having been unable to attend personally.

Participants:
Dr. Denise M. Ackermann, Professor Extraordinary at the Faculty of Theology of the University of Stellenbosch, South Africa

Dr. Richard Albertine, Professor at the Catholic Theological Seminary, Namibia

Richard W. Bauer, MM, LCSW, Chief Executive Officer, Catholic AIDS Action, Namibian Catholic Bishops Conference, Namibia.

Dr. Michael Czerny, SJ, Coordinator, African Jesuit AIDS Network, Kenya

Dr. Musa Dube, HIV/AIDS and Theology Consultant, World Council of Churches, Botswana

Dr Robin Gill, Ramsey Professor of Theology, University of Kent, United Kingdom

Rev. Janet Guyer, Regional AIDS Consultant for Southern and East Africa, Presbyterian Church United States of America USA. Living in South Africa

Dr. Douglas John Hall, Professor at the Faculty of Religious Studies, McGill University, Canada

Ms Linda Hartke, Coordinator, Ecumenical Advocacy Alliance, Switzerland

Rev Japé Heath, Coordinator, African Network of Religious Leaders Living with and Affected by HIV and AIDS, South Africa

Dr Paul John Isaak, Professor at the Faculty of Theology, University of Namibia

Monsignor Henri Isongoma, Bishop of Katanga, Anglican Church of Congo, Democratic Republic of Congo

Rev Dr Colin Jones, Programme Director, Office of HIV/AIDS Community Ministries and Mission, Church of the Province of Southern Africa (Anglican), South Africa

Rev Dr Thomas Kalam, Director, St John's National Academy of Health Sciences, Bangalore, India

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Bishop Dr Ambrose Moyo, Lutheran Communion in Southern Africa, South Africa

Dr Mercy Oduyoye, Director, Institute of Women in Religion and Culture, Trinity Theological Seminary, Ghana

Rev Lisandro Orlov, Iglesia Evangelica Luterana en Argentina y Uruguay, Argentina

Ms Gillian Paterson, Consultant, Paxworks, United Kingdom

Père Dr François Sedgo, President du Comité National Catholique du Lutte Contre le SIDA, Conférence Episcopale Burkina-Niger, Burkina Faso

Jan Bjarne Sodal, The Christian Council of Norway

Rev Monsignor John Strynkowski, Executive Director, Secretariat for Doctrine, United States Conference of Catholic Bishops, USA

Sr Dr Rose Uchem MSHR, Senior Lecturer, Spiritan International School of Theology, Attakwu, Enugu, Nigeria

Dr Vuadi Vibila, Faculty of Theology, Protestant University of Congo, Democratic Republic of Congo

Rev Robert Vitillo, Executive Director, Catholic Campaign for Human Development, United States Conference of Catholic Bishops, USA; Special Adviser on HIV and AIDS to Caritas Internationalis, USA

Rev Dr Spiwo Xapile, JL Zwane Memorial Church, Uniting Presbyterian Church in Southern Africa, South Africa

Rev. Magdalena Ya-Shalongo, Evangelical Lutheran Church in Nambia

Ms. Helene Yinda, World YWCA, Switzerland

The following persons were invited to the workshop but were unable to attend. However, to show support for the contents of this framework they have expressed a wish for their name to appear:

Dr V Munyika, General Secretary of Evangelical Lutheran Church in Namibia

Timothy Radcliffe OP, Blackfriars, Oxford, United Kingdom

Rev. Dr. Rebecca Larson, Executive Director, Division for Church in Society, Evangelical Lutheran Church in America, USA

Charles A. Briggs Distinguished Professor of Systematic Theology
Union Theological Seminary

Stuart C Bate, Professor of Religious Education and Pastoral Ministry
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Father Dr K.M. George, the Orthodox Theological Seminary, India

Dr. Steve de Gruchy, School of Theology and Religion
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Birgitta Rubenson, R.N., Lutheran Church of Sweden

Reverend Mvume Dandala, General Secretary, All African Conference of Churches, Nairobi, Kenya

Reverend Erny Gillen, President, Caritas Luxembourg, Luxembourg

Teresa Okure, S.H.C.J, Lagos, Nigeria

Reverend Canon Gideon Byamugisha, World Vision International, Kampala, Uganda

Professor Dr Mary Getui, Nairobi, Kenya

Doctor Robert Shreiter, Catholic Theological Union, Chicago, USA

HIV and AIDS: The Challenge and the Context
Stigma and Discrimination: Incarnation and the Namibian Experience

Father Richard W. Bauer, MM, LCSW is a priest with the Maryknoll Fathers and Brothers. He has been working with people with HIV and AIDS since 1982. He is currently Chief Executive Officer of Catholic AIDS Action, a program of the Namibian Catholic Bishops Conference. He is based in Windhoek, Namibia.

The first day of the workshop provided the concrete context in which we were to begin our deliberations. An attempt was made to incarnate our theological reflections in the actual lived experience of those affected by the HIV pandemic. Local Namibians were able to recount their own experiences of stigma and discrimination, yet each also clearly articulated their own need for support from their faith communities.

The workshop received and heard the experience of Maria Nashilongo, Godfried Kanao, Helena Nghinaengulwa, and Silvia Nghinhihange. Esther Andreas assisted with translation and Rev. Richard Albertine, MM facilitated the theological reflection.

HIV and AIDS: The Challenge and the Context
Why Should Churches Respond to Issues of Stigma and Discrimination in Reaction to HIV and AIDS?

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When first asked to prepare this presentation about why churches should respond to issues of stigma and discrimination in reaction to the pandemic of HIV and AIDS, I thought the effort might be unnecessary. Is it not a basic premise of Christianity that stigma and discrimination are contrary to gospel-based responses to the problem of HIV and AIDS or any other human challenge? Even after two thousand years, have we not been able to witness the example of Jesus, let alone be willing to "take up his cross" and follow him? Jesus' actions spoke of acceptance and welcome for those who would be considered automatic targets of stigma and discrimination by his contemporaries. He asked to be invited to the home of a tax collector, frequented the company of those considered defiled or of ill repute, saved the life of a woman caught in adultery, and deigned to speak with and seek a cup of water from a Samaritan woman and later offered her the "living water" that came from His Father.

Despite the teaching and tradition of the churches for these past two millennia and the extensive influence of the churches in most parts of the world, I regret to state that stigma and discrimination in reaction to HIV and AIDS continue to rear their ugly heads.

Attempts to "cast out" those affected by the disease - from villages, hospitals, educational institutions, and faith communities - have been experienced in virtually all parts of the world and among all racial and ethnic groups, as well as in all social and economic classes. Many governments at one time or another have enacted policies of forced isolation and restriction of travel by HIV-infected persons, while others have tolerated, and even encouraged, violence toward such individuals. This type of discriminatory behaviour tends to create fear and secretive activity, even among those who already have basic knowledge about the pandemic.

In one Caribbean country that I visited a few years ago, I heard the horror stories of how, when the infection was first known there, in the late 1980s and early 1990s, people found to be HIV-positive were picked up by the police, inserted into large plastic bags, and hauled off to one of many HIV isolation centres in the country. Even now, in this country, a pregnant woman who is diagnosed as infected with HIV is "strongly encouraged" to abort the baby carried in her womb. Moreover, although the policy of forced isolation in *sidatorios* (or asylums for persons living with AIDS) has been rescinded, only persons living in such institutions can qualify for health services,

medications, and other benefits from the government.

Studies in Côte d'Ivoire and South Africa show that, in places with extremely high HIV prevalence, women refused HIV testing or did not return for their results. In southern Africa, a study on needle stick injuries in primary health care clinics found that nurses did not report the injuries because they did not want to be tested for HIV. In one study on home-care schemes, fewer than 1 in 10 people who were caring for an HIV-infected patient at home acknowledged that their relative was suffering from the effects of this virus.1

UNAIDS has reported on a 2002 study conducted among some 1,000 physicians, nurses, and midwives in four Nigerian states, that resulted in some very disturbing findings related to discrimination by health care professionals toward people living with HIV:

- 10% of respondents admitted to having refused care to a patient with HIV or AIDS;
- 40% expressed the belief that a person's appearance could indicate his/her HIV status;
- 20% claimed that persons living with HIV or AIDS had behaved immorally and thus "deserved" his or her fate.

Some of the root causes behind such prejudicial attitudes noted in this study were seen as the following:

- fear among doctors or nurses of exposure to HIV in the health care setting due to lack of protective equipment;
- frustration at not having medications to treat people with HIV or AIDS.2

UNAIDS also conveyed reports about experience of stigma or discrimination as recounted by people living with HIV or AIDS:

- In the Philippines, 50% of respondents said they had encountered discrimination at the hands of health-care workers;
- In Thailand, 11% of respondents claimed to have been denied medicine because of their seropositive status, and 9% reported delays in receiving treatment;
- In India, 70% of respondents said they had faced discrimination, most commonly in families or within health-care settings.3

Other studies have shown that, in many countries, people living with the virus are not allowed to decide how, when and to whom they will reveal their sero-status. Respondents to such surveys in India (29%), Indonesia (38%), and Thailand (40%) indicated that their HIV status had been revealed to other persons without their consent. In fact, many

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1 AIDS Epidemic Update, UNAIDS, 2000.
2 *AIDS Epidemic Update*, UNAIDS and World Health Organization, December 2003, p. 31.
3 *Ibid.* p.32.

respondents said claimed that test results were shared with persons other than their respective spouses or other family members.4

In my opinion, the most objectionable - and sinful - forms of discrimination and "scapegoating" occur under the guise of religious denunciation of people affected by HIV and AIDS. While visiting many different countries to facilitate HIV and AIDS workshops for pastoral personnel, I have heard the "horror stories" of pastors refusing to anoint HIV-infected people or forcing them to publicly confess the "sins" that caused them to be infected. A document published by UNAIDS also has detailed such occurrences. It relays the testimony of one woman who was both active in her parish and in the local HIV and AIDS support group. She was forced to leave her parish because the priest accused her openly of "living in sin"; another of her peers in the same parish was forced to publicly confess her "sin" of being HIV-infected. In Cameroon, some people living with HIV or AIDS were invited to the front of the congregation for special prayers because they had "sinned and would be punished up to the 5th generation".

Once, when I travelled to an Asian country in order to facilitate a workshop for religious leaders there, I was asked by one of the participating bishops whether I believed that AIDS could be a punishment by God for those who are promiscuous. This bishop was dissatisfied with my negative response and queried both persistently and insistently, "Have you not read the Old Testament where God does such things?" I replied that I had indeed read the Old Testament but had also read and reflected on the New Testament in which Jesus brought a message of acceptance and reconciliation. The leader was not one to concede and thus continued to stress his point that promiscuous people deserved to be punished. Finally, I pointed out to him respectfully but forcefully:

- that, while sexual transmission was the most frequent means of contracting the virus, it certainly was not the only one;
- that, even among those who had been infected by sexual means, many (especially women) had been faithful to one partner - namely, their husbands - for life;
- that many of history's greatest saints - including Saint Augustine - had admitted to being "promiscuous" at one or other time in their lives and yet none was reputed to have been punished with a virus sent by God;
- and, finally, that I simply could not place my faith and hope in a capricious, vindictive and punitive God.

During the coffee break, many of his fellow bishops complimented me for my response, but none of them were willing to support me during the discussion which had been held earlier.

The discriminatory behaviour of some religious leaders may be based more in ignorance or fear of infection or of negative reactions by others than on punitive attitudes such as those mentioned earlier. On one occasion, a member of the hierarchy asked me how to "spot" people with AIDS so that he and his priests could avoid coming too close to them. The pastor of a parish in Scandinavia once invited me to speak about AIDS in his church;

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4 *Ibid.* p. 32.

upon my arrival, he seemed very concerned about what I would say. I re-assured him that I would never cause scandal in his pulpit. He then admitted that he had never included the word "AIDS" in any of his homilies or public prayers even though this epidemic had already deeply affected numerous people in his country. I also recall vividly one religious sister who selflessly directed a rural hospital in a developing country; despite the fact that her hospital was treating large numbers of patients with AIDS-related illnesses; this sister became so anxious about the pandemic that she sputtered and choked each time she attempted to say the word “AIDS”.

The first and, in my opinion, the most compelling reason for churches to be engaged in combating stigma and discrimination is, as I mentioned in the opening of this presentation, the lived experience of Jesus Christ when He walked among us on this earth and that of the Holy Spirit who continues Jesus’ presence among us to this very day. Both the doctrine and tradition of the churches have been built upon Jesus’ preaching, His sacrifice on the Cross, and His resurrection from the dead. These salvific experiences should guide us to a selfless and non-judgmental acceptance of all in the human family, and, most especially, of the most vulnerable and marginalized in society. My frame of reference for church teaching in this regard is from the Catholic tradition, and I will base my reflections and conclusions on that tradition. I am certain, however, that each of you present in this workshop can present equally insightful and inspiring examples from your own respective doctrinal traditions.

Pope John Paul II has made frequent and emotional appeals to avoid discriminatory treatment of people living with HIV or AIDS. In his visit to AIDS patients in the United States (1989), he held out the unconditional love of God himself as the guideline to be followed:

> God loves you all, without distinction, without limit … He loves those of you who are sick, those suffering from AIDS. He loves the friends and relatives of the sick and those who care for them. He loves all with an unconditional and everlasting love.5

The bishops of the Southern African Catholic Bishops’ Conference leave no room for any possibility of stigmatisation or marginalisation based on the false premise that God has “willed” AIDS for sinful individuals:

> ***AIDS must never be considered as a punishment from God.*** He wants us to be healthy and not to die from AIDS. It is for us a sign of the times challenging all people to inner transformation and to the following of Christ in his ministry of healing, mercy and love.6

In their October 2002 pastoral statement, the bishops of Chad are even more strident in their condemnation of so-called “faith-based” discrimination:

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5 Pope John Paul II, Address given at Mision Dolores, 1989.
6 *A Message of Hope to the People of God from the Catholic Bishops of South Africa, Botswana, and Swaziland.* July 30, 2001.

> We sometimes hear people say that AIDS is a punishment from God. This belief sometimes prompts us to point fingers at people, to stigmatize, to isolate our brothers and sisters who suffer from AIDS. Many people say that they are sick 'through their own fault', or because they have sinned. In the Gospel of John, to a question put to Him on the origin of evil concerning a person who was born blind, Jesus answers : "Neither this man nor his parents sinned …" (Jn. 9, 3). Indeed, God loves the man to the extent that He cannot wish his death. God cannot contradict His act of love. He cannot call Himself Love and at the same time want the suffering and the death of the man …! AIDS is not therefore a punishment from God.7

A second cogent reason for the churches to be involved in combating stigma and discrimination comes from its divine mandate to be of service. In his powerful and prophetic vision of the Last Judgment (Mt. 25:31-46), Jesus went as far as identifying himself with those who are hungry, and naked, and sick, and imprisoned and proclaimed that personal salvation itself would be conditioned on an adequate response to the needs of the poor. The early Christian community immediately dedicated itself to the work of diaconal service by sharing the goods of creation with one another according to their needs (Acts 2:44; 4:32-34), caring for the widow and orphan (James 1:27), avoiding the accumulation of wealth and the unjust treatment of their employees (James 5:1-6), and appointing deacons to ensure that the needs of the poor were met and that justice was served within the community (Acts 6:1-7).

From our reading of church history, we know of the active tradition of Christians in the works of charity. Many religious orders were founded during times of public health and other social crises in order to preserve life itself and to comfort the sick, dying and bereaved. Many of the first hospitals, orphanages, social service agencies, and schools can trace their roots to such undertakings and continue to serve those in need not only with professional excellence but also with compassion and integrity.

Several years ago I was asked by the Catholic Health Association of India to assist them with writing guidelines for care of AIDS patients in their affiliated institutions. Some of the administrators present for this small working group admitted with regret at that time that some such patients were being turned away by Catholic facilities. At the same meeting, there appeared a man from the United States who identified himself as a "sociologist" and "expert" on HIV and AIDS and who quickly betrayed himself as a disciple of U.S.-based scientist who denies that HIV is the cause of AIDS. This so-called "expert" caused great havoc during our meeting, since he tried to convince the participants that HIV could be transmitted by casual or even air-borne means and that admission of an AIDS patient to one of their surgical theatres could contaminate the hospital. I must admit that the man tested the limits of my civility.

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7 Catholic Bishops of Chad "Statement on HIV AND AIDS", October 2002.

I cite this experience not so much for its extremely negative nature but rather to point out the strength of the Christian call for service. By the end of the meeting, the working group members had rejected the message of gloom and doom brought by the man who counselled against the care of AIDS patients. Moreover, they endorsed a strong statement that insisted that Catholic health facilities in India open their doors to those affected by the pandemic. This same call to service was re-articulated by the Chairman of the Health Commission of the Catholic Bishops Conference of India when he said on the occasion of World AIDS Day 2003:

> All the Catholic healthcare institutions, as we are serving the Lord in the abandoned and afflicted, will admit and care for the people living with HIV or AIDS. As Blessed Teresa of Calcutta used to say, 'a person affected by HIV and AIDS is Jesus among us. How can we say no to Him?' Every baptised [person] is invited to show compassion and love to those already infected. The family members of the person infected play a major role in the home-based care, which is palliative in nature. Families and caregivers at home need to be trained in day-to-day care of the patient. We need to know how to fight this disease, while taking care not to discriminate and stigmatize the infected. 8

Finally, I would like to cite the churches' calling to be an advocate for and with those who are excluded from the mainstream and rejected by others in society as one additional reason for it to be engaged in combating AIDS-related stigma and discrimination. In an address to the bishops of Honduras, Pope John Paul II said:

> The Church must be attentive to the clamour of the neediest … It must not be forgotten that concern for the social is part of the Church's evangelizing mission and that human development is part of evangelization, because the latter tends toward the integral liberation of the person.9

This vocation to serve as advocates has led many religious leaders and their followers to speak out against the unjust situations that lead to the further marginalization of people such as those living with HIV or AIDS and thus deprive them of such essential resources as access to balanced nutrition, to basic medicines and health care, and to the combination, anti-retroviral medications that could prolong and even improve the quality of their lives. Thus, in June 2002, the African Religious Leaders Assembly on Children and HIV and AIDS committed itself to:

> Advocate with all levels of government and their agencies to establish policy priorities and devote resources that adequately support and protect

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8 Bishop Bernard Moras, Chairman, CBCI Health Commission, *The Challenge to be His Light Today: A Message for the World AIDS Day 2003,* October 18, 2002, Feast of St. Luke.

9 "Pope Urges Equity in Wealth Distribution: Receives Honduran Bishops in Audience," Vatican City, December 4, 2001 (Zenit.org).

> children, in particular we will push African governments and the international community to fulfil the commitments they have made through the Abuja Declaration, the Global Fund for AIDS, TB, and Malaria, and at G8 Summit meetings, as well as at United Nations General Assembly Special Sessions on HIV and AIDS (June 2001) and Children (May 2002).10

In his statement to the UN Special Session on HIV and AIDS, Javier Cardinal Lozano Barragan, President of the Vatican's Pontifical Council on Health Care, linked the HIV and AIDS pandemic with other structural injustices present in the world and demanded a change in such misplaced global priorities:

> An important factor contributing to the rapid spread of AIDS is the situation of extreme poverty experienced by a great part of humanity. Certainly a decisive factor in combating the disease is the promotion of social justice, in order to bring about a situation in which economic consideration would no longer serve as the sole criterion in an uncontrolled globalization.11

In his statement to the 2001 World Health Assembly, Cardinal Lozano focused more specific attention on the denial of access to appropriate treatment for people living with AIDS in developing countries, which constitutes another form of AIDS-related discrimination:

> It is necessary to expand the list of generic medicines destined for the majority of the worldwide population, and to promote national legislation and international agreements in order to counter the monopoly of a few pharmaceutical industries and thus bring down prices, in particular, of products destined for developing countries. Finally, it would be necessary to promote agreements for the proper transfer of health-care technology to these countries.12

These advocacy efforts have resulted in slow but positive action toward eliminating the divide between the "haves" and the "have nots" in AIDS care. The bishops of Southern Africa played a key role in pressuring the South African government to re-consider its resistance to making anti-retroviral therapies available in order to prevent mother-to-child transmission of HIV. The Catholic Medical Mission Board, based in New York, has succeeded in negotiating with pharmaceutical companies to make such medications available *gratis* or at very low cost. Its "Born to Live" Initiative is facilitating the implementation of prevention programs in Southern Africa, and more recently in Haiti,

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10 Plan of Action by 'African Religious Leaders Assembly on Children and HIV AND AIDS' 9-12 June 2002, Nairobi, Kenya

11 Javier Cardinal Lozano Barragan, Statement of the Holy See to the UN Special Session on AIDS, New York, June 2001.

12 Javier Cardinal Lozano Barragan, Statement of the Holy See at World Health Assembly, 2001.

and includes voluntary testing and counselling for pregnant women, administration of nevirapine to the mother during labour and to the newborn within 72 hours of birth, antibiotic therapy, as well as encouragement of 24 weeks of exclusive breast-feeding by the mother, and longer-term nutritional alternatives for the child.

In August 2001, Caritas Internationalis convened religious, development and health professionals, mainly from developing countries, to articulate guidelines for the responsible use of anti-retroviral therapies as they become more available in those parts of the world. Particular concerns were raised regarding continuity and sustainability of such programs, involvement of locally-affected people in the formulation of protocols, and the need to avoid discrimination in outreach to potential beneficiaries.

In May 2003, a consultation was convened in Nairobi by the World Council of Churches, Caritas Internationalis, and the World Conference of Religions for Peace to assist representatives of faith-based organizations in developing countries to access funds from the recently-established Global Fund to Fight HIV, Tuberculosis, and Malaria. The participating FBOs discerned the need to better research and report on successes and failures in the field of HIV and AIDS education and service. They committed themselves to "scale up" their responses in a measure that corresponds to the rapidly mounting needs of local communities affected by the pandemic.

Why should churches be engaged in combating stigma and discrimination as these phenomena rear their ugly heads in the presence of AIDS–affected people throughout the world? In my opinion, churches have no choice but to respond in this manner. As communities of Christian believers sent on an apostolic mission to proclaim the gospel of Jesus to all who would listen to it, churches must teach the truths that God loves all men and women equally, without regard to their HIV status. In similar fashion, churches are called to be servants, most especially of the poor and vulnerable. In many parts of the world, people living with or otherwise affected by HIV and AIDS can be counted among the "poorest of the poor" and thus have a right to demand compassionate and non-judgmental acceptance and care by local parishes and by faith-based organizations. Finally, the commissioning of churches to speak out for and with the poor puts them front and centre in the struggle for equitable access to the goods of creation, including both essential and more sophisticated anti-retroviral medications.

I will close with the words of Pope John Paul II in his apostolic exhortation subsequent to the convening of a special synod on Africa:

> "The battle against AIDS ought to be everyone's battle. Echoing the voice of the Synod Fathers, I too ask pastoral workers to bring to their brothers and sisters affected by AIDS all possible material, moral and spiritual comfort. I urgently ask the world's scientists and political leaders, moved by the love and respect due to every human person, to use every means available in order to put an end to this scourge."13

13 Pope John Paul II, *Ecclesia in Africa*, 14 September 1995, #116.

HIV and AIDS: The Challenge and the Context
HIV and AIDS Related Stigma: Living with the Experience

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In May 2000 I tested HIV+. I can remember my first thought with great clarity, I was not afraid to die, I was not angry, I did not question why this was happening to me; for me my first thought was one of great sadness, because I knew that I was not going to be able to watch my only child grow up. From all the information which I had received as part of the prevention messages, I knew that I would die, and die soon. Of course over time I realised that this did not necessarily need to be so, but right in the beginning I had been filled with this great sadness.

I knew I needed to tell my family, but I did not what to give my family the message which I thought I had first heard. When I first tested HIV+ I already had a viral load of over 500000, and a CD4 count of under 250. This meant that I was ready for Antiretrovirals almost immediately. I was on the church medical aid but believed that if the Church found out that I had AIDS, as I did, I would loose my job. So I sought to find a trial that I could participate in. Baragwaneth Hospital was running a number of trials, and I qualified for a trial call "Charm". Charm was all about seeing just how much medication the body could take, and testing to see whether a control group given steroids in addition to the Antiretrovirals would have fewer side effects. I was put in the group with maximum Antiretrovirals, but no steroids. So I started treatment on 5 drugs; AZT, 3TC, ABC, Novirapin and Hydria. Up until that moment I had never been ill, had never had any opportunistic infections, but now I was sick. I became so nauseous that I could keep nothing down. I was taking medication to try and control the nausea as well as the other drugs. I was told by my doctor that I had to keep the medication down for at least 30 minutes. I remember sitting with a friend of mine, taking the medication and then lying down in the vain hope that I would be able to keep it down. I would ask Murray, "Is it half and hour yet?" No. Wait a while, "Is it half an hour yet?" OK now it is. Jump up immediately and be violently ill. In less than three weeks I had lost over 10 kg's, and I felt as if I had something stuck in my throat permanently. When I had this checked out, they found that all the vomiting had caused me to tear my oesophagus.

As soon as I had got onto the medication I told my family that I was HIV+. For me it was a case of not wanting to tell my family that I am going to die, but rather tell them that I have an illness which is now medically under control. It didn't work of course, because just as when I had first heard I was HIV+ I had thought this meant I was going to die, my family had the same reaction. To this day I have virtually no contact with my father. My mother had died a year before I tested HIV+, and he has just not been able to

allow himself a relationship with yet another family member who is dying. My sisters have been wonderful, and from the first they have been hugely supportive of me.

HIV and stress are not good friends. The one eats on the other in a vicious circle. I therefore decided that I needed to go and tell my bishop. I could no longer live with the pressure of thinking that my job was constantly under threat. I can remember the day very well. We were having a clergy quiet day. The bishop had taken a room in the retreat centre where his clergy could come and see him if we had something we wanted to talk to him about. I was already so weak from my bad reaction to the antiretrovirals that I could hardly climb the steps up to the room he was in. I just fell into the chair in front of my bishop and said to him, "Bishop Brian, I am HIV+. I can't cope with the stress of waiting for you to find out from someone else, so here I am, I'm telling you, so if you are going to fire me please just do so now."

I must give Bishop Brian credit; he did not fall out of his chair. And I think he then really sought to help me in the best way he knew. He said to me; "Thank you so much for telling. Please don't tell anyone else." He also told me that he looked forward to may years of ministry with me. Bishop Brian told me that if my HIV status became known, he would have no way of guaranteeing me a job in the diocese. I really believe that what the bishop said and did he believed to be in my best interest, but the reality is that in many senses it bound me from being effective within the field of HIV & AIDS for a number of years.

By the following year I had been taken off my first set of medications, been in Hospital with serious complications because of Lactic Acidosis, been introduced to one set of medications which I had to be removed from because the medical Aid would not pay, and been put on to what was then my third regiment of Antiretroviral therapy. My health was good, and I was continuing my ministry within my parish as if nothing at all had happened, but deep in my soul I knew that I needed to be doing something more. I tried a number of ways of getting more involved in the field of HIV within the diocese, but nothing seemed to fit or work.

I share my home with another pastor who is HIV+, Paul Mokgethi. Paul's family knew that both of us were HIV+. Paul's brother came to us and asked us whether we could help a friend of his who was dying of AIDS related illnesses. This was the beginning of a new ministry for me. Over the next year we took various people into the home and nursed them back to health, got them on treatment where it was necessary, and sent them home. It was terrifying to see the level of ignorance which both families of these people as well as doctors they were taken too had. In one case we had a young man called Allen brought to us. Allen was so sick when we were called in that he could no longer eat, he could no longer walk, and he was just lying back in his bed waiting to die. At that stage his family had already had him to some 15 different doctors or traditional healers in and around Johannesburg. In all they had spent some R30000 on rubbish medication for Allen, and not one of the 15 doctors or traditional healers had even suggested antiretroviral therapy. I took Allen to my doctor. At that stage his CD4 count was 32, and his viral load was through the roof. Because of the family's financial resources now

having been dried up to all intense and purposes, Roland put Allen on duel therapy. We had two big issues to deal with, the one was that Allen believed that he was going to die, and that no one could help him. The other was that his mother had a need to nurse Allen constantly, preparing him for a good death. I asked for Allen to be brought to our home. Allen was carried into our home because he could no longer walk. Every meal was a trial because Allen had long since stopped eating. Keeping his medication and his food down became a major issue, and then we had to try and get Allen to move again. What followed was a month of bullying Allen back into life. At one point I sat Allen down and said to him "Allen in this house everyone is HIV+. Here there is no special treatment. If you what to live, I will help you live, but if you just want to die go and do it somewhere else, but make up your mind." Allen decided to live.

Today, two years later, Allen is healthy, has a CD4 count of 640, an undetectable viral load, is working full time and is engaged to a beautiful young girl who knows his HIV status, and will therefore never be at risk. I believe God sent Allen to me so that I could see what was really possible. After Allen I did not need to look for an HIV ministry. People came to me in their droves because among people living with HIV I became known as the HIV+ priest who could save life, not something I could always live up to.

In the August of 2001 the Archbishop of Cape Town called an all African Anglican consultation on HIV & AIDS. I bribed my way into it. Bart Cox who ran the Johannesburg Diocese AIDS desk knew I was HIV+ and allowed me in on the understanding that there was no accommodation for me, and I would drive in and out every day.

Two things of great significance happened for me at that consultation. The first was that I saw Canon Gideon Byamugisha get up and tell us that he was a priest living with HIV. Suddenly I was not alone. I felt that for the first time there was someone who I could talk to and someone who would understand.

Later in that day Bart Cox made an announcement that all the PLWA's needed to stay behind after the service. This was my first conference on HIV ever. I had no idea that it was standard practice to invite some people who were living with HIV so that delegates would know that there were people living with HIV in their midst. So when Bart had made his announcement, I knew I was HIV+ and so I stayed behind. There were quite a few people who were rather shocked. But Gideon, seeing me there also stayed behind, and so it was that he sat down and spoke to me about his dream of arranging a retreat for clergy living with HIV.

This dream was eventually made a reality in February 2002. Sadly the stigma was so strong that the only way Gideon was able to get people there was to advertise it as a retreat for clergy living with or affected by HIV or AIDS. This in tern meant that of 40 participants who travelled to Mount Claire in Zimbabwe, only 8 were actually HIV positive. Out of that retreat came a statement of resolve or intention. Those of us living with HIV were going to go out there and be advocates, make a difference, break stigma and discrimination.

I returned back to my diocese full of vim and vigour. First person I went to was my Bishop. Bishop Brian had to sit and listen to me rambling in my enthusiasm. I told him that I thought that I should move to a position of being more involved in HIV and AIDS work in the diocese, and that for this reason I needed to disclose my HIV status.

Bishop Brian was very affirming of the idea, and said to me that as soon as I was able to raise my salary for 5 years he would be delighted to release me to that ministry. He felt that 5 years of work in this area would place the church in a position that my HIV status would no longer exclude me from being accepted by a parish. Needless to say, I have not been able to raise 5 years salary, and so this has never happened.

In April of this year the Church of the Province of Southern Africa launched a major three year program funded substantially from DIFID and Christian AID. This program focuses strongly on the breaking of the stigma and discrimination around HIV & AIDS, and the enhancing of care being extended to people living with and affected by HIV and AIDS. This program is called *Isiseko Sokomeleza* or Building the foundation. We had a large and wonderful launch service of *Isiseko Sokomeleza*. Christian AID needed to interview someone, preferably a priest, who was living with HIV. The message was given to the Archbishop, who leaned over to my Bishop in the service and asked him if he had anyone. 5 Minutes later someone came tiptoeing down the central aisle to where I was sitting giving me the message that if I wanted to break the silence I would now be allowed to.

In September of this year I was invited to participate on a panel discussion at the beginning of ICASA. After that talk I was suddenly invited all over the place and I thought the time had come to speak to my congregation. So on the Sunday closest to St. Luke's day, we held a service focusing on the Stigma and discrimination around HIV and AIDS. At that service I disclosed my status to my congregation. Standing up and telling a congregation of people that I was HIV+ was one thing, standing at the door to greet everyone after the service was quite another. To my congregation's credit, no one skipped me at the door. Every one was very affirming and supportive. I have since heard of a few incidents in the parish. One of my parishioners, a gentleman, said to another, a lady that he did not think he could any longer go to Christ Church because "The priest has AIDS". The said lady in my congregation then started attacking him with an umbrella, and shouting at him, "Ho dare you insult Father. Father is our priest, he needs our support."

Lessons learned:
This closing section is not as fully developed as I would have liked and is taken from my notes, but it is a summary of the important lessons that I have learned through this whole process. Maybe I will find the time to write it up more fully one day.

1. Disclosure is not a one off event, it is a constant process.

2. There are some common misconceptions around in society which one has to deal with all the time. In summary AIDS equals SEX, equals SIN, equals DEATH, in the minds of many people And more specifically:
    a. AIDS is God's punishment for sin
    b. It's not our problem
    c. We have no one living with HIV in our congregation

3. The church's inability to affirm sex and sexuality is a major problem in dealing with HIV or AIDS. This leads to a multitude of different responses from those who are HIV positive and those who are negative as listeners.

4. The Anglican theme, `towards a generation without AIDS`. Led me to think: `Must I die to make my church's vision come true. `

5. The use of language is extremely important surrounding HIV and AIDS. This was also mentioned by Prof. Denise Ackerman. We should use affirming language for example: `Living with` rather than `suffering from,` tested positive` rather than `infected with.` The language of prevention could be effective in prevention if it were carefully chosen, but often promote misunderstanding and advances stigma for example: ABC"D" does the D stand for discrimination?

6. Holistic Care is critical in our approach to those living with HIV or AIDS. People may need help to access adequate nutrition and appropriate medication. Families and churches may need encouragement to support PLWH or AIDS. Counseling should be for life, not a good death.

7. There are lots of misunderstandings surrounding healing. I heard a story from Swaziland, telling how you must now stop using ARV's, you have been healed.

8. It's not only people living with HIV who need healing, but also the Church. I believe that God has that God has allowed HIV to heal the Church, to force us to become Christian.

9. ANERELA+

HIV and AIDS: The Challenge and the Context
Conceptualizing Stigma

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Introduction

Stigma, we are told, is the most powerful obstacle to the prevention of HIV transmission, and to the implementation of effective care for people living with HIV or AIDS. When people fear that they are HIV positive, but know that they will not be in a position to access effective treatments, there is little incentive for them to seek help or change behaviour. If they do so, they are risking the stigma attached to those who are known to be living with HIV or AIDS, and which spreads out, in waves, to their families, their survivors, and others who are close to them. Treatment may be available to prevent mother-to-child transmission, but pregnant women may not come forward to ask for it. Rather than risk the stigmatization and discrimination that will follow if they are discovered to have HIV or AIDS, they may prefer to take the risk of giving birth to an HIV positive child. So stigma is a problem. It is a moral problem, and a spiritual problem; and for churches, it is also a theological problem.

But just what is stigma? Stigma and stigmatisation have theological *implications*, and our scriptures are full of descriptions of stigmatisation in action, but they're not (or at least not primarily) theological *concepts*. For a deeper understanding of what we are talking about, in discussing stigma, we must turn, rather, to the work of sociologists, public health professionals, anthropologists and psychologists: and even here we may not find much clarity. Almost all academic texts on stigma open with the comment that existing definitions are 'vague and uncritical', or 'provisional and off the cuff'.

I don't actually agree with this view. Yes, stigma is complex and multi-facetted. Yes, stigmatised categories vary with the cultural and historical context. A one-size-fits-all definition will never work. But conceptualisations of stigma, complicated and contextual as they may often be, will not necessarily be vague and uncritical. In this paper I intend to look at five different, reasonably coherent attempts to conceptualise stigma, and suggest how they might prove helpful in our present task.

A Medical Perspective[14]

Medical views of stigma are mainly concerned with it as something that reduces the effectiveness of public health strategies. Weiss and Ramakrishna offer the following definition.

'Stigma is a social process or related personal experience characterized by exclusion, blame, or devaluation that results from an adverse social judgment about a person or group. The judgment is based on an enduring feature of identity attributable to a health problem or health-related condition, and this judgment is in some essential way medically unwarranted.

But all exclusionary measures should not be defined as stigma. For example, it may be judged *appropriate* to protect health personnel from actively infectious tuberculosis patients with tuberculosis, but *stigmatizing* to continue with such measures after treatment has been started and there is no further risk[15]. Also, the nature of stigma may vary in different cultures. Public health measures need to take into account local concepts and categories based on anthropological and epidemiological research. This is particularly true in resource-poor countries, where it is too often (and wrongly) assumed that insights gained from high-income countries are applicable everywhere.

Leprosy is an example of stigmatized disease with a known history. 'Like HIV/AIDS,' say Weiss and Ramakrishna, 'the motivation for examining the stigma of leprosy has been to help manage the social exclusion, the emotional suffering, and the barriers to effective health care that follow from local cultural meanings of the disease.[16]' As a general rule, the best formula for reducing the stigma of leprosy has proved to be the easy availability of interventions to control the disease. 'From the early 1980s, leprosy control programs have made effective use of the simple message, "leprosy can be cured". As the message became believable, it changed the condition from a transformation of personal identity to a treatable disease, and by doing so, it countered the impact of stigma that prevented people from even considering treatment.[17]'

For our purposes, the lesson is inescapable. For as long as a disease is regarded as untreatable, the stigma remains. Convince people that it is treatable, and the stigma diminishes; convince them that it is curable, and strategies for controlling it stand a real chance of success.

The strength of the medical approach to stigma is that its objectives are clear, and it is embedded in dominant discourses about public health that are scientific and also institutionalized. It has weaknesses, though. First, it generally lacks the capacity to come to grips with the systemic implications of stigma, and also with the way it is embedded in the hearts both of the stigmatizers and their victims. In addition, it tends, inevitably, to

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[14] Mitchell G Weiss and Jayashree Ramakrishna, *Research on Reducing Stigma*. Address to Stigma and Global Health Conference 2001 (in publication, but available on website)

[16] Weiss and Ramakrishna 2001

[17] Weiss and Ramakrishna 2001

turn for answers to scientific paradigms of disease, although in practice those answers may lie elsewhere. The anthropologist-priest Gerry Arbuckle has focused his recent work particularly on the role of churches in health care provision. Arbuckle proposes a helpful distinction between *disease* and *illness*. '*Disease*,' he says, 'describes scientifically or medically endorsed breakdowns of a physical or biological nature, whereas *illness* is the subjective experience of the individual or the knowledge that one is ill.[18]' The idea of 'disease' is *scientifically* constructed. The idea of 'illness' is *socially* constructed, and it includes the pain of stigmatization: an observation that has great relevance for the healing narratives of the gospels.

Goffman's *Stigma*[19]

One work that is generally regarded as a canonical text for students of stigma is Erving Goffman's *Stigma*, published in 1963.

The origin of the word, says Goffman, came from the Greeks, who 'originated the term *stigma* to refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier. The signs were cut or burnt into the body and advertised that the bearer was a slave, a criminal or a traitor – a blemished person, ritually polluted, to be avoided, especially in public places.'

Goffman's definition distinguishes between three types of negative stigma, connected with 'abomination of the body, blemish of individual character, and membership of a despised social group[20]'. The element they have in common, he suggests, is 'spoilt identity'. However, the real problem is not the 'abomination', the 'blemish' or the 'membership'. Stigma, says Goffman, is not ultimately to do with *attributes* but with *relationships*. 'An attribute,' he says, 'is neither creditable nor discreditable as a thing in itself.'[21] Race and gender are examples that spring to mind. For me, being white or female can count as stigmatizing attributes in all-black or all-male gatherings, but may be passports to entry in gatherings where they constitute the norm, namely groups that are either mainly white or mainly female. Thus a stigma, says Goffman, becomes 'a special kind of relationship between attribute and stereotype'[22].

Stigmatized people learn to manage this situation by cultivating categories of 'sympathetic others', in whose presence they can be sure of acceptance. Goffman calls these 'the own' and 'the wise'. The 'own' are those who share the stigma, among whom the stigma itself may become an advantage. In this group, the person is free to speak openly and without pretence, and is thus able to develop his or her own 'story'.

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[18] Gerald A Arbuckle, Healthcare Ministry: Refounding the Mission in Tumultuous Times. Collegeville Liturgical Press 2000, p14

[19] Erving Goffman: Stigma – Notes on the Management of Spoiled Identity. First published 1963; London Penguin 1990

[20] Goffman 1963 ed 1990 p.14

[21] Goffman 1963 ed 1990 p13

[22] Goffman 1963 ed 1990 p14

The 'wise', on the other hand, consist of persons who are what he calls 'normal', but whose relationship with the stigmatized individual gives them 'courtesy membership of the clan.[23]' These may be friends and family members, or those who are involved professionally with the stigmatized group. As Goffman points out, the problems faced by stigmatized persons spread out in waves, but of diminishing intensity,' so that these individuals may – to some extent - come to share the stigma.

Sometimes the stigmatized condition is obvious. Sometimes society finds ways of *making* it obvious: Jewish people in Nazi Germany being made to wear a yellow star, for example, or leprosy sufferers to carry a bell. But often the stigmatized condition is invisible: mental illness, for instance; or in our case, HIV infection. 'The issue then,' Goffman says, 'is one of managing information…. To display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; in each case, to whom, how, when and where.'[24]

One answer is 'passing', which Goffman claims everyone does from time to time, and which can be defined as 'the management of undisclosed discrediting information about the self.[25]' Passing makes social relations very complicated, with people going to huge pains to keep their separate worlds apart. A housewife, engaging from time to time in commercial sex work, may keep an entire secret wardrobe of clothes and make-up for the purpose. An unemployed man may preserve the fiction that he's going out to work for many weeks after losing his job. And the fact is that it is often with one's own family that fictions are most needed.

Disclosure is not an easy option, though. Being accepted by society depends on the stigmatised individual learning to put up with society's stereotypes of his or her condition. 'The stigmatised,' says Goffman, 'are tactfully expected to be gentlemanly and not to press their luck. Some claim that they are made to feel grateful for being accepted. But in going along with this, says Goffman, the so-called 'normals' will never come to understand the pain and unfairness of carrying a stigma, nor will they have to admit to themselves how limited their tactfulness and tolerance is. 'It means', he says, 'that normals can remain relatively unthreatened in their identity beliefs.[26]'

He ends with three interesting insights.

The first is that, where norms exist, there will also be deviation. The existence of category of the 'normal' actually depends on some kind of consensus about what it means *not* to be 'normal'. In European society, normalness includes physical appearance, sexuality, youth, literacy, having a job, being a parent, owning a colour TV and a car and so on. But the problem is we all have secret doubts about whether we measure up fully to the ideal norms of our society, which makes stigma management into 'a general feature of society, a process occurring wherever there are identity norms.'

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[23] Goffman 1963 ed 1990 p41
[24] Goffman 1963 ed 1990 p57
[25] Goffman 1963 ed 1990 p58
[26] Goffman 1963 ed 1990 p147

The second is that there is nothing ontological about stigma. Social attitudes can and do change, and the last half-century, in Western society at least, has seen a massive shift in stigmatising attitudes to (for instance) divorce, mental illness, homosexuality and premarital cohabitation. In addition, such attitudes are often highly culture-bound or contextual. Being poor or unemployed or illiterate or gay may be stigmatised in one setting but fully acceptable in another.

The third insight is that 'stigma involves not so much a set of concrete individuals who can be separated into two piles, the stigmatised and the normal. … In the end, the normal and the stigmatised are not persons but rather perspectives.'

Goffman's work is still regarded as a seminal statement on the management of stigma, and his analysis cannot fail to strike a chord. But his work has limitations, foremost among which are its narrow focus, and also the very Western character of his concentration on spoiled identity. Health anthropologist Veena Das[27] says that Goffman, 'has loaded his analysis towards a highly individualistic rendering of the subject – the individual appears in his analysis as the sole bearer of value'. Others have commented that Goffman's work is virtually incomprehensible outside the context of Western industrial societies.

The gaps in his analysis become obvious when a more communal, anthropological perspective is adopted. Now it is not the individual who is responsible for his or her stigmatisation; it is society. Instead of asking 'how can an *individual* manage his or her differentness', we should rather be asking 'why does *society* react in such a way to particular kinds of differentness, and what can *society* do about it?' The point is that a study of stigma focusing purely on individuals is ignoring the organic nature of human community. 'Culture,' says Gerry Arbuckle, 'is a system of felt meanings encased in symbol, myth and ritual. These dictate who should be included or excluded. They also legitimate the violence that's required in order to maintain exclusion.[28]'

Sectarianism as stigma[29]

The next section provides an example against which the helpfulness of the above approaches might be judged.

Many of us here are familiar with situations of communal violence. The stigmatization of 'the other' (whether it's Palestinian or Jew, Hindu or Muslim, Hutu or Tutsi) plays a key role in allowing people to commit atrocities with a good conscience. If we can

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[27] Dr Veena Das gave the keynote address at a groundbreaking consultation, Stigma and Global Health, held at the National Institutes of Health in Washington DC in September 2001. The resulting book is still in publication.

[28] Private letter outlining his new book. Gerald A Arbuckle: Violence, Society and the Church: A Cultural Approach. Liturgical Press, to be published March 2004

[29] Joe Liechty and Cecelia Clegg: *Moving Beyond Sectarianism*.

persuade ourselves that 'the other' is less than human, then we don't have to worry about treating them like animals.

In Northern Ireland, the conflict between Catholics and Protestants has been going on for most of my lifetime. For the past 15 years, Joe Liechty and Cecelia Clegg have worked with divided communities. In talking about these things, they say, most people typically begin with *personal* attitudes and *personal* actions. … 'So when we say of someone, "She doesn't have a sectarian bone in her body," we think we absolve them of responsibility. In one sense this concern with the personal is not only appropriate, we need more of it, not less. At the same time, however, an exclusively personal approach fails to take the systemic issues seriously enough.' To misquote Liechty and Clegg: a stigmatizing system can be maintained by people who, individually, do not have a stigmatizing bone in their bodies.[30]

Like sectarianism, stigma can work with sledgehammer directness and brutality, or with great subtlety.[31] An HIV positive woman in murdered in a township; a family of orphans, whose parents have died of AIDS, are burned alive in their home. A Catholic woman hides in her house during the annual Orange (Protestant) parade in the neighborhood where she grew up. The parade isn't specially rowdy or violent: and yet it is deeply threatening. It has shaped her attitudes to Protestants. And what distresses her most is 'her sense, as a middle-aged mother of older children, that …… she had somehow passed on the same limitations to her children. In one sense little or nothing happened, and yet the quietly destructive effects could shape a life and pass silently into a new generation.[32]'

Neither stigmatization nor sectarianism requires 'any direct, active response at all from most of us, it simply requires that we do nothing about it. … We can always find a "them" out there whose actions can plausibly be construed as worse than ours, so we can justify ourselves in identifying "them" as the real sectarian problem.'

A further problem is that systemic stigmatization, like sectarianism, can use our best intentions to build itself up. It feeds on the motivation of Christians to build strong communities, with clear boundaries, where people feel safe. But because those boundaries are defined by 'difference' from those outside them, 'our best pastoral efforts can end up strengthening existing divisions. In this way, systemic sectarianism (or stigma) will go on employing well-intentioned, positive community-building activities as ways of sustaining its beliefs.[33]'

Liechty and Clegg found they turned a corner in their work when they began to reflect aloud about 'the nature of the beast we were confronting.[34]' 'By reifying sectarianism', they say, 'we mean to connect it to the biblical concept of principalities and powers,

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[30] Liechty and Clegg 2001, p 9
[31] Liechty and Clegg 2001, p10
[32] Liechty and Clegg 2001, p 10
[33] Liechty and Clegg 2001, pp 13-14
[34] Liechty and Clegg 2001, p 15

especially as mediated to us by Walter Wink's work on the powers, principally *Engaging the Powers: Discernment and Resistance in a world of Domination*.[35]

It might reasonably be argued that stigma is only one aspect of sectarianism. Just the same, we may find that the insights of people engaged in the work of reconciliation within divided communities, which must address issues of stigma if it is to succeed, have valuable material to offer in the present task.

Mary Douglas and the meaning of purity[36]

When Jonathan Mann was Director of WHO's Global AIDS Programme, he used to say that Mary Douglas' work should be required reading. He was particularly keen on the classic work, *Purity and Danger: An Analysis of the Concepts of Pollution and Taboo*.

When society stigmatizes and excludes, claims Douglas, it is trying to protect itself from contagion and ensure its own survival. The stigmatized person is believed to be a polluting influence, and therefore dangerous to the rest of the community. Potential polluters become scapegoats, individuals who have broken a taboo of some kind and must be cast out or punished. Religion plays a key role in this process by the way it underpins social order. Order, says Douglas, is society's highest value, and it is laws governing purity and pollution that safeguard it. It is religion that articulates the belief system and institutionalizes the rituals in which society's corporate life finds expression.

In some societies, 'rules of holiness and rules of uncleanness are indistinguishable.[37]' One example of this is the traditional Hindu caste system, in which the highest, Brahmin castes are 'set apart' from the lower castes, not just by rituals of cleanliness but by a complex of rules and customs that govern the whole structure of their lives. To maintain their purity, the upper castes are dependent on a cadre of lower caste groups to deal with sanitation, the preparation of certain foods, the care of animals and so on. The lowest castes, by carrying away the waste matter, carry the stigma of impurity and thus enable the higher ones to remain free of bodily pollution. As a result, the lower castes then become literally 'untouchable'. On the Indian sub-continent, Christian mission has actively challenged this system by prioritizing the most stigmatized sections of the community. As a result, Christian education and health care programmes have played a foundational role in building up the social infrastructures of the sub-continent's countries.

In the caste system and elsewhere, pollution laws generally affect women more than they do men. 'Women,' says Douglas, 'are the gates of entry to the caste. Female purity is carefully guarded and a woman known to have had sexual intercourse with a man of lower caste is brutally punished. Male sexual purity does not carry this responsibility. Hence male promiscuity is a lighter matter. A mere ritual bath is enough to cleanse a man from sexual contact with a low-caste woman[38]. '

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[35] Walter Wink, *Engaging the Powers*. Minneapolis, Fortress Press 1992
[36] Mary Douglas, *Purity and Danger: An Analysis of the Concepts of Pollution and Taboo*. London and New York Routledge 1966
[37] Douglas 1966, p 11
[38] Douglas 1955,p 126

'A polluting person', says Douglas, 'is always in the wrong. He has developed some wrong condition, or simply crossed some line which should not have been crossed and this displacement unleashes danger for someone.'[39] By crossing its internal or external boundaries, we risk polluting the whole system, and order will not be restored until purification processes have taken place.

Sex, in particular, is a trigger point for pollution-thinking. 'No other social pressures,' says Douglas, 'are so potentially explosive as those which constrain sexual relations[40].' A particularly interesting situation arises when 'the social structure is cushioned by fictions of one kind or another. … The norms of behaviour are contradictory.[41]' In these situations, *official* sexual scripts do not coincide with the *real* sexual scripts that people act out in their lives, and which are passed down from generation to generation. The 'sinner', then, is somebody who is only doing what everybody does, but has been 'caught out', and finds him or herself the bewildering position of being judged in relation to the official script, before whose courts of law or she has never expected to stand. Douglas describes this as 'the system at war with itself': a state of affairs dramatically exposed by the ferocity of the AIDS pandemic (since the person who has contracted HIV sexually is often in precisely this position) but for which 'the system' has few answers.

Wholeness and completeness may be signs of freedom from pollution: an idea that played a powerful part in Judaeo-Christian tradition. For example, physical perfection and an absence of blemishes are required both of temple sacrifices and of people approaching the temple (Leviticus 21: 17-21). The messianic counterpart of the Mosaic Law, says Douglas, is the Sermon on the Mount. 'From this time on, the physiological condition of a person, whether leprous, bleeding or crippled, should have become irrelevant to their capacity to approach the altar. The foods they ate, the things they touched, the days on which they did things … should have no effect on their spiritual status. … *But continually the spiritual intentions of the early church were frustrated by spontaneous resistance to the idea that bodily states were irrelevant to ritual.*[42]'

Robin Gill, in an article written for the British *Church Times* in December 2003, argues that Douglas' analysis does not do justice to Christian history, which has a long tradition of resisting the purity laws of particular cultures. He offers a variety of examples, to which I would add that of the many Christian health care institutions that involved themselves in the care and support of people living with HIV/AIDS and their families, at a time when secular, government maintained hospitals were turning them away. So pollution laws must be understood, but they must also be challenged. What Douglas' analysis does (like the Northern Ireland example) is to name the subconscious role of religion in supporting purity rules; what Robin's response does is to point towards the resources that exist, within the Christian tradition, for challenging them.

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[39] Douglas 1966, p114
[40] Douglas 1966, p 159
[41] Douglas 1966, p 144, 159
[42] Douglas 1966, p 61

Stigma and power[43]

My final contribution to the process of conceptualization comes from a psychologist and a sociologist. Link and Phelan analyse the relationship between stigma and discrimination, and outline the dynamics involved in resisting them.

Stigma, they suggest, offers a basis for devaluing, rejecting and excluding. Human beings instinctively create hierarchies, and the connection with an undesirable characteristic provides a rationale for moving someone downwards. First the person experiences structural discrimination: which is not the same thing as stigma, although it is one of its consequences. Expectations are lowered in terms of job opportunities, marriage possibilities and housing. Eventually, stigmatized people come to internalize the stereotyping they receive, and to believe it. 'To the extent that stigmatized groups accept the dominant view of their lower status, they are less likely to challenge structural forms of discrimination.[44]'

What is sometimes forgotten is that stigma is almost entirely dependent on social, economic and political power. It was the power of the Nazis that allowed their stigmatization of the Jewish people; it was the power of the white apartheid state that allowed the systemic stigmatization and discrimination suffered by black South Africans.

If you have *no* power, you may stereotype but you cannot stigmatize. For example, mental patients in a treatment programme may 'identify and label human differences in staff members'[45]. One is a pill-pusher; one is always touching the female patients; a third is cold, paternalistic, arrogant. The patients may treat these people differently, and make jokes and derogatory remarks. But 'although the patients might engage in every component of stigma we identified, the staff would not end up being a stigmatized group. The patients simply do not possess the economic, cultural and political power to imbue their cognitions about staff with serious discriminatory consequences.[46]'

Link and Phelan go on. 'Consider further that scenarios similar to the one just described exist for all sorts of other circumstances in which relatively powerless groups create labels and stereotypes about more powerful groups and treat members of the more powerful group in accordance with these stereotypes. This clarifies why the definition of stigma *must* involve reference to power differences. Without such a reference, stigma becomes a very different and much broader concept. … *Stigma is dependent on power.*[47]' (My italics)

There have been many targeted attempts to address the social effects of stigma-related discrimination (in relation to employment, housing, access to services and so on): Indian efforts to eliminate discrimination based on class, laws against discrimination on grounds

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[43] Bruce G Link and Jo C Phelan, Conceptualizing Stigma. Annual Review of Sociology 2001, 27: pp 363-385

[44] Link and Phelan 2001, 375

[45] Link and Phelan 2001, p376

[46] Link and Phelan 2001, p 376

[47] Link and Phelan 2001, p 376

of disability, affirmative action programmes wherever they occur. Sometimes enforced by legislation, these have generally involved attempts to outlaw particular behaviour. But this, say Link and Phelan, 'leaves the broader context untouched. ... There exists a flexible package of mutually reinforcing mechanisms linking the attitudes and beliefs of dominant groups to an array of untoward outcomes for stigmatized persons.[48]'

In considering how to alter stigmatizing attitudes and behaviour, they propose focusing on two principles. The first is that any approach must be multi-faceted and multilevel: *multifaceted* in order to address the many mechanisms that can lead to disadvantage*;* *multilevel* in order to address issues of individual and structural discrimination. But important as that is, it is not as important as addressing the fundamental *cause* of stigma. To succeed in making a lasting difference, an approach 'must either (1) change the deeply held attitudes and beliefs of powerful groups that lead to labeling, stereotyping, setting apart, devaluing and discriminating, or (2) change circumstances so as to limit the power of such groups to make their cognitions the dominant ones. …. *Thus in considering a multifaceted, multilevel approach to stigma, one should choose interventions that either produce fundamental changes in attitudes and beliefs, or change the power relations that underlie the ability of dominant groups to act on their attitudes and beliefs*.[49]'

So stigma is there, and the stigmatization of groups and individuals who are 'different' is part of the dynamics of community life. Stigma leads to exclusion and to discrimination. And religion plays a key role in underpinning the process. However, stigma can be resisted and overcome, and Christian theology has demonstrated its capacity for doing so. But it cannot do that without addressing issues of power, both outside the church and within it.

[48] Link and Phelan 2001, p 381
[49] Link and Phelan 2001, p 381

HIV and AIDS Related Stigma: Possible Theological Approaches
Stigma and Christian Theology

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I apologize for not having the text. Bob, in his heroic fashion has experienced this before, and he knows the curious way in which I work. I have to become immersed in some way into the situation before I can begin to think theologically. This has been successful at some times in the past, but not always. And I do not know whether this will work this time. I had a good friend, an English theologian, Fr. Herbert McCabe. We met at a meeting in Florence. He told me, "I have lived in the dread that some day, somehow I might be found out". He said he was happy to see me at that meeting so that we could be "found out" together. So once again today I may be "found out".

In seeking to find some theological starting points for our understanding of stigmatization and HIV and AIDS, it would be helpful to give a short response. Each of us is created equally in the image of God, loved equally and unconditionally by that God - not just as individuals but in the process of forming a single community, the family of God, a single creation of God. And that equality of persons in community has been confirmed, renewed, and transformed in the Incarnation – in the life, ministry and death of Jesus Christ. And we, as the disciples of Christ, have been called by the gift of the Spirit to be sure that the relationships within the family of God are not stigmatizing, violating. That is a short summary of why we must assure that the relationships among us are not stigmatizing.

At that level of preaching and teaching, it might seem that stigmatization is clearly un-Christian and might be countered if we took our Christian faith seriously. But it is not that simple – partly because, in Christian understanding, we are not only a communion of saints but also a communion of sinners. We are not only graced but also sinful, not only repentant and forgiven but continue to fall into sin in various ways.

Yesterday, it occurred to me that perhaps one of the words that may be stigmatized out of use itself is the word "sin".

Let me reflect on the creation of the world, creation of humanity, the celebration of the world, the celebration of humanity. God looked on creation and saw that it was good; God looked on humanity and, in the Genesis language, saw that it was "very good". That

in a way brought into being a counter-point to God - a group of persons that were “other” than God. In the Hebrew Bible, the word “holy” is related to “other”. In the concept of “otherness” of God, there is the idea of the “otherness”, a separateness of creation. We can see that without differentiation, there is no celebration of the good. But with differentiation, there is the potential of separation from the good. Creation is a continuing process of differentiation which is at once celebratory and also threatening. With the continuing process of differentiation, there is the continuing problem of estrangement, and the continuing need to turn this separation into the ongoing process of reconciliation.

Thus in Scripture, we find God the Creator also as God the Reconciler. We, as humans, are at once creators, potential destroyers, and thus called upon to be reconcilers. That differentiation, with its potential for further creativity and for destruction, also brings about the need for further reconciliation in communion. We can read a good deal of the Jewish and Christian Scriptures and find within them the theme of our creative potential and our further destruction of that creation and thus the need for reconciliation. Relationships among people in communities can easily turn into destructive relationships. In order to protect ourselves, we have to define out of our lives the particular people who come to us as “strange” and therefore threatening. It is not surprising to find in the prophetic critique of Israel and its leaders that it is this very neglect of certain stigmatized people with whom we cannot deal, it is the neglect of the widows and orphans which is seen as making the worship worthless in the eyes of the prophet. This applies at the level of power structures and at the level of personal relationships.

The problem of estrangement applies in particular to the treatment of women. In the first chapter of Genesis, we find the lyrical song of Adam – “bone of my bone, flesh of my flesh, leave father and mother and become my spouse for life”. This quickly changes in the next chapter when they find that they are naked and hide themselves and they see God as “other” and hide from him, Adam accuses his wife “she did it” and blames her. Thus we can see how easily the gift becomes the threat. This relates so much to the gender alienation that we find so often in the Scriptures, as in the book of Numbers. The strangeness between men and women brings out the point that where the power lies, that is where the stigmatization works.

But that needs to be balanced by so many other points in the Scriptures. It would be hard to find another piece of language as erotic as the Song of Songs, where the speakers, man and woman, are totally in tune with each other, and where the words of the woman are as erotic as the words of the man.

One of the great sources of differentiation is sexual differentiation, and we see the potential this has for creating and celebrating, but also for destruction. This is just one of the points which go back; it seems to me, to the very heart of creation – that creation includes this potential. But we see in the Scriptures, Genesis 3, that creation is accompanied by – calls for- celebration and includes both the possibility for estrangement and the resources for reconciliation.

That is one useful starting point.

There is another useful starting point in relation to this. It is the differentiation not just between God and creation, but the differentiation that emerges when God enters creation, the differentiation that we associate within Incarnation when God becomes one of us. This also is a source of alienation. Jesus said, "I came not to bring peace, but the sword". Jesus also cried, "My God, my God, why did you abandon me". It is a matter of estrangement (differentiation of Incarnation), but also is a matter of the beginning of reconciliation. That differentiation of Incarnation had, on the face of it, no historical guarantee of success, and still has no historical guarantee of success.

But there are a number of elements in that pattern. One is contained in the Nativity Stories, the summons to go to Bethlehem, the homelessness of the pregnant Mary. This enlightens us about the homelessness of God in God's own world. That is one striking part of the alienation. And the cost of that is not only to God, but to the people, even the innocent people – "not peace, but the sword". Of course, the growing child, as he becomes the rebel that Miriam was for us in the Scripture reading this morning, and leaves his parents, runs away, and causes these questions – "why have you done this to us?" "Did you not know I had to be about my Father's business"? He brings to us the process of estrangement and the process of the need for reconciliation. That kind of estrangement, even from his earthly family, and maybe from his heavenly family ("who are my mother and brothers?"), leads him to seek the company of the alienated and stigmatized, and leads him to be alienated from the political and religious leaders of His time.

Even in the parable of the prodigal Son parable, can we not wonder where Jesus is not the prodigal Son – leaving the wealth and beauty of his father's home and spending, wasting his time with us. It becomes clearer with the arrest, the show trial, the Passion, the execution outside the city gates, that we share some of the reach of the estrangement of this stranger from His God and from His people. It is to crucifixion between two thieves - that the alienation and stigmatization finally brings Him. And it is that crucifixion story that we must be careful not to miss-interpret. One of the great criticisms of the Christian story by one of its most powerful critics, Nietzsche, was that it was a religion for the "victims". We have to be careful about how we view the crucifixion – that is not a sign of weakness, but a sign of strength. It is there that the estrangement (the disciples all left him, only a few women and John stayed by) – that estrangement from his people, and to a certain extent by God, that Jesus found himself. Theologians take this in different directions – Moltmann on Good Friday, van Balthazar on the Holy Saturday experience. That is the final alienation – God from humanity and God from God – that makes it clear that God was reconciling humanity to Himself and we are called to be ambassadors to bring about reconciliation.

We might be tempted to say to the "stigmatized" that they have to endure – it's all for the good. That, it seems to me, is exactly the opposite of what Jesus was calling people to. Thus I have some questions about the statement that "God allows the situation of HIV and AIDS to come about". From our comfortable armchairs, we have to avoid calling for subtle complicity with stigmatization. We have to start thinking about a theology of

suffering – that those of us who aspire to be disciples of Christ – to take on the suffering of others – alleviate the suffering of others, break the silence of stigmatization, changing the structures, criticizing the powers that allow stigmatization to happen.

Thus, in the Creation story and in the Jesus story, in each case, we see the creation, but also the potential for destruction, and the consequent need and potential for reconciliation. The reconciliation that occurs with resurrection has to be diffused through the world. And that comes with the sending of the Holy Spirit. This is another form of differentiation within God and between God and creation, which also has its problems. We have simply ignored the Holy Spirit for so long. Or we are too quick in invoking the Holy Spirit as being on our side. That also is part of the problem within our churches – e.g., how the mainstream churches look on the Pentecostal churches and vice-versa.

In all our structures, differentiation is essential to life, growth, and health, but at the same time it is threatening and destructive. At the very beginning of the Church, we see Peter and Paul confronting each other on issues of differentiation. The whole history of heresy in the early Church is about the differentiation of a particular group and stigmatizing of them by the "mainstream".

This is about the human need for order and the human fear of anarchy. This enters into the strength and weaknesses of many positions on sexual ethics - the structure that preserves relationships within community and protects against anarchy, abuse. In the writing of Paul, we see the portrayal of differentiation within the Pentecost story. The Holy Spirit came upon differentiated people. In the Catholic tradition, we have seen the differentiation within different religious orders. We speak of the charism of the founder, but this also could be turned into an oppression of a regime. There is difficulty of maintaining differentiation in the Spirit with communion in the Spirit.

The word "other" is the Greek word "allos" but is related to the Hebrew word "kadosh" which speaks of the holiness, "otherness" of God. The word "reconciliation", which is used twice in New Testament (in Matthew's account of reconciling yourself with your brother) but Paul speaks in Galatians 5 of "bringing all others together in Christ". This is what we are called to do: to bring others together in communion in this way.

This relates to another point – Mary Douglas' reference to the relationship between "holiness" and "uncleanness". In order to preserve the holy, we define out certain things that were "other" to the definer rather than to God – e.g., menstruation was a threatening otherness to the men who served in the sanctuary.

I would like to come back to my struggle with this idea- that of the separating out by people in power, their defining out of people who are others – that leads to stigmatization – e.g., of people with HIV and AIDS. It brings us back to the Creation and Incarnation stories that are about overcoming the "threatening" otherness to bring them back to being the enriching' otherness. Often, it is the people who have managed this type of differentiation, discrimination, and people with power, who need to overcome

stigmatization. In order to overcome the estrangement, God had to let go of the power. We ask “how could God allow this”.

The story of salvation is the progressive revelation of God’s “divestment” of power. In Philippians 2, we see the powerful self-emptying of God that occurs – “he did not consider himself equal to God, but took the form of a slave.” One form of stigmatization was the branding of slaves. This was not something that Paul had a mystical experience about; this was Paul understanding the Gospel stories as they revealed Jesus in this fashion – as the salve or servant who let go – “are you a King?” “My kingdom is not of this world”.

Thus we have the creator God revealing himself in Jesus Christ who sheds power in order to be properly with the stigmatized. This is something the churches have to take seriously in overcoming stigmatization.

There is a further point on the dispersal of God’s reconciliation. Yesterday we spoke of the religious conflicts in Northern Ireland as an example of stigmatization. But we can also see how churches stigmatize one another. Only recently, with the ecumenical movement, do we begin to see differentiation as a source of enrichment. We cannot look for unity only for the sake of order – this could become oppressive. Unity must be sought as a fruit of accompanying each other, understanding each other, thus desiring unity.

God may be challenging us to deal with stigma to shed our oppression of others and thus to seek reconciliation of ourselves with the stigmatized – “all shall be all in God”. It is in that sense that sectarianism challenges the Irish, that stigmatization challenges the whole world that calls us to face the challenge and to allow the resources to take us to a new stage of human dignity and community and a new stage of Christian companionship. The struggle for humanity is to celebrate differentiation by enabling it to be equally enriching in community. Unless Church leaders are willing to be with the stigmatized publicly and consistently, then our actions will not be credible or effective.

HIV and AIDS Related Stigma: Implications for Theological Education, Research, Communication and Community
Stigma: Implications for the Theological Agenda

Dr. Denise Ackermann is Professor of Theology at the University of Stellenbosch in South Africa. This is not presented as a formal academic paper but is a transcript of her talk. She is based in Cape Town, South Africa.

Introductory remarks

I have been asked to talk for half an hour on the implications of our theme for theological education. Last night I saw a new publication entitled *HIV/AIDS and the Curriculum* edited by Musa Dube in which this topic is addressed exhaustively by a number of contributors. My remarks are somewhat random, no more than footnotes to this new publication.

At the beginning of this workshop, Calle Almedal stressed the importance of challenging the power of stigma with the help of church leaders. This is a necessary and an ambitious project that will require time and dedication from the leaders in our respective churches. My experience of my church's bishops is that they are caught up in a vast maze of administrative responsibilities, traveling around their respective dioceses, conducting confirmations, and dealing with difficulties experienced by the clergy. In the face of all this activity, the question arises: Do our bishops have the time to read a framework such as the one we are intent on composing? Hopefully some do; our task is to enter into dialogue with those who are open and aware of the dangers of stigma and discrimination in the church.

Whatever we say, analyze and critique, we must do so in hope. Hope is the antidote to the despair bred by stigma. Stigma produces social inequality. It is deployed by concrete social actors who seek to legitimize their own dominant status. It therefore operates on a religious and political economy of exclusion, often at the point of intersection between culture, power and difference. Stigma rarely functions exclusively in relation to HIV and AIDS. When culture, gender, race and sexual stigmas work together with stigmas engendered by HIV and AIDS, the effects are complex and often devastating. For example: AIDS is seen as either the disease of the rich or the poor, depending on one's class perspective; or AIDS is a women's disease, or a disease caused by men, depending again on one's gender perspective; or AIDS is a black disease or a white issue, depending on one's race perspective, and so on. As theologians seek to grapple with difference, we find out just how profoundly stigma - in its many guises - permeates all of life.

Stigma, HIV and AIDS and the theological curriculum

Theological education should be devoted to the critical academic pursuit of the theological disciplines. It is, however, also theology done in service of our communities of faith. It combines academic knowledge with a compelling interest in the activities of communities of faith and their relationship with their contexts. It is not solely a quest for knowledge. It is also about meaning and the pursuit of truth in our lives.

When faced with the challenge of teaching in a context that is deeply affected by HIV and AIDS, lecturers resort to a variety of inappropriate approaches. Feeling ill-equipped to deal with the topic of AIDS and having not given sufficient attention to the theological implications of HIV and AIDS, the "one-off" or "add-on" approach is resorted to. The local university AIDS bureau is invited to send an "expert" to give a one-day update on what is happening in the fields of HIV and AIDS and to speak about prevention. After the expert departs, the students are subjected to a quick theological gloss and the matter is then considered closed.

A second approach is the "new sensitivity mode". A faculty dean earnestly instructs lecturers to incorporate HIV and AIDS into the teaching of all their subjects in some way or other. This is similar to earlier efforts to incorporate gender sensitivity into teaching when lecturers were told to use inclusive language and to be aware of the implications of gender for their disciplines. Most lecturers are baffled about how to apply the "new sensitivity mode". After numerous attempts it is usually quietly shelved.

A third approach is the "immersion experience". The professor of pastoral theology takes a group of students off for a day to "immerse" them into the experience of suffering caused by HIV and AIDS. Hospitals, hospices or homes are visited and people are interviewed. By the end of the day, the students are completely overwhelmed, often because they have not been sufficiently prepared for these encounters. This approach is heavily focused on practice with little theoretical backing. These three approaches are clearly caricatured but I have experienced all of them in some form or other.

Theological education which takes the challenge of HIV and AIDS seriously will have to re-conceptualize the theological curriculum. Why? Because HIV and AIDS and its related stigmas impinge on virtually every aspect of the theological curriculum. Our doctrines of God, sin and salvation, our understanding of suffering, the nature the human being and the nature of the church are all, for instance, related to our struggle to live faithfully in contexts ravaged by suffering and death, exacerbated by stubborn stigmas. As central as theoretical knowledge is to the academic pursuit, I do not want to overemphasize its role. As I have said, I do believe that theological education is done in service of our communities of faith. This calls for specific attention to be paid, on the one hand, to the relationship between our theoretical knowledge and belief systems and, on the other hand, to the way in which knowledge translates into actions and shapes them.

In order to hold the tension between our theological theories and our Christian practices, I suggest that we theological educators examine our theological methodology. How many of us are still working with a *depositum fidei* method? This method assumes that theological knowledge is received from on high and that theological educators are to play the role of enlightened go-betweens imparting it to students. There are other ways of teaching theology that are more effective in dealing with HIV and AIDS and their related stigmas.

First, there is the critical role of narrative in disseminating knowledge. Life stories are important in countering stigma. Telling stories is critical in claiming one's identity. Instead of having one's identity subsumed under the label of being "an HIV positive", speaking and being heard affirms both dignity and identity. Narrative has a further function: the very act of telling our stories helps us to make sense of situations that are often incomprehensible - even chaotic. The need to counter stigma and deal with HIV and AIDS in a theologically responsible manner begins with lived experience. When our stories intersect with the meta-narrative of our faith – the life, ministry, death and resurrection of Jesus Christ – despair can give way to hope, and God's caring presence can be affirmed, even in the midst of trying circumstances.

Second, theological methodology must be alive to the creative tension between theory and praxis. Too often praxis is seen as subsidiary to theory. Praxis has to do with the inter-connectedness of historical experience and the concerns for freedom on the one hand, and our responsibility to change oppressive conditions into the possibility of human flourishing, on the other. Such praxis is done in the interest of those who experience stigma. It is collaborative by nature, and it is culturally sensitive to the different ways of experiencing reality. Christian praxis is a willingness to be God's hands in the world.

Third, an appropriate theological methodology requires critical analysis. The need to understand the relationship between, for instance, culture, religion and gender, or between knowledge and power, or the challenge that difference poses to theological education, all point to how essential critical analytical thinking is for the theological enterprise.

To illustrate the point I want to refer to a critical analysis done by an African woman theologian at a conference on AIDS in Pretoria in 1998. Teresa Okure stated that there are two viruses that are more important than HIV. The audience reacted with shock. She proceeded to explain that the first virus is one that stigmatizes and demeans women in society. This virus causes men to abuse women. It is the virus that is responsible for the shocking fact that in many countries in Africa the condition that carries the highest risk of HIV infection is that of being a married woman. HIV and AIDS thrive on disordered gender relations. It is the virus which is deadly for the poor woman who lives in a patriarchal relationship and has little power over what happens to her body. The second virus that enables HIV and AIDS to spread at a devastating speed is found mostly in the developed world. It is the virus of global economic injustice that causes terrible poverty in parts of the developing world. Capitalist market economies are thrust on societies that are not geared for them and structural adjustment programmes imposed that do not meet

the needs of the poor, who too often consist of uneducated, rural women and their dependants.

Rethinking two theological themes

Having asserted that HIV and AIDS challenge us in virtually all fields of theological education, I want to suggest how we might reframe our theological thinking on two well known theological topics in order to deal more appropriately with HIV and AIDS related stigma.

First, we are challenged by the constant theme that underlies all debates on HIV and AIDS – the question of how we understand human sexuality and its place in our teaching of theological anthropology. What does it mean to be a sexual human being? The church is a community of sexual beings who find sexual expression in different ways. Sexuality challenges us to confront difference. It also challenges us to acknowledge the centrality of the body in our theological thinking. All reality and all knowledge are mediated through our bodies. We do not live disembodied lives. Our bodies are more than skin, bones, and flesh. The fact that we can see, hear, touch, smell and feel is the source of what we know. The nonsense that the body is secondary to the soul has plagued Christian history for too long and must be countered with embodied theological thinking. Thus theology that takes human sexuality seriously pays attention to the nature of the human being as created by God and the nature of our relationships with one another as expressions of our humanity in its fullness. Emphasizing the call to mutual, caring relationships and the fact that human sexuality is a gift from God, are both important when dealing with stigma and discrimination. It is strange that Christians, whose faith is grounded in Incarnate Love, are so reluctant to grapple with what it means to have bodies.

Second, we are challenged by our lack of an effective language to deal with HIV and stigma. Stigma is nourished by silence. Internalized trauma, fear of rejection, cultural restraints and wrong understandings of sin and punishment, all rob people of the ability to speak out and to name their reality. I suggest that our scriptures have given us a language that can deal with suffering. In the ancient language of lament we have a way of naming the unnamable and of crying out to God in situations that are unbearable. What is lament? It is a form of mourning but it is more purposeful. It signals that relationships have gone terribly wrong and it reminds God that God must act as a partner in the covenant. It is both individual and communal. It is a primal cry that comes out of the human soul and beats against the heart of God. It calls God to account for our human suffering. Lament is risky and dangerous speech; it is restless; it pushes the boundaries of our relationships, particularly with God; it refuses to settle for things the way they are. Israel knew the power of lament. The psalms bear witness to this as they express the rawness of human suffering as well as hope and trust in God. Israel discovered that lament and praise go hand in hand.

When the language of lament is applied in our present context, it has important implications for the political and social witness of the church. The church claims to be an

inclusive and caring community. Why is it not publicly lamenting the devastation caused by HIV and AIDS? Lament can be politically subversive and therefore dangerous. It is never for the preservation of the *status quo*. This is the challenge to our churches – to lament the present suffering. Lament can also enrich our liturgies and pastoral care. Liturgical praise often comes too easily. It is not praise that is hard-won and that names the truth to God while confirming that God *will* hear our cries and *will* act to bring relief. The language of lament is also a powerful pastoral tool for dealing with suffering. Lastly, lament makes for a more intimate and authentic relationship with God. We live in a situation that raises legitimate questions about God's justice and God's power and presence in a suffering world. Is God's justice reliable and where is? There is much cause for lament, yet its loss stifles our questions about evil in the world. Instead we settle for a God who is covered in a sugar coated veneer of religious optimism whose omnipotence will "make everything right in the end". Religious optimism differs deeply from the life of faith. The former prefers to sanitize God by removing God from the ugliness of suffering. This is a God we dare not approach with our genuine grief and with whom we are in a relationship of eternal infantilism.

The language of lament is direct and truthful about suffering; it names the unnamable to God and in so doing helps to heal our doubts and restore our faith in our power to call on God to act on our cries. Why not teach our students about the richness of the tradition of lament as a means of countering the pain of HIV and AIDS related stigma?

In conclusion

I agree with those who have said that HIV and AIDS constitute a time of kairos. This takes me back to the Kairos Document which appeared in South Africa in 1985. The first few phrases went something like: "The time has come, the moment of truth has arrived, and South Africa has been plunged into a crisis that is shaking its foundations…" These words have a new and startling relevance in 2003.

This *is* a moment of truth. It encompasses crisis and opportunity, despair and hope, struggle and grace. It is in the very nature of our profound crisis that I find hope – hope in the Holy One who has promised to be with us always. Finally, this kairos requires that we should nurture a spirituality that breathes the air of hope, is unafraid of ambiguity, is ready for works of justice and charity, but also takes time to reflect on what we should be doing. Then hearts can change and hands can become willing tools in hastening the coming of God's reign on earth.

HIV and AIDS Related Stigma: Responding to the Challenge
Stigma: Communicating the Message, Influencing Church Leaders and Members

Dr. Musa Dube is Professor of Theology and Consultant on HI/AIDS and Theology to the World Council of Churches. She was based in Gaborone, Botswana

I am neither a statistic nor an object of curiosity… People living with HIV/AIDS, are people like everyone else. They are neither to be discriminated against nor condemned. It is by listening to people living with HIV/AIDS that Africa [and the world] will learn how to act well to prevent HIV/AIDS. We no longer think HIV/AIDS is the fault of rape victims, sex workers, or homosexuals. HIV/AIDS is our reality and we can only change the situation if we treat the illness and those who are suffering from it with a sense of value and dignity."[50]

If we are going to counter stigma and deal with HIV & AIDS in a responsible manner theologically, the place to start is with the lived experience… Praxis is willingness to be God's hand in the world… Praxis must be done in the interest of those who experience the stigma, it must be collaborative, and it must be culturally sensitive to different ways of experiencing reality." Denise Ackermann, 2003:3

Introduction

We have gathered here as academic theologians and under the initiative of UNAIDS, to produce a persuasive theological framework on eradicating HIV and AIDS stigma. It is hoped that Peter Piot, the director of UNAIDS, will write a covering letter to accompany this document; then it will be sent to church leaders and members. The organizers hope that this document will persuade the church leaders and members to develop a zero tolerance for HIV and AIDS stigma and discrimination and to work towards the same. In other words, this should be a theological framework, which will challenge and convict our church leaders and members to work actively for the eradication of HIV and AIDS stigma—through word and deed. In this act, a number of things have been assumed. One can say that by our coming to work on producing this document, we have in many ways agreed to some of the following underlying assumptions: That:

- As theologians we are responsible for empowering the church to be HIV and AIDS competent.

- As theologians our voices will be listened to, acknowledged and honored by our churches. If not, we have acknowledged that we should be working hand in hand with our churches, or that it is our fitting duty to persuade them.

- By coming here and working on this framework we have acknowledged that as theologians, we should be servants of and educational experts to the church leaders and members in this time of HIV and AIDS crisis as in all other situations.

[50] Quoted from the "Aids and Stigma: An African Christian Context," in the Beads of Hope Campaign: Education and Advocacy Kit. The United Church of Canada, p. 1, 2003.

I have heard some of you saying you have been particularly moved by the fact that this workshop is an initiative from the UN halls—that you were particularly challenged that your expertise and its relevance to HIV and AIDS were being acknowledged--as academicians and members of the church. By coming here, we have also somehow agreed (I want to believe this) that we will continue the process—beyond this workshop---to make efforts to work with our faith communities to empower them (and to let them challenge us accordingly) to eradicate HIV and AIDS stigma.

Be that as it may, there are varying views concerning our ability to communicate effectively to our church communities. Clearly many of you here, while being academicians, are heavily involved with your faith communities. On the other hand, some church leaders here, have expressly said they often need our input and do not necessarily feel they have our support. On the latter, I have heard some theologians say that the churches do not listen to their theologians. Various reasons are advanced, such, as church leaders are suspicious of theologians; church members do not understand when theologians speak. Its is also said that theologians are high up there in theory and are not in touch with reality; theologians regard themselves as an upper class above their church leaders and members, and they also want to guard their academic freedom. It is also said that theologians are under pressure to remain faithful to academic standards and are afraid to lose their credibility in the guild, if they get too involved in the life of the church.

Of course these statements cannot be generalized. For example, most academic African theologians are, more often than not, in danger of being absorbed by the church and its organizations, which increasingly calls upon them to give leadership in various departments and issues. The fear of an African theological academician is: how long will my lifespan as a productive academician last, before the church absorbs me? This is particularly because the African church tends to lack sufficiently trained personnel, and so it often calls upon its academic theologians. This, however, cannot be assumed in the Western world—where many academicians may have a choice of being 'pure' academics—and hence run the danger of being detached from their faith communities. The point however is that communication channels between the academic theologians and their faith communities cannot always be assumed. They are not always smooth. So how do we intend to make this theological framework an agenda for eradicating HIV and AIDS stigma? How will we effectively communicate the message and encourage our faith communities and their leaders to have zero tolerance for HIV and AIDS stigma?

I do not claim to have answers. Given that many of you are working within your church communities, many will share on how we can break the barriers and create effective channels of communication. Many are already connected. This is important because with HIV and AIDS, every discipline has been challenged to look and search again, for our given knowledge has been shown up as inadequate. As I said elsewhere,

> HIV/AIDS has debunked many known truths and exposed the limitations of many scientific, economic and cultural truths/knowledge. Subsequently HIV/AIDS has

> called for intense research, re-examination and re-organization of all aspects of our lives. Theological education in the church and its institutions is not an exception (Dube 2002a: 545).

Furthermore, no matter how lamely church leaders may be handling HIV and AIDS; they are nonetheless at the very epicenter of the storm. As one of the few institutions that have direct connection with families and individuals; and being, by conviction, aspiring to be a caring community, the church is often obliged to visit the sick, counsel people living with and affected by HIV and AIDS, bury the dead, run orphans' projects, hospices and home-based care etc. With the epidemic, the work of an average church leader has more than doubled (Dube 2003b: iv-vii) while the cash inflow has gone down since members spend money on HIV and AIDS related costs. This state of affairs leaves an average church leader, with very little space for research, intellectual reflection and acquiring skills. The latter, however, are much needed since this same church leader is challenged to re-read the Bible in the light of HIV/AIDS; to develop and utilize new theological frameworks in the context of HIV and AIDS; to acquire new skills of pre and post HIV test counseling; new skills of preaching, to break the silence, to be capable of speaking prophetically given that HIV and AIDS is an epidemic that functions within social injustice. Our churches and their leaders are expected to speak decisively and effectively against HIV and AIDS stigma, but more often than not, these same church leaders are not educationally empowered to have the know-how—nor do they have the time to educate themselves. The role of theologians as educators and producers of new knowledge, therefore, cannot be over emphasized. Academic theologians have the space to research, write and produce relevant knowledge for the new HIV and AIDS context. Therefore, on this HIV and AIDS era, we cannot afford to have academic theologians who are not accountable or committed to their faith communities and institutions. We cannot afford to be theologians who are out of touch with their communities and the context—theologians who produce knowledge, which is irrelevant to the crisis, that confront our world today. And for those academicians who are busy producing excellent and relevant research and knowledge, one which can empower our churches—we cannot have the luxury of having that knowledge remain hidden in exclusive academic journals, books and halls, with little or no way of reaching the church leaders and members who need it the most. Similarly, we cannot afford to have church leaders and faith communities who feel threatened by academic leadership—if effective communication is to happen. Our relationships, therefore, need to be healed to enable the production of useful theological reflection in the HIV and AIDS era and to ensure that such knowledge can easily be communicated back and forth between the two levels. The academy and the church should feed one another.

Storytelling

If I do not particularly have an answer to such a long-standing division between the academy and the church, why then have I been asked to share with you on communicating the message of eradicating HIV and AIDS stigma in such a way that it will influence church leaders and faith communities? I would say there are two reasons:

First, I am regarded as one of the academicians who have been working very closely with HIV and AIDS in my academic work—in teaching, research, writing and publications.

Second, for the past two and half years I have been involved in challenging and training both theologians and church leaders. Concerning theologians, my task was to challenge and train them to review their theological programs in the light of HIV and AIDS to ensure that our trainee ministers graduate fully equipped to minister in HIV and AIDS contexts as well as to challenge educators to become responsible for re-training ministers who are already in field. Concerning church leaders, I collaborated with regional coordinators in challenging and training church leaders on adopting a theology of compassion in order to have a zero tolerance for HIV and AIDS stigma. In this exercise, compassion is defined as the capacity to suffer with those who suffer and to actively seek for changes. Compassion, in other words, must always move us to actively seek change, to end the pain, the suffering, and the hurting. Compassion is thus not just charity. It must always involve activism and liberation from all forms of oppression. It is defined as revolution.

I have been doing this under the banner of the Ecumenical HIV/AIDS Initiative in Africa—whose main objective was to break HIV and AIDS stigma and discrimination (and whose banner hangs is a heart made of people holding each other's hands). We have been a team of five, four regional coordinators and a manager, Dr Christoph Mann. With breaking the HIV and AIDS stigma as our main objective, everything that we did was aimed at empowering the church and its leaders to be an HIV and AIDS competent church. The approach underlined that breaking the stigma requires effective prevention, provision of quality care, and reduction of impact and provision of treatment. I have, therefore, been asked to share with you some insights, on communicating the message of breaking the stigma. What I will do is to share some details of my story and then draw out a few methodological insights, which I regard as some strategies for communicating the message to the church and its leaders. Lastly, I will highlight various methods that come from this workshop.

The First Story—Confronted and Confronting HIV & AIDS in the Academy

In the book, entitled *HIV/AIDS and the Curriculum: Methods of Integrating HIV/AIDS in Theological Programmes,* I tell some of these stories in the introduction and in my article, "Methods of Integrating HIV and AIDS in biblical studies." I will retell the stories. I begin with the question of how, as an academician, I began to break the silence and the stigma and to feature HIV and AIDS in my teaching, research and writing.

One Pedagogical Response to HIV and AIDS

Like many others, while I saw the theological questions raised by HIV and AIDS, I did not immediately see a direct link between my work as a New Testament lecturer and the struggle against HIV & AIDS.[51] My earliest response was in fact liturgical. As I was writing my PhD dissertation, I was also writing HIV and AIDS gospel songs, but the two

[51] The bulk of what follows here is drawn from, Musa W. D ube, "Methods of Integrating HIV/AIDS in Biblical Studies," pp. 12-15, in Musa W. Dube eds., *HIV/AIDS and the Curriculum: Methods of Integrating HIV/AIDS in Theological Programmes, Geneva*: WCC Publications, 2003.

remained separate. My second move was an attempt to use my skills as an educator to produce a teaching tool for church ministers. I worked on producing a video entitled, *Africa Praying: Orphans Need Love*." The video was a documentary on the state of orphans, examining what churches are doing about their plight and what they can and wish to do as well as to note their limitations. The video was thus both documentation and a mobilizing and teaching tool on behalf of orphans. The process of doing this video took me to real sites and brought me face to face with affected children and their caregivers and the reality of HIV and AIDS stigma. The intensity of stigma and its impact, at this particular time was vivid (the situation has improved in Botswana). For example, we could not find even one orphan who was willing to speak out concerning their plight—despite our many attempts and appointments, we always came back carrying our cameras in disappointments. Further, for the most time we were not allowed to videotape orphans (only their caregivers standing in barricaded doors or their singing voices or their backs)—for this would expose them to stigmatization. At that time, the government social welfare workers pointed out that due to stigma, they cannot supply orphans with food, clothes and other needs because the arrival of a government vehicle would immediately mark such children to the neighborhood as those who lost their parents to AIDS. The worst part was that since these children were too young to follow the services themselves and they mostly left with old grandmothers, who could not follow the services at the government offices orphans lived in poverty. Orphans could not be registered or identified and they could not benefit from services that have been put up for them. This experience demonstrates the impact of stigma on the provision of quality care to the affected.

Despite all this work, I still had not brought HIV & AIDS to the academic halls of my classes in the University of Botswana as a New Testament lecturer. What finally brought HIV and AIDS into classroom was a confrontation with the futility of my teaching. I was then giving a second year course on Synoptic Gospels to a huge class of two hundred students. The classroom was mainly composed of people between 18 and 40years. With the HIV infection rate in the range of 38% among the sexually active people, I was suddenly struck by the fact that almost half of my class may not be alive in the next ten years. This devastating realization brought me face to face with the futility of my teaching. I began to ask myself, what is the point of teaching Synoptic Gospels to this group of young people if it cannot help them stay alive and operate in an HIV and AIDS context—if they cannot even live long enough to utilize this knowledge? I began to ask myself how I could teach the New Testament in such a way that it assist my students to have an understanding of HIV & AIDS; how could my teaching equip students for HIV and AIDS prevention; for the provision of quality care and for the eradication of silence and stigma?

There was a second reason that pushed me towards mainstreaming HIV & AIDS in New Testament studies. This had to do with the contents of the synoptic gospels, namely, the miracles of healing performed by Jesus. As I narrate this story elsewhere,

> The miracles of healing seem to be throughout these texts. As we read, we become consciously aware that we are reading two texts: the ancient biblical text

> and the text of our lives. The merging of these two texts is sharply ironic, for Jesus goes about healing all diseases and illness, while we believers in Christ know too well that there is no healing where we stand. Despite this overt contradiction, Jesus, who heals all diseases instantly and without demanding payment, represents our deepest prayers and wishes (Dube 2002c: 122).

Confronted with this crisis in my teaching vocation, I began to devise ways of integrating HIV & AIDS in my university work. This took three forms. First, I encouraged students to write their dissertations on the subject by making it clear that I would be happy to supervise any work in this area.[52] Second, for assignments, I gave students various passages on the miracles of healing and asked them to design a questionnaire and find four or five people from the outside community to read the passage with them following the questionnaire. So students would read the miracles of healing with people in the community compile their findings and present some of them in the classroom. This helped to achieve several things. First, it enabled us to discover the theology that emerges from our HIV and AIDS context. Second, and most importantly, it broke the silence surrounding HIV and AIDS and brought all of us to talk. What I found in this broken silence was that

> In this process of talking, we participate in our own healing as we come to define ourselves as "all affected" by HIV and AIDS in our country, region and continent. The classroom becomes a social space for "tough encounters" as we take the moment to talk about what is really happening and how best we can bring ourselves to live with each other and our situation (Dube 2002c: 125).

This owning up and the capacity to define ourselves as "the affected" was a method of breaking the stigma," for instead of seeing HIV and AIDS as a problem of someone out there, classroom discussion became a space of owning the epidemic with the wider community and a joint search for answers.

In addition, my examination always included a question on some aspect of HIV and AIDS and how it can be seen from the perspective of the New Testament.

The third method was to mobilize the members of my department of theology and religious studies to mainstream HIV and AIDS in our research, writing and publications. I happened to be the seminar coordinator for the department at the time, charged with organizing speakers from the department and the community to give papers. So I proposed to the department that we have an academic yearlong series of papers that focused on HIV and AIDS and from our various areas of specialties as scholars of religion. Although the majority rejected this idea, some supported it. The refusal was really motivated by stigma, since people asked me: do you want us to be talking about HIV and AIDS for the whole academic year? Well, to make it more appealing, I

[52] Some of them include, Tom Lekanang, *Church Men Can Make a Difference in the Struggle Against HIV/AIDS*; Baboshe Ndweza, *The Role of the Church in the Fight Against HIV/AIDS*; Portia Liphoko, *Married Women, the Church and AIDS. A*ll these are University of Botswana dissertation projects for undergraduates.

successfully approached one refereed journal and proposed to edit a special issue on HIV and AIDS and theological education, using the papers from the seminar. With a promise to get papers published in a refereed journal, I got the support of more colleagues and also found speakers from outside the university community. With everything set, I drew up an academic yearlong program for fortnightly presentations. I e-mailed it to the whole university community, posted the schedule all around and things began to roll. Every two weeks, except during exam time, we had a presentation. The seminars brought together students, staff, and the general university community and interested outsiders. Soon our department was noted for its exemplary leadership in mainstreaming HIV and AIDS in our work. Again, the seminar served as a space for breaking the silence and hearing each other out. The end result of these seminars is now published in *Missionalia 29*. I also began to take whatever opportunity in my international talks, especially to various ecumenical bodies, to ensure that HIV and AIDS be heard.

Some Insights on Communicating the Message

The above story, I believe, undertakes various methods of communicating the message as academicians. What are these methods? First, it calls for intellectuals that are interconnected with both their religious communities and general society. This method led, even before I brought HIV/AIDS into my university teaching, to liturgical writing and to producing a teaching tool for mobilizing religious community. Clearly, this method calls for an activist biblical and theological scholar. Second, the method of reading the Bible with and from the community was employed to generate a contextually relevant theology of our time. The method of communicating here calls for a socially engaged scholar. One who generates knowledge with and from the community; one who learns and produces knowledge from, with and for the community, without compromising one's critical stand. Third, the research and seminar approach helped to bring the academic community and general community into some space of dialogue.

Second Story—Confronting HIV and AIDS with the church

But if I began to throw HIV and AIDS at the ecumenical bodies, they began to demand more from me. First, the Norwegian Church Aid asked me to be their conversation partner, to help them to draw up the regional HIV and AIDS programme in anticipation of the money that Norway's national fundraising campaign would raise. So from early January to March I was doing this programme. When the WCC held its Southern African regional consultation on HIV and AIDS in March 2001, in preparation for an Africa wide consultation, I was invited to give a paper. I wrote what has become a very popularly read paper, entitled "Preaching to the Converted: Unsettling the Christian Church." Many of you here have confirmed that you using this paper. In this paper, I was a free academic speaker who was not afraid to tell church leaders what I thought they ought to hear. I was happy to bomb and then retreat back to the academic space. But one of the things I said, which is important for us as theological educators, was that HIV and AIDS has exposed our theological mediocrity and that "a theological shift is needed in an HIV/AIDS context," (2001:42). This paper, also underlines the need to shift our stance from a narrow focus on sexual ethics to a broader theology of life. Based on this paper, Kurian Manoj said to me, "I am convinced that you are the right person to talk to church

leaders about HIV and AIDS." The days of bombing and the retreating to the safe space of the academy were slowly coming to an end!

From this point on the WCC and other ecumenical bodies gave me more responsibility. First, I was asked to work with southern African scholars to review a curriculum, designed in Kenya, to make it more gender sensitive, ecumenical and theologically grounded. Second, I was asked to organize and run two trainers of trainers (TOT) workshops for southern African theological institutions and educators. During these workshops I would trial test the newly proposed curriculum and review it again. Between June and October I researched who is there in Southern Africa and trained about sixty-five lecturers on integrating HIV and AIDS in the curriculum. My schedule became crazier, as I was called by ecumenical boards and institutions to speak and train worldwide. One thing led to another and I was finally asked to move from doing this job on part-time basis and to take the job of training theologians and church leaders fulltime. I applied for unpaid leave from my university. My task has been to assist theological institutions and lecturers to realize that we cannot continue doing our theological discourse as if nothing is happening to our world and time. The context of HIV and AIDS should shape our theological programs as we seek to contribute towards healing the world and healing ourselves, by empowering the church leaders and its members to be competent in dealing with all aspects of HIV and AIDS. As I have said elsewhere, perhaps the single most pertinent call of scholars in this age is to become, "prophets of life."

So far, I have trained up to 350 theologians of eastern, southern and west Africa, covering French, English and Portuguese-speaking Africa, on mainstreaming HIV and AIDS in their programs. I have worked with the regional coordinators in training more than 110 church leaders of Southern and Central Africa on breaking HIV and AIDS stigma through a theology compassion. These tasks of empowering theologians and academicians to break the silence and the HIV and AIDS stigma also involved producing relevant theological resources. Towards this end, I have produced and encouraged others to produce and publish relevant theological works, which tackled various issues of HIV and AIDS, including stigma. One such paper was published in the *Ecumenical Review of Mission* entitled, "Theological Challenges: Proclaiming the Fullness of Life in the HIV & AIDS and Global Economic Era[53] I first presented at a mission consultation jointly organized by WCC, UEM and Cevaa in London and attended by various ecumenical bodies. In the paper, I held that:

> The church has AIDS," for many of our members are infected, sick, dead or dying of HIV/AIDS and because if one of us has it we all have it, it means that Jesus Christ himself has AIDS, for the church is the body of Christ (1Cor. 12:27). It is my contention therefore, that we do not have to wait until the judgment day to hear Jesus saying, "You saw me sick with AIDS." Today Jesus Christ stands amongst us saying, "Look at me, I have AIDS." Do we love him any less? Do we

[53] This paper was published in the International Review of Mission, October 2002, Geneva: WCC Publications.

> worship him? Are we holier than him?' In this HIV/AIDS era, our greatest theological challenge is to grasp that Jesus is the face of every individual who is suffering with HIV/AIDS and who is threatened by this disease. Whenever and whoever and wherever a person is stigmatized, isolated and rejected because of their HIV/AIDS status, the church needs to grasp that Jesus himself is discriminated and rejected (2002a).

At my first presentation of this perspective, which sought to confront stigma and discrimination head on, people were shocked. It was scandalous. People argued. My theological friends were too embarrassed and looked the other way. But soon after, it was taken up by major ecumenical church bodies, who quoted it, illustrated it in art form and commented upon it in Christian magazines and journals that were read worldwide by their churches. I have heard how the illustrated form caused tough debates between the youth and church leaders in Zambia. The statement that "Jesus has HIV and AIDS" continues to question any form of stigma. The impact of these two articles, "Preaching to the Converted: Unsettling the Christian Church" and "Theological Challenges: Proclaiming the Fullness of Life in the HIV/AIDS and Global Economic Era" communicating with church members and leaders had to do with two factors: 1. They were written with the church audience in mind 2. They were published in journals that target church audience. I dare say between these two articles, I had other articles come out in highly academic books and journals, which never caught the eye of church leaders and ecumenical bodies. The impact in communication had to do with writing for a certain group and using particular journals, which target the church readership.

This morning, however, I am especially glad to introduce two books that are an important part of communicating the message. First, this small purple book, *HIV/AIDS and the Curriculum: Methods of Integrating HIV/AIDS in Theological Programmes*—which is targeting theological institutions and educators—challenging and equipping them to mainstream HIV and AIDS in their disciplines and programmes.

The second book is *Africa Praying: A Handbook on HIV/AIDS Sensitive Sermon Guidelines and HIV/AIDS* (in English and a French equivalent) –which is targeting church leaders and members. This book seeks to break the silence and the stigma, by ensuring that the church's worship space and practice is used for healing. The book consists of sermon guidelines for various occasions, groups, themes and various social issues that fuel HIV and AIDS. Released only a month ago, this week in Namibia, I have seen this liturgy used at the Ecumenical service, in Paul Isaack's worship and this morning by Mercy Oduyoye. One can only imagine that from the AACC 8th assembly, where we used this liturgy and distributed the book to participants, many countries and churches all over Africa have began to use it. Various speakers in this workshop have underlined the importance of liturgy in communicating the message of de-stigmatization. Denise Ackermann ended her talk by calling for a language of lament in our theological discourse and worship as an effective way of breaking the HIV and AIDS stigma and its various faces, especially dealing with its close association with injustice. Indeed, much of our worship, throughout this week, underlines that the production and use of relevant liturgy is central to communicating the message effectively. Education alone is not

enough—we need to find ways of speaking to the heart, and liturgy is one such effective way.

In Conclusion: Strategies of Communicating the Message From This Workshop

I want to conclude by outlining some of the methods of communicating the message that emerge from this week's workshop:

1. We began with a self-assessment process, where we examined how we have experienced stigma at various points of our lives and how it felt, and assessed how we are part of the stigmatizing cultures. This is a method which underlines that the message of de-stigmatizing will only take root when each of us begins to stand critically against the practice in all its various forms, at all times and everywhere.

2. Producing and using appropriate liturgy among church members is, perhaps one of the most effective ways of communicating the message of breaking HIV and AIDS stigma. It allows us to confess, to become reconciled with one another and with God, at an openly articulated setting—and to leave as renewed people who are better positioned to renew God's creation.

3. Putting the PLWHA at the very centre of the production of a theology of de-stigmatization is indispensable to an effective way of communication and conversion from stigmatizing. This became evident from the first two opening days of the workshops, which featured testimonies of PLWHAs. The participants and presenters also verbally expressed it. For example, Rev. Spiwo Xapile, who said that, in his congregation, they have a policy that before the preacher speaks, one PLWHA testifies and there is no eye that remains dry, shared one such policy. Although he finds it difficult to preach anything better afterwards, he does not need to persuade his church members to reach out to PLWHAs rather they immediately reach out to them. Denise Ackermann underlined the same: "If we are going to counter stigma and deal with HIV & AIDS in a responsible manner theologically, the place to start is with the lived experience… Praxis must be done in the interest of those who experience the stigma, it must be collaborative, and it must be culturally sensitive to different ways of experiencing reality" (2003:3).

Similarly, in a paper, that I gave at the 8th AACC assembly, I underlined that, "we have a duty to listen attentively to the stories and experience of the PLWHAs, the most vulnerable groups and the affected, and to let them be the champions of the struggle against HIV and AIDS by giving them space and voice to speak and be heard, while as church leaders we offer accountable solidarity, which programmatically and effectively tackles HIV and AIDS prevention, provision of quality care and affordable treatment as well as breaks the stigma and discrimination." (Dube 2003). I cannot over-emphasize the importance of this point. *Our theological framework, should not fail* to highlight the centrality of the voices and the agency of PLWHAs in breaking the stigma. On this issue, I find the following words of Brigette Syamalevwe, a Zambian PLWHA who has now passed on, helpful:

> I am neither a statistic nor an object of curiosity… People living with HIV/AIDS are people like everyone else. They are neither to be discriminated against nor condemned. It is by listening to people living with HIV/AIDS that Africa will learn how to act well to prevent HIV/AIDS. We no longer think HIV/AIDS is the fault of rape victims, sex workers, or homosexuals. HIV/AIDS is our reality, and we can only change the situation if we treat the illness and those who are suffering from it with a sense of value and dignity."[54]

4. Language is central in communicating the message of breaking the stigma. This was particularly underlined by Rev. J. P. Heath's paper and by some participants. According to Heath, we cannot expect to de-stigmatize if we equate HIV with AIDS; if we equate comdomizing with failure in abstinence and faithfulness; if we equate sexuality with sin and thus with HIV and AIDS. We have also come to understand that the word "scourge" is problematic, since it connotes being cursed.

4. The training of theological educators to communicate the message of de-stigmatizing is a long-term strategy. Rev Spiwo Xapile insists that we also need a short-term strategy of carrying out community theological reflections, which will bring church leaders and all interested parties to discuss methods of breaking the HIV and AIDS stigma.
5. Rev Lisandro Orlov, underlines that HIV and AIDS is a global crisis, thus part of communicating the message includes translating the available documents into different languages.
6. Various group reports emphasized that taking cognizance of the specific contexts is essential in communicating the message. HIV and AIDS stigma, in other words, may work with various other cultural forms in different contexts. This may necessitate context-specific ways of breaking the stigma and of communicating.
7. Prophecy has also been noted as a method of communicating the message and breaking the stigma. Given that HIV and AIDS works with many various forms of social evils/injustice—such as poverty, gender injustice, racism, stigma, violence, war, human rights violation, international exploitation---prophecy is particularly important. Both church leaders and theologians need to utilize prophecy to name openly and courageously counteract the various social evils that expose people to HIV and AIDS infection, to stigma and to lack of quality care. On this area, the northern church of the developed worlds has a major role to play on insisting that all PLWHAs need to have access to affordable ARVs. HIV and AIDS stigma is closely related to lack of necessary medicine—it is in fact, a denial of human rights. If and when the appropriate medication is provided to enable PLWHAs to live a long, healthy and productive life, then HIV and AIDS, like cancer, hypertension and sugar diabetes, would be not be stigmatized. Rather, HIV and AIDS would be seen as a manageable disease. The move to provide affordable ARVs to all those who need them will go along way in breaking the stigma.

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[54] Quoted from the "Aids and Stigma: An African Christian Context," in *The Beads of Hope Campaign: Education and Advocacy Kit*. The United Church of Canada, 2003, p.1.

8. Participants also suggested that we could utilize e-mail lists, web-sites, church magazines, church councils, WCC regional offices, collecting a good bibliography in CD publishing, education and empowering PLWHAs to speak in church and public.
9. Final group reports made several suggestions: using academic societies to put breaking the stigma on the agenda; speaking to appropriate/influential boards of governors/examiners/liturgists to initiate the necessary changes; continuing to attempt to work with the UN at different regional, national and international levels; committing ourselves to be resource persons of the theological framework produced in this workshop; producing catechetical material, liturgy, and research, curriculum review, stories of PLWHAs combined with theological interpretation; using other resources such as film; producing simple but effective/useful bible notes; exploring the area of sexuality and the area of sin.

10. The best method of communication, it was noted by the participants, is when we all do it!! So let every one of us use our disciplines, institutions, organizations, contacts, networks and power to present the theological framework on breaking HIV and AIDS stigma and discrimination, wherever and whenever we can.

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"He was despised and rejected by others; a man of sorrows and acquainted with infirmity; and as one from whom others hide their faces he was despised, and we held him to no account. Surely he has borne our infirmities and carried our diseases; yet we accounted him stricken, struck down by God, and afflicted. But he was wounded for our transgressions, crushed for our iniquities; upon him was the punishment that made us whole, and by his bruises we are healed. All we like sheep have gone astray; we all have turned to our own way, and the Lord has laid on him the iniquity of us all. He was oppressed and he was afflicted, yet he did not open his mouth. By a perversion of justice he was taken away. Who could have imagined his future? For he was cut off from the land of the living, stricken for the transgression of my people. They made his grave with the wicked and his tomb with the rich, although he had done no violence and their was no deceit in his mouth."

- Isaiah 53, 3-9 (NRSV)

Back page summary

UNAIDS recognizes and values the efforts carried out by religious groups in care and treatment for PLWHA. As religious academicians and theologians, (who often are also the) moral leaders and teachers are stimulated to do more HIV related work and thus to influence religious education and opinion, there will be greater support for practical work in the field.

In December 2003 UNAIDS supported a workshop on HIV and AIDS related stigma and discrimination. This brought together 37 leading academic theologians from different Christian traditions and countries, to consider and debate the major theological issues that contribute to and can help eradicate stigma related to HIV and AIDS, to engage in dialogue with people living with HIV and to provide a framework for Theological reflection. This is the first of what we hope will be a series of documents reporting on the work of leaders from different religions (Christian, Islamic, Hindu and Buddhist) addressing the challenge of HIV and AIDS from their own religious perspective.

This report of the workshop contains the framework for Theological reflection and the related speeches presented at the workshop. The text belongs to the participants and those who have signed it, it does not represent the views of UNAIDS (which is not a competent authority on theology.) It is not a document of doctrine, but a base for further research and discussions among theologians and church leaders.