World Council of Churches

Working with People Living with HIV/AIDS Organizations

Background Document
Acknowledgements

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Chapter 1

Introduction

This document has been written to accompany World Council of Churches, *Partnerships between Churches and People Living with HIV/AIDS Organizations: Guidelines*, (2005). Whereas the partnership document explores the question of why churches should work with People Living with HIV/AIDS (PLWHA) organizations and networks, this document has a focus on how churches may work with PLWHA organizations and networks. For example: What issues do you need to think about? What are the needs of PLWHA? How should you interact PLWHA? It is hoped that this document of practical suggestions will assist in helping make partnerships functional and effective.

Chapters two and three look at some of the issues which confront churches and PLWHA organizations in their attempts to forge partnerships. Essentially this is an appraisal of the point churches and PLWHA organizations are at now. Many of the issues described are testing the compassion and HIV and AIDS competency of churches and often there are no easy answers. For examples, issues such as HIV prevention, including prevention inside marriage and abstinence before marriage, and human sexuality, including same-sex relations, have the potential to divide churches and to create obstacles to partnerships with PLWHA and between faiths. Even if some positions are contentious or unpopular, churches need to be able to articulate their positions logically and coherently.

Similarly, PLWHA organizations are also faced with an array of issues some of which may be divisive such as how to respond to PLWHA who knowingly put others at risk of exposure to HIV; HIV-positive husbands and partners who force themselves on their wives or partners; and in some regions, inter-generational sex as a perceived method of curing HIV infection.

Acknowledging these difficulties and working towards a common understanding with partners, is one step in defusing the divisive nature of some of these challenges and perhaps finding solutions. Defining boundaries means that both parties can see what is possible and what is not; thereby creating clarity when making decisions.

While chapters two and three provide background on churches and PLWHA organizations, chapter four is the heart of the document. Chapter 4 provides concrete information on an array of issues which may need to be addressed in working with PLWHA organizations. Particularly note worthy are the sections on confidentiality, tokenism, capacity building, and monitoring and evaluation. A recurrent theme is the role of churches in advocating for access to treatment, including anti-retroviral therapy.

Boxes are used throughout the text to highlight specific issues or to provide examples of projects or programmes or partnerships that have been successful. The illustrative material in this document comes from a number of existing studies and reports. One
of the benefits of increased cooperation and the development of partnerships between churches and PLWHA organizations will be a growing body of knowledge of how to work together and work through periods of uncertainty, discontent and perhaps even confrontation. This will strengthen the partners involved as well as churches and PLWHA organizations generally.

The Annexes contain sections on a self assessment framework for AIDS competence, the correct use of HIV- and AIDS-related language, the Covenant Document on HIV/AIDS and human capacity development.

Please note that the full texts of the declarations by churches on HIV listed in Box one “List of Declarations and Policy Statements by Churches and Faith-based Organizations from 2001 to 2004” are available on the World Council of Churches website at http://www.ecuspace.net/contact.nsf. If you do not have access to internet; you can obtain copies from:
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Chapter 2

Looking inside …

This chapter looks at some of the issues which confront churches and PLWHA organizations in their attempts to forge partnerships.

The section on churches acknowledges the transition that has occurred in many churches but questions whether words have been translated into actions. The section also highlights the practical difficulties that can occur in involving PLWHA and different strategies or initiatives to eradicate HIV-related stigma.

With regards to PLWHA organizations, the section highlights the diversity of people captured under the term “PLWHA” and charts the history of the PLWHA movement both before and after the formulation of the Greater Involvement of PLWHA (GIPA) Principle at the Paris Conference, 1 December 1994. It also highlights some of the taboo subjects in relation to PLWHA and suggests that partnerships with churches will enable a dialogue to find solutions to these difficult subjects.

2.1 Looking Inside Your Church

Covenant 8: Church, PLWHA and HIV/AIDS

We shall remember, proclaim and act on the fact that we are one body of Christ and if one member suffers, we all suffer together with it; that the Lord our God identifies with the suffering and marginalized and heals the sick (1 Corinthians. 14:26; Matthew 25:31–46). We shall, therefore, become a community of compassion and healing, a safe place for all PLWHA to live openly and productively with their status.

As many good ideas can suffer face insurmountable obstacles if people begin on the wrong foot, both churches and PLWHA organizations need to be prepared to work together before commencing the common journey of a partnership. Many PLWHA have been stigmatized in their communities and discriminated against institutionally sometimes by churches. The perceptions that churches condemn sinners and promote very narrow guidelines on HIV prevention have created negative popular views in many people in some regions of the world of churches and their response to HIV. There is a need for reconciliation for the individual, but also between individuals, and between individuals and their churches. For this to be possible churches and PLWHA need to be able to listen and be open, humble, forgiving and most of all capable of showing true love.

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A climate of denial regarding HIV and AIDS issues has affected, and in some cases continues to affect, some churches and faith-based organizations. For example, the Siyam’kela study, South Africa found that this was especially the case in more middle-class Christian congregations, as well as the Muslim-faith community, which did not believe that HIV and AIDS was a problem in their communities.\

As was outlined in the introduction of the accompanying document World Council of Churches, *Partnerships between Churches and People Living with HIV/AIDS Organizations: Guidelines* (2005) churches are in many different places in responding to HIV; some are still in denial. While many churches and faith-based organizations have begun the proverbial trek across the Red Sea or are struggling in the wilderness, AIDS raises many issues for churches – some of which have previously been taboo or extremely difficult to confront, for example, from sexual abuse and violence, rape, incest and infidelity, drug use as well as death and dying to accepting the innate sexuality of every human being. As discussed in chapter three, churches are faced with an array of issues around HIV prevention, sin and sexuality. In some respects, it is not surprising that twenty years into a global pandemic, churches are still struggling with how to respond.

Many churches have implemented a wide range of interventions, mainly focusing on interventions and programmes to provide care and support to PLWHA – traditional responses by churches. Faith-based organizations have responded to the specific needs of PLWHA in terms of material support such as nutritional programmes and the distribution of food parcels, setting up support groups for faith community members who were living with and affected by HIV and AIDS, as well as pastoral care. Churches have also formed support groups and prayer groups.

Where possible, faith-based organizations have attempted to respond to the health care needs of PLWHA in the form of home-based care or establishing hospices in the community. The provision of antiretroviral therapy is also becoming a reality. The Pontifical Council for Health Pastoral Care estimates that 26.7% of the centres dedicated to treating HIV/AIDS in the world are Catholic centres. However, such work is dependant on the funding and having relevant trained personnel.

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4 For example, to aid this work, on 17 December 2004, Cardinal Javier Lozano Barragan, head of the Pontifical Council for Health Care Workers, unveiled Pope John Paul II's newly established The Good Samaritan Foundation. The foundation provides economic support to the sick, who are most in need, particularly those suffering from AIDS. The foundation will direct funds to any legitimate facility, not just Catholic-run centers, that are desperate for financial assistance. The foundation will not withhold funding a group even if it also promotes condom use in preventing the spread of HIV. The foundation will earmark money first for Ethiopia, because when it comes to medical or social assistance, there is little available. More information from goodsamaritan@hlthwork.va And http://www.healthpastoral.org/events/good_samaritan_en.htm

Religious leaders can be sensitive to the needs of PLWHA and are beginning to play a major role in promoting a culture of acceptance and respect for PLWHA, including notions of responsibility and tolerance. Provision of spiritual and moral care to those living with and affected by HIV and AIDS is often needed because people may experience a range of difficult emotions, including fear of death, depression, suicidal ideation, guilt, anguish, anger, denial, shock, rejection and isolation arising from stigmatization. Thus, for example, one faith leader in the Siyam’kela study, South Africa, suggested that the church could facilitate the emotional healing of a person who has learnt that they are HIV-positive by providing a ‘humane and loving’ environment through, for example, pastoral counselling and prayers.

Given the newness of HIV and AIDS as a serious endeavour for churches and/or congregations, some churches like many governments and other organizations, made mistakes in their initial response, which contributed to HIV-related stigma and discrimination. In 2001 Canon Gideon Byamughisha pointed out that, It is now common knowledge that in HIV/AIDS, it is not the condition itself that hurts most (because many other diseases and conditions lead to serious suffering and death) but the stigma and the possibility of rejection and discrimination and loss of trust that HIV-positive people have to deal with. Some churches and individuals still stigmatize HIV and discriminate against PLWHA; however, overwhelmingly churches have made, and are making, great efforts towards breaking the stigma both within their church and in society more generally. The extent of such change is extremely variable across regions, and between and within churches. There can also be different reactions between church leadership and church members. Sometimes leaders are moving faster than their flock and sometimes a stubborn bishop stops his members from acting in a Christian way. As an example of the variability of responses, see the reactions described in box two “Jamaica Council of Churches drafting policy on HIV/AIDS” below.

From 2001 onwards there have been a series of declarations and policy statements from various churches’ governance bodies. The most significant ones are listed in the box one.

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Box 1: List of Declarations and Policy Statements by churches and faith-based organizations from 2001 to 2004

2001

Church of Norway, *Statement from the Bishops’ Conference*. April 2001


2002


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9 The full texts are available on the World Council of Churches website at [http://www.ecuspace.net/contact.nsf](http://www.ecuspace.net/contact.nsf). If you do not have access to internet; you can obtain copies from:
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World YWCA. *Executive Committee*. Geneva, Switzerland, November 2002


**2003**


**2004**

Romanian Orthodox Church. His Beatitude Teoctist, Patriarch of the Romanian Orthodox Church. *A message, urging to love and tolerance for those suffering from AIDS/HIV*. Romania, 27 January 2004.

Regional Meeting facilitated by the Latin American Council of Churches (CLAI) and supported by the World Council of Churches (WCC), *The Church and HIV/AIDS in Latin America and the Caribbean*, Panama City, Panama, 27 January–1 February 2004.


The United Methodist Church. *Drugs and AIDS Resolution – Adopted by 2004 General Conference*. Pennsylvania, United States, 27 April–7 May 2004
Asian Muslim Action Network, Asian Resource Foundation and Thai Muslim Network. *International Pre-conference Muslim Workshop on HIV/AIDS. In the name of Allah, the Beneficent, the Merciful.* Bangkok, Thailand, 9 July 2004.


United Evangelical Mission, Anti HIV/Aids Programme Policy, Adopted by the UEM General Assembly in Manila, October 2004.


Interfaith. *International Interfaith Conference on Prevention and Control of HIV/AIDS, Delhi Declaration*. Delhi, India, 1–2 December 2004


In the history of HIV and AIDS there have been literally hundreds of declarations made by PLWHA organizations locally, nationally and internationally, by nongovernmental organizations (NGOs), the UN and governments, few of which have been put into effect. Declarations can be ways of directing the attention of a church to an issue. The question for churches, who want to be seen as credible and accountable, is whether all the time, energy and money expended in gathering leaders together and formulating declarations really leads to concrete coherent actions in countries and parishes, which in turn have measurable effects on the lives of people.

Most declarations highlight that churches and church and ecumenical organizations are grappling with the HIV- and AIDS-related stigma. An effective way of moving from declarations to implementation of intentions is to find concrete and sustainable ways of working with PLWHA and their organizations. This can form an indicator for monitoring and evaluating the partnership.

**Discuss**

- Is your parish or church updated on declarations made by its leaders?
- What has been done in your parish to implement the points in the declaration made by your church?
- Who in your parish or church is responsible for following up on the implementation of the commitments made in the declaration?
The example offered below in box two “Jamaica Council of Churches drafting policy on HIV/AIDS” illustrates how churches in Jamaica and in the wider Caribbean are responding and highlights the difficulties in countering HIV-related stigma.

**Box 2: Jamaica Council of Churches drafting policy on HIV/AIDS**

Several church leaders admitted that their biggest obstacle to getting an HIV/AIDS outreach going in their community was the stigma and discrimination against persons infected with the disease. *They (churches) are not getting a favourable response from the community*, programmes officer for the Jamaica Council of Churches (JCC) HIV/AIDS project, Ainsley Reid, said. *People (clergy) are excited and willing to do something, but in rural Jamaica there is a big challenge because of the stigma that exists at the level of the community.*

He said that pastors and lay leaders participating in a workshop in St James had their own 'misconceptions' about the disease and how it is contracted. The December 2004 workshop was the second of four being hosted by the Jamaica Council of Churches to sensitise more than 140 clergy and lay leaders island wide about HIV.

The JCC's work is part of a bigger project which started in June 2003, involving a number of inter-religious organizations in 13 other CARICOM territories. The project, called "Building a Faith-Based Response to HIV/AIDS in the Caribbean", is being spearheaded by the Caribbean Council of Churches with a Canadian$ 2 million grant from the Canadian Development Agency (CIDA). A major component is the formulation of a set of guidelines that will guide churches in the region in developing their own intervention strategies.

An inter-religious HIV/AIDS policy committee, convened by the CCC in May this year, is now preparing a document outlining "Guidelines for Caribbean Faith-Based organizations in Developing Policies and Action Plans to Deal with HIV/AIDS".

Many different strategies are required to counter stigma. Box three “Strategies for Hope Trust: What can I do?” describes a new video, designed to combat HIV-related stigma, shame, discrimination and denial in churches. The video features Rev. Canon Gideon Byamugisha from Uganda – one of the first African priest to disclose his HIV-positive status. For more information on Rev Gideon, see box 20 “Canon Gideon Byamugisha – the Anglican Church stands behind its pastors” in 4.3 Confidentiality.

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Box 3: Strategies for Hope Trust: What can I do?

While churches throughout the world have provided health care, counselling and material support to many people living with HIV and AIDS, they have been less effective in addressing issues such as HIV-related stigma and discrimination. Many churches have ignored HIV and AIDS as an issue affecting their own members, or have expressed judgemental attitudes towards people living with HIV.

In this video, entitled 'What can I do?', Canon Gideon talks about the need for his fellow Christians to do away with judgemental attitudes towards HIV-positive people, and instead to offer them love and support. Churches need to spread hope, not fear, he says. He goes on to tell how his wife died of an HIV-related illness and that he too found out he was HIV-positive. He accepted his status and disclosed it to his family and friends, and also to his Bishop. Later he married a woman who was also HIV-positive.

Canon Gideon speaks on the video about the difficulty he has faced when buying condoms, because people usually associate condoms with immorality. He describes how he has turned these situations into impromptu AIDS education sessions.

The video is divided into short segments on topics such as 'Coping with stigma', 'Why be tested for HIV?' and 'Challenges for the church', and is accompanied by a Facilitator's Guide. The production of the video and the Facilitator's Guide has been supported by Christian Aid, World Vision International, The World Bank and Lutheran World Federation.

These new materials are available from Teaching-aids At Low Cost (TALC): the video in VHS format (£16) or DVD (£20) and the Facilitator’s Guide (£2). African organizations without funds to purchase these materials may request free copies. Please write to introduce your organization, explaining how you plan to use these materials. The video and guide can be ordered from TALC:

Email: info@talcuk.org
Tel: +44 (0) 1727 853869

Reducing stigma involves a wide variety of activities, many which churches and faith-based organizations are already involved in. Box four on the “Church of the Province of Southern Africa HIV programme” highlights this – the goal is to be achieved through the sum of all the component activities.
Box 4: Church of the Province of Southern Africa HIV programme, 2003–2006

The Christian Aid supported CPSA programme is ambitious and complex – attempting to challenge stigma and discrimination within the church and wider community and support a wide variety of HIV care and prevention programmes. Although churches in Africa often have relatively conservative views and have sometimes been instrumental in promoting stigma and negative attitudes to PHWLA this programme aims to counteract these views. In the 6 countries (and 26 dioceses) in which it works there are a wider range of approaches with some dioceses having more active involvement of PHWLA and have more developed programmes. The challenge is to support all dioceses to develop and expand their work, and working with the African Network of Religious Leaders Living with or personally affected by HIV/AIDS (ANERELA+) is seen as key to this.

As of June 2004, the programme had recruited and trained CPSA HIV staff and set up an HIV office to manage the programme. Twenty-three dioceses in six countries had been supported in their HIV work and helped to access other sources of funding. In addition, they were assisted in strengthening ecumenical and interfaith dialogue and collaboration. Training was given to clergy and lay leadership, and was assisted closely by ANERELA+. CPSA has now embarked on a program to actively support and encourage members living with HIV into fuller involvement in the program, starting with a residential retreat planned for later in 2005, in which ANERELA will be playing a leading role.

Workplace programmes and policies are being developed to protect the rights of church workers, clergy and lay leaders living with HIV and AIDS. Information on access to social grants has been developed, and linkages have been established with other churches and faith-based and community organizations.

See “From Boksburg to Canterbury - Steps to Putting HIV/AIDS on the Anglican Map” http://www.anglicancommunion.org/special/hivaids/

Even though many faith-based structures are now beginning to realize the importance of encouraging openness and realism in responding to HIV and AIDS; religious communities still have a long way to go, especially when it comes to actually understanding how to communicate about HIV and AIDS in all aspects of their work. It is not sufficient to set up a network or a self-help group of PLWHA; if the religious

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community continues to stigmatize in other areas. Norwegian Church Aid (NCA) experienced a striking example of such a situation as described in box five below.

Box 5: Destigmatizing HIV within a church – internal communications

Norwegian Church Aid (NCA) supported a large faith-based organization, working in a very poor urban area, to set up a self-help group for PLWHA. The group met regularly once a week at the church campus. As stigma and discrimination was a serious problem in this area, the group soon became very popular and was appreciated by PLWHA as a “refuge”, a place for receiving support and for joint counselling.

A striking feature of the group was that it mainly consisting of men and women over 35–40 years of age, even though the HIV prevalence in the area was very high among young adults 18–24 years of age. How come they never showed up at the group? After some informal chats with group members, the reason was clear. Just up the street, the church was running some vocational training programmes and income generating activities for urban poor. It turned out that PLWHA were not admitted to these programme. In other words, the younger PLWHA could not afford to be associated with the PLWHA group and had to conceal their status, as they were dependent on the training and income from the activities in order to sustain themselves and their families. When the church leaders were confronted with this, they were aware of the practice. They had not realized either the ethical dilemma or the mixed messages that the church was putting out.

Similarly, a UNAIDS sponsored Theological Workshop Focusing on HIV/AIDS Related Stigma in Namibia, December 2003, stated:

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

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12 Communication with Anne-Marie Helland, Special Advisor, Dept. for Advocacy and International Development Policy Norwegian Church Aid, anne-marie.helland@nca.no
'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\textsuperscript{13}.

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\textsuperscript{14}. 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\textsuperscript{15}. There are some practical materials available which are written specifically on a theological response to HIV/AIDS\textsuperscript{16}; however, more churches need to develop curricula with input from the lived experience of PLWHA that focus on a theology of compassion, support and healing related to HIV/AIDS and which discusses judgement and condemnation.

Finally, 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\textsuperscript{17}.


\textsuperscript{19} Some useful materials include:


2.2 Looking inside the PLWHA movement

Around the world, when HIV has appeared, PLWHA have often established networks or groups of self-help, support and empowerment as well as organizations, generally based on the notion of “positive living”, which involves the following.

- **Looking after spiritual health**, for example asking the divine for strength, meditating, praying or seeking pastoral counselling.
- **Looking after mental health**, for example, joining self-help groups, sharing feelings with family and loved ones, including children, thinking positively and renewing reasons to live.
- **Making good health choices**, for example, getting medical help whenever ill, eating nutritious food, drinking plenty of water, practising good hygiene, taking extra rest when needed, avoiding smoking, alcohol and drug use, protecting the health of others by not exposing them to HIV infection, and taking antiretroviral therapy if medically indicated (this assumes that it is available).
- **Putting worldly affairs in order**, for example, making peace with others, arranging for the care of children and making a will.
- **Living as normally as possible**, for example working for as long as possible, spending time with friends and family, and staying active in religious, professional and community organizations.

Many people, both HIV-positive and others, recognize the importance of such a response to both a HIV diagnosis and an impaired immune system. It is striking a balance between life and the reality of death. Yet this response has sometimes been ignored or belittled by policy-makers and medical professionals. PLWHA have fought for their involvement in making decisions about their own health care, policy debates on both national and international HIV-related issues, and particularly on access to treatment.

In June 1983 in Denver, United States, a movement of PLWHA emerged. The ‘Denver Principles’ adopted at the forum called for those living with HIV to be supported when they opposed AIDS-related stigma and discrimination.

These principles gathered greater support over time and were formally recognized in the principle of the Greater Involvement of People Living with HIV/AIDS (GIPA) signed by 42 countries at the 1994 Paris AIDS Summit. The countries agreed to support an initiative to “strengthen the capacity and coordination of networks of PLWHA and community-based organizations”. They added that, “by ensuring their full involvement in our common response to the pandemic at all—national, regional and global—levels, this initiative will, in particular, stimulate the creation of

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18 See [http://www.napwa.org/who.html](http://www.napwa.org/who.html)
supportive political, legal and social environments”. The governments also undertook to “ensure equal protection under the law for PLWHA”\(^{19}\).

In 2001, the United Nations General Assembly Special Session on HIV/AIDS in the Declaration of Commitment endorsed the GIPA principle\(^{20}\), which was further upheld in the Guiding Principles of the “3 by 5” Treatment Initiative, which aims to provide three million people with antiretroviral therapy by the end of 2005\(^{21}\).

In section “4.4 Tokenism”, the texts of declarations and strategic plans by churches and faith-based organizations, which require or promote the involvement of PLWHA, are set out.

Despite these pledges and commitments, the active involvement of PLWHA in decision-making relevant to their lives is still far from universal. Furthermore, the involvement of HIV-positive women, youth and children has lagged far behind that of men in most parts of the world. One constraint is that, globally, only about 10% of PLWHA know their seropositive status, and many other PLWHA are unwilling to be open about their status because of fear of discrimination and stigma.

PLWHA organizations also have their limitations and weakness. Firstly, the majority of PLWHA do not belong to PLWHA organizations, which raises the issue for both the church and PLWHA organizations of how to bring PLWHA into some form of support group. Secondly, how do church and PLWHA organizations respond to angry, isolated or desperate PLWHA who knowingly put others at risk of HIV infection or, in some regions, who may have sex with virgins in the belief that this will cure HIV infection? How do church and PLWHA organizations respond to authoritative, HIV-positive husbands or partners who insist that their wives or partners provide unprotected sex? Such acts are the effects of unjust social structures and stigmatized, isolated, rejected and silenced PLWHA. Partnership with PLWHA organizations will offer both PLWHA and churches a way forward, through creating an environment where discussion of taboo subjects can take place and cooperation on finding solutions for HIV- and AIDS-related stigma that places many PLWHA in distressing situations.

PLWHA organizations face challenges like any other grouping of people. Unfair and discriminatory power dynamics can occur within the PLWHA organizations. For example, women in some support groups headed by men, often complain that public roles are given to men and that women are allocated jobs which do not pay much or are or given the unpaid jobs. Similarly, orphaned girl-children face greater challenges due to their gender and age. As a group, they are likely to be subjected to sexual violence, exploitation, human trafficking and face greater possibilities of dropping out of school due to work commitments, forced marriages or teenage pregnancy. Women and grandmothers who are HIV-positive due to their gender may be hindered from HIV education, access to information, services and resources Other challenges are associated with class, race, age, ethnic and sexual orientation.

\(^{19}\) UNAIDS. *From Principle to Practice Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)*, 1999. http://www.unaids.org

\(^{20}\) http://www.unaids.org/en/events/un+special+session+on+hiv_aids.asp

\(^{21}\) http://www.who.int/3by5/en/
Power struggles can lead to open jealousy, competition and conflict of interest may occur. In most countries, there is a history of internal fighting within PLWHA organizations, and conflict between organizations. While this is wasteful of time and resources, normally, the PLWHA movement that has evolved has been strengthened, though the cost is high. Unfortunately, this appears to be a normal part of the evolution of PLWHA movements.

PLWHA needs are not uniform – they reflect the diversity of PLWHA. PLWHA include HIV-positive infants, prisoners, orphans, widows, single women, migrants, poor or unemployed men or women, people dying from AIDS-related causes; older people, men who have sex with men, injecting drug workers, commercial sex workers, care-giving grandmothers, recipients of blood and blood products – in short PLWHA come from a broad spectrum of society. All these groups of PLWHA have different needs and they may form different organizations to reflect and address their particular experiences and needs, and may require particular forms of partnership.

The International Community of Women Living with HIV and AIDS (ICW)\(^\text{22}\) was formed as a result of women’s needs to have a support network which reflects their needs and experiences. In 2003, the UN Secretary General, Kofi Annan, established a task force to investigate the impact of HIV/AIDS on women and girls. This was part of a movement, which included the 2004 World AIDS Campaign focus on women and girls\(^\text{23}\), and the formation of the Global Coalition on Women and AIDS initiative.\(^\text{24}\) In 2004, the World AIDS Campaign slogan “Have you heard me today,” highlighted the unique and complex burdens of HIV and AIDS experienced by women and the girl-child due to their gendered identities\(^\text{25}\). To help churches grasp the plight of many woman around the world; the Ecumenical Advocacy Alliance developed liturgy that encouraged the use of a poetic prayer, highlighting biblical women and their experiences, tying it together with the stories of contemporary women as shown in the following box.

\(^{22}\) http://www.icw.org/tiki-view_articles.php

\(^{23}\) The Task Force was established in 2003 under the leadership of Ms Carol Bellamy, Executive Director of UNICEF. Members of the Task Force included parliamentarians, the Ministers of Health for Zambia and Namibia, religious leaders, educators, women living with HIV/AIDS from South Africa and Swaziland, Supreme court justices from Botswana and Zambia, senior government officials from Mozambique and Malawi, and women’s rights activists from Lesotho and Zimbabwe. The Task Force examined the situation of women, girls and HIV in nine countries in southern Africa most affected by HIV/AIDS: Botswana, Lesotho, Malawi, Mozambique, Namibia, South Africa, Swaziland, Zambia and Zimbabwe.


\(^{24}\) The Global Coalition on Women and AIDS is a new initiative, a movement of people, networks and organizations supported by activists, leaders, government representatives, community workers and celebrities, to raise the visibility of issues related to women, girls and AIDS and lead to concrete, measurable improvements in the lives of women and girls.

http://womenandaids.unaids.org/default.html

Box 6: Have you heard me today?26

Woman 1: I am Eve, the bone of your bone, and the flesh of your flesh.
Woman 2: I am Sarah, the woman who calls you Lord and master.
Woman 3: I am Hagar your maidservant; your unofficial wife, expelled from your house.
Woman 4: I am Leah, the woman you married against your will.
Woman 5: I am Dinah your only daughter who is raped by Shechem.
Woman 6: I am Tamar, your desperate widow who plays the sex worker.
Woman 7: I am Ruth, your young widow sleeping at your feet, asking for your cover.

Woman 8: I am Bathsheba, raped by your king and married by the same.
Woman 9: I am Vashti, your wife banished so that all women can obey husbands.
Woman 10: I am the Levite’s concubine, raped by the mob and cut up by my lover.

ALL Women:
We are the broken women of the Hebrew Bible
We are broken women in a broken world.
We are women searching for our own healing.
*Have you heard us today?*

Woman 11: I am Mary, the pregnant woman with no place to go.
Woman 12: I am the Samaritan woman, with five husbands and none for her own.
Woman 13: I am Martha, the woman who is cooking while you sit and talk.
Woman 14: I am Mary, the woman who silently anoints your feet with oil.
Woman 15: I am the street woman, washing your feet with my tears.
Woman 16: I am the bent over woman, waiting for your healing touch.
Woman 17: I am the bleeding woman, struggling to touch your garment of power.
Woman 18: I am Anna, the widow praying for liberation in your temple
Woman 19: I am the persistent widow in your courts, crying, “Grant me Justice.”
Woman 20: I am Jezebel, the demonized woman, blamed for all evil.

ALL Women:
We are women of the Christian Testament.
We are broken women in a broken world.
We are women searching for our own healing.
*Have you heard us today?*

Woman 21: I am the woman in your home, I am your wife.
Woman 22: I am the woman in your house, I am your lover, your live-in girlfriend.
Woman 23: I am the woman in your life, I am your mother.
Woman 24: I am a woman in your workplace, I am your secretary.
Woman 25: I am a woman in your streets, I am your sex worker.

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Woman 26: I am a working woman in your house with no property of my own.
Woman 27: I am the woman in your life with no control over my body.
Woman 28: I am the woman in your bed with a blue eye and broken ribs.
Woman 29: I am the woman raped in your house, streets, offices and church.
Woman 30: I am the woman in your church, cooking, cleaning, clapping & dancing.

ALL WOMEN:
We are women of the world.
We are Women of Faith.
And we are secular women.
We are women seeking for our own healing

Have you hear us today?

Similarly, Young Positives came into being to address the needs of young HIV-positive people

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27 Youngpositives is the youth section of the Dutch HIV Association and cooperates with (among others) Sensoa Flanders, the Youngpositive Foundation and Klavertje Vier. The website is a platform for young people, between the ages of zero and thirty, who live with HIV and AIDS. Besides information for young people, you can read personal stories, enter discussion groups or place a contact advertisement. Youngpositive also organizes discussion groups and forums.

http://www.youngpositive.org/
Chapter 3

Challenges for Churches

This chapter explores in depth issues related to prevention such as the position of women and condom use for serodiscordent couples. The ‘ABC’ approach to prevention – Abstain, Be faithful, use Condoms – is discussed and particularly what “B” – be faithful, could mean if the church was more involved in the sex lives of its congregation. An alternate model to the ABC preventive approach is also provided.

Further sections explore the relationship between sex, HIV and sin, the need for churches to be open and positive about sexuality and pre-marital HIV testing. The final section focuses on drug use, and particularly injecting drug use, as a mode of HIV transmission.

Many of these issues are testing the compassion and AIDS competency of churches; often there are no easy answers. These issues have the potential to create obstacles to partnerships with PLWHA and between faiths. Even if some positions are contentious or unpopular, churches need to be able to articulate their positions with reason and coherently, so that all partners know where they stand in a relationship. While the material presented does specifically refer to partnerships with PLWHA, it has been presented so that churches and PLWHA organizations have clear statements of different churches positions and the theological underpinnings on an array of contentious issues.

3.1 HIV Prevention – sexual transmission

Churches and faith-based organizations continue to debate what constitute appropriate HIV prevention messages. While there is uncertainty regarding what the content of prevention messages should be, the caring and support role of faith-based communities in relation to HIV and AIDS is broadly accepted. For example, the Catholic Church and the Seventh Day Adventist Church\(^28\) are heavily involved in providing medical care for PLWHA.

\(^28\) In Africa, the Seventh Day Adventist Church operates 29 hospitals and approximately 300 clinics in Africa all of which serve PLWHA but additionally congregations have numerous support groups helping PLWHA.

Communication with Allan Handysides, HandysidesA@gc.adventist.org, Director Health Ministries, General Conference of Seventh Day Adventists.
Covenant 1: Life and HIV/AIDS prevention

We shall remember, proclaim and act on the fact that, the Lord our God created all people and all life and created life very good (Genesis 1–2) We shall, therefore, seriously and effectively undertake HIV/AIDS prevention for all people - Christians and non-Christian married and single, young and old, women and men, poor and rich, black, white, yellow, all people everywhere-, for this disease destroys life and its goodness, thus violating God's creation and will.

The Siyam’kela study suggested that as many churches are struggling with how to deal with prevention, churches have found a safer response in providing for PLWHA’s welfare, in line with the traditional role of the church as a ‘carer’. It’s a very difficult one. I don’t know for how long we will be emphasising the problem of care and support and not on prevention. Because I think churches tend to want to address caring for the sick. I think that is important, but what do we do to make sure we have methods that will help prevent the spread of the virus? Faith leader

Indeed this perspective has long been viewed as a theological misfit. Dube writes:

There is no doubt that as a church we pride ourselves for our care-giving roles. We visit the sick, we pray for them, we counsel them and their relatives; many times we take care of the sick—we wash them, we pray for them, we feed them and when they die we bury them. We are also there for the orphans, doing all that is within our power to help. But the problem with our excellent ‘care programmes is that they lack an equally effective prevention programmes. This unbalanced approach castes the church (and its leadership) as an institution that focuses on symptoms. We only come in to manage crisis, but we do not deal with the root problem. What is even more problematic with this care-oriented picture is that it seriously puts doubts in our theology of respect for life, if at all it exists. If we really respect all life as sacred, if we really regard every human being, Christian or non-Christian, as made of God’s image—shouldn’t we demonstrate this theological stance by designing programmes that make us effective instruments in the prevention of HIV/AIDS as well?

The overarching prevention messages conveyed by churches and faith-based organizations are in line with religious teaching, that is, demanding abstinence before marriage and faithfulness within marriage. Box seven “Prevention: as addressed in Declarations” outlines the position and commitments of various churches around the

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31 Dube, Musa, W. Preaching to the Converted: Unsettling the Christian Church, pp. 38-50, Ministerial Formation 93, (2001).
world on some HIV prevention issues. Some of messages give life to the deeper issues of developing greater respect for one’s own body and for the bodies of other persons, especially persons with whom one engages in intimate relationships.

THE pastoral challenge of the Church in Africa, I suggest, is to develop a pastoral approach that forms and informs our people so that, in the depths of their being, they can decide about HIV – rather than being its victims in a passive or fatalistic manner. Instead of saying things like “AIDS happened to me” or “I didn’t know I was getting HIV or “I had sex but it wasn’t really my decision,” to take their stand as Christian youth and adults.

What I am expressing is an ideal, not a judgement, and I recognize that there are people, especially girls and women, who really have been victimized. But I am convinced that people can say “no” to HIV and AIDS, and I pray that from now on the Church will do everything necessary so that our people can decide maturely and responsibly. If they learn consistently to say “no,” HIV/AIDS will go away.

Let us help young people to learn about their bodies, about the drive to develop strong and even intimate relationships with others, along with the discipline needed to prevent those relationships from becoming manipulative or exploitive. Let us form consciences according to traditional Church teaching and promote appropriate interventions that strengthen the family, reinforce healthy norms, protect youth and encourage abstinence and mutual fidelity in an effective and sustainable manner. Let us try to reach the whole man and every man, since HIV/AIDS is an affair of the integral person: body, soul, mind and feelings, sexuality, family and community, relationships. Whether single or married or widowed, priestly celibate or vowed religious, the fundamental choice is whether to remain faithful or not.

The Symposium of Episcopal Conferences of Africa and Madagascar also placed such an emphasis, stating:

Besides teaching the morality of the Church and sharing her moral convictions with civil society, and besides informing and alerting people to the dangers of HIV-infection, we want to educate appropriately and promote those changes in attitude and behaviour which value abstinence and self-control before marriage and fidelity within marriage.

On World Aids 2004, Cardinal Javier Lozano Barragán, President of the Pontifical Council for Health Pastoral stated:

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On many occasions John Paul II has addressed this question and has provided us with illuminating approaches that throw light on the nature of this disease, its prevention, the behaviour of patients and those who look after them, as well as the role that civil authorities and scientists should perform. I would like to emphasize his thinking as regards the immunodeficiency of moral and spiritual values and the accompanying of AIDS victims, to whom full care and services should be provided because they are the most in need. In particular, in his message for the World Day of the Sick 2005, the Holy Father emphasises that the drama of AIDS is a ‘pathology of the spirit’ and that for it to be combated in a responsible way it is necessary to increase prevention through education in respect for the sacred value of life and formation as regards the correct practice of sexuality.\(^\text{34}\).

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**Box 7: Prevention: As Addressed in the Declarations of churches**

In 1987, The World YWCA resolved that The World YWCA Council urge national YWCAs to establish programmes providing preventive health education on the subject of AIDS.\(^\text{35}\)

The Seventh Day Adventist Church in 1990, stated: “Adventists are committed to education for prevention of AIDS. Adventists support sex education that includes the concept that human sexuality is God's gift to humanity. Biblical sexuality clearly limits sexual relationships to one's spouse and excludes promiscuous and all other sexual relationships and the consequent increased exposure to HIV”\(^\text{36}\).

The Plan of Action formulated by the Ecumenical Response to HIV/AIDS in Africa (EHAIA) stated concerning prevention\(^\text{37}\):

1. We will promote effective means of prevention, practices that save lives, and behavior that minimizes the risk of infection. In doing so, we will support the churches' historic commitment to faithfulness and abstinence, while recognizing that life may present us with contexts in which these ideals are unachievable.
2. We will always lift up, as the priority, those who are most vulnerable to the risk of infection, people living with HIV/AIDS, and those persons who are more broadly affected by HIV/AIDS.
3. We will encourage networking (among churches, faith-based organizations, international and non-governmental organizations, institutions of higher education, and governments) which aims to build relationships, and which maximizes the benefit and efficiency of prevention efforts.
4. We will promote voluntary testing and counseling. These play an important part in HIV education, offering constructive advice on life-protecting

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behavior, and clearing the way for resolutions regarding abstinence and faithfulness. They also help to overcome stigma. As churches, however, we will engage in dialogue and question the practice of mandatory testing (pre-marital and other forms) and its consequences for the person who is diagnosed as HIV-positive.

5. We will encourage and support creative prevention programs. These might include, clubs in parishes, schools and hospitals, especially for girls, and the utilization of schools as information and counseling centers.

The Pan-African Lutheran Church Leadership stated:

We commit ourselves to prevention.
We commit ourselves to examine attitudes and behavior that can cause harm to our neighbor in the light of our Lutheran ethics.
We commit ourselves to taking a strong role to ensure prevention of HIV by assisting in efforts to reduce the spread of the pandemic.
We will speak the truth about the spread of HIV/AIDS and its prevention including the behavior change that is necessary.
We will not stand in the way of the use of any effective methods of prevention.
Listening to the Spirit of Truth, we make this commitment with the help of God.

The Council of Anglican Provinces in Africa (CAPA) stated:

Prevention saves lives.

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40 Lutheran World Federation, Adopted version of message from the Tenth Assembly, Winnipeg, Canada, 21–31 July 2003.
42 Symposium of Episcopal Conferences of Africa and Madagascar, The Church in Africa in face of HIV/AIDS Pandemic, Message issued by Symposium of Episcopal Conferences of Africa and Madagascar (SECAM), Dakar, Senegal, 7 October 2003
43 Education for Life, Youth Alive, Action Familiale, Pro Vita.
We are committed to teaching our children and their parents life-preserving skills to inhibit the virus that causes AIDS. The time for preparation for sexual maturity is well before adolescence and the onset of sexual activity. Our energies must focus on our daughters and sons at an early age. While we know that information alone cannot save lives, information and action can.

Lutheran World Federation in the *message from the Tenth Assembly* stated: Therefore, we commit ourselves and call on member churches to further awareness regarding prevention of the HIV/AIDS pandemic through education and information, including speaking-out against harmful, abusive and exploitative sexual practices, treating sexually transmitted diseases, promoting faithfulness in marriage and advocating effective means of prevention (e.g. abstinence, use of condoms, sterilized needles, clean blood supply).

The Interfaith: Christian Conference of Asia stated, “It is our common understanding that we should speak openly about the basic facts of the HIV/AIDS crisis and about all effective means of prevention”.

The Message issued by Symposium of Episcopal Conferences of Africa and Madagascar stated:

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Let’s change behaviour.
Besides teaching the morality of the Church and sharing her moral convictions with civil society, and besides informing and alerting people to the dangers of HIV-infection, **we want to educate appropriately and promote those changes in attitude and behaviour** which value abstinence and self-control before marriage and fidelity within marriage. We want to become involved in affective and sexual education for the life to help young people and couples discover the wonder of their sexuality and their reproductive capacities. Out of such wonder and respect flow a responsible sexuality and method of managing fertility in mutual respect between the man and the woman.

**This type of education can only be undertaken effectively with the active collaboration of lay men and women who not only speak about principles of morality but also**, as youth and as couples, give living testimony that fidelity to these moral principles yields a humanising and fulfilling affective and sexual life. **Such education also contributes to promoting healthy and stable families, and these are the best prevention against AIDS.** Organizations which specialise in such education for young people and for couples exist throughout Africa and are having a small but gratifying degree of success. We give them the support and encouragement they deserve.
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The Lutheran World Federation and the United Evangelical Mission in the *Statement of Commitment of the Asian Church Leadership Consultation on HIV/AIDS* agreed:
“Knowing that only through education and prevention we can curb the spread and effects of this pandemic, we commit ourselves to:

- Integrate a good quality HIV and reproductive health education in the Christian Education curriculum to “ensure that young people have information and life skills they need before they become sexually active and sexual behavior starts to form.” This should also include adequate information about the protective use of condoms in the context of HIV/AIDS prevention, the danger of needle-sharing in intravenous drug use and other preventive measures;
- Continue to promote fidelity in marriage in a context of gender equality and informed choices.”

In the *Memorandum of Intention* by Churches in central and eastern Europe stated, “The political, social and economic changes in Central and Eastern Europe throughout the last two decades have made certain population groups vulnerable to HIV/AIDS. We resolve to focus our church-related HIV/AIDS work on the following groups:

1. Children and Youth, including those who are orphans and/or homeless/street children
2. Women
3. Children born of HIV-infected Mothers
4. Prisoners
5. HIV-infected and affected Persons
6. Drug users

We will continue to assess the needs of other groups that may also be vulnerable to HIV infection.

The battle against the HIV/AIDS crisis is a battle for the dignity of life. It calls us to use all effective means of prevention within a context of Christian ethics.”

World Council of Churches’ Pacific Member Churches stated “Whilst we are mindful of the ethical issues that HIV presents to the church, we are faced with a more urgent reality that drives us to consider the highest ethic, which is the preservation of life. The church lives in the context of the wider community and has a clear responsibility to adhere to the ethical principles that guide society. We are therefore committed to address:

- *Prevention and Condoms* – Condoms, when appropriately targeted and promoted, are scientifically proven to be an effective part of the prevention strategy against sexually transmitted infections. We are committed not to focus our efforts working against the use of condoms – but rather recognize the freedom for individuals to make informed choices and to have access to condom use.”

The International Interfaith Conference on Prevention and Control of HIV/AIDS in 2004 stated:

We reaffirm that the primary goal and task before all religions and faiths
is to assist people to stay away from risk behaviour affecting their physical, moral and spiritual growth and development. This mandate before us when effectively fulfilled will equip every one to protect himself or herself and society against HIV/AIDS that has no cure or vaccine.

We recognize that Religions and Faiths have a mandate to light up the path of the youth since they have to carry the torch of life on its eternal journey. In facing the challenge of HIV/AIDS they are our best, first line of defence, while being the most vulnerable as well. We pledge to work with the youth in this fight.

We affirm that Religions and Faiths have a critical role in placing the scientific facts of HIV/AIDS in their due perspective. We recognize the importance of scientific efforts for developing effective vaccine against the epidemic and the need for requisite support for achieving a breakthrough in such efforts.

The Cairo Declaration from an interfaith meeting stated:

The family is the foundation for building and defending society. It is therefore necessary to encourage starting families in accordance with heavenly decrees, and we should remove all obstacles in the way.

We emphasize the need to break the silence, doing so from the pulpits of our mosques, churches, educational institutions, and all the venues in which we may be called to speak. We need to address the ways to deal with the HIV/AIDS epidemic based upon our genuine spiritual principles and our creativity, and armed with scientific knowledge, aiming at the innovation of new approaches to deal with this dangerous challenge.

We reiterate that abstinence and faithfulness are the two cornerstones of our preventive strategies but we understand the medical call for the use of different means to reduce the harm to oneself and others.

We view as sinful anything that may cause infection through intention or negligence – as a result of not using all possible preventive means available.

We emphasize the importance of reaching out to vulnerable groups which are more at risk of being infected by HIV/AIDS and/or spreading it, including commercial sex workers and their clients, injecting drug users, men having sex with men, and those who practice harmful behaviors. We emphasize the importance of diverse approaches and means to reach out to those groups, and although we do not approve of such behaviors, we call on them to repent and ask that treatment and rehabilitation programs be developed. These programs should be based on our culture and spiritual values.

We call upon the media to abide by ethical codes regarding the material
they present.

We advocate the rights of women to reduce their vulnerability to HIV/AIDS.

Nevertheless, churches are faced with challenges in following the ‘abstinence and be faithful’ prevention strategy. Research on HIV transmission indicates that messages of abstinence and faithfulness do not adequately account for the issues facing communities; when they are promoted as the only forms of HIV prevention. Such prevention messages also focus exclusively on sexual transmission, ignoring other methods of HIV transmission such as injecting drug use. And an exclusive abstinence and faithfulness prevention message may reinforce views that PLWHA are sinners.

For years, secular prevention programmes for the general population have focused on the ‘ABC’ strategy – Abstain and delay sexual initiation; Be faithful (and be safer) or reduce the number of sexual partners; and use Condoms correctly and consistently. For many people, particularly women and girls, this approach is of limited value. They lack social and economic power, and live in fear of male violence. They cannot negotiate abstinence from sex, nor can they insist their partners remain faithful or use condoms.

Ironically, trust and affection within marriage and other long-term relationships are sometimes part of the problem. Studies from various parts of the world suggest married couples have sex more frequently than unmarried individuals, but use condoms less often. Global studies of relationships between sex workers and their clients show a similar pattern: condom use was less consistent if sex workers felt a level of intimacy with their regular clients. For example, in Kenya’s Nyanza Province, surveyed clients of sex workers reported using condoms less consistently if they were with their usual sex worker.

Vulnerability to HIV exposure – an individual or community’s inability to control their risk of infection – is multifaceted, so no single prevention intervention will be effective on its own. Key elements in comprehensive HIV prevention include:

- AIDS education and awareness;
- behaviour-change programmes, especially for young people and populations at higher risk of HIV exposure, as well as for people living with HIV;
- promoting male and female condoms as a protective option, along with abstinence, fidelity and reducing the number of sexual partners;
- confidential voluntary counselling and testing;
- preventing and treating sexually transmitted infections;
- primary prevention among pregnant women and prevention of mother-to-child transmission;
- harm reduction programmes for injecting drug users;

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49 For example, Bearman, Peter. The Relationship between Virginity Pledges in Adolescence and STD Acquisition in Young Adulthood. After the promise – the long term consequences of adult virginity pledges. Columbia University, 2004.

• measures to protect blood supply safety;
• infection control in health-care settings (universal precautions, safe medical injections, post-exposure prophylaxis);
• community education and changes in laws and policies to counter stigma and discrimination; and
• vulnerability reduction through social, legal and economic change\textsuperscript{51}.

Comprehensive prevention addresses all modes of HIV transmission. Since HIV epidemics are extremely diverse across regions, within countries and over time, programme planners need to place different emphases on the mix of strategies:

• in \textit{low-prevalence settings}, prevention among key population groups (e.g., sex workers and their clients, injecting drug users, men who have sex with men) can be effective in keeping HIV at low levels across society;
• in \textit{high-prevalence settings}, prevention among key populations continues to be important, but broad strategies reaching all segments of society are needed to reverse the trend of the epidemic; and
• in \textit{all countries}, prevention is impeded if universal access to treatment, as well as impact and vulnerability-reduction measures, are not clearly parts of the response\textsuperscript{52}.

Churches and faith-based organizations are struggling with prevention messages when faced with the realities of sexuality and drug use in their congregations, particularly among the youth. As one faith leader questioned: \textit{Is it really possible for them (people) to totally abstain? I think there are a lot of things that we need to discuss as the church and see what actually works}\textsuperscript{53}.

Another challenge facing faith-based organizations is the best strategy to adopt to promote HIV-transmission prevention within marriage. The feasibility of merely advocating faithfulness and rejecting the use of condoms in marriage has been questioned. \textit{See} box eight “Women and HIV”. While some churches rejected the use of condoms, others feel that the occurrence of unfaithfulness in marriage is a reality that should be reflected in churches’ responses to HIV and AIDS. Certain churches and faith-based organizations, in light of the high rate of infection among married couples, serodiscordant couples, and the belief that some women are disempowered in intimate relationships, encourage married women to insist on the use of condoms to protect themselves from infection. For example, the Pan-African Lutheran Church Leadership, the Lutheran World Federation and the World Council of Churches’ Pacific Member Churches. \textit{See} relevant texts in box seven “Prevention: as addressed in Declarations”.

Box nine “The Use of Condoms – Theological Perspectives” outlines different theological grounds underpinning different views on the use of condom in HIV prevention within marriage.

**Covenant 6: Gender Inequalities and HIV/AIDS**

We shall remember, proclaim and act on the fact that the Lord our God, created humankind in his image. In his image, he created them male and female, he blessed them both and gave both of them leadership and resources in the earth; he made them one in Christ (Gen. 1:27-29; Galatians 3:28–29). We shall, therefore, denounce gender inequalities that lead boys and men to risky behaviour, domination and violence; that deny girls and women leadership, decision making powers and property ownership thus exposing them to violence, witchcraft accusation, widow dispossession, survival sex – fuelling HIV infection and lack of quality care and treatment.

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**Box 8: Women and HIV**

Women are twice as likely as men to contract HIV from a single act of unprotected sex, but they remain dependent on male cooperation to protect themselves from infection.

Women are particularly vulnerable to HIV, with about half of all HIV infections worldwide occurring among women. This vulnerability is primarily due to inadequate knowledge about HIV and AIDS, insufficient access to HIV-prevention services, inability to negotiate safer sex, and a lack of female-controlled HIV-prevention methods, such as microbicides. The female condom allows women some control but is not widely used and is relatively more expensive. In some of the regions worst-affected by AIDS, more than half of girls aged 15 to 19 have either never heard about AIDS or have at least one major misconception about how HIV is transmitted.

Across the world, between one fifth and a half of all girls and young women report that their first sexual encounter was forced. From a very early age, many young women experience rape and forced sex. Violent or forced sex can increase the risk of transmitting HIV because forced vaginal penetration commonly causes abrasions and cuts that allow the virus to cross the vaginal wall more easily.

Marriage is no protection against HIV. Across the developing world, the majority of women will be married by age 20 and have a higher rate of HIV infection than their unmarried, sexually active peers.

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The “ABC” slogan – Abstain, Be faithful, consistently use a Condom – is the mainstay of many HIV prevention programmes. But for too many women and girls, this message holds no weight. Where sexual violence is widespread, abstinence or insisting on condom use is not a realistic option. Because of their lack of social and economic power, many women and girls are unable to negotiate relationships based on abstinence, faithfulness and use of condoms.


**Box 9: The use of condoms – theological perspectives**

There is clear consensus among (Catholic) Church leaders on the norm and value of abstinence outside marriage. For example, Pope John Paul II told young people during his visit to Uganda in February 1993:

> Do not let yourselves be led astray by those who ridicule your chastity or your power to control yourselves. The strength of your future married love depends on the strength of your present effort to learn about true love. Chastity is the only safe and virtuous means to put an end to the tragic plague of AIDS.

On the other hand, there appears to be a diversity of opinions among the hierarchy with regard to information and education about HIV prevention for those who do not share the Catholic tradition or who will not or cannot remain faithful to its teaching. The bishops of New Zealand, for example, refused to participate in a government-sponsored preventive education campaign:

> Values cannot be separated from health, whatever people’s religious beliefs may be. The public is seriously misled if the impression is given that technical means alone can solve problems that require profound changes in human attitudes and behaviour …

Other Church leaders, however, have advanced more flexible positions with regard to information about the use of condoms in preventing HIV transmission. In so doing, they explained that their intent was not in any way to compromise the fundamental values of the Church on marriage, but rather to respond to the current health crisis from a framework of traditional moral principles.

Thus the Administrative Board of the United States Conference of Catholic Bishops

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turned to the principle of toleration of a lesser evil in order to avoid a greater one when they foresaw the provision of information about condoms for those who might be prone to sexual acts which could put them or others at risk of HIV infection:

We recognize that public educational programs addressed to a wide audience will reflect the fact that some people will not act as they can and should; that they will not refrain from the type of sexual or drug abuse behaviour which can transmit AIDS. In such situations educational efforts, if grounded in the broader moral vision outlined above, could include accurate information about prophylactic devices or other practices proposed by some medical experts as potential means of preventing AIDS. We are not promoting the use of prophylactics, but merely providing information that is part of the factual picture\textsuperscript{58}.

The bishops of Papua New Guinea signalled an openness to cooperate with their national government in order to facilitate a comprehensive approach to HIV prevention education:

Both the government and the Churches must play an active role in the prevention of disease since this is the only means to fight against the spread of the disease and so far there is no cure for it. They must give honest, complete information to everybody, because everybody has the right to know what HIV and AIDS is, what are the ways of transmission of the virus, and what are all the possible means of protection\textsuperscript{59}.

In a statement by its Social Commission, SIDA: La Société en Question (AIDS: Society in Question), the French Bishops’ Conference seemed to make use of another traditional moral argument, i.e., that of gradualism. This approach recognizes that individuals find themselves in differing stages of moral development and thus will require diverse solutions for moral challenges. Cardinal Lustiger of Paris seems to have paved the way for such reasoning when he stated in a public television interview on World AIDS Day, December 1, 1988:

\textit{You who suffer from this illness, you who cannot be chaste, use the means that are proposed to you, out of self-respect and out of respect for others. You must not cause death}\textsuperscript{60}.

\textsuperscript{60} \textit{La Croix}, December 6, 1988.
\textsuperscript{61} \textit{Vienna Archbishop says condoms morally acceptable to fight AIDS}, Catholic News Service, April 3, 1996.
\textsuperscript{63} \textit{Theologians say condom use OK in certain cases, not as policy}, Catholic News Service, September 22, 2000.
\textsuperscript{64} \textit{Theologians say condom use OK in certain cases, not as policy}, Catholic News Service, September 22, 2000.
Many bishops and theologians have pointed out that, in all this discussion, the fundamental imperative to preserve life is primary. Thus Cardinal Schonborn of Vienna said, in commenting on the French Bishops’ Statement: Love can never bring death … In given situations, the condom can be seen as the lesser evil\(^6\). Belgian Cardinal Godfried Danneels has spoken in favour of using condoms in certain circumstances to protect against AIDS, saying not using prophylactics could transgress the Biblical commandment which states, "Thou shalt not kill"\(^6\).

Cardinal Simonis of Utrecht used the principle of self-defence when considering the situation of discordant couples: *In this precise condition, and only in the realm of marriage and not in other situations, the condom may be seen as a form of self-defence.* Cardinal Agré, Archbishop of Abidjan, advanced a similar argument in 1997: *In our struggle, we prefer abstinence, of course... The use of condoms is specific in ethical cases when one of the partners knows that he is HIV-positive or ill.* The bishops of Chad placed this issue even more squarely in the realm of individual conscience as well as of the intimate space between husband and wife:

> It is up to each and everyone of us to train one’s conscience and to assume one’s responsibility according to the situation in which one finds oneself. Because ‘no one is bound to do the impossible’, spouses cannot be asked to abstain from sexual intercourse; we therefore understand that a person, through love, may be led to use the condom to protect himself/herself or to protect his/her partner. But everybody must understand that the condom does not provide 100% protection and that it does not ultimately solve the real problems raised by AIDS.

Within the context of preserving life and of self-defence, the use of the condom to avoid HIV transmission, especially in circumstances involving discordant couples and involuntary sexual activity, also has been seen from the perspective of the principle of double effect whereby the condom would not be seen as a contraceptive device but rather as the means to safeguard life which is threatened by a deadly disease agent. Two prominent theologians in Rome seemed to recognize such an approach when they considered the situation of a prostitute who insists on condom use with clients as long as she feels compelled to continue her commercial sexual activity. Father George Cottier, Secretary General of the International Theological Commission and theologian to the Papal Household, commented:

> A woman [prostitute] who understands that she cannot put her life or the life of another in danger is a woman who has grown morally, in comparison to a woman who has no consideration for her health or the health of others ... I personally think that one must take into account the fact that these circumstances lead to death. The principle fully holds: Do not kill\(^6\).

Speaking about a similar situation, Maurizio Faggioni, MD, moral theologian and member of the Congregation for the Doctrine of the Faith, said: *Only in this path of pastoral graduality is it possible to tolerate – here, Catholic ethics does not approve, but tolerates – the use of a prophylactic*\(^6\).
Finally, the Southern African Bishops Conference in a “message of Hope” in July 2001 stated:

There are couples where one of the parties is living with HIV/AIDS. In these cases there is the real danger that the healthy partner may contract this killer disease. The Church accepts that everyone has the right to defend one’s life against mortal danger. This would include using the appropriate means and course of action.

Similarly where one spouse is infected with HIV/AIDS they must listen to their consciences. They are the only ones who can choose the appropriate means, in order to defend themselves against the infection. Decisions of such an intimate nature should be made by both husband and wife as equal and loving partners65.

Religious leaders can play a vital role in educating people about HIV prevention, over and above the current discourse of abstinence and being faithful to one partner. The ideal for religious leaders is usually the promotion of ‘sound family values’ and no sex outside of marriage; however, the reality for many people is very different66. Religious leaders need to look more closely at making their teaching relevant to the everyday existence of their members.

HIV is fast changing the world in which we live, and churches need to change as well. AIDS is demanding that churches respond. How is a church in a country with 20% HIV prevalence dealing with 20% of its members being HIV-positive? Have church teachings on abstinence worked? The answer to the latter question is no, given the prevalence of HIV infection among believers. Simply, the fact that of the approximately 40 million people living with HIV and AIDS, 30 million are Christians, means that we have to get churches to take action. The church is just as affected by AIDS as society around it. If we can get the churches to fight the illness rather than those who are ill, then we will have achieved a lot. If people who are HIV-positive are integrated into church life, or if pastors can speak openly in their parishes about being HIV-positive themselves, then we will have achieved a great breakthrough67.

Responding to AIDS does not mean that traditional teachings are irrelevant; but rather that teachings need to be given without judgement and adapted to fit today’s lived realities. For example, box 10 below describes the African Network of Religious Leaders Living with or personally affected by HIV and AIDS model of HIV prevention and care, which offers a comprehensive HIV prevention and care approach.

Some of the messages given to mitigate the spread of HIV have sadly added to the stigma. “ABC” is one such message.\(^68\) Within the African Network of Religious Leaders Living with or personally affected by HIV and AIDS (ANERELA+), a new model has been developed, called SAVE (Safer practices, Available medications, Voluntary counselling and testing, and Empowerment through education).

HIV prevention will never be effective without a care component and the SAVE model combines both prevention and care components as well as providing messages to counter stigmatization. HIV is a virus not a moral issue. As such the response should be based on public health measures tempered by human rights principles.

\(S\) refers to safer practices covering all the different modes of HIV transmission. For examples, safe blood for blood transfusion, barrier methods for penetrative sexual intercourse, sterile needles and syringes for injecting, safer methods for scarification and adoption of universal medical precautions.

\(A\) refers to available medications. Antiretroviral (ARV) therapy is by no means the only medical intervention needed by people living with HIV or AIDS (PLWHA). Long before it may be necessary, or desirable, for a person to commence antiretroviral therapy, medical needs concerning opportunistic infections and pathology tests arise. Treating opportunistic infections results in better quality of life, better health and longer term survival. Of vital importance to every person are good nutrition and an adequate supply of clean water, and this is doubly so for PLWHA.

\(V\) refers to voluntary counselling and testing, one intervention which may mitigate HIV-related stigma and increase the effectiveness of HIV prevention efforts. A person who knows his or her HIV status is in a better position to protect him or herself from infection or from infecting another, depending on the person’s status. In addition, someone who is HIV-positive can be provided with information and support to live positively. People who are ignorant of their HIV status or who are not cared for can be sources of new HIV infections.

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\(68\) The way in which ABC has been presented and understood by most people is; firstly abstain, if you can’t abstain then be faithful, and if you can not be faithful then use a condom. This in no way takes any cognizance of a person’s HIV status. If you or your partner or prospective partner are living with HIV, and you have not been tested but have unprotected sexual intercourse, this puts the other person at risk of HIV infection. It is also true that while abstinence may be appropriate at some stages of live, faithfulness is always appropriate. In addition to this the use of a condom automatically falls into the category of being used by people who can not be faithful and do not want to abstain. This fuels stigma and keeps people from safer sexual practices.
E refers to empowerment through education. It is not possible to make an informed decision without all the facts. Misinformation and mis-action are two of the greatest factors driving HIV- and AIDS-related stigma and discrimination. Correct information needs to be disseminated to all within churches so as to ensure that people respond to others through knowledge and from a perspective of Christ centred love. This will assist people to live positively – whatever their HIV status – and break down barriers which HIV has caused between people and within communities. Education also includes information on good nutrition, stress management and the need for physical exercise.

Clearly, ABC has come under much scrutiny, including the need for additional prevention methods to be included, for example, D for drugs; E for education, F for fighting contaminated needles and G for good practice of medicine. However, some of the more potential positive benefits of the ABC strategy have perhaps not been fully explored. Box 11 “Better sex as a solution to prevention of HIV infection in relationships: the B in ABC” opens up the question of satisfying sexual relations within a relationship and explicitly raises the question for churches and faith-based organizations – what is their role in ensuring that their congregation live full and satisfying sex lives, both for their physical and spiritual wellbeing as well as an effective mode of HIV prevention.

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Box 11: Better sex as a solution to prevention of HIV infection in relationships: The ‘B’ in ABC

Reflections by David Patient, a PLWHA, and Neil Orr, who worked with a specific church in Mozambique - from the very highest levels to the lay preacher as well as about 200 people from Vida Positiva Training. Once the feedback was assessed then started the education of the lay preachers around 'Tantric sex' [name later changed due to objections] and the subsequent feedback from the ministers was quite profound.

The objective of this article is to introduce an HIV prevention strategy that may actually work in married and other committed relationships: Teaching committed couples how to have better sex, this reducing the need and incidence of infidelity. And yes, this implies the absence of condoms. Why?

We need to distinguish between relationships with procreation versus recreational sexual objectives in HIV education and prevention strategies. The reason is simple: Couples want babies, which means condoms are simply not used.

The statistics regarding condom use in this category of at-risk population speak for themselves: Condom use is high and effective – in youth and sex worker sectors, but not elsewhere, at least in the developing world. As stated, the reason is simple: People want children when they get married or commit to each other in the long term. This aspect of committed relationship is deeply entrenched and reinforced culturally and via religious institutions.

At the same time, the statistics show that a woman who gets married increases her risk of HIV infection the day she gets married, because she loses the cultural and religious right to protection (i.e., condoms) when she gets married: she now needs to conceive. The question is: how do we protect her, her husband, and her children.

Here are the realities we have encountered

Often, it is considered acceptable for the husband to have extramarital sex, as long as he provides for his family. We do not agree that this is an intrinsically traditional cultural norm. Our experience is that this norm is relatively new.

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70 David Patient david@empow.co.za and Neil Orr, Better sex as a solution to prevention of HIV infection in relationships: The B in ABC. PWHA-NET, 10 November 2004
The wife may not prevent conception through condom use. The situation is not the same as contraception through other means, which are largely invisible to the husband. A condom requires his full attention and participation, which rarely occurs; the consent of the husband is the key to condom use. This can be circumvented through the use of femidoms (female condom), but they are difficult to obtain, relatively expensive, and conspicuous unless carefully used. The husband's consent is only obtained – sometimes – after after several children have been born, and the couple assured that the procreation aspect of their relationships is fulfilled. What do we do till then?

If a man asks his wife to have sex other than in the standard missionary position, she may accuse him of treating her like a sex worker and be offended. Often she will go to her mother to complain who in turn will go to the husband's father and he then questions his son as to why he is treating his wife with such disrespect.

So this is the man's justification for having sex outside the marriage: 'I want better sex with my wife, but she won't let me have it.'

The next logical step was for us to speak to the wives. So we did, and asked why they refuse to have sex other than in the standard position, the response was that 'I am never asked what I like in sex, if I like sex and if I even want sex so why should I do anything that gives him pleasure. He doesn't care about me and my sexual needs so I will simply lie there, let him do his business. Why should I give him pleasure? If he wants that then he must use a working girl.' So it's a case of two wrongs and neither making a right.

We are aware that these reasons are the surface rationales that disguise a range of dysfunctional communications and role definitions for men and women in sexual relations. For example, it is common practice to suppress sexual pleasure in women, whether through the practices of 'dry sex' (i.e., removal of vaginal fluids before sex, to maximise friction – thus pleasure – for the man); clitoral circumcision, and so forth. For women, sex is often painful, and few connect it with pleasure.

The only conclusion we can arrive at is the following: Neither husbands nor wives particularly enjoy sex with each other. Furthermore, there is anger and resentment from both sides regarding this situation, which leads to high-risk sexual activities outside of the marriage. Is it much wonder that there is such resistance to sex education, if it is a source of frustration and often – for women particularly – pain?

Furthermore, if a wife does not conceive and bear children, she is often rejected by not only the husband, but by the community too. When this situation is placed within a context of gender inequity and often strong cultural and religious role definitions regarding sex, it appears that the situation is extremely difficult to change, at least from a HIV-prevention perspective.

**Here is what we propose as a solution**
What if the structure of religion was engaged to teach people in committed relationships how to have better sex? What if religion started taking an active role in
human sexuality and relationship-building through educated intimacy? Sounds simple, but when you think through the methodology, it will become abundantly clear that this approach will also have a radical impact upon gender inequity, for the simple reason that the best sex is dependent upon a disciplined effort to communicate and learn about your sexual partner.

Why religious structures, such as ministers and priest? The reasons are more practical than anything else: Religion as an institution is the most vulnerable to the impact of HIV/AIDS in their married congregation.

Quite simply put, the very institution of marriage is under threat. By endorsing and facilitating marriage, churches are facilitating women – in particular – in shifting to a higher HIV-infection risk category.

Under the banner or morality (e.g. no sex before marriage; go forth and multiply, etc), religion is putting women at risk, unless they simultaneously provide the practical methods for avoiding such risks.

Protestant morality permits condom use within marriage, but still supports marriage as the appropriate place for procreation; Catholics do not permit condoms within marriage, and the same can be said for other non-Christian religions. It is true that all main-stream religions strongly discourage infidelity. So they think they are off the hook on the morality aspect.

Not quite: it is an illusion – and currently, a life-threatening one – to pretend that committed relationships will endure through simple 'thou shalt not' proscriptions. It is time that the religious institutions started figuring out what 'thou shall do', to prevent the disintegration of the sacred nature of marriage. The time for shouting the moral odes from the side-lines of sexual activity is over, unless you are content to see the game end, permanently. It's time for religion to update it's commitment to protecting the sanctity of marriage, and getting a little more involved in the mechanics of the process. People – married people – need help, and they need it from people they trust. It is not acceptable that people are told where (married, not married) they can have sex, without any instruction on how sex can be experienced as sacred.

This is where religion can play a huge corrective role in this pandemic

Imagine the following: a young couple approach their families to inform them that they are in love, and intend to get married. The families are delighted, and make an appointment with the minister/priest of their religion. Over the next six months – individually at first and then later as a couple – the couple are given instructions in the art of relationships, trust, communication and sex. No, they do not have sex until they get married. The couple discuss love, love-making, fears, pleasures, children, their future, and a range of issues which create an intimate bond of understanding and trust. During the first few months of marriage, the instruction continues, with exercises to enhance sexual experiences, and to consolidate trust and communications. Breathing
and muscle control exercises are included, to prolong orgasm, the difference between orgasm and ejaculation, and a range of information that ensures that the sexual experience between the husband and wife is of such a nature that sex outside of marriage becomes unthinkable, and certainly not appealing.

Impossible? Not at all! These skills exist, and those that practice them are very adamant that the best sex possible can only be achieved within a relationship of love and trust. Extramarital sex is simply not as good.

Many religions have made sex a taboo subject, blamed it for AIDS, and have used the pandemic to further instil/impose their values without even trying to meet people where they are and not where they feel they should be. In a nutshell, religion, by and large, has made sex the problem and what we are suggesting is that they can use sex as the possible solution. Sex, from our understanding and experience can be an incredibly spiritual revitalization.

We would also like to highlight one additional benefit to this notion: Great sex can only be achieved with disciplined communication. That means both ways i.e., husbands – in order to have the best orgasm of their life – will need to communicate with their wives about sex, build trust, and essentially treat them with tenderness and respect. Apparently, this is called love.

We can also imagine that young (unmarried) men will be pitied by married men, for not having access to great sex, instead of the reverse!

Box 12 “Talking about sex – The Evangelical Churches of West Africa” describes a programme, which again highlights how clergy can be involved with their congregation - talking and education can assist couples to have a fulfilling sexual life, aiding fidelity.

Box 12: Talking about sex – The Evangelical Churches of West Africa

Evangelical Churches of West Africa (ECWA) is a faith-based organisation involved in community programmes in Northern Nigeria. Programme activities include: theological education, media and information, work within hospitals, with Challenge bookshops and Challenge cinema. They also run a pharmacy, printing press and radio station amongst others. They address a variety of sexual and reproductive health issues in the communities where they work through the involvement of church leaders.

One sexual reproductive health issue that is being addressed in the Christian communities is that Christians would much rather talk about reproduction than the accompanying issues of sexuality and the problems around it, e.g. frigidity, erection problems and premature ejaculation. Many Christians in Nigeria feel that sex between couples is strictly for procreation and nothing more. If procreation is not affected,
then there are no problems, they argue. However, the reality faced by many Pastors and Counsellors in the church is that sexual problems are fundamental to a lot of the marital dysfunction they see among their members, but that no one was willing to talk about it.

The challenge was how to get Church members to discuss their sexuality problems and get appropriate help. ECWA approached respected theologians who were specialized in teaching and writing on the biblical reasons for marriage, to find ways of working on issues around sexual reproductive health. As a result, books, bible study materials and other pamphlets were prepared indicating the appropriate place of sexuality in marriage. The curriculum for the seminaries and theological colleges was also modified to include material on sexuality and possible problems. Local churches were stimulated to have a retreat for couples, where members are encouraged to share and seek help concerning their sexuality problems. The church also made sexuality a required section of counselling for couples intending to marry.

Out of this has grown a willingness by couples to contact their Pastor or Counsellor concerning sexual health problems they would hitherto have kept to themselves. There are also a growing number of experienced counsellors who are able and willing to help couples with these problems.

All HIV-prevention efforts are subject to many variable socioeconomic and cultural conditions, which can hamper efforts. At one level, 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 poverty and the spread of HIV are intimately associated; HIV exacerbates existing problems. HIV leaves people economically poor, hungry, illiterate and with inadequate access to health-care services. The impact of HIV and AIDS is to stretch poor nations’ already limited resources to breaking point and make 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 interventions are 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 multinational corporations with whom many of the strategic economic and political decisions lie. International economic injustice is therefore a significant factor in the production of poverty, which makes people likely to be exposed to HIV and lack access to care. In addition, national, 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 national political corruption and international economic injustice.

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.\footnote{UNAIDS. A Report of Theological Workshop Focusing on HIV and AIDS Related Stigma, Windhoek, Namibia, 8-11 Dec 2003. Forthcoming www.unaids.org keyword search “Religion” under select a topic.}

Accordingly, even when education, generally, and HIV education, in particular, is provided, people – particularly women and young girls – are still raped in war or at home or they still become involved in sex work due to poverty. These structural forces behind the spread of HIV need to be factored in all interventions. Churches, however, are often unable to grasp the structural forces driving HIV. Rather, their approach, which tends to focus on an individual’s choices, often reduces HIV and AIDS to an individual’s morality or lack of morality. Overcoming this narrow individualistic approach may be helped by collaborating with PLWHA organizations and listening to their experiences and visions. Some churches are beginning to factor the structural injustice to their HIV/AIDS projects and programmes. For example, the Symposium of Episcopal Conferences of Africa and Madagascar stated:

The solidarity that we spoke of earlier binds us to joint responsibility in tackling the global and complex challenges facing us: interminable and recurrent wars, conflicts and violence in which rape is often used as a weapon, not just psychologically violent but physically destructive through HIV/AIDS!

We have also come to realize that poverty goes hand in hand with HIV and AIDS. It concerns us that our already fragile economies should be further weakened with much of the trained labour force lost to HIV and AIDS. Poverty facilitates the transmission of HIV, makes adequate treatment unaffordable, accelerates death from HIV-related illness and multiplies the social impact of the epidemic.

In all these senses, “Let all the parts [of the one body] feel the same concern for one another” (1 Corinthians 12:25). This solidarity among us and this fidelity to our faith, this resolve to change behaviour and assume our entire responsibility for the future of our continent.\footnote{Symposium of Episcopal Conferences of Africa and Madagascar, The Church in Africa in face of HIV/AIDS Pandemic, Message issued by Symposium of Episcopal Conferences of Africa and Madagascar (SECAM), Dakar, Senegal, 7 October 2003. Emphasis added.}

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:

\textit{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.\textsuperscript{74}

3.2 Association of sex, HIV/AIDS and sin

At the beginning of the HIV epidemic, in both developing and developed, churches and faith-based organizations often associated HIV and AIDS with allegations of sexual immorality, leading to severe negative sanctions, which reinforce stigmatizing attitudes and discrimination. This is connected to the perception that sexual sin is more serious than other forms of sin. Many churches also believed that HIV is a punishment from God. Some doctrinal teachings made it difficult to deal with HIV and AIDS in a non-stigmatizing manner, and at times the prevention messages of churches were presented in a punitive and discriminatory manner. Faith-based organizations, including churches, have a key role to play in challenging both these perceptions. Fortunately, many have begun.

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 (Romans 3:23). To stigmatize the other is to deny this truth.\textsuperscript{75}

The stigmatization of PLWHA 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. The tendency to reduce sin to an individual activity without factoring structural sins, such as gender inequality and economic injustice that often determine people’s choices, also adds to stigmatization. So sex may come to carry the stigma of sinfulness, and is also stigmatized among other sins. Consequently, PLWHA 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. Further, it is important to acknowledge that what might seem on surface as “an individual sexual sin of immorality,” for example, sex work, is in fact a symptom of both structural poverty and gender inequality, which have led to feminized poverty. Sexual violence, such as the rape of girls and women at home and in war zones, is a symptom of the sin of patriarchal structures that define women as subordinates and defines masculinity in violent terms. The structural sin of reducing women to subordination, which pervades most of our societies, unfortunately characterises the church as well. Indeed, the failure of ABC strategy is largely linked to patriarchy and the gender


inequality that it authorizes. Unhygienic methods of collecting blood, failure by governments to screen blood donations, and the multiple use of unsterilized needles for injecting drugs can also cause HIV transmission\textsuperscript{76}.

However, as one faith leader in the South African Siyam’kela study stated:

The problem with associating it [HIV] with sex is that the Church sees sex as a sin, particularly if it’s outside the confines of marriage. If you contract HIV it must have been through sex. It must have been unlawful sex. Therefore you are a sinner and it’s a punishment from God. That is where much of the stigma originates. From our own teachings\textsuperscript{77}

\begin{center}
\textbf{Covenant 9: Human sexuality and HIV/AIDS}\textsuperscript{78}
\end{center}

We shall remember, proclaim and act on the fact that the Lord our God, created human sexuality and created it good (Genisis 2:18–25). We shall, therefore, test for infection, denounce sexual violence, abtain before marriage, be faithful in marriage and practice protected sex to avoid HIV/AIDS infection and plunder on life, for all life is sacred and prevention should be seriously pursued to protect life.

The challenge for churches is how best to non-judgmentally respond to prevention, while upholding religious teachings. Some churches are attempting to mitigate stigma, trying to get the message across that HIV is not a sin. Some religious leaderships such as the Anglican hierarchy in Kenya\textsuperscript{79} and the Catholic leadership in the United States\textsuperscript{80} have taken a strong stand in declaring stigma and discrimination sinful and unacceptable. Similarly, in the Ecumenical Response to HIV/AIDS in Africa in its Plan of Action, churches through confession, explicitly stated that HIV/AIDS stigma and discrimination is an unacceptable sin before God\textsuperscript{81}. A statement by the Primates of the Anglican Communion, Canterbury, United Kingdom, 17 April 2002, clarified that:

We raise our voices to call for an end to silence about this disease – the silence of stigma, the silence of denial, the silence of fear. We confess that the Church herself has been complicit in this silence. When we have raised our voices in the past, it has been too often a voice of


\textsuperscript{80} Vitillo, R.J. \textit{The role of the Catholic Church in meeting the challenge of HIV/AIDS in Africa}. Paper written for the Center for Strategic International Studies, Washington DC, 2002.

condemnation. We now wish to make it clear that HIV/AIDS is not a punishment from God. Our Christian faith compels us to accept that all persons, including those who are living with HIV/AIDS, are made in the image of God and are children of God.\(^{82}\)

Other statements by churches on HIV/AIDS and stigma can be found in box 1 “Breaking the silence - Declarations by Churches on HIV/AIDS” in chapter two “The response of churches to date” in World Council of Churches, Partnerships between Churches and People Living with HIV/AIDS Organizations: Guidelines, 2005. Such messages need to filter down to clergy at the parish level and to congregations if they are to be effective.

In addition to confession, eradicating HIV-related stigma requires a full understanding of social injustice and structural sin. For, unless churches realize that individual choices (e.g., ABC) are often dictated by one’s social status, which either empowers or disempowers a person, it is unlikely that the stigma surrounding individual sexual sin will be eradicated. This is precisely because under “an individual approach” those people, who are single and HIV-positive, have failed to abstain, and the married who are HIV-positive have failed to be faithful. The position overlooks that many people may abstain and be raped, or many women, who are too poor due to feminized poverty, have to engage in sex work, and many faithful wives are betrayed by cultural double standards that allow men to have multiple sex partners. Also the global economic system (and politically motivated displacement of populations) that is characterized by job insecurities and massive movements of people, separating families over long periods, increasingly puts the virtue of faithfulness in marriage to a hard test.

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 picture 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. Others speak of an unconditionally loving and ever-forgiving God, the Creator-Mother God. For the latter, HIV is a virus (albeit extremely dangerous to human beings), but it is not a divine punishment for sin.\(^{83}\) However, changing people’s view of God can be difficult. For example, box 13 “Differing understandings of God” describes the disputes that can arise over theological interpretations of HIV.

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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.

Another challenge pertains to prevention and the sexuality of single people. Sex outside of marriage is condemned as a sin and as a result, people who are single and sexually active are seen as sinners. Churches are grappling with how to reconcile the message of compassion and acceptance towards PLWHA, while holding onto the teaching that sex outside of a marital relationship is forbidden and a sin. While churches insist on sexual purity as THE answer to HIV prevention; the biblical perspective of the sacredness of ALL human life has not received adequate attention.

As one theologian argues, this failure to take into account the sacredness of ALL human life:

sadly indicates that we have ceased to realize that life is sacred; that all life was created by God and remains sacred to God. The world belongs to God. It indicates that we have perhaps forgotten that we are stewards of God’s creation. Our concern should be that anything that destroys life must be stopped, for it violates God’s creation. Our respect for God should lead us to respect life of both the believers and unbelievers… I am calling for a theological maturity in our service to humanity and to God. My point, therefore, is not so much about the condom, it is not even about abstaining or faithfulness. Rather, it is about respect for life as a respect for God, and as our acts of worship. Our theological standpoint should be that anything that violates God’s life must be stopped.85

The church approach to HIV and AIDS must be holistic and based on the teachings of Christ, whose earthly ministry was characterized by healing all diseases unconditionally (Mark 1:29–34), forgiving sins (John 8:1–12; Luke 7:36–49; 15:11–32), and breaking the stigma associated with leprosy by touching people with leprosy and restoring them to physical and social health (Mark 1:40–45; Luke 17:11–19). In a world living with AIDS, the churches are given the opportunity to find healing, forgiveness and wholeness. Churches need to acknowledge more fully in concept and practice that “Churches are hospitals for sinners rather than mausoleums for saints”.

As was summarized at the UNAIDS, Theological Workshop Focusing on HIV and AIDS Related Stigma in Namibia, “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 stigmatization 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”86.

Jesus spent his time with the despised outcasts and powerless members of his time and society – the tax collectors, sex workers, the sick, women, children, strangers etc. to the extent that other teachers complained. For the church to effectively eradicate HIV-related stigma and run effective HIV and AIDS projects and programmes, they must surround.

As Donald Messer underlines, “Around the world, committed Christians are struggling to move Christian communities into the vanguard of helping and healing during this global emergency… But the starting point of this mission and ministry is admitting that ultimately we are all HIV-positive. As long as we deny our own vulnerability and risk, rebuff our own oneness with the suffering of the world, and

pretend we are separate from our infected and affected sisters and brothers, then perhaps we best step aside.\(^87\).

### 3.3. Not dealing sufficiently with issues of human sexuality

According to UNAIDS estimates, there are some 14 000 new HIV infections per day, 12 000 in people aged 15-49 and 50% of these in young people aged 15–24, equalling some 6000 young people.\(^88\) While HIV can be transmitted in to any age group, we must ask ourselves, are we doing enough for the young people in terms of human sexuality or youth sexuality? If we are quiet about sex and sexuality then we are not dealing with the issue.

The Siyam’kela study,\(^89\) South Africa, found that some faith leaders were ill equipped to deal with people who turned to them for advice on issues related to sex, sexuality, safer sex practices or disclosure of HIV-positive status. For examples:

- one faith leader was uncertain on how to respond to a 13-year-old girl asking what she should do in the case of an allergy to condoms; and
- a faith leader spoke of an acquaintance who disclosed to his bishop that he was HIV-positive, ‘The problem was that the Bishop kept quiet. The only advice was he gave was not to speak to anyone else. There is no support.’

A useful question for churches to discuss is: What is sex/sexual activity? Related questions include:

- is sex only penetrative sex?
- does sex include anal intercourse?
- where does fellatio fit into your understanding of sex?

Your understanding of sex greatly influences how you communicate on the topic as well as having serious consequences in HIV prevention.

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.\(^90\)

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The United Evangelical Mission stated in its Anti HIV/AIDS Programme Policy provides further Biblical basis:

In the biblical narrative of creation, God introduces women and men to each other in a very special relationship of love. Erotic love and sexuality are a way to express this love. They are God’s good gifts and a central part of the creation.

Sexuality in all its meaning however remains a mystery. In the Song of Songs the Bible describes in an astonishing way this love, desire and longing.

Sexual relationships are the most intimate kind of relationships, which require reciprocity, trust and respect for each other. In sexuality, men and women are most vulnerable. There are many examples where sexuality is misused for cultural, industrial, ideological or even religious reasons and where people exploit each other, especially by linking sexuality with violence or by denying people the right for sexual self-determination and -expression. Even the Bible gives account of such stories, e.g. in 2 Samuel 13:1–21, the story of Amnon and Tamar.

We underline our desire to live the gift of sexuality in a responsible way and therefore value sexual self determination and exclusively covenanted relationships based on love and trust.

However, in the churches we have often found it difficult to speak appropriately of sexuality as a gift from God, but have rather related it to sin in many ways. The existence of Aids can reinforce this attitude on the one hand, since it links sexuality with disease and consequently with death. On the other hand, the existence of Aids could be an “opportunity” of liberating us from such an attitude.

The prevention strategies of churches for young people should not be simply advocating for ‘abstain from sex’, but should also encompass providing knowledge about human sexuality and a sexual health. Sexuality should not be viewed as a taboo topic and open discussion about sexual issues needs to be encouraged. The history of silence and negative perceptions of human sexuality has led to contradictory messages and narrow approaches regarding safer sex and HIV prevention. Churches need to speak about relationships, the positive aspects of sexuality as well as being open to discussing sexual health issues. The extent of the HIV pandemic is such that we need to overcome shyness in relation to sexuality and start talking about it in a constructive way.

As the World Council of Churches (WCC) and Christian Conference of Asia (CCA) stated, “churches are challenged to break the silence and go beyond cultural taboos in order to approach topics of sex and sexuality in a more positive and non judgmental

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way, recognizing also the need to include gender justice in church teaching and practice. The suggested actions were to:

- Provide opportunities for clergy and lay leaders to understand sex and sexuality and gender justice, within both theological and health education frameworks, through workshops, discussions, seminars.
- Develop, collect and promote appropriate materials keeping in mind language, cultural sensitivity, and biblical foundations.
- Introduce the topic of sexuality, understood in a positive fashion, into curricula for clergy training.
- Introduce sexual education in a value-based manner within the context of broader training in life skills in secondary and Sunday school wherever possible. This must be done in a culturally sensitive way with the cooperation of teachers, parents, and school authorities.\(^2\)\(^92\).

In terms of theological training a useful resource is Human Sexuality and HIV/AIDS Teaching and Talking about Our Sexuality: A Means of Combating HIV/AIDS\(^3\).

In some parts of Africa, the traditional source of sex education culturally has been the paternal aunt or uncle. It was taboo for a parent to discuss sex with his/her child. This cultural tradition has rapidly become eroded and lost some credibility in the process of urbanization and social change. Negative attitudes, towards sex education provided by schools and other such institutions, have been legion and, sadly, promoted by many church leaders. The perception is that it violates religious teaching, is insensitive to cultural traditions, is a parent's domain, will encourage early sex and that abstinence should be the rule of the day. At the same time, young people are exposed to double standards and receive mixed messages from media, advertising, culture and religion.\(^4\).

In the name of morality, culture or religion, young people are also often denied their right to education on sexual health and risk behaviours without important tools and services for protection. There is lack of access to youth-friendly health services and negative attitudes from health workers are what often deter youth and others from soliciting services from clinics. Youth are also vulnerable to abuse and exploitation and the age of sexual debut, especially for girls, is very young.\(^5\)

Education on human sexuality and sexual health is needed, both for the prevention of HIV, and for a fuller understanding of how the body functions for those wanting to

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abstain from sexual encounters. Although the epidemic is well into its third decade, basic AIDS education remains fundamental to the response. Yet, for instance, in India, recent behavioural survey data showed that 30% of women had not heard of HIV or AIDS\textsuperscript{96}.

Churches need to be cognizant of and speak out against the structural injustices which mean millions of people never receive a basic education, and churches need to speak out about social justice so that the current situation whereby even when orphans, widows and women are educated, they are still raped in war or at home; or still becoming involved in sex work due to poverty etc. For example, a Statement from the Bishops’ Conference from the Church of Norway\textsuperscript{97} highlighted that:

There are many reasons why the pandemic is spreading so quickly. Large groups of people are migrating in order to find work, or because of wars and conflicts. Many people do not know how the virus spreads or how to protect themselves against it. The use of condoms, which reduces the spread of HIV/AIDS, is often a taboo issue, and for a great number of people condoms are unavailable. Irresponsible sexual behaviour, suppressing the facts about the pandemic and social isolation of the people infected, all make the situation especially difficult.

HIV is about relational issues at both personal and structural levels. At the latter, it is about how we distribute power within our structures along gender, class, race, age, ethnicity and sexual orientation at the national and international levels. At a personal level, it is about how power distributions within the structures that we inhabit inform our choices. As a relational issue HIV is about what we do to ourselves and what we do to others while having sexual relations with or without a person who happens to be HIV-positive. It is about respect for our humanity and the humanity of others. HIV/AIDS raises issues of inter-generational sex, when such sexual relations are perceived as a method of HIV prevention, and places the spotlight on incest, which cannot be ignored, unless we as churches are willing to accept HIV infection in children and young people as a result of coerced sex with a relative. The Provincial Anglican Bishop, Malawi, has taken up this challenge, stating, “As a Province, we pledge to speak out regarding child abuse, especially the increasing levels of child defilement which contribute to the spread of HIV/AIDS”\textsuperscript{98}.

The United Evangelical Mission stated in its Anti HIV/AIDS Programme Policy:

Due to the prevailing silence, we have also often failed to clearly name and renounce the different forms of sexual violence that exist around us. This has left many victims alone and has reinforced the atmosphere of taboo and silence. We have to look for ways to overcome this.

The Aids crisis challenges us with urgency to strive for a better understanding of human sexuality, to identify harmful taboos or

\begin{itemize}
\item \textsuperscript{97} Church of Norway, \textit{Statement from the Bishops’ Conference}. April 2001
\end{itemize}
destructive cultural traditions and to search for appropriate ways of communicating about sexuality in the church and world-wide.\textsuperscript{99}

HIV also requires churches to acknowledge the reality of anal sex for pleasure as a means of avoiding pregnancy, particularly among the young, and as practiced in some countries, for example, South Africa, as a form of HIV prevention, which indicates a gross misunderstanding of how HIV is transmitted.\textsuperscript{100}

Finally, HIV and AIDS programmes themselves may unwittingly contribute to the development of stigma.\textsuperscript{101} It has been suggested, for example, that government HIV/AIDS prevention programmes are often targeted at the so-called ‘general population’, often omitting mention of at-risk behaviours in some populations such as men who have sex with men, injecting drug users or sex workers. In so doing, these groups are implicitly labelled as less important or of lower priority. This reinforces pre-existing stigmatization of such groups.

### 3.4 Pre-marital HIV testing

A highly contentious issue confronting churches is pre-marital HIV testing. For PLWHA as with any person, marriage is defining point in a person’s life. To have this right negated by either church or state causes much pain and suffering both to the individuals involved and the PLWHA community at large. Box 14 below, “Pre-marital HIV testing” focuses on different churches role and positions on this issue. Knowing your HIV status before marriage can assist preventing HIV transmission within marriage; however, the bottom line is such testing should always be voluntary.

#### Box 14: Pre-marital HIV testing\textsuperscript{102}

Pastors of souls are sadly aware of the human weakness that often results in transgressions against the Church’s commandments with regard to sexual activity. For that reason, many such pastors have raised the question about whether or not the Church should require mandatory pre-marital HIV testing before allowing a couple to enter into the state of matrimony with full recognition and sanction by the Catholic Church and with the consequent dignity and grace that is conferred by the sacrament of marriage.

On the secular scene, and within diverse cultural contexts, there have been many attempts, to mandate pre-marital HIV testing or, even more radically, to prevent those

\textsuperscript{99} United Evangelical Mission, Anti HIV/Aids Programme Policy, Adopted by the UEM General Assembly in Manila, October 2004.


living HIV from entering into marriage. Most of those attempts failed miserably but, worse yet, left in their wake the scars of discrimination toward those affected by the pandemic.

The legal relationship between HIV testing and a person’s right to marry came under scrutiny in India between 1998 and 2002, when Mr. X petitioned the court to clarify its previous judgment that suspended his right to marry in view of his positive HIV status. In December 2002, the Supreme Court of India reversed its previous finding and recognized that those already known to be infected with HIV could marry provided that such persons revealed their HIV status, when known, to his/her prospective spouse.\(^{103}\)

The ecclesial aspects of the pre-marital HIV testing debate require even greater discernment than those of the secular arena. The Church deals not only with legal and social institution of marriage but also with the sacred reality that the sacrament of matrimony creates “a covenant by which a man and a woman establish between themselves a partnership of the whole of life” and “is by its nature ordered toward the good of the spouses and the procreation and education of offspring”.\(^{104}\) Neither The Code of Canon Law nor The Catechism of the Catholic Church makes specific reference to HIV or AIDS in their respective treatments of marriage. In view of the absence of specific teaching or law in this regard, and of the fact that the priest (or deacon) is not the minister of the sacrament of matrimony,\(^{105}\) it is quite perplexing to hear that, of their own accord, some members of the clergy have enacted mandatory pre-marital HIV testing policies. On numerous occasions, this writer has heard the following remarks from priests (and deacons): “I insist that couples contemplating marriage be tested for HIV, because I am not going to ‘marry’ them, if one of them is infected with this virus!”

Recently, The Nigerian Anglican church called for other denominations to join in demanding that members intending to wed must undertake HIV tests to qualify to marry in church. The Church of Nigeria (Anglican Communion) said its decision to make it mandatory for intending couples to be screened for HIV was to contain the spread of the disease.\(^{106}\)

Some bishops already have grappled with the issues related to pre-marital HIV testing; in so doing, they listened, with keen intellect and pastoral sensitivity, to the medical and scientific experts, the guardians of public health, and the first-hand experience of those living with or otherwise affected by HIV and AIDS. Among the Episcopal declarations related to HIV testing, we can find the following:

\(^{103}\) Lawyers Collective HIV/AIDS Unit. Mandatory Pre-Marital Testing, Positive Dialogue, Newsletter #15.


\(^{105}\) “… the spouses as ministers of Christ’s grace mutually confer upon each other the sacrament of Matrimony by expressing their consent before the Church”, Catechism of the Catholic Church, 2nd edition, 1994, Libreria Editrice Vaticana, #1623.


• The Bishops of the United States wrote: “With respect to HIV/AIDS, it is important to infringe as little as possible, in light of community needs, on individual liberty, privacy and confidentiality … Although specific exceptions might be made, universal mandatory testing does not seem justified at this time”107.

• The Bishops Uganda counselled the following: “Before marriage, each member of a prospective couple should be encouraged to choose wisely and look into his or her past. If there has been risky behaviour, the couple should be advised of the optional pre-marital HIV test, clearly pointing out the pros and cons and the consequences of the test result”108.

• The Social Commission of the bishops of France maintained: “It is asserted that testing is most effective when it is willingly sought and not undergone because it is mandated. The effectiveness of testing is based on trust”109.

Thus it appears that, while a priest (or deacon) rightfully may be motivated, out of pastoral solicitude, to encourage a couple preparing for marriage to voluntarily submit to HIV testing (and to receive the result of that testing as their own unique property), he has no right to require or mandate such pre-marital testing.

3.5 HIV prevention and drug use

Another issue confronting churches is drug use, including alcohol, and its relationship to HIV. In many countries, for both young men and women, the age at which they have their first sexual experience correlates with the age at which they have their first experience with alcohol and/or other mind-altering substances. Much drinking takes place in bars, at parties and in nightclubs where people are often searching for sexual partners. Research suggests that excessive alcohol and other drugs, including the so-called ‘party drugs’, are often linked to unsafe sex (penetrative sex without using a condom) and drinking has been associated with people having more than one sexual partner110.

Being drunk often provides the necessary excuse for inappropriate, unsociable or risky behaviour, such as having unintended or unprotected sex or being sexually aggressive. Peers may put pressure on their friends and convince them to have unsafe sex. Rape or other forms of sexual violence can result from excessive drinking.

Some churches such as the Methodists and most charismatic churches promote abstinence from drinking. However, most churches tolerate alcohol. As part of HIV education churches should include responsible drinking behaviour in the curricula for young people and encourage a culture of responsible drinking.

Over the past century, and increasingly in the last decades, governments in many countries have adopted strict policies against the provision, sale and use of illegal substances.

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110 UNAIDS. Boys, young men and HIV/AIDS, I care ...Do you? World AIDS Campaign 2001
drugs as well as on the possession of drug use paraphernalia.\textsuperscript{111} The objective has been to create a society free of illegal drugs. At the same time, most cultures accept other drugs of addiction such as tobacco, alcohol, quat, betelnut and caffeine. And these are used by governments to raise revenue through taxes, even though conclusive medical evidence exists that some of these drugs can cause serious social and health problems, including death.

In some parts of the world, the HIV epidemic is been driven by injecting drug use, and yet it is the most preventable means of transmission. Harm-reduction\textsuperscript{112} measures, particularly the provision of sterile needles and syringes, have been proven to reduce the risk of transmission of HIV and other blood borne viruses, and do not increase illicit or injecting drug use. Drug substitution treatment, for example, methadone, an orally administered prescription drug that manages opiate craving, also reduces HIV risk by eliminating drug users’ reliance on needles and syringes.

Many injecting drug users are occasional or opportunistic recreational users. They do not fit the stereotype of the ‘drug addict’. Some individuals report being able to regulate their drug use for long periods and maintain work and family responsibilities; this is referred to as ‘functional drug use’. However, such delineation does not protect recreational users from HIV and other blood borne infections.

Worldwide there are more than 13 million injecting drug users (IDUs), and in some regions more than 50% are infected with HIV. During the last decade of the 20\textsuperscript{th} century the number of countries reporting injecting drug use rose from 80 to 134 and

\textsuperscript{111} United Nations Single Convention on Narcotic Drugs, 1961 aims to combat drug abuse by coordinated international action. There are two forms of intervention and control that work together. First, it seeks to limit the possession, use, trade, distribution, import, export, manufacture and production of drugs exclusively to medical and scientific purposes. Second, it combats drug trafficking through international cooperation to deter and discourage drug traffickers.
United Nations Convention on Psychotropic Substances, 1971, establishes an international control system for psychotropic substances. It responded to the diversification and expansion of the spectrum of drugs of abuse and introduced controls over a number of synthetic drugs according to their abuse potential on the one hand and their therapeutic value on the other.
United Nations Convention against the Illicit Traffic in Narcotic Drugs and Psychotropic Substances, 1988, provides comprehensive measures against drug trafficking, including provisions against money laundering and the diversion of precursor chemicals. It provides for international cooperation through, for example, extradition of drug traffickers, controlled deliveries and transfer of proceedings http://www.unodc.org/unodc/en/un_treaties_and_resolutions.html

\textsuperscript{112} Harm reduction takes a morally neutral stance to drug use, neither condoning nor opposing drug use. It focuses on actual harm and assumes that some people will continue to inject drugs despite government repression and therefore they should be given the possibility to do so in an in a way that reduces the risks and causes least harm to themselves and others.

Harm reduction programmes for HIV prevention for IDUs have shown to be most effective when a comprehensive approach is taken, including:

- information, education and communication,
- drug treatment services, including pharmacotherapy substitution programs,
- NSPs, including needle and syringes exchange programmes, disinfection and safe disposal,
- community outreach
- peer education,
- risk reduction counselling,
- voluntary counselling and HIV testing, and
- HIV treatment and care.
the proportion of countries with HIV outbreaks among IDUs rose from 65% to 84%\textsuperscript{113}. Recent estimates indicate that at least 10% of all new infections in the world – a figure that rises to 30% when Africa is excluded – can be attributed to injecting drug use\textsuperscript{114}.

Today, drug injecting with contaminated equipment is the major HIV transmission mode in many countries in Europe, Asia and Latin America, and is also driving HIV transmission in North Africa and the Middle East. In several countries, HIV epidemics have been driven almost entirely by injecting drug use. These include the states of the former Soviet Union of which Estonia, the Russian Federation and Ukraine appear to have the largest and most widespread epidemics. The recent, dramatic rise in HIV prevalence in South and Southeast Asia is substantially related to injecting drug use\textsuperscript{115}. Countries that have been particularly affected include China, Indonesia, Myanmar and Viet Nam. Not surprisingly those are the countries where needle and syringe programmes are not widely available, drug-substitution treatment is illegal and law enforcement is the modus operandi for dealing with drug use.

Injecting drug use is a global phenomenon including, most recently, in Africa, which is also, increasingly being used for the trafficking of heroin and cocaine. According to the 2001 UN Office on Drugs and Crime (UNODC) \textit{World Drug Report}, the opiate use prevalence in Nigeria was 0.3%. The joint study between the World Health Organization (WHO), the ministry of health and the University of Ilorin on drug abuse concluded that injecting drug use with associated health consequences was an emerging problem in Lagos, Nigeria. Injecting drug use has already been described as a major problem in Mauritius. Reports indicate increasing numbers of injecting drug users in Kenya\textsuperscript{116}. There is strong anecdotal evidence from Tanzania of an evolving drug problem\textsuperscript{117}.

Explosive growth is one characteristic of injecting drug use-based HIV outbreaks. In several well documented instances, HIV seroprevalence among injecting drug users


\textsuperscript{115} Rhodes T, Ball A, Stimson GV et al. (1999). HIV infection associated with drug injecting in the newly independent states, eastern Europe: the social and economic context of epidemics. \textit{Addiction} 94:1323–1336.


\textsuperscript{116} The prevalence rate of opiate abuse in Kenya is 0.1%, \textit{World Drug Report}, UNODC, 2001, in \textit{Assistance to country responses on HIV/AIDS associated with injecting drug use by the UN and other agencies}, Report for the Interagency Task Team on injecting drug use, 2003.

\textsuperscript{117} United Nations Interagency Task Team. \textit{Assistance to country responses on HIV/AIDS associated with injecting drug use by the UN and other agencies}, Report for the Interagency Task Team on injecting drug use, 2003.
rose from 1%–2% to 60%–70% in a few years\textsuperscript{118}. The most obvious explanation is the efficacy of blood-borne transmission through contaminated needles and syringes (and other drug injecting equipment) being used by several people. An additional factor may be due to the elevated viral-load characteristic of the first weeks and months after HIV infection. Exposure to a very high viral load increases an HIV-negative person’s risk of infection. A universal characteristic of injecting drug use-based HIV epidemics is that although males constitute the majority of those seroconverting in the early stages, eventually there is sexual transmission to male and female partners as well as to new-born children through mother-to-child transmission.

In addition to HIV infection, the prevalence of both Hepatitis C (HCV) and Hepatitis B infection is high among injecting drug users with coinfection(s) being commonplace. Coinfections complicate treating all of the different infections but does not make it impossible.

Some countries have passed laws prohibiting persons from having access to sterile needles to protect people from the harm of injecting drugs. No study has ever shown that these laws are effective in preventing injecting drug use. But these laws have been effective in preventing people who inject drugs from having access to sterile needles. It is a tragic irony that the laws prohibiting access to sterile needles, laws meant to protect people, are now the cause of people dying from AIDS\textsuperscript{119}.

In the Bible, there is no explicit teaching prohibiting injection drug use, though the term the “sin of injecting drug use” has been coined. The Bible says that the wages of sin are death; however, the Bible also says that vengeance belongs to God. Injecting drug users are in need of care and compassion, and real alternatives. Instead, they routinely face harassment, stigmatization, violence and social exclusion, including by some churches. The stigma attached to drug use causes further marginalization of this most vulnerable group and this is directly impeding efforts to prevent HIV transmission.

Most churches are silent on the issue of injecting drug use or use terms such as “vulnerable populations” without ever stating which populations are covered by the term. For example at the UNGASS on HIV/AIDS in 2001 neither the Holy See nor the Faith-based organizations, which made statements to the session spoke of injecting drug use specifically\textsuperscript{120}. While the silence on HIV in terms of sexual


transmission has been largely broken, there are still many churches which do not acknowledge injecting drug users and the devastating, yet preventable, impact of HIV on their lives.

The Catholic Church has described drugs as\textsuperscript{121}:

93. Drugs and drug addiction are almost always the result of an avoidable evasion of responsibility, an aprioristic contesting of the social structure, which is rejected without positive proposals for its reasonable reform, an expression of masochism motivated by the absence of values.

One who takes drugs does not understand or has lost the meaning and the value of life, thus putting it at risk until it is lost: many deaths from overdose are voluntary suicides. The drug-user acquires a nihilistic mental state, superficially preferring the void of death to the all of life.

94. From the moral viewpoint "using drugs is always illicit, because it implies an unjustified and irrational refusal to think, will, and act as free persons"\textsuperscript{122}. To say that drugs are illicit is not to condemn the drug-user. These persona experience their condition as "a heavy slavery" from which they need to be freed\textsuperscript{123}. The way to recovery cannot be that of ethical culpability or repressive law, but it must be by way of rehabilitation, which, without condoning the possible fault of persons on drugs, promotes liberation from their condition and reintegration.

95. The detoxification of the person addicted to drugs is more than medical treatment. Moreover, medicines are of little or no use. Detoxification is an integrally human process meant to “give a complete and definitive meaning to life”\textsuperscript{124}, and thus to restore to those addicted that "self confidence and salutary self-esteem" which help them to recover the joy of living\textsuperscript{125}.

In the rehabilitation of persons addicted to drugs it is important “that there be an attempt to get to know individuals and to understand their inner world; to bring them to the discovery or rediscovery of their dignity as persons, to help them to reawaken and develop, as active subjects, those personal resources, which the use of drugs has suppressed, through a

http://www.un.org/ga/aids/statements/  
\textsuperscript{121} Drs in \textit{Charter For Health Care Workers. Pontifical Council for Pastoral Assistance to Health Care Workers. Vatican City 1995, pp. 77–80.}  
http://www.healthpastoral.org/emergentpains/drugs/index.html  
\textsuperscript{122} John Paul II, To the participants at the International Conference on Drugs and Alcohol, Nov. 23, 1991, in Insegnamenti XIV/2 (1991), 1249, no.4.  
\textsuperscript{123} Cf. John Paul II, To the participants at the VII World Congress of Therapeutic Communities, Sept. 7, 1984, in Insegnamenti VII/2, p. 347, no. 3.  
\textsuperscript{124} Cf. John Paul II, To the participants at the VII World Congress of Therapeutic Communities, Sept. 7, 1984, in Insegnamenti VII/2, p. 350, no. 7.  
\textsuperscript{125} Cf. John Paul II, Message to the International Congress in Vienna, June 4, 1987, in Insegnamenti VII/2, p. 347, no. 3.
confident reactivation of the mechanisms of the will, directed to secure and noble ideals”126.

96. Using drugs is anti-life. “One cannot speak of 'the freedom to take drugs' or of 'the right to drugs,' because human beings do not have the right to harm themselves and they cannot and must not ever abdicate their personal dignity, which is given to them by God”127, and even less do they have the right to make others pay for their choice.

And the causes of drug use as:

A leading cause of drug use among young people and adults is a dearth of clear, convincing motivations in life, an absence of values, the conviction that living is not worthwhile, a sense of loneliness and lack of communication, insufficient intimacy with God, a paucity of dynamic proposals on a human and spiritual level, an attempt at escapism, and a social structure not offering satisfactions –all within the framework of a materialistic outlook which is destructive of human needs128.

Angelo Cardinal Sodano, Secretary of State, has outlined the teachings of the Catholic Church on drug use:

Speaking to the therapeutic communities in 1984, John Paul II said, "Drugs are an evil, and one does not give in to evil. Legalization, even if partial, apart from being disputable in relation to the nature of the law, does not evade the already established effects. This is confirmed by an already common experience. Prevention, suppression, and rehabilitation are the focal points of a program conceived and applied in the light of the dignity of man, sustained by the honesty of relationships among people; such a program enjoys the trust and support of the Church" (Teachings, VII, 2, 1984,p.349)…

Addiction does not work through drugs themselves, but in what leads the individual to addiction.…. Why do they (drug users) do it? The extension of the drug phenomenon makes one think of a deeply rooted malaise which touches the conscience and at the same time the collective ethos, culture and social relationships. The Pope calls for attention to this issue. He observes that usually at the root of the addiction problem there is an "existential void caused by an absence of values and lack of self-confidence, trust in the others, and life

126 John Paul II, To the participants at the VII World Congress of Therapeutic Communities, Sept. 7, 1984, in Insegnamenti VII/2, p. 347, no. 3.
127 John Paul II, To the participants at the International Conference on Drugs and Alcohol, Nov. 23, 1991, no. 4. "The use of drugs inflicts very grave damage on human life and health. Their use, except on strictly therapeutic grounds, is a grave offense. Clandestine production of and trafficking in drugs are scandalous practices. They constitute direct cooperation in evil, since they encourage people towards practices gravely contrary to the moral law" (CCC 2291).
in general" (Teachings, XIV, 2, 1991, p. 1249). Furthermore, drug use involves an interior emptiness that seeks to escape and leads first to the darkness of the spirit before physical destruction (Teachings, XIII, 2, 1990, p.1579). There is a connection between illness caused by the abuse of drugs and the pathology of the spirit which leads the person to run away from himself and seek illusory satisfactions avoiding reality, to the point of negating the significance of his own existence.

However, one cannot deny the fact that drug addiction is also closely related to the present state of a secularized permissive society in which hedonism, individualism, pseudo-values, and false models prevail. Familiaris Consortio considers this to be the consequence of a society risking being ever more depersonalized and standardized and also inhuman and dehumanizing (Teachings, IV, 2, 1981, p.1087)…

Given the nature of the problem, it is obvious that prohibition, though necessary, is not enough. "This evil," says the Pope, "has to be overcome by a new pledge of responsibility within the structures of civil life, and in particular through the proposals of alternative models for life" (Teachings, XII, 2, 1989, p.637).

This is the strategy of prevention, for which, emphasizes John Paul II, the assistance "of the whole society – parents, schools, social environment, means of social communication, international organizations – is necessary, as is a commitment to form a new society on a human scale: education for being human" (Teachings, VII, 1, 1984, p. 1541). This entails concerted action proposing authentic values and, in particular, spiritual values at all levels of community life.

For those already entangled in the abuse of drugs, there is need for appropriate forms of treatment and rehabilitation which exceed simple medical treatment because in many cases one finds a complex set of problems which require the help of psychotherapy for both the individual and the family nucleus, together with appropriate spiritual support, and so on. The replacement drugs to which people often resort do not offer sufficient treatment; they are more or less a veiled way of surrendering to the problem. Only the personal effort of the individual, his own will to revive and ability to recover, can guarantee a return to normality from the hallucinating world of narcotics.

However, one undergoing such a demanding process also has need for social help. The family remains, of course, the principal reference point for any preventive action. This has been emphasized by the Holy Father on various occasions, without overlooking the importance of "therapeutic communities," "which by aiming at and indefatigably keeping their attention fixed on ‘human value,’ under their various aspects have shown themselves to be a good system" (Teachings, VII, 2, 1984, p.346)129.

The Seventh Day Adventist Church has a similar stance, stating in 1990, “Adventists are committed to education for prevention of AIDS. For many years Adventists have fought against the circulation, sale, and use of drugs, and continue to do so”130.

In September 1996, the WCC Central Committee on the basis of the WCC Consultative Group on AIDS Study Process adopted a statement on HIV/AIDS and possible responses by churches, including:

C. The witness of the churches: in relation to long-term causes and factors encouraging the spread of HIV/AIDS
   6. We ask the churches to address the pandemic of drug use and the role this plays in the spread of HIV/AIDS and to develop locally relevant responses in terms of care, de-addiction, rehabilitation and prevention131.

Certain churches and faith-based organizations, in light of the high rate of HIV infection among injecting drug users, are advocating for harm reduction measures, or reaching out to or working with vulnerable populations, including injecting drug users, or education and prevention of drug use.

The Lutheran World Federation members from Argentina, Uruguay, Paraguay, Chile, Brazil, Peru and El Salvador in the Declaration of Buenos, in 1998 stated:

“We observe the rapid increase of cases of HIV/AIDS due to the sharing of needles, a situation which is closely related to the living conditions of these persons. We observe with concern how society responds to this problem with repressive police solutions

We demand, in the face of this social problem, social responses, which include specific prevention and education programs as well as new therapeutic responses.

We as church commit ourselves to going out to meet and integrate persons living with HIV/AIDS due to drug dependencies into our communities, and to support the processes of rehabilitation and/or diminishing the damage”132.

Lutheran World Federation in the Message from the Tenth Assembly stated:

Therefore, we commit ourselves and call on member churches to further awareness regarding prevention of the HIV/AIDS pandemic through education and information, including speaking-out against harmful,

abusive and exploitative sexual practices, treating sexually transmitted diseases, promoting faithfulness in marriage and advocating effective means of prevention (e.g. abstinence, use of condoms, sterilized needles, clean blood supply).  

The Lutheran World Federation and the United Evangelical Mission in the *Statement of Commitment of the Asian Church Leadership Consultation on HIV/AIDS* agreed:

“Knowing that only through education and prevention we can curb the spread and effects of this pandemic, we commit ourselves to:

- Integrate a good quality HIV and reproductive health education in the Christian Education curriculum to “ensure that young people have information and life skills they need before they become sexually active and sexual behavior starts to form.” This should also include adequate information about the protective use of condoms in the context of HIV/AIDS prevention, the danger of needle-sharing in intravenous drug use and other preventive measures”.

In the *Memorandum of Intention* by Churches in central and eastern Europe stated, “The political, social and economic changes in Central and Eastern Europe throughout the last two decades have made certain population groups vulnerable to HIV/AIDS. We resolve to focus our church-related HIV/AIDS work on the following groups:

- Drug Users

The battle against the HIV/AIDS crisis is a battle for the dignity of life. It calls us to use all effective means of prevention within a context of Christian ethics.”

The Cairo Declaration from an interfaith meeting stated:

We emphasize the importance of reaching out to vulnerable groups which are more at risk of being infected by HIV/AIDS and/or spreading it, including commercial sex workers and their clients, injecting drug users, men having sex with men, and those who practice harmful behaviors. We emphasize the importance of diverse approaches and means to reach out to those groups, and although we do not approve of such behaviors, we call on them to repent and ask that treatment and rehabilitation programs be developed. These programs should be based on our culture and spiritual values.

The United Methodist Church has recently specifically addressed the issue of drug use and AIDS, stating:

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In response to the alcohol, drug and HIV/AIDS crisis in the world, The United Methodist Church commits itself to a holistic approach of awareness, education, prevention, treatment, community organizing, public advocacy and abstinence. Out of our love and concern for our brothers, sisters and children in our local and global communities, we therefore:

1. urge the Office of the Special Program on Substance Abuse and Related Violence (SPSARV) of the General Board of Global Ministries and all boards and agencies of the Church to work cooperatively on issues related to drugs and AIDS;
2. encourage local churches to include problems of alcohol, drug abuse and unsafe sex and the value of abstinence as part of Christian education;
3. encourage United Methodist churches and institutions to provide support, comfort and care to those afflicted with alcohol-related problems, drug addiction and HIV/AIDS within their given mandate;
4. urge the Federal Government to improve interagency cooperation and coordination to fight the double scourge of drugs and AIDS;
5. make available creative programs and activities for school children, youth and young adults that keep them away from alcohol and drug abuse; and
6. promote and make available peer education models based on empowerment and self-determination

Churches must promote the deeper issues of developing greater respect for one’s own body and for the bodies of other persons. Yet injecting drug use is a reality, and the number of people involved is growing. Box nine on “The use of condoms – theological perspectives” put forward various points of view on condom use. Notably, within the context of preserving life the use of condoms were viewed by some as being permissible. Similar arguments can be put forward for the provision of harm reduction measure for preventing injecting drug use – related HIV transmission. God has given us the knowledge of how to slow the spread of HIV, let us use it. If we abandon the person who injects drugs to HIV and AIDS, we may also be abandoning their non-drug-injecting spouse or partner and their new born infants as well.

137 The United Methodist Church. Drugs and AIDS Resolution – Adopted by the General Conference, Pennsylvania, United States, 27 April – 7 May 2004.
Chapter 4

Working with PLWHA organizations

This chapter is the heart of “How to work with PLWHA Organizations”. Many different issues relating to partnering with PLWHA organizations are discussed. The sections on:

- confidentiality (HIV-related stigma and the relationship to confidentiality, the situation of HIV-positive clergy, putting a HIV workplace policy in place and breaching confidentiality, putting a face to the epidemic);
- tokenism (the issue of tokenism, churches statements to involve PLWHA organizations and guidelines for involvement);
- capacity development of both churches and PLWHA organizations); and
- monitoring and evaluation (definitions, traditional model and participatory approach)

are particularly pertinent. Another crucial issue which reoccurs is access to HIV treatment, including antiretroviral therapy, and the role of church advocacy efforts.

4.1 Background requirements

The partnership between the International Federation of the Red Cross and Red Crescent Societies (IFRC) and the Global Network of People Living with HIV/AIDS (GNP+) has been well documented, including the start-up process. Extrapolating from the findings; there are some essentials that need to be in place before instigating a partnership.

- Mutual respect and consideration.
- Openness. Churches need to be open about past failures to tackle the reality of HIV/AIDS, and the fact that churches have AIDS. Conversely, in many cases, PLWHA need to tackle their negative feelings and attitudes towards churches.
- Professionalism, which requires that people are committed to their work and keep to deadlines and appointments. Simply put: if you say you are going to do something, do it.
- Listening to each other.
- Ability and willingness to take risks and to experiment – ‘learn by doing’.

A practical tool to measure your church’s “AIDS competency” is the “Self assessment framework for AIDS competence” described in Annex 1.

Judgemental attitudes can be reinforced by using inappropriate language. In Annex 2, there is a list of appropriate and inappropriate terminology for discussing HIV- and AIDS-related issues. You should become familiar with these terms and the different meanings of each. In Annex 3, The Covenant Document on HIV/AIDS, provides biblical basis for constructive engagement with PLWHA in all the issues of the

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139 UNAIDS, IFRC and GNP+. A vital partnership: the work of GNP+ and the International Federation of Red Cross and Red Crescent Societies on HIV/AIDS, A UNAIDS Best Practice Case Study, October 2003.
epidemic. It gives a language to both the churches and PLWHA, and for facilitating partnership in the struggle against HIV/AIDS.

4.2 Managing organizational fears, stigma and discrimination

<table>
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<tr>
<th>Covenant 4: Compassion, HIV/AIDS stigma and discrimination&lt;sup&gt;140&lt;/sup&gt;</th>
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<tbody>
<tr>
<td>We shall remember, proclaim and act on the fact that the Lord our God, is a compassionate God, who calls upon us to be compassionate, to suffer with those who suffer, to enter their places and hearts of pain and to seek lasting change of their suffering (Luke 6:36; Matthew 25:31–46). We shall therefore, have zero tolerance for HIV/AIDS stigma and discrimination and do all that is necessary to eliminate the isolation, rejection, fear and oppression of the infected and affected in our communities. We shall declare HIV/AIDS stigma and discrimination an unacceptable sin before God and all believers and in all our communities.</td>
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Opening the door to a partnership between churches and PLWHA organizations could meet with considerable opposition, based on fears, anxieties, prejudice, denial, stigma or discrimination from both sides. It is important for PLWHA and their organizations to be assured by churches that churches will abide by the above covenant so that successful partnerships can occur. The IFRC/GNP+ partnership used a simple strategy to ease the way, which included low-key initial contacts, which resulted in an agreed process of milestones and engagement, including test cases that would decide whether to continue the development of the partnership or not. EHAI A has been using a strategy of promoting HIV/AIDS sensitive worship to break the silence and stigma surrounding HIV in order to prepare churches and faith-based organizations for engagement on HIV/AIDS and with PLWHA organizations<sup>141</sup>.

The creation of tools and opportunities for discussion are useful stepping stones in developing a partnership. The IFRC/GNP+ partnership used a number of strategies to ease the Red Cross/Crescent Movement<sup>142</sup> into accepting the partnership.

- The video ‘Living with…’, which portrays Red Cross/Red Crescent people who have all somehow been touched by HIV/AIDS, had a considerable impact and helped to create organizational change of attitude and behaviour. Churches planning to form partnerships with PLWHA organizations should consider making such a video, especially for internal use. See box 15 “Living with...” below for details of the content and contacts for obtaining a copy.
- Events such as the International AIDS Conferences and regional Red Cross and Red Crescent meetings were used to promote understanding of, and strengthen, the partnership policy base. In a similar manner, the United Nations General Assembly Special Session on HIV/AIDS in 2001 and International Federation of the Red Cross and Red Crescent Societies Board

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<sup>142</sup> The Movement consist of International Federation of the Red Cross and Red Crescent Societies (IFRC), the International Committee of the Red Cross and Red Crescent (ICRC) and Red Cross and Red Crescent National Societies.
meetings were used. In the case of churches, this translates into using national and regional meetings as well as making HIV part of the agenda of synods and other policy-making forums. The international and regional AIDS Conferences are also useful forums for churches to promote their work and strengthen partnerships. Issues such as a HIV/AIDS workplace policy and HIV/AIDS as a core component of a church’s work are appropriate for such forums.

- Public commitments at public events by IFRC leaders were used to gain and retain the commitment to HIV/AIDS. This was vital in ensuring that the IFRC remained focused on HIV/AIDS during a period when there were many leadership and management changes. Again, in the context of churches, church meetings as well as World AIDS Day, 1 December, and launches of activities in country are useful events for recommitting churches.

- It is also important early on to develop and support people that could best act as a bridge between the partners – people living with HIV/AIDS. See box 16 “IFRC/GNP+ Partnership: Recruiting a regional PLWHA partnership officer” which describes the process.

**Box 15: “Living with...”**

The video “Living with...” is a video produced by the International Federation of Red Cross and Red Crescent Societies to contribute to the development of open and supportive National Societies that enhance HIV and AIDS prevention and care. The main target audience for the video is leadership and middle-management of the Federation secretariat, National Society headquarters and branches. The video portrays Red Cross/Red Crescent people who have all somehow been touched by HIV/AIDS and who talk about their experience of “Living with”.

“Thereof those of us from Societies who don’t have this problem have an obligation to help Societies who do. And though we aren’t losing our volunteers at the rate that the African Societies are losing theirs, or in Societies in other developing countries, we have an obligation to understand their need and to help them.” David Brooks Arnold, HIV-positive, Director of International Relations, American Red Cross

The video shows that HIV/AIDS is a problem with which we live, day-to-day, in the Red Cross/Red Crescent and that we must all become actively involved in taking positive action, in particular National Society’s leadership and management.

“In Nairobi I had to deal with AIDS first hand, on a daily basis, when one of our colleagues got it. To have lived that, every day, to stand by someone who is sick – to defend his interests, to understand the fears of his colleagues, his family – was a source of tremendous inspiration to commit myself more personally in the fight against AIDS.” Francoise LeGoff, Head of the Federation’s regional delegation in Nairobi.

The video is part of a strategy to create a compassionate, tolerant and supportive environment for people living with HIV/AIDS. In other words to make National Societies “AIDS competent” The advantages include:

- Individuals will be encouraged to undergo testing for HIV because there will
be no discrimination or stigmatization to frighten them away

- People living with HIV/AIDS and receiving all possible support and compassion from their friends, work-mates, families and institutions where they work will have the moral obligation to behave in a responsible way to prevent the transmission of the virus to others.

- People living with HIV/AIDS who live in a supportive and tolerant environment will have psychological, material and moral backing with access to the best possible treatment and hence will have a longer productive life span contributing to the economy of the country and also supporting their families.

- The longer the productive life span of people living with HIV/AIDS the fewer the number of orphans there will be.

- People who are seronegative or who are unwilling to take the test, will benefit from a supportive environment which will reduce the risk of transmission. The more a community talks frankly about HIV, the more chance there is for a supportive environment and the less chance there is of people contracting the virus.

The steps for National Societies to become “AIDS competent” are:

- Break the silence. Create space for open discussion about sexual education and HIV/AIDS
- Encourage voluntary testing and counselling
- Involve people living with HIV/AIDS in all activities and on all levels
- Develop HIV/AIDS friendly human resource policies
- Include HIV/AIDS in all relevant policies and programmes
- Advocate for a more coherent involvement of community leaders
- Build partnerships with organizations of people living with HIV/AIDS and others
- Scale up interventions

The video is available on the CD-Rom Reducing vulnerability to HIV/AIDS: Policies, images, videos and related documents, 2003 version. Copies can be obtained from:

Mrs. Polly Catsicalis Manansala
Senior Assistant, Health and Care Department
International Federation of Red Cross and Red Crescent Societies
P.O. Box 372 1211 Geneva 19, Switzerland
Tel: +41-22-7304411
Fax: +41-22-7330395
Polly.Catsicalis@ifrc.org
Box 16: IFRC/GNP+ Partnership: recruiting a regional PLWHA partnership officer

The IFRC Regional Delegation Nairobi (RDN) was the first region of the IFRC to put into operation a clear strategy and programme for a partnership between itself and the Network of African People Living with HIV/AIDS (NAP+).

One of the first, and most important, steps in making the partnership operational was recruiting a Regional PLWHA Partnership Officer, whose main responsibility was to develop the partnership, ‘in order to promote a meaningful involvement of PLWHA in Red Cross/Red Crescent interventions’.

The advert certainly caught people’s attention. It carried the emblems of both organizations and called for applicants to be persons living with HIV/AIDS. Some people assumed it was a mistake, maybe a printing error. Many others sent messages of congratulations. The advert alone gave good visibility to the partnership.

Dorothy Odhiambo was recruited in June 2002. She is a well-known and highly respected activist and member of NAP+ in Kenya. She had been a member of the Programme Coordinating Board of UNAIDS. Though her salary is paid in full by the RDN, Odhiambo was hired to work 50% for both organizations, as the Senior HIV/AIDS Partnership Officer for the RDN and as an Advisor to NAP+ (where she had been working as a volunteer). In a sense, Odhiambo is the embodiment of the partnership, working for both organizations. She has brought considerable experience and expertise to the post, able to communicate and work at every level, from small communities to government ministers.

Patrick Couteau, Regional HIV/AIDS Coordinator, explained that only someone who is HIV-positive can talk on behalf of PLWHA. They have a unique personal viewpoint and this cannot be learned from books. If I am to translate the concept of the partnership into practical action, I cannot do this without working closely with someone living with HIV/AIDS. And importantly, donors listen to her.

However, Dorothy Odhiambo’s appointment and the establishment of a workplace programme on HIV/AIDS confronted the Head of the IFRC Delegation Francoise, Le Goff, and her Human Resources Manager, Winnie Maganda, with a major challenge: the provision of free or low-cost antiretroviral (ARV) therapy. Not only had Dorothy received this in her previous job but Couteau and Le Goff agreed that access to ARVs is an essential part of any workplace programme.

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143 UNAIDS, IFRC and GNP+. A vital partnership: the work of GNP+ and the International Federation of Red Cross and Red Crescent Societies on HIV/AIDS, A UNAIDS Best Practice Case Study, October 2003.
If the Federation is to offer ‘a good home’ for people living with HIV/AIDS, it must provide access to effective care and treatment, stressed Couteau. This is a particularly key issue in African countries where only a small proportion of people needing ARV treatment have access to it, as neither individuals nor the national health services can afford to pay for this therapy.

If we don’t ensure access to treatment, said Couteau, why are we empowering people such as Dorothy Odhiambo? For them to go to the grave?

A major achievement in Nairobi was that the RDN, through its Human Resources Manager, was able to renegotiate its health insurance package; it now includes 100% free access to ARVs for all staff (and their families) who are HIV-positive. It was a hard and complicated deal, and it may not be possible to replicate it in other countries. Everyone consulted, especially PLWHA, agreed that access to ARVs could prove a major obstacle to the development of the partnership between the IFRC and the associations and networks of PLWHA. “Otherwise”, said Couteau, “we’re building capacity that will soon disappear without effective treatment.”

4.3 Confidentiality

Confidentiality in the context of HIV/AIDS means keeping your HIV status – HIV-positive, HIV-negative or untested – private. Guaranteeing confidentiality is critical in reducing the experience of discrimination and stigmatization related to HIV status, and in increasing the number of people who seek voluntary testing for HIV and treatment. While some 40 million people are estimated to be living with HIV, only 10% know their HIV status. Fear of stigma and discrimination as well as lack of testing facilities are some of the reasons for this situation.

Partnerships with PLWHA involves many types of activities, some public, others not. Yet one of the consistent themes of PLWHA is their need for confidentiality and to be able to choose to whom to disclose their status and in what circumstances. Paradoxically, providing confidentiality can hinder efforts to break the silence surrounding HIV. To date HIV and AIDS researchers have not fully explored positive models, from various cultures, on living and managing life threatening diseases, without resorting to the confidentiality model.

Discrimination against PLWHA is a global phenomenon. There are many reports of PLWHA receiving discriminatory treatment, including ostracism, from faith-based organizations because of their status or lifestyle. This has, in instances, resulted in PLWHA being summoned for special prayers or confessional sessions before congregations, often based on fraudulent and insistent claims about miracle cures for AIDS. Exaggerated fears of contagion have led to PLWHA being ordered to be last

when taking Holy Communion in churches, or being excluded from religious rites altogether.\textsuperscript{146}

Discrimination and stigmatization continue to be experienced by PLWHA. HIV- and AIDS-related discrimination is exacerbated by the vulnerability to further stigmatization of certain groups, including injecting drug users, men who have sex with men, migrants, prison populations, sex workers and women.

Confidentiality is often an issue in communities where ties between people are close. Even in urban areas people know each other. Confidentiality may be breached through gossip, rumours, discussion between friends, family and others, or through the effects of seemingly innocuous policies – for example, bills for health services being sent to the place of employment of a person being tested for HIV. Box 17 “Findings from the Siyam’kela study concerning confidentiality” provides examples of faith-based organizations’ responses to the need for confidentiality in South Africa.

\begin{boxed quotations}
Lack of confidentiality was a concern raised by the faith-based organization participants in the Siyam’kela study.\textsuperscript{147} In particular, there was criticism of how faith leaders deal with people’s disclosure of their HIV-positive status. The issue was raised that there are no confidentiality regulations within faith-based organizations, other than those related to confessions in the Catholic Church, to offer standards and guidance: How do we deal with confidentiality? I don’t know, because we are not good at it. Faith leader

A faith leader spoke of the experience of a friend who disclosed to church leaders, and of his own personal experience of disclosing his status within his church. In the case of his friend, he went to tell his dominee (minister) who said he thought the council should be told, “and they were so shocked by [the news] that they needed to share it with their wives, who were so shocked that they just felt that they needed to share it with their friends, who were so shocked that they needed to talk about it at the tea party.”

The faith leader’s own experience was not much different – he told his bishop who told the chaplain who shared it with his wife, who spread the news further. Faith community members voiced similar concerns about trust and confidentiality within their faith communities.
\end{boxed quotations}


\textsuperscript{147} POLICY Project, South Africa; Centre for the Study of AIDS, University of Pretoria; United States Agency for International Development (USAID); and Chief Directorate: HIV, AIDS & TB, Department of Health. \textit{Siyam’kela: A report on the fieldwork leading to the development of HIV/AIDS stigma indicators and guidelines}, December 2003.
It was highlighted that the issue of confidentiality is a particular problem for faith communities which do not practice confession between priests and community members. The problem was highlighted by one participant and described as follows: *In churches where confession is not practised there is no respect for private sensitive information. We think that we need to share [information], that’s where the problems come.* Faith leader

In the light of this it was emphasized that every faith community should come up with policies regarding HIV and AIDS and confidentiality.

As confidentiality is difficult to ensure in communities, education about HIV and AIDS is essential in reducing HIV- and AIDS-related discrimination. With HIV and AIDS education, inappropriate responses to HIV may be replaced by caring, compassion and community support. In such situations, confidentiality becomes less of an issue.

Working with PLWHA on a daily basis, and having a name and face to associate with the concept of “a person living with HIV or AIDS” – where previously the association was with a virus or terrible disease – helps people overcome their fears and prejudices, and changes perceptions of PLWHA. By providing a basis for partnership, mutual respect and understanding, a partnership can break down simplistic concepts of “service giver” (that is, the person who is not HIV-positive) and “service receiver” (the person who is). As well as reducing discrimination, a partnership with PLWHA can expose a church to the unique perspectives that PWLHA’s direct experience can bring. Working with PLWHA can lead to a deeper understanding of their value as precious resource, as they are the ones who know the problems best.

There is nothing wrong with sharing information; rather, what is important is the purpose and impact of such sharing. In many places, the issue of confidentiality has evolved into shared confidentiality. In the African context, confidentiality is problematic i.e., unAfrican and Western, and has contributed greatly to stigma and discrimination by suggesting from the beginning that HIV should be a secret rather than a burden to be shared and carried together. In African thinking every illness is a family illness, one’s health is always part of the collective health and consulting a doctor is a collective act. It is clear that HIV-positive people who are open about their status live longer and better, for it is a shared burden made lighter. In fact, many people who keep their status secret die sooner. For the church, the concept of confidentiality also breaches the goal of being one body of Christ, which is HIV-positive - where there exists no “us and them”.

However, due to the existence of stigma and discrimination, the sensitivity surrounding HIV-related information is higher than for other medical data. As a result many governments have passed laws to protect confidentiality in the workplace as well as anti-discrimination legislation, and organizations have similarly formulated and implemented HIV and AIDS workplace policies. In such a policy, confidentiality should be widely defined to include information that identifies an individual or raises a suspicion that the person:
• is or may be infected with HIV, or have AIDS or any HIV-related condition;
• has undergone an HIV test;
• is or has received therapy that suggests that the person may be HIV-positive;
• has been asked or advised to have an HIV test, or received counselling about testing;
• has engaged in behaviour that could put the person at risk of contracting HIV; and
• is or was an associate of another person with HIV/AIDS, e.g., a partner.

The issue of HIV-positive clergy is difficult for churches. While Canon Gideon Byamugisha, Uganda was supported by the Anglican Church (see box 20); other churches may not be so supportive. For example, His Holiness Abune Paulos, Patriarch of the Ethiopian Orthodox Church, replied, when questioned on what would he do if you found a priest in your Church was HIV positive, First of all we would sympathise and we would be ready to help him, to assist him, but he would be relieved of his post and offices because he has been out of line. So he would be relieved and taken care of and the congregation will be told, will be instructed, will be orientated. I would treat him like any other one. I am against stigma and discrimination. With regards the Catholic and Methodist churches, there is no comprehensive or public statement on priests living with HIV.

Thus confidentiality for clergy is an issue within some churches, and how churches respond to HIV-positive clergy is a test of a church’s commitment that “the church has AIDS” and all that this entails.

Box 18 below “The Church of Scotland – implementing a HIV workplace policy” provides insight into the processes and challenges of developing a HIV workplace policy for a church. Box 19 “Suggested confidentiality clauses in a HIV/AIDS workplace policy” provides specific wording for clauses concerning confidentiality in a HIV workplace policy.

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**Box 18: The Church of Scotland – implementing a HIV workplace policy**

The Church of Scotland committed in 2002 to supporting an HIV/AIDS project to raise awareness and offer practical support to partner churches. However, this was perceived as having a largely overseas focus and the Kirk’s (church) administrative headquarters had no reference to HIV in its Employees’ Handbook (in common with many Scottish employers).

The Kirk employs 260 people in Edinburgh, Scotland, through its Personnel Department. The Employees’ Handbook contains a variety of policies and procedures, some as required by law. A Staff Association represents the interests of the staff, though is not a negotiating body. Most of the staff are not unionized.

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148 Interview with Ethiopian Patriarch, Abune Paulos, on HIV/AIDS. Published by UN Integrated Regional Information Networks, 8 May 2003.
http://www.orthodoxnews.netfirms.com/Interview%20With%20Orthodox%20Church.htm

149 Communication with Nigel Pounde, HIV/AIDS Project Co-ordinator, Church of Scotlandhivaids@world-mission.org
It was recognized that if the Kirk was to demonstrate its commitment to addressing HIV/AIDS and seek to offer leadership, then it must display accountability by offering best practice as an employer. However, the particular structures of the organization and its modus operandi indicated that there would have to be considerable give and take on what could realistically be included in a HIV workplace policy and also how quickly this might be achieved.

The HIV/AIDS Project Coordinator first had informal conversations with both the Staff Association and Personnel Department. This led to broad agreement that an HIV policy supported by the offer of training/information would be relevant and desirable. Both the Personnel Department and the HIV/AIDS Project Coordinator researched examples of United Kingdom best practice in HIV workplace policy before a succession of drafts were discussed. After several months a final draft was agreed in committee and issued to all staff. However, this lacked the clear commitment to providing training and information recommended by the HIV/AIDS Project Coordinator.

Churches as major employers should ensure accountability to PLWHA by acting as role models to other employers by developing HIV policies; while recognizing the particular constraints in their structures, which may influence the final shape and delivery of any such policy.

Box 19: Suggested confidentiality clauses in a HIV/AIDS workplace policy

1. Churches must encourage a supportive work environment in which employees, volunteers and ordinands can discuss HIV/AIDS openly, including their own experience living with HIV/AIDS. Where employees, volunteers and ordinands disclose that they or their spouse and/or dependents are living with HIV/AIDS, the confidence will be respected. Disclosure under all circumstances will be treated as shared confidentiality between the parties, unless expressly stated to the contrary. If there is any doubt, the person living with HIV/AIDS should be consulted before further disclosure takes place.

2. HIV-related information concerning prospective ordination candidates or employees or volunteers, or current employees or volunteers or any of the above mentioned people’s spouses and/or dependents will be kept strictly confidential.

3. Employees and volunteers working for churches as well as ordinands shall sign a confidentiality agreement, and shall be informed that the unauthorised disclosure of HIV-related information is a disciplinary offence. It may also lead to legal proceedings against the person who disclosed the information and the church.

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One of the paradoxes of HIV- and AIDS-related discrimination is that these will only be reduced if the epidemic becomes humanized as opposed to a medical or development problem. While confidentiality is important; ultimately PLWHA need to ‘breach’ their own confidentiality. What was originally a form of protection overtime becomes a prison. Not only can openness about HIV status lead to increased opportunities for care and support; personnel growth comes from accepting a HIV diagnosis, which includes being open with family and friends about your HIV status and perhaps even more generally. It is accepting AIDS as part of life.

Involving PLWHA in AIDS responses has proved extremely valuable. The example of Canon Gideon, who has worked nationally in Uganda and internationally to counter HIV-related stigma has helped in opening churches to the reality of HIV/AIDS. Box 20 below outlines Canon Gideon’s work as well as the support he has received from the Anglican Church.

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**Box 20: Canon Gideon Byamugisha – the Anglican Church stands behind its pastors**

In 1992, Canon Gideon Byamugisha, a Ugandan Anglican priest, stunned his fellow clerics and parishioners when he revealed his HIV-positive status. Canon Gideon is believed to have been the first religious leader in Africa to make public his HIV-positive status at a time when churches were consumed by denial about the phenomenon.

A teacher by profession and a pastor by calling; Canon Gideon left his teaching job at Bishop Tucker Theological College, Uganda to start the Church of Uganda Provincial HIV/AIDS Program as Educator/Trainer under the leadership of the Rev. Sam Ruteikara in 1993. He later joined The Diocese of Namirembe under The Rt. Rev Bishop Samuel B. Ssekkadde and headed the Diocesan HIV/AIDS Programmes, 1995–2002, before joining World Vision International where he now serves the HIV/AIDS Hope Initiative Team as Church/FBO Partnerships Advisor.

Now he travels the world and is serving as a global role model and urging churches in Africa to help develop the right attitudes, skills, services and supportive environment to roll back the pandemic. Canon Gideon, as a resource person, has supported churches, faith-based organizations, PLWHA, NGOs and UN Agencies in Botswana, Benin, Burkina Faso, Burundi, Cameroon, Democratic Republic of Congo, Ethiopia, Finland, Germany, Haiti, India, Kenya, Malawi, Namibia, the Netherlands, Nigeria, Norway, Rwanda, Senegal, South Africa, Swaziland, Sweden, Switzerland, Tanzania, Uganda, United States, United Kingdom, Zambia and Zimbabwe to break the silence, the stigma and inaction associated with HIV/AIDS. He is a founding member of ANERELA+.

The story of Canon Gideon, is also the story of a Ugandan Anglican Bishop, who listened and used his institutional position to welcome an HIV-positive priest and gave him a role in the response to HIV/AIDS. This breaking of stigma by Canon Gideon’s Bishop had a massive impact not only in Uganda and across the continent.
but within the Anglican church and worldwide. This is not the story of “one individual maverick” but institutional collaboration and support of PLWHA as evidenced the installation of Canon Gideon as Canon of St. Paul Cathedral, Namirembe, Uganda, in 2001 and as Canon of Holy Cross Cathedral, Lusaka, Zambia, in 2003.

Creating the environment for PLWHA to disclose their status requires recognizing a range of needs. Many programmes depend on the commitment and courage of HIV-positive individuals. An HIV diagnosis for many people is already a life-changing event causing shock, grief, and a sense of loss of control over one’s life. Disclosing one’s HIV-positive status can be traumatic, even under the best of circumstances. Doing so publicly – as many HIV-positive activists have – is never easy, even when done with the support of the organizations in which they are active. Many United Nations, governmental and NGO initiatives around the world encourage such disclosure in order to prevent further spread of the virus, but they often fail to help PLWHA prepare for it, and do not provide adequate support for the ongoing work that activists do.

Boxes 21 to 23 illustrate methods and initiatives for putting a human face to the HIV epidemic and harnessing the positive views many PLWHA have of living with HIV. It should be noted that such initiatives expressly require PLWHA to be open about their status – to breach their own confidentiality. In addition to the projects described in the boxes, World Vision has produced a leaflet, "Telling Stories", which consists of nine church leaders whose lives have been deeply and personally affected by HIV/AIDS telling their stories. In a similar vein is the book by the Very Reverend Colin Jones, *African Tales for Canterbury*, (2002).

**Box 21: Putting a face to the HIV epidemic – photographs of PLWHA**

One of the most successful strategies in destigmatizing HIV/AIDS is someone saying, "I am HIV-positive". This humanizes the epidemic. Talk shows, television, magazines have been used throughout the world to effect this. There is always a danger for the person who 'comes out' in that he or she might be prepared for the media attention or the reaction of family, friends and colleagues. People who take this step need support. However, in terms of destigmatization of the HIV epidemic there always needs to be a first.

Another successful medium for this process has been books published by PLWHA.

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151 [http://www.chaa.info/index.htm](http://www.chaa.info/index.htm)
152 These stories were commissioned by the POLICY Project, South Africa. They were first read by the author to the Primates of the Anglican Communion in Canterbury in 2002. They are based on the lives of South Africans living with HIV and AIDS. Some names and facts have been fictionalized by the author so as to respect the wishes of those who shared their stories and to endeavour to locate them within the rich cultural and social context of South Africa.'

Copies are selling at US $5.00 each obtainable from:
The CPSA HIV and AIDS Office
1 Braehead House
Kenilworth 7708
Cape Town.
South Africa.
showing the various faces of HIV in a society and sometimes with texts written by PLWHA. Examples include:

- People Living with HIV, Ukraine\(^{153}\),
- De Frente a la Vida, Mexico, 2004\(^{154}\),
- Living Openly HIV positive South Africans tell their stories.

Churches could adapt this concept locally, nationally, regionally or globally using photographs of people in the churches who are responding to HIV and AIDS with name, age and a text from the heart. There are two possibilities:

1. PLWHA who are part of the church either as ministers, volunteers, members of the congregation.
2. People from the church hierarchy embracing/standing with PLWHA.

To ensure that the book reflects the epidemic, people of different ages, sexes, races etc should be portrayed.

Another option is to use the same concept to make a calendar – something people see each day.

A further option is a photograph exhibition. In Thailand, in 1999, *My Positive Life*, a photograph exhibition captured the faces of people with HIV and AIDS, showing they are capable of leading an ordinary life – and feeling happiness and despair – just like everybody else. The exhibition was displayed in prominent, public areas such as department stores in Bangkok and Chiang Mai.

\(^{153}\) Copies can be obtained from: Central office of All-Ukrainian Network of PLWHA Mezhygorskaya Str. 24b, Kiev, Ukraine, 04071.
Contact person Nataliya Kovnir. Tel: (38044) 416-1274, 416-69-89, office@network.org.ua, http://www.network.org.ua
\(^{154}\) www.policyproject.com
Box 22: Putting a face to the HIV epidemic - Ambassadors of Hope

One reason for partnering with PLWHA is to show the human face of the epidemic, so promoting understanding and combating stigma. PLWHA organizations have long recognized the power of this, and the Network of African People Living with HIV/AIDS (NAP+) has for some years had an Ambassadors of Hope programme that specifically uses putting a human face to the epidemic.

The IFRC Regional Delegation Nairobi (RDN) recognized the value of this in promoting the IFRC/NAP+ partnership and building up much needed skills among PLWHA. A workshop was organized as part of the joint training initiative between RDN and NAP+.

This was held in Pretoria in September 2002, with a number of Ambassadors of Hope and five Red Cross National Societies (Eritrea, Ethiopia, Kenya, Tanzania, Uganda). Participants came from Botswana, Eritrea, Ethiopia, Kenya, Lesotho, Malawi, Mauritius, Namibia, Rwanda, South Africa, Swaziland, Tanzania, Uganda, Zambia and Zimbabwe. Funding and technical assistance were provided by UNAIDS, the IFRC and the Cape Town-based Policy Project. Staff and volunteers from the IFRC who are living with HIV/AIDS joined members of NAP+ and were trained as Ambassadors.

The aim of the workshop was to train potential ambassadors for future missions. Existing ambassadors shared their experiences and lessons learnt from previous missions, and participants received training in policy formulation and advocacy, public speaking and other communications skills, and media relations. The workshop also intended to enhance the greater involvement of PLWHA in IFRC activities, to promote networking and the GIPA principle, and to prepare them to be major actors in the IFRC’s campaign against stigma and discrimination.

During the workshop, strategies were developed for joint Ambassador of Hope missions to strengthen advocacy and networking for stigma reduction. Ambassadors visit countries to support PLWHA, helping them where necessary to form support groups, to promote care and treatment, and to sensitize and lobby governments, National AIDS Commissions/Councils and other influential groups to respond effectively to the epidemic. Following the workshop, Ambassadors of Hope went on mission to work with National Societies and to develop partnerships between them and associations of PLWHA.

In a similar vein, the African Network of Religious Leaders living with or personally affected by HIV and AIDS (ANERELA+) and the Churches United against HIV and AIDS in Southern and Eastern Africa (CUAHA) are working together on CUAHA’s Ambassadors of Hope Programme. The Programme has run media workshops in Dar es Salaam, Tanzania, March 2004 and in Mbabane, Swaziland, September 2004, aimed at informing journalists and clergy of the role that they have in destigmatizing

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HIV and AIDS including sensitization on language use. CUAHA provided support and ANERELA+ provided expertise. The two organizations’ goals are the same: providing support and positive role models for PLWHA. In addition, CUAHA provides exposure for various ANERELA+ members, which builds these individual’s capacity. The first CUAHA video, “Ambassadors of Hope”, was launched in Dar es Salaam, on November 30, 2003. The video is available in English and Swahili. Contact Maria Owen info@cuaha.info.
Box 23: World Vision International - HIV-positive lives

The Latin America and Caribbean Regional Office (LACRO) of World Vision International published a major new study on HIV/AIDS in Latin America and the Caribbean; entitled: "HIV-positive lives". The study is available in English, Portuguese and Spanish.

"HIV-positive lives" (published under the title "Acercandonos" in Spanish) presents the diverse stories of 28 individuals in 14 countries of Latin America and the Caribbean who are either living with HIV and AIDS or reaching out to those who do. Their personal stories reveal the deeply rooted stigma and prejudices surrounding HIV and AIDS, and their foundations in myths that perpetuate ignorance, indifference and fear. Yet these stories are for the most part positive - transitioning from times of profound crisis and loss into phases of recovery, hope and newly found purpose.

Each of the 14 chapters focuses on a particular myth about HIV and AIDS and its relationship to the lives of the people who have been interviewed and photographed for this book. Finally, an Epilogue presents World Vision's strategy in responding to HIV and AIDS, with a call to action.

The publication is a joint initiative of LACRO Communications and HIV/AIDS programme staff in all 14 National Offices of the LAC region, with four key objectives:

- Raise public awareness about the myths, realities and responses surrounding HIV and AIDS
- Promote discussions on HIV- and AIDS-related stigma and discrimination
- Give a voice and communicate hope to those who are infected, affected and marginalized by HIV and AIDS
- Raise funds for care and prevention

Due to budgetary constraints, a limited number of copies are available for international distribution. However, at least a few copies can be provided in English, Portuguese and Spanish should you request them. For hard copies, please write to: Kevin Cook

World Vision
Communications Director, Latin America & Caribbean Regional Office San Jose,
P.O. Box 133-1200
Curridabat, San Jose
Costa Rica
Tel.: (506) 257-5151, ext. 114
kevin_cook@wvi.org

Ramon Soto ramon_soto@wvi.org

World Vision International provides copies in CD format (high-resolution) at http://www.wvi.org/wvi/publications/publications.htm
What churches can do:

- Educate about HIV and AIDS as this is an important component in getting a church and its members to understand that due to the prevailing stigma, confidentiality is important and, in some contexts, vital for the survival of PLWHA and their families.
- Protect the confidentiality of a person who tests positive for HIV, including shared confidentiality.
- Where they have not already done so, churches and faith-based organizations should develop confidentiality policies as part of broader workplace policies.
- Acknowledge that confidentiality is necessary due to the stigma and discrimination surrounding HIV and AIDS. However, churches should be working for eradication of stigma and the day that confidentiality of HIV status is no longer required.

Confidentiality is not an end in itself and must not be an end in itself. The ideal towards which all work is aimed is a world where confidentiality will not be necessary anymore, as people will not be discriminated against on the basis of their health status. A time when we will all suffer and rejoice together as the body of Christ.

For churches, the promised land in the HIV/AIDS era is the capacity to dismantle the power of HIV-related stigma through identifying itself as “an HIV-positive church” which is labouring for its own healing. In this promised land of zero tolerance for HIV-related stigma, social, spiritual, emotional and indeed physical healing will occur. Working with PLWHA organizations and seeing the face of Christ in all PLWHA will enable this goal.

4.4 Tokenism

‘Token’ is defined as hollow, minimal, nominal, perfunctory, superficial, symbolic. When PLWHA participation is not meaningful, this is referred to as tokenism.

Meaningful involvement does not mean having one or more HIV-positive individuals attending meetings or being present at events. Instead it means participating meaningfully, which involves having a number of appropriately skilled representatives of PLWHA networks and groups actively engaged. It is about each PLWHA member recognizing and being confident in the value of their contribution and it is also about their contribution being valued by others. In addition, these representatives need to be supported by, and work with, members of the networks and organizations that have nominated them to articulate the organization’s views.

The issue of tokenism has haunted the response to HIV over the past two decades. In the early days of the epidemic, gay men fought for seats at the table with government. This fight continues today. Many pay lip services to the notion of the involvement of PLWHA yet reality often does not meet expectations. There is no other single, simple way of destroying a partnership than if PLWHA feel that they are being used and only
present to sign documents, sit on a podium and be quiet, or stand next to someone ‘important’ for a photo shoot.

Steps to prevent tokenism:

- Public commitment through declarations, press and other public events etc. by churches and faith-based organizations to the involvement of PLWHA including in programme and project design, implementation, monitoring and evaluation as well as the development and implementation of a HIV workplace policy.
- PLWHA representation on governing and executive Boards. This is an example of commitment translated into action. Being part of top level decision making will hopefully ensure that PLWHA views and needs are listened to and incorporated in decision making.
- Providing full documentation in an appropriate language so that PLWHA can participate fully and effectively. Such practical issues require consideration as some PLWHA may have only a poor or moderate grasp of official languages, and can be effectively excluded from effective involvement if materials are not in an appropriate language.
- Consider affirmative action in terms of a specific number or percentage of seats or positions for employment of PLWHA. This can be controversial but guarantees PLWHA representation.
- Providing support to PLWHA organizations and capacity building for PLWHA. See section 4.7
- Anonymous questionnaires are one way of assessing how PLWHA see their involvement and may be a useful method for encouraging critical feedback.

A number of churches and faith-based organizations have stated their commitment to the involvement of PLWHA in declarations and policy statements. For example:

- The All Africa Conference of Churches, Mukono - Kampala Declaration stated: We therefore recommend that protect, support and involve the marginalized and most vulnerable in society such as youth, women, people living with HIV/AIDS and the people with disabilities.\footnote{All Africa Conference of Churches, \textit{Mukono - Kampala Declaration}. Mukono - Kampala, Uganda, 15–17 January 2001.}
- The All Africa Conference of Churches in The Dakar Declaration stated: Considering the seriousness of the HIV/AIDS pandemic, we recommend that the churches in Africa involve PLWHA in the planning and implementation of HIV/AIDS activities.\footnote{All Africa Conference of Churches. \textit{The Dakar Declaration}. Dakar, Senegal, 23–25 April 2001.}
- The Plan of Action developed for the Ecumenical Response to HIV/AIDS in Africa a joint undertaking of African churches, northern churches and agencies, and the WCC stated, “We will ensure that people living with HIV/AIDS are supported so that they may be actively involved in all activities of the churches, as an essential resource: especially in areas of work which relate to education, training, prevention, advocacy, theological reflection and
program development”158. The Ecumenical HIV/AIDS Initiative in Africa (EHAIA) established in 2002 has been strengthened by the involvement of PLWHA organizations and networks in governance and planning. Canon Gideon Byamugisha, a PLWHA, is part of the Reference Groups, which guide the initiative both internationally and sub-regionally in Africa. The four Regional Reference Groups also have PLWHA representation: Central Africa: Marianne Djamba, Kinshasa, Democratic Republic of Congo (DRC); Eastern Africa: Rose Njeri, Nairobi, Kenya; Southern Africa: Lynde Francis, Harare, Zimbabwe and Japé Heath, Johannesburg, South Africa; and West Africa: Samuel Williams, Freetown, Sierra Leone. All are members or part of the leadership of a PLWA networks.

- The Christian Conference of Asia stated: “The church at all levels, international, regional, national and local, has an important role to play in encouraging equal participation of PLWA in planning and delivering HIV/AIDS programs and services”159.

- The Consultation on An Ecumenical Agenda to combat HIV/AIDS in South Asia suggested one of the actions to counter stigma and discrimination is to involve PLWHA in program planning, implementation and management160.

- The Symposium of Episcopal Conferences of Africa and Madagascar stated “…faithful to our Gospel convictions, with you we commit ourselves to promote closer partnerships with civil society, the business sector, governments, the United Nations, international and intergovernmental agencies, and particularly with organizations of people living with HIV and AIDS, in order to increase the capacity for care and support, without diluting our evangelical convictions” and “in shared responsibility with you, we commit ourselves to encourage people living with HIV/AIDS or affected by it to become actively involved, in our local communities, as resource persons in the struggle against the pandemic”161.

- The Indian Catholic Bishops released a Pastoral Letter for World AIDS Day 2003, stating:

  o 10. We need to acknowledge that people living with HIV/AIDS continue to contribute to their family and society. They are to be reassured of the value of their lives, their worth in the larger society and the positive contribution they can make to further enrich it. Persons living with HIV/AIDS are to be part of the planning and decision making process of the interventions162.

- The Lutheran World Federation and the United Evangelical Mission stated: “Realizing that our pastoral care, our ministry and diakonia have so far failed...”

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161 Symposium of Episcopal Conferences of Africa and Madagascar, The Church in Africa in face of HIV/AIDS Pandemic: Message issued by Symposium of Episcopal Conferences of Africa and Madagascar (SECAM), Dakar, Senegal, 7 October 2003

to adequately address the needs in relation to the HIV/AIDS pandemic, we commit ourselves to:

- Urge and assist local congregations in planning, implementing, monitoring and evaluating programs addressing HIV/AIDS pandemic. People living with HIV/AIDS should be involved in the whole process. This may include income generating projects for and by people living with HIV/AIDS;
- Establish peer support groups of/for people living with HIV/AIDS & family for caring and sharing;
- Support legal advocacy for people living with HIV/AIDS.

Knowing that only through education and prevention we can curb the spread and effects of this pandemic, we commit ourselves to:

- Reach out to people living with HIV/AIDS to learn from their testimonies and stories through workshops and field trips163.

• The Regional Meeting facilitated by the Latin American Council of Churches (CLAI) and supported by the WCC stated:

  - 9. In accordance with the signs of the times that we have shared at this CLAI/WCC meeting, people living with HIV/AIDS, in all situations and circumstances, represent both an opportunity and a challenge for the pastoral ministry of our churches today.
  - 10. We recognize that this situation does not only affect the people who are living with HIV/AIDS, It also affects all people right across the world. It is, therefore, imperative to announce prophetically the responsibility of church and society to work in solidarity, so that, as one, we can take on the task required by the situation. It is our duty to ensure respect for the human rights of all people living in this situation164.

• The World YMCA stated in March 2004, “Therefore, the YMCA around the world hereby commits itself to ensure the involvement of people living with HIV and AIDS in every aspect of programme planning, execution and evaluation”165.

• The United Evangelical Mission’s Anti HIV/Aids Programme Policy states that People who live with HIV and Aids are central in Aids programmes. Therefore, churches should endeavour to involve them actively in all stages of their programmes. Where wanted and possible, people living with Aids should be offered capacity building for this (in Africa e.g., through the organisation ACCLIWA+)166.

More importantly is putting such commitments into action. For example, in the Norwegian Church Aid (NCA), Global Strategic Plan for 2005-2009, it is a clear

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164 Regional Meeting facilitated by the Latin American Council of Churches (CLAI) and supported by the World Council of Churches (WCC), The Church and HIV/AIDS in Latin America and the Caribbean, Panama City, Panama, 27 January–1 February 2004.
166 United Evangelical Mission, Anti HIV/Aids Programme Policy, Adopted by the UEM General Assembly in Manila, October 2004. see 4.8. Involving people living with HIV or Aids.
policy guideline that GIPA is to be prioritised in programme and policy development, implementation and evaluation. This new policy guideline is a direct result of the experiences and learning processes we have undergone in cooperation with networks and organizations for PLWHA.167

Box 24 “Project guidelines and minimal criteria” describes how the involvement of PLWHA can be integrated into project design by making it a requirement or a criteria of faith-based organization’s support for projects.

<table>
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<th>Box 24: Project guidelines and minimal criteria168</th>
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The AIDS Funding Network Group and Caritas Internationalis seek to encourage holistic programmes which:

- include prevention, care, and advocacy, and collaboration and networking;
- work to address the psychological, spiritual, social, economic, pastoral and health needs of people affected and infected with HIV;
- aim to prevent stigma and discrimination by breaking the silence around HIV and AIDS, defending human rights and seeking to achieve justice.

These guidelines and minimal criteria are a guide to enable decisions to be made about which HIV projects and programmes to fund, often within a context of limited resources. They outline five key principles, four basic and minimal criteria and three major areas which will be considered for funding.

Programmes need to be working towards the following five key principles:

- The Involvement of people living with HIV in programme planning, implementation and evaluation
- Gender-sensitive perspectives
- Being Community-owned/led at all stages
- Mainstreaming within other pastoral, development and humanitarian activities
- Collaborative working as part of a multi-sectoral response

Four basic and minimal criteria will be applied in the assessment of all HIV project

167 Communication with Anne-Marie Helland, Special Advisor, Dept. for Advocacy and International Development Policy Norwegian Church Aid, anne-marie.helland@nca.no See also Norwegian Church Aid. HIV/AIDS, A policy statement from Norwegian Church Aid. Approved by NCA Board 29 September 2003.

proposals:

- HIV projects must respect human rights provide objective, scientifically accurate, non-judgmental and non-discriminatory information and services.
- HIV project proposals must as far as possible help to create and to strengthen indigenous coping mechanisms which will be characterised by self-help and community involvement, including involvement of people living with and affected by HIV.
- HIV projects should have clear objectives, activities and appropriate change indicators as a means of monitoring application of these criteria over the life of the project.
- HIV project proposals must not stand alone but relate appropriately to existing development and/or health activities.

Three major areas that qualify for funding

- Care and support.
- Advocacy, human rights and networking for example, empowerment programmes for people who are HIV positive and persons with AIDS directed towards the improvement of their quality of life, including access to treatment for opportunistic infections ARVs and vaccines.
- Prevention for example, education and empowerment programmes by and for people who are living with HIV and AIDS directed towards the improvement of their quality of life including access to treatment for opportunistic infections, and ARVs.

In practice these guidelines mean, for example, that the programmes the Catholic Agency for Overseas Development (CAFOD) supports in countries such as Nicaragua, Cambodia, Rwanda, Serbia and Albania, involve education and prevention as well as care for PLWHA. These programmes involve PLWHA as active participants and not only receivers of services and care.

See http://www.cafod.org.uk/about_cafod/what_we_do/hivaids
4.5 Exploitation

Covenant 5: Poverty and HIV/AIDS\textsuperscript{169}

We shall remember, proclaim and act on the fact that the Lord our God, who created all the resources of the earth, blessed both women and men and gave them the resources of the earth for their sustenance (Genesis.1:28–29). We shall, therefore, work to empower all the poor and denounce all the cultural, national and international structures, laws and policies that have condemned billions to poverty thus denying them their God given rights and, in the HIV/AIDS era, exposing them to infection and denying them quality care and treatment.

The presence of people openly living with HIV in the workplace shows it is possible to go on living and working normally, a critical first step in successfully dealing with work-related discrimination.

Often PLWHA do not get paid for caring for supporting other PLWHA, or for providing services or advising organizations. HIV-positive African women taking on activist roles have faced enormous challenges. They are frustrated over the pressures they encounter to disclose their status as part of prevention campaigns, while their own financial, medical and emotional needs are ignored. The commitment and volunteerism of PLWHA has also been exploited by NGOs and government programmes that use this cheap or free labour in place of health-care services.\textsuperscript{170}

Steps to prevent exploitation:

- Volunteer work which should be properly remunerated in cash or kind, where possible, and acknowledged.
- Payment for providing services or time taken to attend meetings
- Direct support to organizations including financial support and providing capacity building. See section 4.7.
- Support for travel and accommodation costs, if necessary.
- Development and implementation of workplace policies, which cover volunteer work.

Payment for volunteer work can be a very sensitive and delicate issue. In an ideal world where every country and church has money, this would not be debatable. However, in many countries, especially in Africa, home-based care, care of orphans care etc. are dependent on women volunteers and most governments, churches, projects and programmes cannot pay these women.


\textsuperscript{170} Manchester J. Hope, involvement and vision: reflections on positive women’s activism around HIV. 2003 (in press).
Voluntary work is a cherished principle within churches, which over many years has enabled churches to take on a heavy burden of care and support in societies, particularly those where few other institutions are operating. Payment for voluntary work has the potential to erode this principle, particularly, if people demand payment for all and any work. A recent example of a trend, which is destroying voluntary work, was the refusal of people to attend a meeting on HIV and their churches unless they were paid the United Nations per diem rate.

If payment for volunteer work is made mandatory, there will be a great suffering and neglect of many PLWHA. Furthermore, PLWHA not only can provide voluntary service, but are, or perhaps will be, receiving it. While cash payment may not be possible, payment in kind such as food may be an option.

Another challenge to paying volunteers is the fact that most donors refuse to include money for paying workers. Churches can advocate with and challenge donors to change their operating procedures. The restrictions by donors on providing resources only for a project itself and not to pay workers/consultant/volunteers are a matter of a mindset on the part of donors.

When people have been trained as a volunteer and acquire skills, they often become employable. “Often Church projects become aware that they have trained volunteers and carers who move on elsewhere, perhaps to formal employment, or to a position in a government setting where there may be remuneration for what had been done voluntarily before. This loss of trained people is an expense the Church can ill afford in its programmes, but nonetheless the training becomes an asset in another setting, and the Church’s impact is more widely felt”171.

One of the limitations of working with and through the church is that the church is a non-profit making organization, which often has no money, although this depends on the country and the church. While some churches can not afford to pay; some churches, which can afford to, will not pay volunteers because this is a long standing tradition that church work is not for pay, for it is done to and for God.

**Discussion**

Should your church pay PLWHA volunteers?
If yes, how? In cash? In kind?
How can your church raise funds to pay PLWHA to avoid exploitations?

**4.6 Practical Issues**

**Health Care**

Churches and faith-based organizations provide enormous quantities of health-care service delivery throughout the world, including for HIV and AIDS. However, in

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developing countries, despite lower prices for antiretroviral (ARV) drugs and initiatives such as WHO “3 by 5” (three million people on antiretroviral drugs by the end of 2005)\textsuperscript{172}; as of June 2004, only some 440 000 people in low- and middle-income countries were receiving antiretroviral therapy.

Access to drugs for both opportunistic infections and HIV treatment is a major, if not the central, issue for PLWHA. The issue of care and treatment for PLWHA has the potential to become a major barrier to the development of partnerships between churches and PLWHA in many countries; since many PLWHA cannot function effectively without these drugs and so cannot sustain their responsibilities in a partnership. Simply put: PLWHA, struggling with their day to day survival, cannot work as needed in an effective partnership. And even where capacity is built this can be lost if a person falls ill and is unable to work or dies.

A first step, for all churches and faith-based organizations is to develop and implement a HIV workplace policy\textsuperscript{173}. In the situation where churches are directly employing PLWHA; the implementation of a workplace policy, including providing medical benefits, is a prerequisite for creating a supportive environment in which PLWHA can work. Developing a workplace policy is a process. Many churches and faith-based organizations as employers may lack an environment and facilities that are necessary for PLWHA such as health care facilities, medical insurance and psychosocial support, and such inadequacies will become apparent during the process of reviewing existing workplace conditions, including health care coverage.

\section*{Covenant 3: Treatment and HIV/AIDS drugs\textsuperscript{174}}

We shall remember, proclaim and act on the fact that the earth and everything in it belongs to the Lord and that He has given it over to all human beings for custodianship (Psalms 24:1 and Genesis 1:29). We shall therefore, openly and persistently undertake prophetic and advocacy role for all the infected who are denied access to affordable HIV/AIDS drugs until antiretrovirals are available to all who need them.

One main benefit to PLWHA organizations of partnerships with churches is that churches are respectable. Whereas PLWHA may be stigmatized and discriminated against in society, churches generally form part of the establishment. Churches can give a voice to the voiceless. Many churches are already deeply involved in care and support and are able to articulate needs. This means that churches have a duty to use their positions of influence to advocate with government and donors on access to treatment including treatment for opportunistic infections and antiretroviral therapy,

\textsuperscript{172} ”3 by 5” is the global target to get three million people living with HIV/AIDS in low- and middle income countries on antiretroviral treatment (ART) by the end of 2005. It is a step towards the goal of providing universal access of HIV/AIDS prevention and treatment services for all who need them as a human right. http://www.who.int/3by5/en/


increased spending on health infrastructure, implementation of a system of home and community care, and increasing the number of medical professionals trained to treat HIV and AIDS.

For example, in his statement to the 2001 World Health Assembly, Cardinal Lozano Barragan, President of the Vatican’s Pontifical Council on Health Care, focused 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.

And the World YWCA Executive Committee in 2002 and 2004 recommended respectively:

As well as programmatic responses, that all YWCAs join and/or initiate networks to lobby for effective, gender sensitive government policies to contain the spread of HIV/AIDS and ensure availability of medicines and care for victims.

That the World Alliance develops a policy framework on the issue of access to treatment for persons living with HIV and AIDS (that will include the contextual analysis, international laws) and possible actions for national movements to undertake.

While universal access to antiretroviral therapy is the goal, some organizations are putting in place stop-gap measures to ensure organizational survival. One example of an innovative effort is the Treatment Fund for HIV/AIDS Advocates in Uganda, which currently provides six advocates with antiretroviral treatment, and is funded by Rotary International, and its Belgian and Ugandan branches. The Fund is co-managed by the PLWHA Forum, which brings together all of Uganda’s relevant networks and associations.

Another fund has been developed by the International Federation of the Red Cross and Red Crescent Societies (IFRC), which established the Masambo Fund in 2003-2004 to provide access to life-saving drugs to National Society staff and volunteers living with HIV/AIDS. This fund is supported by:

179 www.ifrc.org search “Masambo Fund”
requesting all National Societies to raise a voluntary annual contribution using the equivalent of 1% of that Society's statutory contribution (bareme) as a minimum annual fundraising target; and

individual contributions mainly through IFRC staff at the Geneva Headquarters.

The Masambo Fund to date has received funds to support HIV treatment for 40 PLWHA for the coming five years.

While such measures can be controversial as they favour some individuals with skills over other people; in high prevalence countries or areas organizational survival is of real concern, including for churches and faith-based organizations.

Finally, the President’s Emergency Plan for AIDS Relief (PEPFAR) is a new potential avenue for funding for prevention, care, support and treatment. While the programme is heavily weighted in favour of abstinence, it also is seeking to provide antiretroviral therapy for two million people and specifically targets faith-based organizations. Box 25 below “President’s Emergency Plan for AIDS Relief” outlines the basic information on the programme.

Box 25: President’s Emergency Plan for AIDS Relief (PEPFAR)

In January 2003, United States President Bush announced the President’s Emergency Plan for AIDS Relief (PEPFAR), a five-year, US$ 15 billion initiative to turn the tide in combating the global HIV/AIDS pandemic. This commitment of resources is for countries in Africa and the Caribbean (Botswana, Cote d'Ivoire, Ethiopia, Guyana, Haiti, Kenya, Mozambique, Namibia, Nigeria, Rwanda, South Africa, Tanzania, Uganda, and Zambia) as well as Viet Nam to respond against HIV/AIDS. Specifically, the initiative is intended to:

- Prevent 7 million new infections (60% of the projected new infections in the target countries): The initiative will involve large-scale prevention efforts, including voluntary testing and counseling. The availability of treatment will enhance prevention efforts by providing an incentive for individuals to be tested.
- Treat 2 million HIV-infected people: Capitalizing on recent advances in antiretroviral treatment, the PEPFAR will be the first global effort to provide advanced antiretroviral treatment on a large scale in the poorest, most afflicted countries.
- Care for 10 million HIV-infected individuals and AIDS orphans: The initiative will provide a range of care, including support for AIDS orphans.

An example of the size of the funds involved is the grant provided to Catholic Relief
Services, which includes projects supported by Catholic Medical Mission Board and several other organizations. The five-year, US$ 330 million PEPFAR grant is to deliver antiretroviral medications for both treatment and prevention of HIV transmission from mother-to-child.

PEPFAR creates a new emphasis on abstinence-only education, through doubling the funding for abstinence-only programs. This may be a disincentive for some churches or faith-based organizations to apply. Furthermore, the countries eligible are limited, the United States attitude towards generic drugs and obligations to buy from United States pharmaceutical companies is not without problems, and only United States NGOs, churches or companies can receive funds. Nevertheless, many faith-based organizations have been, and will continue to be, recipients of funding under the PEPFAR initiative.


Travel Insurance

Participation of PLWHA at the international level can be hindered by difficulties obtaining travel insurance to cover any HIV-related illnesses while travelling. Churches must face the issue that bringing PLWHA to conferences and other forums might involve costly medical interventions. The more people travel, the more likely they are to become ill due to jet lag, eating at odd hours, lack of sleep etc.

Churches can do several things to keep PLWHA healthy. Firstly, spread the travel between several people, rather than always having the one individual travelling. Also minimize the amount of travel. Many offers to participate in different meetings are received. The question needs to be asked, whether participation is actually necessary. Is it a meeting for a meeting’s sake or will the meeting truly bring concrete results.

Nevertheless, the bottom line is: if a PLWHA cannot obtain travel insurance, churches need to be able to cover medical emergency costs that may arise, if the church is sending the PLWHA on mission.

Travel Restrictions

Since the very beginning of the AIDS epidemic, countries have established travel restrictions in an effort to prevent HIV from crossing their borders. Such measures include mandatory HIV testing for persons seeking entry to the country and the requirement that would-be entrants declare themselves to be uninfected. Based on these mandatory tests and declarations, a number of countries have excluded PLWHA or people suspected of being infected from entry. Restrictions have been imposed upon people wishing to enter the country for short-term stays such as for sport, business or personal visits or tourism, or for longer periods such as for study, employment, refugee resettlement or for immigration.

Depending on the country, normally it is people from developing countries, who need to obtain a visa. The individual may be faced with a question asking if he or she has
an infectious or contagious disease. If a PLWA answers “yes”, then depending on the country, he or she will be denied entry or have to seek a waiver. It is also an option to answer “no”, but if there is a record of the person’s status, that person will be denied entry for life not on the basis of his or her HIV status, but rather for having provided a false declaration on an immigration form. It is a difficult situation.

Steps churches should take:

- When arranging short- or long-term travel or reassignment to other countries for church employees, volunteers and ordinands as well as PLWA travelling for church-related business, the relevant church authority should notify the individual of any legal restrictions on entry for PLWA to the country of final destination or any transit countries.180.
- When HIV screening is required, the relevant church authority must ensure referral to pre- and post-test counselling for the person, and should reimburse the cost for such counselling if it is not otherwise available free of charge.
- Churches should find out what restrictions apply to PLWA entering their country. If there are restrictions, churches should advocate with the government for these to be repealed.

4.7 Capacity Building

Development efforts increasingly recognize the need to support people to decide for themselves what their problems and solutions are, and to find their own voice and means of expression. From this perspective, development is about facilitation and supporting people to develop the skills and capacities they need to organize themselves around their own agendas. As such, capacity building is an indigenous change process and must be initiated and steered by local organizations and communities. The willingness of local organizations and communities to assume responsibility, to make their own inputs and to independently continue and refine the innovations achieved is vital if change processes are to be effective and sustainable. The more actively local organizations and communities participate in defining the goals and measures, and the greater their determination to assume ownership of the changes to be made, i.e. the more closely they identify with measures and the greater their willingness is to continue these on their own responsibility, the more successful change processes will be.

The effective development of capacities presupposes a systematic reflection by participants about the planned change process. When approaching capacity building, an essential first step is to undertake a capacity/needs assessment in order to identify and assess the situation. Questions such as:

- Where are there capacity gaps?
- What sort of interventions can be used to close these gaps?

180 Entry and Residency Regulations For People Living with HIV/AIDS Information on 168 countries, online in English, French and German www.aidsnet.ch/linkto/immigration/. In order to procure the most up to date information the embassy of the relevant country should be consulted.
• How can these interventions be managed and incorporated into existing projects and programmes?

are useful in assessing needs and determining interventions. Furthermore, such a needs assessment provides the baseline data against which capacity building interventions can be monitored and evaluated.


Examples of general approaches to capacity building include:

• Pre-service and in-service training as well as continuing education, including workshops
• Developing and using national or regional consultants
• Targeted technical assistance
• Twinning for training
• Distance learning

Capacity development requires a systemic approach. Traditional capacity building strategies places emphasis on strengthening the performance capacity of individuals and organizations, experience indicates that, depending on the situation, these kinds of measures must also include efforts to increase the accountability, effectiveness and transparency of institutions and policies. However, improved political and institutional frameworks alone cannot make a significant contribution to boosting the performance capacity of individuals, organizations and societies. These need to be accompanied by capacity building measures at the local level.

Capacity building needs a long-term, consistent approach that cannot be sacrificed for short-term expedience or for providing rapid results in order to be able to report “success” stories. Capacities can only be built gradually, over a period of time, and once developed capacities can quickly diminish or be lost if they are not used and nurtured. The long-term nature of capacity building is juxtapositioned with donor requirements. Globally, donor funding policies tend to be geared towards donor priorities and short-term interests, and are further subject to change due to shifts in priorities. Effective capacity building requires finding ways of convincing a donor or a series of donors of the long-term nature of the work, if results are to be sustainable. Furthermore, effective capacity building means building capacity for local needs rather than for fulfilling donor requirements. For example, complicated reporting requirements by some donors are the responsibility of the donor rather than the local organization. Local organizations should produce financial statements but if a particular donor requires a particular format or more in depth analysis of the data, then the local organization should budget in its proposal for the donor to pay for an external person or organization to do this rather than build capacity within its own organization to be able to effect this.
Capacity building focuses on the question of how a project or programme changes people, organizations and societies, and what incentives it creates for the participants to maintain these impacts in the long-term. Indicators should be used at all levels to quantify improved performance or the achievement of results (performance and results indicators) or to assess the inputs in terms of their effectiveness in supporting particular performance improvements or the achievement of results. In the final analysis, the only real measure of the impact of capacity building is the benefits to individuals, organizations and local communities resulting from improved performance, resources and structural conditions.

It is generally accepted that capacity needs to be developed in both churches and PLWHA organizations at all levels for running organizations, advocacy work, public speaking, communications, and fund raising for responding to HIV and AIDS. This is especially true for PLWHA networks which are often underdeveloped organizationally, which often makes it difficult for PLWHA to participate in a meaningful way and as equal partners.

Churches

In terms of specific training it would be around trying to understand the crisis and the response to HIV/AIDS and particularly around notions of deserving the disease. Faith leader\textsuperscript{181}

In the Siyam’kela study, the training initiatives, which were reported, tended to focus on sensitizing faith leaders on issues regarding HIV and AIDS. This included how to respond to HIV and AIDS in faith-based organizations in a compassionate and non-judgemental manner, thereby removing the perception that HIV and AIDS is a sin. While the main thrust of the interventions is towards the welfare of PLWHA, there were some awareness-raising interventions in the community, which were not only geared towards specific denominations but targeted the general community\textsuperscript{182}.


http://www.policyproject.com/siyamkela.cfm or http://www.csa.za.org
Resources need to be made more widely available to support awareness raising, training and exchange of experience, including worship, theological/ethical, and sex education materials. Many helpful resources already exist, including good examples of what churches are doing. New resources also need to be developed or collected, and materials need to be translated into local languages. Much of this work can and should be done ecumenically, (for example) in cooperation with the EAA Website www.e-alliance.ch183.

Churches need to build their expertise and experience in HIV and AIDS, and in many cases to formulate a clear strategic plan for a response to the epidemic. While declarations outline a churches commitment and position on HIV and AIDS, including the need for capacity development184, a strategic plan or framework require reflection on what a church can practically do and finances and commitment to make it happen. Some examples of strategic frameworks on HIV/AIDS by churches at the international level include the following:

- United Evangelical Mission, Anti HIV/ Aids Programme Policy, Adopted by the UEM General Assembly in Manila, October 2004.

At the national level, a further step in reaching parishes and people at the community level, there are also examples of strategic plans being developed, such as:

- Church of Nigeria (Anglican Communion), HIV/AIDS Policy, 10–14 November 2003, which is in effect a strategic plan.

The Ecumenical HIV/AIDS Initiative in Africa has set up a HIV/AIDS desks in Geneva and has employed project managers in Kinshasa Democratic Republic of Congo for Central Africa, in Nairobi, Kenya for Eastern Africa, in Harare, Zimbabwe for Southern Africa and in Accra, Ghana for West Africa, in addition to the formulation of policies. A Theology Consultant has been appointed. Similarly, ANERELA+ is developing a regional network of offices with the principle office already established in Johannesburg, South Africa.

Churches also need to build their capacity to meet the challenges of eradicating HIV–related stigma, HIV prevention and exploring issues of human sexuality. Towards this

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183 The Lutheran World Federation, Compassion, Conversion, Care: Responding as churches to the HIV/AIDS pandemic. An Action Plan of the Lutheran World Federation, 18 January 2002

end, the Ecumenical HIV/AIDS Initiative in Africa has a programme for theological training. It focuses on training theological educators to mainstream HIV and AIDS in their programme; and training church leaders on a theology of compassion, gender issues and producing relevant literature. By January 2004, at least 700 theological educators have been trained from all over the continent of Africa; 110 church leaders from central and southern Africa have been trained in a theology of compassion and gender issues. Relevant literature has been produced to provide theological lecturers and church leaders with relevant theological frameworks.

As the World Council of Churches (WCC) and Christian Conference of Asia (CCA) strongly urged churches to be involved in and partners to support need-based interventions. Recognizing the wide reach of Christian congregations through our health and educational institutions, churches are challenged to prioritise capacity-building in order to be fully and effectively mobilised in the response to HIV and AIDS. Capacity-building initiatives could focus on clergy, lay leaders, women, youth groups, and staff of the church institutions and include training in programme management, communication and counselling skills, documentation, monitoring and evaluation, and value-based education. Suggested actions include:

- Advocacy with church leaders and lay leadership in a focused, intensive, time-bound programme aimed at achieving personal commitments, through an advocacy unit to be set up by National Council of Churches (recommended time period of six months).
- Incorporate training on HIV and AIDS prevention and care in the curricula of theological schools and for other church leaders.
- Capacity-building in life skills and responsible behaviour among youth through Sunday school teachers, peer groups, Vacation Bible Schools, and youth group leaders; among women through women pastors, fellowship group leaders, women’s networks in churches; and among men in the same manner and intensity.
- Training of staff of Christian education and health institutions to serve as vehicles for future action in their respective areas.
- Utilisation of the expertise of selected institutions that provide specialised services (e.g. behavioural change communications for risk groups and general population, counselling services, blood screening, care services for PLWHA, drug harm reduction, condom services, STI interventions, etc.).
- Cooperation with government programmes and policies that address HIV/AIDS.

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In the era of increased access to antiretroviral therapy, churches also need to be trained on monitoring (journeying/walking with) people on antiretrovirals and on managing the possible side effects. This helps support adherence to sometimes complex drug regimens; adherence is important in reducing the possibility of the development of drug resistance.

This volume highlights the many challenges and opportunities facing the Catholic Church and its individual members to serve as agents for change, as actors working for solutions with and for those living with the virus and their families. The authors, drawing examples from their fieldwork, illustrate how the Catholic Church and others must take on multiple roles, as educator, health providers, carers, counsellors and advocates. This book is a testimony to the courage of those living with HIV and AIDS whose stories are told throughout the text. It sets out to unite the conceptual underpinnings and the values in Catholic Social Teaching, which inspire the work of CAFOD and Trócaire in relation to HIV and AIDS, with their practical experience of working with partner programmes living with the daily devastation and challenges wrought by the pandemic, exploring the role of various stakeholders from community to global levels.

The book costs £4.50 and available from CAFOD's Resources Department. To order a copy, phone +44 20 7733 7900, or email resources@cafod.org.uk. Single copies will be given free of charge to applicants in developing countries, who are unable to purchase this publication.


188 WHO has developed the human capacity-building plan for scaling up HIV/AIDS treatment, which outlines a strategic plan to support the development, strengthening and sustaining of the workforce necessary to radically scale up and maintain antiretroviral treatment. The strategic approach is based on the understanding that achieving this goal critically depends on joint efforts between communities, countries and international organizations. It builds on the experience of successful capacity-building efforts and harnesses existing expertise to strengthen training capacity at the regional and country level in the context of an emergency response. The proposed plan identifies five elements that are critical for building and sustaining human capacity for the 3 by 5 target at the point of service delivery:

- Making available simple and appropriate training programmes on key competencies for antiretroviral therapy;
- Designing country-specific approaches to training and human resource development;
- Providing targeted technical assistance for rolling out training programmes;
- Developing training certification and quality control mechanisms; and
- Ensuring the availability of sufficient funds for implementing training.

http://www.who.int/3by5/publications/documents/3by5study/en/

189 International HIV/AIDS Alliance, WHO, UNAIDS, Mobilising NGOs, CBOs and PLHA groups for improving access to HIV/AIDS - related treatment, 2002.

http://www.aidsalliance.org/_res/training/Toolkits/Treatment.pdf

WHO. Scaling up antiretroviral therapy in resource-limited settings: Treatment guidelines for a public health approach, 2003 Revision.


Also see http://womenchildrenhiv.org/wchiv?page=cp-01-02 which provides International Antiretroviral Treatment Guidelines and Reports by country and region.


A manual about care and support for people with HIV at home, for health workers and communities, aims to give confidence about people’s own ability to provide safe, compassionate and helpful care to people with HIV.


The needs for capacity building extend beyond what is generally seen as HIV prevention and care. “Often in Church projects the required skills are not directly related to AIDS. Instead what people struggle with, as is often the case in NGOs and community-based organizations, are leadership, management and financial skills. When these are better in place, projects flourish with regard to other enterprises such as vegetable gardening, sewing projects, jam- and candle-making, and various other income-generating activities. … The role of training and capacity building in church projects in leadership and management skills may not be underestimated. The role of the programme coordinator is key and the transfer of skills to others is an ongoing process as new people join”\textsuperscript{190}.

Finally, boxes 26 to 28 provide information on networks and faith-based organizations which specifically provide resources for capacity building ranging from education materials and contact information to the development of educational and training programmes in countries.
### Box 26: Networks: A useful source of resources and contacts


**Christian HIV/AIDS Alliance (CHAA)** is a network of Christian agencies, churches and individuals praying and working together to serve and empower those affected by HIV/AIDS. Most of the organizations are based in the United Kingdom but work all over the world. CHAA exist to facilitate a compassionate, strategic Christian response to the HIV/AIDS pandemic. CHAA recognize the invaluable part that the Christian community has to play in bringing life in the face of death and hope in the face of despair, through servant-hearted advocacy and action. http://www.chaa.info/index.htm

**Global Connections** is the evangelical network for world mission. It is a membership network of mission agencies, colleges, development organizations, churches and others, all committed to world mission, and to working together where possible. Global Connections is primarily a network, but also provide services such as business services, educational resources, world prayer news and has a code of best practice. Global Connections also represents the UK world mission movement, both in the United Kingdom and internationally. Through Global Connections, you can get the contacts, information and services you need, to help you to be more effective in world mission. http://www.globalconnections.co.uk/

### Box 27: AIDS Care Education and Training (ACET) International Alliance

AIDS Care Education and Training (ACET) International Alliance is a rapidly growing global network of independent Christian organizations and church-based agencies responding to AIDS, run and staffed almost in every case by nationals. We are united in a race against time to prevent another generation in African nations and elsewhere being devastated by AIDS, and to provide help to the sick, dying and bereaved.

Member organizations provide sexual health and drugs education, home-based and in-patient AIDS care, housing support, income generation projects, orphan support, bereavement support, professional training and technical advice in communities across many nations on issues relating to HIV/AIDS. An important part of their role is to help mobilise churches of all denominations in compassionate, effective, Christian AIDS action.

ACET Member organizations are found in Uganda, Burundi, Zimbabwe, Thailand, India, Russia, Czech Republic, Slovakia, Slovenia, Ukraine, Croatia, England, Scotland, Ireland, Jersey, Barbados and Guyana with a new Nigeria partnership about
to begin. Work is growing most strongly in countries with low national income and high HIV incidence.

All those who are a part of ACET International Alliance are united in common aims as different expressions of a Christian response to AIDS, working in partnership with government and other national and international organizations including UNAIDS, UNICEF and the World Health Organization.

While most members are exclusively AIDS/sexual health agencies, others include HIV-related issues as part of their work – all working in partnership where possible with local churches of many denominations to serve all those in their locality who need help, regardless of ethnicity, religious affiliation or any other factor.

The principle values of the ACET International Alliance are:

- Compassionate, unconditional care for all who are affected by HIV, regardless of how they come to be so, fighting stigma and discrimination and encouraging acceptance of those with HIV by their communities.
- Life-saving education respecting the historic teachings of the church, encouraging long-term healthy lifestyle choices, seeking to give young people confidence to resist peer pressure, and to find their own way.
- Effective training with a holistic, culturally sensitive approach to personal and community development, strongly encouraging indigenous leadership, emphasising "South to South" or "East to East" knowledge transfer- rejecting the common assumption that "West is usually Best".

ACET International Alliance members have:

- Given practical support to more than 3500 people with AIDS
- Supported over 1000 orphans
- Educated more than one million children in school lessons about sexual health and drug abuse
- Distributed 1.4 million educational resources to teenagers
- Provided 60 000 free books to workers in hard-hit nations
- Given access for a million free online book chapters
- Educated more than 100 000 healthcare professionals
- Provided technical support and advice to a large number of national and international agencies based in more than twenty nations, mostly in the poorest parts of the world.

In addition, more than one million book chapters and AIDS resources have been downloaded from the website / resource area in the last 18 months. http://www.acet-international.com/

Another useful information resource is Faith and Values http://www.faithandvalues.com/channels/aids-hiv.asp
Box 28: The Balm In Gilead’s Africa HIV/AIDS Faith Initiative

The Balm In Gilead is a non-profit, nongovernmental organization with a mission to stop the spread of HIV/AIDS throughout the African Diaspora by building the capacity of faith communities to provide AIDS education, service and support networks for all people living with and affected by HIV/AIDS. For over 15 years, The Balm In Gilead has enabled thousands of faith institutions in the United States to become leaders in HIV prevention by providing comprehensive educational programs and offering compassionate support to encourage PLWHA to seek and maintain treatment.

The Balm In Gilead’s Africa HIV/AIDS Faith Initiative is designed to build a sustainable health education and service delivery system within African faith communities. The goal of the Africa HIV/AIDS Faith Initiative is to increase the capacity of faith communities to become an effective force in the fight against the AIDS pandemic in Côte d’Ivoire, Kenya, Nigeria, Tanzania and Zimbabwe.

The Africa HIV/AIDS Faith Initiative is building the capacity of Africa’s faith communities to:

- Speak out against the stigma of AIDS.
- Educate people about AIDS.
- Support and provide interventions that prevent maternal-to-child transmission of the virus.
- Support and provide faith-based voluntary counselling and testing.
- Provide effective AIDS prevention education to adolescents and youth.
- Develop interventions that support low risk behaviours and seronegative status.
- Provide long-term care and support for people living with HIV and orphans.
- Advocate for people living with HIV/AIDS, including the rights of women, widows and orphans.

The focus of The Balm In Gilead's work includes working with the religious leadership, as well as those responsible for the daily activities of building the infrastructure capacity of each faith organization. The Balm In Gilead identified the following strategic areas:

1. Infrastructure Development
2. Capacity Building
3. Community Mobilization
4. Training and Technical Assistance
5. Assessment/Evaluation
6. Communication/Media

http://www.balmingilead.org/
In these six areas, The Balm In Gilead specifically works to assist its faith partners to:

- Develop and conduct community asset assessments to determine the previous and current levels of involvement in HIV/AIDS related activities and the barriers reducing the participation of faith communities in HIV/AIDS prevention, education and care.
- Develop or strengthen the infrastructure of an HIV/AIDS office within the national headquarters of each faith partner.
- Build the capacity of each HIV/AIDS office within the national headquarters of faith partners to effectively design and support the delivery of HIV/AIDS intervention services through local churches and mosques.
- Develop effective, culturally appropriate, HIV/AIDS education materials for mass distribution through each country’s faith community.
- Develop and implement proven strategies for effective mobilization of the faith community.
- Conduct a series of in-country skills-building training programs to build and support strong HIV/AIDS service delivery networks via local church and mosque communities.

**PLWHA organizations**

In order for PLWHA organizations to operate effectively, capacity needs to be built for running an organization, advocacy, public speaking, communications and fund raising. Involving PLWHA in outreach education, before they receive the necessary training and ongoing support, can have a negative impact on service quality, and can also harm the individuals themselves. A study of 17 NGOs providing HIV and AIDS services in four countries (Burkina Faso, Ecuador, India and Zambia) revealed that failure to account for the needs of HIV-positive people reduced the effectiveness of the services provided\(^\text{192}\).

Within organizations seeking real (and not token) involvement, creating a supportive, enabling environment requires a great deal of thought and commitment. The diversity of PLWHA, their experiences and needs must all be taken into account. PLWHA need training and support so they can participate more actively, and churches need to make their procedures more participatory and accessible to people who may not be used to the customary formality of meetings and other institutional requirements. This is especially necessary if more HIV-positive women and young people – traditionally excluded from decision-making processes – are to be empowered to contribute in a meaningful way.

More formal involvement of networks and organizations of PLWHA (as opposed to informal personal involvement) would also help in implementing the GIPA principle in a sustained manner. The World YWCA and International Community of Women Living with HIV and AIDS (ICW) are building capacity in both organizations by exchanging staff and expertise. In this regard, ICW will be training World YWCA

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http://www.popcouncil.org/pdfs/horizons/plha4cntrysum.pdf
staff on workplace behaviour towards staff and colleagues living with HIV. In addition, a former YWCA intern from Zimbabwe is currently a staff member of ICW and the two organizations plan to continue identifying young women for staff exchange and volunteer roles as well as providing training opportunities through ICW and World YWCA programmes.

The transition from self-help groups to representative organizations has taken place in many countries, creating additional needs to build organizational, management, advocacy, and leadership capacities.

A useful resource underpinning the response of organizations to the HIV/AIDS epidemic is the Code of Good Practice for Non Governmental Organizations (NGOs) responding to HIV and AIDS (the Code). The WCC, and some 30 related networks and member organizations as well as GNP+ and ICW signed the Code at the end of October 2004. Their signature makes these organizations accountable to the norms contained in the Code.

Box 29 below “Positive Development” describes one tool developed to assist PLWHA groups in their formation and in building their capacity. Box 30 “PLWHA Handbook on Participation in the Global Fund Country Coordinating Mechanism” outlines the process of writing a handbook for PLWHA dealing with Global Fund mechanisms, its content and from whom copies can be obtained.

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193 Renewing Our Voice: Code of Good Practice for NGOs Responding to HIV/AIDS
http://www.ifrc.org/what/health/hivaids/code/

Since the mid- to late 1990s, there has been a considerable increase in the number and range of NGOs involved in responding to the multiple challenges presented by HIV/AIDS: NGOs undertaking HIV/AIDS work; NGOs integrating HIV/AIDS-specific interventions within other health programming, such as sexual and reproductive health and child and maternal health programmes; and NGOs mainstreaming HIV/AIDS within development, human rights and humanitarian programming. There have also been significant changes in the global funding environment, particularly in ensuring that the lessons learned over the past 20 years are used to guide the allocation of resources in scaling up responses to HIV/AIDS.

These changes both support and complicate the process of expanding the scale and impact of NGO programmes, so urgently needed. The proliferation of NGOs and programmes has, at times, occurred at the expense of accountability and quality programming and has led to fragmentation of the NGO ‘voice’ in the HIV/AIDS response.

The purpose of the Code is to address these new challenges by:

- Outlining and building wider commitment to principles and practices, informed by evidence, that underscore successful NGO responses to HIV/AIDS
- Assisting ‘Supporting NGOs’ to improve the quality and cohesiveness of our work and our accountability to our partners and beneficiary communities
- Fostering greater collaboration between the variety of ‘Supporting NGOs’ now actively engaged in responding to the HIV/AIDS pandemic, and
- Renewing the ‘voice’ of NGOs responding to HIV/AIDS by enabling us to commit to a shared vision of good practice in our programming and advocacy.
Box 29: Positive Development

As part of the process of self-empowerment of people living with HIV/AIDS, the Global Network of People Living with HIV/AIDS (GNP+) produced *Positive Development: Setting up self-help groups and advocating for change, a manual for people living with HIV*, which was launched in English at the XII International AIDS Conference, Geneva, Switzerland, 1998. Positive Development is a capacity building and self-empowerment tool for the development and maintenance of community-based organizations that provide support and self-help for PLWHA.

Authored by PLWHA from all over the world, “Positive Development” helps people living with HIV/AIDS improve their personal and collective abilities in various interrelated ways. Written in simple language, the manual leads the reader through a series of discussions and interactive exercises. The manual covers the importance, purpose and key features of group work as well as basic guidance on accessing resources and support, and group dynamics. It also provides training on project design, public speaking, communications and media relations, negotiation skills, networking, outreach, advocacy, and monitoring and evaluation.

In 1999, Positive Development was translated into Russian with the financial support of UNAIDS and the technical assistance of Healthlink. UNAIDS also provided financing for the translation and layout of the French, Portuguese and Spanish versions, and the translation, layout and printing of the Swahili version. The International Federation of Red Cross Red Crescent Societies (IFRC) supported the printing and distribution of the Spanish, Portuguese and French versions.

The following translations of Positive Development have been recently completed:

- The Khmer and Vietnamese versions have been completed through a partnership between the Australian Red Cross and local organizations of people living with HIV/AIDS in Cambodia, and Vietnam.
- The Mandarin version has been completed through a partnership between the International Federation of the Red Cross and people living with HIV/AIDS in China.
- The Hindi version has been printed by UNAIDS India and the Indian Network of People Living with HIV/AIDS (INP+) and this collaboration is currently producing the Bengali, Gujarati, Marathi, Telugu, Kannada and Tamil versions.
- The Arabic version was completed by the Egyptian Initiative for Personal Rights, Cairo, Egypt.
- The Basha Indonesia version was supported by UNAIDS Indonesia, AIDS Fonds and Yayasan Spirita.

Currently, the Arabic, Basha Indonesian, English, French, Hindi, Khmer, Mandarin, Portuguese, Russian, Spanish and Vietnamese versions are available online at:
http://www.gnpplus.net/programs.html
GNP+ aims to make the manual available in more languages. In terms of building partnerships between churches and PLWHA organizations, the process of translating Positive Development and holding training workshops is one concrete project which can be undertaken.

The benefits of working on translating Positive Development stretch beyond the content of the manual. It offers the opportunity for participants to build their language skills, to deepen their understanding of the HIV epidemic and their ability to access information, and to learn about the process of developing information, education, and communication (IEC) materials. It also can also have an important role in organizational capacity building by providing additional revenue and improving skills of staff and members in organizational management, planning, and fundraising.

Box 30: PLWHA Handbook on Participation in the Global Fund Country Coordinating Mechanisms (CCMs)

In Cape Town, South Africa, in March 2003, a group of more than 150 treatment activists, including many PLWHA, met for several days at the International Treatment Preparedness Summit in Cape Town, South Africa. Over the course of the meeting it became apparent there was great interest in the Global Fund and widespread anticipation that this new funding mechanism would make a massive difference in the lives of people living with and affected by HIV, TB and/or Malaria. Yet, despite the hope the Global Fund offered, these same people were experiencing difficulties in actually becoming part of this new global partnership or even accessing accurate information about it.

At the Summit, a call was made to document these failures by Country Coordinating Mechanisms (CCMs) to engage in meaningful partnerships with PLWHA communities. Shortly after, the Global Fund commissioned GNP+ to oversee thirteen country studies (Bolivia, Cameroon, Chile, El Salvador, Haiti, Honduras, India, Malawi, Moldova, Nepal, Nigeria, Peru and Ukraine) focusing on the involvement of PLWHA in the CCM process through a series of interviews with key players and stakeholders, including but not limited to the Chair of the CCM, PLWHA CCM members, other CCM members and PLWHA not on the CMM.
The study demonstrated:

- Low levels of understanding about CCM.
- Little understanding of the roles and responsibilities of CCM members, including PLWHA members.
- The need for technical assistance and training, including organizational support for PLWHA organizations and networks,
- The need for easily accessible information related to the Global Fund and CCMs.


These studies had a catalytic effect in many of the countries involved, bringing people together and stimulating discussions about what the Global Fund was and about the operation of CCMs. This put pressure on some CCMs and the Global Fund Board to begin to make changes and initiate reforms.

A follow-up meeting to the study was organized during the 11th International Conference for People Living with HIV/AIDS in Kampala, Uganda, in October 2003, where many of the people who conducted the country surveys came together with other PLWHA to validate the results. Participants at the Kampala Conference agreed there was clearly a need for a guide or manual to assist communities of PLWHA to participate effectively in CCMs.

Over the months that followed, five country consultations (Honduras, Malawi, Nepal, Nigeria and Ukraine) were held, bringing together people who had been involved in the studies along with other representatives from national PLWHA networks, to analyze the role and performance of PLWHA in the CCM process in their country, and based on this, to determine what would be the most useful information for the handbook to include.

On 25 June 2004, the Global Fund Board delegation of Communities living with the three diseases met to review the country reports and discuss the next steps for developing the handbook. A further workshop on 10 July 2004 brought together 20 PLWHA from 18 countries in Bangkok, Thailand, to review the findings from these consultations and make more detailed recommendations for the handbook.

In the past months, the CCM Handbook\textsuperscript{194} has been developed and drafted in a consultative process with PLWHA organizations and networks from all regions. The CCM Handbook covers the history of PLWHA involvement in the Global Fund and the CCMs, information about the Global Fund, meaningful involvement of PLWHA in the CCMs, roles and responsibilities of PLHIV, communication and coordination, and guidelines. The finalized draft is being translated into French, Russian and Spanish and will be used in a series of training workshops. Churches can use the

CCM Handbook as a tool for increasing their involvement in CCMs and provide training for faith-based organizations around the materials.

You can download the CCM Handbook from www.gnpplus.net

Hard copies can be obtained from:
Francoise Welter
The Global Network of People living with HIV/AIDS (GNP+) Central Secretariat
P.O. Box 11726
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Tel: +31 20 423 4114
Fax: +31 20 423 4224
fwelter@gnpplus.net

The Salvation Army has developed another model for capacity building, based, not on groups i.e., PLWHA, but rather on communities. Box 31 below outlines the framework and rationale for this approach which is currently operational in India, Tanzania, Thailand and Zambia.

Box 31: Human capacity development – The Salvation Army

The theoretical foundation for local response is community development. The 'local response' is the integrated experience of PLWHA and others – family, neighbourhood, friends – going well beyond specific groups, which in many places (but not all) is old news.

Human capacity development refers to the nurturing, refinement and application of the potential of people in local relationships and partnerships to respond to stress situations. The context for development is mutual well being, acknowledgement of challenges, and affirmation of strength, including capacity for caring by standing alongside others, capacity for change, capacity for community building, for leadership, and for hope. Such human values, when affirmed, motivate people in local relationships and other community environments to respond in the interest of a shared future. The essence of the community development process allows the participation of 'outsiders', yet strongly grounds response in local community ownership.

195 Communication with Ian Campbell. For more information contact: The Salvation Army. International Headquarters. 101 Queen Victoria Street. London. EC4P 4EP. United Kingdom. Tel: +44 (0) 20 7332 0101 ext: 8080/1, Fax: +44 20 7332 8079, Ian_Campbell@salvationarmy.org. A Memorandum of Understanding was signed between The United Nations Institute for Training and Research (UNITAR) and The Salvation Army in 2004. The purpose of the partnership is to contribute to global leadership on human capacity development (HCD) in response to HIV/AIDS.
Distinctive areas of human capacity that can be developed for response to HIV/AIDS include:

- Care encompassing emotional, spiritual, and physical well being;
- Capacity for change – not only behavioural change;
- Capacity for acknowledgement.

HIV/AIDS insidiously and increasingly exerts impact, which escapes the attention of insiders and outsiders. Failure to acknowledge the accumulating loss leads to suppression of hope and of community memory formation. In contrast to loss of hope and confidence, it is possible for people in local situations to acknowledge fragility, and threat, and at the same time act for the future through utilising existing resources of human capacity and technical support. It has been commonly observed that when relationship-based home care is linked to acknowledgement of group based anxiety that often leads to stigma, then personalised blame shifts to shared concern on issues that affect the wider group. The community exercises capacity for shared confidentiality. An environment is then created which is destigmatising, and in which care and change can be more easily sustained.

Some activities and responses that help develop local community competence include:

- Locally available team approaches to home care, strategically linked to community driven processes of acknowledgment and response, community counselling is a tool for acknowledgment.
- Responses include behavioural change, support, and income generation, along with more assertive efforts to advocate, and to access health care and other support.
- Environmental influences including appropriate technical support, skills training, and helpful legal policy context are also crucial for nurturing knowledge transfer between local responses, and partner organizations.

Elements, outcomes indicators and some example of a globally relevant HIV/AIDS competence are provided in Annex 4 in table form.

All of this means it is essential to provide more funds for capacity-building, financial compensation for work performed, and treatment and psychological support for PLWHA involved in such work. PLWHA networks need support to develop skills in running organizations, advocacy, public speaking, communications, and fund raising – and to reach out to more people. Also membership of PLWHA organizations needs to be much more representative of the society it comes from, building bridges between people with international or national know how and the grassroots. Furthermore, there is a need to support the development of a new generation of leadership to both expand PLWHA involvement as well as to replace people who move on, retire or die from AIDS-related illnesses.

The theme of the 11th International Conference of People Living with HIV/AIDS, Kampala, Uganda, September 2003, *The Dawn of New Positive Leadership*, recognized these needs, the Conference Declaration noting that “Our communities
and organizations are still starved of the resources they need to effectively fulfil their potential and perform the role that is being demanded of us”. The Declaration demanded “That we are supported in our efforts to build capacity to effectively contribute as equal partners in the response”.

4.8 Differing expectations

Expectations of what a partnership can provide are crucial. Part of the start-up phase of a partnership must involve each partner outlining what they want from a partnership. This may change over time so such discussions should happen periodically. In a partnership, communication is essential to ensure that both sides understand what they can offer.

There may be at times a gap between the partners in their hopes and expectations. One of the challenges of a partnership is that it brings together people whose needs and priorities are different. For example, PLWHA need drugs, adequate nutrition and social support for their day-to-day survival, while churches are responding to gospel imperatives. Any partnership that does not directly or indirectly address these needs might not readily receive adequate support from the membership of the different partners.

4.9 Sustainability

The successes of partnerships are often due in large part to the commitment and hard work of a small number of charismatic and visionary individuals. This is not unusual in such pioneering ventures; it is probably the only way they can work. But if a partnership is to develop, become less ‘fragile’ and be sustainable, then it has to become more ‘institutionalised’ and less dependent on a few people. It is also important to build on and expand joint programmes that will keep the partners together and increase the number of people involved.

Partners need to create sustainable approaches and activities that each can incorporate into their day to day response to the epidemic. For example, in the case that the organizations are well set up; the development of joint work plans with specific goals for each partner to achieve provides each partner with measurable objectives against which the effectiveness and contribution of each partner can be measured. This is one way of assessing each partner’s commitment to the partnership.

4.10 Monitoring and evaluation

Monitoring and evaluation is one of the most critical areas for involvement of PLWHA, as it allows those most affected to exercise a voice in programme formulation and review. The central reason for monitoring and evaluation is to determine whether projects and programmes are having the desired impact and outcomes. Also monitoring and evaluation are increasingly important components of project and programme design as donors are requiring accountability for their funds
and a demonstrated impact from the interventions. As such, partners need to focus on these requirements when seeking support and in designing projects and programmes.

**Monitoring** is an on-going activity during the life of a project or programme. It is through monitoring of a project or programme that it is possible to determine what progress has been made in relation to the work plan. Monitoring helps in ascertaining whether the project is on track, and also in determining whether the project needs to make any changes in its strategies or activities so that it can meet its goals and objectives.

**Evaluation** determines how successful a project or programme has been in meeting its objectives, as well as in assessing the impact of project or programme activities on desired outcomes. Project or programme evaluation begins with a baseline survey which is carried out before activities begin. Evaluation concludes after data has been collected at the end of the project or programme and compared to baseline data. When funds allow, some projects or programmes also have mid-term evaluations which occur half-way through implementation.

The conventional approach to monitoring and evaluation is where people who are not part of the community – such as donor representatives or external consultants – are primarily responsible for identifying needs, developing a general project concept, providing money and other resources, then monitoring and evaluating project activities. While it is true that a local community-based organization or faith-based organization or NGO plays a key role in project implementation, with the conventional approach, there is typically limited or very little input from beneficiaries or participants at the initial stages when the project is being developed.

Box 32 “CORE Initiative: Participatory Monitoring and Evaluation for Civil Society” describes a new approach based on participation of communities and faith-based organizations in the monitoring and evaluation process.
Box 32: The Communities Responding to the HIV/AIDS Epidemic (CORE) Initiative: Participatory Monitoring and Evaluation for Civil Society

In its first year, the CORE Initiative began developing a participatory monitoring and evaluation (PME) manual for grantees. The manual, *Participatory Monitoring and Evaluation of Community and Faith-based Programs: A step-by-step guide for people who want to make HIV and AIDS services and activities more effective in their community*, promotes a collaborative learning process that helps community and faith-based organizations make HIV and AIDS services and activities more effective.

A faith-based reflection in the manual makes it appropriate for both faith-based and community based organizations. The development and field-testing of the manual has been a participatory process intended to solicit views, materials, and field-based experience from the community organizations that will use the manual to improve their programming.

Participatory monitoring and evaluation significantly differs from conventional monitoring and evaluation in that the community, beneficiaries, and people involved in design and implementation are involved in the monitoring and evaluation throughout the project’s duration. Both ethically and practically it is imperative to include the voices and views of the people affected by an initiative in the initiatives design, implementation, monitoring and evaluation.

Participatory monitoring and evaluation is a highly interactive approach, which provides staff and community members with a concrete role in the evaluation of their own programmes. In consultation with donors, the communities decide what will be monitored and how the monitoring will be carried out. Together, they analyze the information gathered and assess whether the project is on track in achieving its objectives. Based on this information they decide whether the project should continue in the same direction or if modifications are necessary.

Faith-based organizations are often confronted with reporting requirements beyond their capacity. Faith-based organizations can, however, serve as valuable data collectors. With their wide networks and human resources, and especially large and committed pools of volunteers, they have the capacity to measure and report on their HIV/AIDS project outcomes. In this context, participatory monitoring and evaluation is an ideal methodology for faith-based organizations to monitor projects and report back to their communities and donors.

Faith-based organizations that use the CORE Initiative participatory monitoring and evaluation manual are encouraged and guided to develop “Faith-Informed Indicators” for HIV and AIDS projects. A prototype version for field-testing has been developed for use by community and faith-based organizations and includes information on becoming a contributor to provide feedback and new materials for the manual. The manual can be downloaded at:

www.coreinitiative.org/core.php?sp=evaluation_core#PME
Some Concluding Comments

Covenant 10: Justice and HIV/AIDS

We shall remember, proclaim and act on the fact that the Lord our God, sees, hears, knows the suffering of people and comes down to liberate them (Exodus 3:1–12; Luke 4:16–22). We shall, therefore, declare the jubilee and we shall proclaim liberty throughout the land and to all its inhabitants (Leviticus 25:10), for unless and until justice is served to all people in the world, until justice rolls down like waters and righteousness like an ever-flowing stream, HIV/AIDS cannot be uprooted.

Experience has shown that involving PLWHA in a meaningful way is a core element of an effective response to the epidemic. Strengthening and sustaining this role requires:

- That people know their HIV status (which, in turn, requires vastly increased access to voluntary counselling and testing facilities). Some churches leaders have championed this course by undergoing public voluntary counselling and testing.
- Creating the practical and political space for PLWHA to expand their role and contribution by addressing HIV- and AIDS-related stigma and discrimination; promoting appropriate legal and policy environments; and supporting participation with resources, including capacity development. For churches, the necessity to eradicate HIV-related stigma, through HIV- and AIDS-sensitive liturgy and theology, will underline the inseparable identification of the church with PLWHA. The church is one body of Christ and churches are HIV-positive.
- Keeping people alive with antiretroviral treatment so they can remain active in their chosen fields of work. For churches, this may mean taking an advocacy stance, pushing for access to and affordable antiretroviral drugs for all people who need them. For all people were created in God’s image, and the world and all that is in belongs to God.

Already, AIDS organizations exist in many forms – from support and service-delivery bodies to advocacy and representational organizations. In the face of a long-standing but constantly changing epidemic, the range of these organizations needs to be extended even further. In particular, as more people learn of their HIV status, it means reaching out beyond recognized AIDS networks, to non healthcare settings. Churches have an important role in this by strengthening their own response, destigmatizing HIV and reaching out to PLWHA not just as care recipients but as effective, unique partners. PLWHA organizations and networks are demonstrating their commitment to forging new partnerships; now they need help in order to enhance their organizational capacities and meet these new challenges.

## Annex 1

### Self Assessment Framework for AIDS Competence

<table>
<thead>
<tr>
<th>Acknowledgement And Recognition</th>
<th>1 Basic Competence</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5 High Competence</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>We know the basic facts about HIV/AIDS, how it spreads and its effects.</td>
<td>We recognize that HIV/AIDS is more than a health problem alone.</td>
<td>We acknowledge openly our concerns and challenges of HIV and AIDS. We seek others for mutual support and learning.</td>
<td>We go for testing consciously. We recognize our own strength to deal with the challenges and anticipate a better future.</td>
<td></td>
</tr>
<tr>
<td>Inclusion</td>
<td>We don’t involve in our work those affected by the problem.</td>
<td>We co-operate with some HIV-positive individuals who are useful to resolve ad hoc issues.</td>
<td>We have a formalised partnership with (an) organisation(s) for PLWHA, but don’t really know how to utilise this</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care And Prevention</td>
<td>We relay externally provided messages about care and prevention.</td>
<td>We look after those unable to care for themselves (sick, orphans, elderly). We discuss the need to change behaviours.</td>
<td>We take action because we need to and we have a process to care for others long term.</td>
<td>As a community we initiate care and prevention activities, and work in partnership with external services.</td>
<td>Through care we see changes in behaviour which improve the quality of life for all.</td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th></th>
<th>1 Basic Competence</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5 High Competence</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Learning And Transfer</strong></td>
<td>We learn from our actions.</td>
<td>We share learning from our successes but not our mistakes. We adopt good practice from outside.</td>
<td>We are willing to try out and adapt what works elsewhere. We share willingly with those who ask.</td>
<td>We learn, share and apply what we learn regularly, and seek people with relevant experience to help us.</td>
<td>We continuously learn how we can respond better to HIV and AIDS and share it with those we think will benefit.</td>
</tr>
<tr>
<td><strong>Adapting Our Response</strong></td>
<td>We see no need to adapt our work, because we are doing something useful.</td>
<td>We are changing our response as a result of external influences and groups.</td>
<td>We are aware of the change around us and we take the decision to adapt because we need to.</td>
<td>We recognize that we continually need to adapt.</td>
<td>We see implications for the future and adapt to meet them.</td>
</tr>
<tr>
<td><strong>Ways of Working Together in The “church family”</strong></td>
<td>We wait for other family members to tell us what to do and provide the resources to do so.</td>
<td>We work as individuals, attempting to control the situation, even when we feel helpless.</td>
<td>We work as teams to solve problems as we recognize them. If someone in the family needs help we share what we can.</td>
<td>We find our own solutions and access help from others where we can.</td>
<td>We believe in our own and other family members’ capacity to succeed. We share ways of working that help others succeed.</td>
</tr>
<tr>
<td><strong>Mobilizing Resources</strong></td>
<td>We know what we want to achieve but don’t have the means to do it.</td>
<td>We can demonstrate some progress by our own resources.</td>
<td>We have prepared project proposals and identified sources of support.</td>
<td>We access resources to address the problems of our community, because others want to support us.</td>
<td>We use our own resources, access other resources to achieve more and have planned for the future.</td>
</tr>
</tbody>
</table>

Please note: This framework is taken from the UNITAR AIDS Competence Programme and adjusted especially for the *Strategy consultation on Churches and HIV/AIDS in central and eastern Europe*. St. Petersburg, Russia, 15–18 December 2003.
For original and complete version of the framework, please see www.unitar.org/acp/
Annex 2

Sensitive language use vis-à-vis HIV and AIDS

Churches have a valuable role in informing members about HIV. But at times, churches have also used terms which can be misleading about the virus, or harmful to people who are living with HIV or AIDS. The appropriate use of language respects the dignity and rights of all concerned, avoids contributing to the stigmatization and rejection of PLWHA and assists in creating the social changes required to overcome the epidemic.

Some general rules are:

- Language should be inclusive and not create and reinforce an “us and them” mentality or approach. Care should be taken with the use of pronouns such as “we”, “they”, “you”, “them”, “their” etc.
- Language should be value neutral, gender sensitive and should be empowering rather than disempowering. Terms and images such as "promiscuous", "drug abuse" and all derogatory terms alienate rather than create the trust and respect required.
- HIV/AIDS prevention messages should show that HIV and AIDS affect all people – all ages, cultures, races, genders and sexual orientations.
- Images of PLWHA “at death’s door” and images of PLWHA as unable to live fulfilling lives because of their HIV-positive status should be avoided.
- Describing HIV and AIDS as a scourge or plague should also be avoided; HIV is simply an infection which has reached epidemic proportions
- It is better if vocabulary is drawn from the vocabulary of peace and human development, rather than from the vocabulary of war and condemnation. For example, “HIV/AIDS response” is better than the “fight against HIV/AIDS”.
- “How did you become HIV infected?” is a question that should not be asked. Of far greater importance is “How are you living with HIV?”

Below are some examples of stigmatizing or inaccurate terms, together with suggestions of alternative terms and phrases:

**1. Use: HIV infection, HIV-positive, HIV/AIDS, HIV and AIDS, HIV or AIDS**

**Do not use: "AIDS" if the intention is to refer to HIV**

AIDS is a range of conditions which occur when a person's immune system is seriously damaged by HIV infection. Someone who has HIV infection has antibodies to the virus but may not have developed any of the illnesses which constitute AIDS.

**Do not use: AIDS Virus, HIV Virus**
There is no such thing as the AIDS virus. There is only HIV (Human Immunodeficiency Virus) - the virus that can cause AIDS. The term "HIV virus" actually means Human Immunodeficiency Virus virus, which is not correct.

Prefer not to use HIV/AIDS
HIV is a retrovirus (the infectious agent), AIDS is the syndrome of a damaged immune system. Using the term ‘HIV/AIDS’ may give the wrong impression that there is one disease called HIV/AIDS. Always specify either HIV or AIDS when possible.

2. Use: Person Living with HIV or Person Living with HIV/AIDS or People Living with HIV/AIDS (PLWHA)

Do not use: AIDS victim or sufferer
Many PLWHA feel these terms imply they are powerless, with no control over their health or lives.

Do not use: innocent victims
This term wrongly implies that people infected through mother to child transmission or by medical means are innocent. This also implies that people infected with HIV through other ways are guilty of some wrong-doing and somehow deserving of punishment. This feeds stigmatization of and discrimination against PLWHA, and should be avoided.

Do not use: AIDS carrier
This term is highly offensive and stigmatizing to many people with HIV and AIDS. It is also incorrect: the infective agent is HIV. You cannot catch AIDS. This term may also give the impression that people can protect themselves by choosing a partner based on their appearance or by avoiding someone who they know is living with AIDS.

Do not use: full blown AIDS
This term implies there is such a thing as "half-blown AIDS". A person only has AIDS when they present with AIDS-defining illnesses such as certain opportunistic infections, or when the CD4 level falls below a certain point.

Do not use: AIDS patient
Use "AIDS patient" only to describe someone who has AIDS and who is, in the context, in a medical setting. Most of the time, a person with AIDS is not in the role of a patient.

3. Use: affected communities or high-risk behaviours (i.e. unsafe sex, or sharing syringes or needles)

Do not use: high risk group
For example, truck drivers, homosexuals, migrants, sex workers, injecting drug users have been labelled ‘high risk’ groups in the past. This is unhelpful as it implies that membership of a particular group, rather than behaviours (e.g., unprotected sex, using contaminated syringes), is the significant factor in HIV transmission. This term may lull people who do not identify with a high risk group into a false sense of security. It
is high-risk behaviours such as unsafe sex or unsafe injecting practices that can transmit HIV, not being a member of particular group.

4. Use: for your country, i.e. Sri Lanka or Jamaica, use: Sri Lankan population/Jamaican population, HIV-negative people, all Sri Lankans/all Jamaicans.

**Do not use: general population**
This implies that people in the populations targeted for HIV prevention, education and care are not part of the general population. It artificially divides the world into those who are infected or likely to be exposed to HIV, and those who are not; falsely implying that identity, rather than behaviour, is the critical factor in HIV transmission.

5. Use: blood, semen, pre-ejaculate, vaginal fluids, breast milk.

**Do not use: body fluids**
Confusion about the body fluids that can transmit HIV is a common cause of fear and misunderstanding about HIV, and continues to cause stigmatization of discrimination against PLWHA. If undertaking education always explain which body fluids contain HIV in sufficient concentrations to be implicated in HIV transmission (i.e., blood, semen, pre-ejaculate, vaginal fluids and breast milk). Emphasise that HIV cannot be transmitted through body fluids such as saliva, sweat, tears or urine.

6. Use: sex worker, which reflects the employment aspect of sex work.

**Do not use: prostitute or whore**
Prostitute and whore are considered disparaging and stigmatizing terms that do not reflect the fact that sex work is a form of employment, not a way of life.

7. Use: Person who injects drugs, people who inject drugs, injecting drug users (IDUs). These days the most commonly used form is injecting drug users (IDUs).

**Do not use: junkie, druggie or drug addict**
Illicit drug use is only one part of an injecting drug user's life. Terms such as “junkie” and “druggie” promote stereotyped images that are not accurate.

8. Use: Men who have sex with men (MSM), gay and homosexual
Men who have sex with men (MSM) are not a group of people, but rather a social phenomenon. Many MSM do not see themselves as homosexual and many are also married or have sex with women. In some regions, there are high levels of bisexual behaviours among men.

In most parts of the world, there are groups of “self-identified homosexual” who use various terms to identify themselves. Such terminology is found in most, if not all, cultures. Some terms denote effeminate men; while others denote more masculine men. Those men in many places form a sub-culture. It is important to bear in mind that all MSM do not necessary feel that they belong to this subculture, the fact that they have sex with another man is, in many cases, just something they do, something that just happens.
Even in these places where there is a visibility and certain openness of MSM, there are many other men, possibly a majority of the total, who do not self-identify as gay or bisexual, because of stigmatization or fear of discrimination or because of a lack of role models, among other reasons. However, self-identification is not essential for recognition that same-sex behaviour exists.

Do not use: queen, queer, poof, faggot, bum boy etc.
Annex 3

The Covenant document on HIV/AIDS

Preamble

The Lord God is the creator of heaven and earth; the creator of all life forms in the earth community. He created all life and everything good. In this HIV/AIDS era, he sees the misery of his people, who are infected and affected by this disease; He has heard their cry on the account of this epidemic. He knows their sufferings and he has come down to deliver them from HIV/AIDS. So he calls to send us to the infected and affected, to bring his people, his creation, out of the HIV/AIDS epidemic. Now therefore this Assembly recognizes God's call to us and hence makes this covenant with God today:

Covenant 1: Life and HIV/AIDS Prevention

We shall remember, proclaim and act on the fact that, the Lord our God created all people and all life and created life very good (Genesis 1–2). We shall, therefore, seriously and effectively undertake HIV/AIDS prevention for all people - Christians and non-Christians, married and single, young and old, women and men, poor and rich, black, white, yellow, all people everywhere-, for this disease destroys life and its goodness, thus violating God's creation and will.

Covenant 2: Love and HIV/AIDS Care

We shall remember, proclaim and act on the fact that love is from God and everyone who loves is born of God and knows God. Those who say 'I love God,' and hate their sisters and brothers are liars, for unless you love your sisters and brothers whom you see, you cannot love God whom you have never seen (1 John 4:7–21). We shall, therefore, do all that is necessary and within our power to encourage both men and women to love, care, support and heal all those who are infected and affected by HIV/AIDS in our communities, countries and continent.

Covenant 3: Treatment and HIV/AIDS Drugs

We shall remember, proclaim and act on the fact that the earth and everything in it belongs to the Lord and that He has given it over to all human beings for custodianship (Psalms 24:1 and Genesis 1:29). We shall therefore, openly and persistently undertake prophetic and advocacy role for all the infected who are denied access to affordable HIV/AIDS drugs until antiretrovirals are available to all who need them.

Covenant 4: Compassion, HIV/AIDS Stigma & Discrimination

We shall remember, proclaim and act on the fact that the Lord our God, is a compassionate God, who calls upon us to be compassionate, to suffer with those who suffer, to enter their places and hearts of pain and to seek lasting change of their suffering (Luke 6:36; Matthew 25:31–46). We shall therefore, have zero tolerance for HIV/AIDS stigma and discrimination and do all that is necessary to eliminate the isolation, rejection, fear and oppression of the infected and affected in our

197 Adopted by the 8th AACC General Assembly, Yaunde, 2003.
communities. We shall declare HIV/AIDS stigma and discrimination an unacceptable sin before God and all believers and in all our communities.

**Covenant 5: Poverty and HIV/AIDS**
We shall remember, proclaim and act on the fact that the Lord our God, who created all the resources of the earth, blessed both women and men and gave them the resources of the earth for their sustenance (Genesis.1:28-29). We shall, therefore, work to empower all the poor and denounce all the cultural, national and international structures, laws and policies that have condemned billions to poverty thus denying them their God given rights and, in the HIV/AIDS era, exposing them to infection and denying them quality care and treatment.

**Covenant 6: Gender Inequalities and HIV/AIDS**
We shall remember, proclaim and act on the fact that the Lord our God, created humankind in his image. In his image, he created them male and female, he blessed them both and gave both of them leadership and resources in the earth; he made them one in Christ (Genesis 1:27–29; Galatians 3:28–29). We shall, therefore, denounce gender inequalities that lead boys and men to risky behaviour, domination and violence; that deny girls and women leadership, decision making powers and property ownership thus exposing them to violence, witchcraft accusation, widow dispossession, survival sex – fuelling HIV/AIDS infection and lack of quality care and treatment.

**Covenant 7: Children and HIV/AIDS**
We shall remember, proclaim and act on the fact that, Lord our God welcomes children. He has given his kingdom to them and he is the father of all orphans (Mark 9:33–37; 10:13–16; Psalms 68:5 and Psalms 146:9). We shall, therefore, work to empower and protect all children and denounce all the national and international structures, cultures, policies, laws and practices that expose children to sexual abuse and exploitation, HIV/AIDS stigma and discrimination, dispossession and poverty thus exposing them to HIV/AIDS infection and lack of quality care.

**Covenant 8: Church, PLWHA and HIV/AIDS**
We shall remember, proclaim and act on the fact that we are one body of Christ and if one member suffers, we all suffer together with it; that the Lord our God identifies with the suffering and marginalized and heals the sick (1 Corinthians 14:26; Matthew 25:31–46). We shall, therefore, become a community of compassion and healing, a safe place for all PLWHA to live openly and productively with their status.

**Covenant 9: Human Sexuality and HIV/AIDS**
We shall remember, proclaim and act on the fact that the Lord our God, created human sexuality and created it good (Genesis 2:18–25). We shall, therefore, test for infection, denounce sexual violence, abstain before marriage, be faithful in marriage and practice protected sex to avoid HIV/AIDS infection and plunder on life, for all life is sacred and prevention should be seriously pursued to protect life.

**Covenant 10: Justice and HIV/AIDS**
We shall remember, proclaim and act on the fact that the Lord our God, sees, hears, knows the suffering of people and comes down to liberate them (Exodus 3:1–12; Luke 4:16–22). We shall, therefore, declare the jubilee and we shall proclaim liberty
throughout the land and to all its inhabitants (Leviticus 25:10), for unless and until justice is served to all people in the world, until justice rolls down like waters and righteousness like an ever-flowing stream, HIV/AIDS cannot be uprooted.
### Annex 4

**Human Capacity Development**

<table>
<thead>
<tr>
<th>ELEMENTS</th>
<th>HIV/AIDS COMPETENCE OUTCOMES</th>
<th>INDICATORS</th>
<th>EXAMPLE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal</td>
<td>Ready to share the news verbally in public, or in intimate family and friends circles</td>
<td>Family inclusion and willingness to declare 'we have HIV/AIDS'</td>
<td>Zambia (Chikambola local community)</td>
</tr>
<tr>
<td>Family</td>
<td>Destigmatisation</td>
<td>Income generating activities in which the family participates.</td>
<td>North East India (Mizoram - programme with drug using youth)</td>
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<tr>
<td></td>
<td>Economic improvement</td>
<td>Inclusion of children in school.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Functioning as a normal part of the community</td>
<td>Family stability, with resolution of conflict and growth of solidarity.</td>
<td></td>
</tr>
<tr>
<td>Local Community</td>
<td>The community continues to exist</td>
<td>Community measurement of change Community to community transfer.</td>
<td>Northern Zambia - (see draft report on the Human Capacity Development Workshop 15-18 October 2001 - Zambia)</td>
</tr>
<tr>
<td></td>
<td>Care and prevention are integrated into everyday life</td>
<td>Community determined indicators</td>
<td></td>
</tr>
<tr>
<td>Local partnerships</td>
<td>Communities with local partners develop a shared vision that is based in local ownership and responsibility for response.</td>
<td>Local responses and other partners facilitate knowledge transfer between communities, and between organizations</td>
<td>Tanzania (Mwanza)</td>
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<td></td>
<td></td>
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<td>Thailand (Phayao, Chiang Mai)</td>
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<tr>
<td>National Partnerships and Networks</td>
<td>Better collaboration. More partnerships that are based in local responses and knowledge transfer. Willingness to learn from local action and experience.</td>
<td>Formation of networks Networks based in shared vision for learning with local responses, and in collaboration National facilitation teams</td>
<td>Zambia (National Facilitation Team.) Regional Networks in support in country responses e.g. (SAT, RATN, The Salvation Army)</td>
</tr>
</tbody>
</table>

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