



**PANCAP**

PAN CARIBBEAN PARTNERSHIP AGAINST HIV AND AIDS

SCALING UP THE CARIBBEAN'S RESPONSE TO HIV AND AIDS



THE WORLD BANK

# HIV Anti-Stigma Toolkit for FAITH-BASED ORGANISATIONS



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Pan Caribbean Partnership Against HIV/AIDS  
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# Acknowledgements

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***This toolkit was developed for use by persons working in the Faith-Based Organisations and seeks to promote a better understanding of HIV related stigma and discrimination in this sector.***

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May the fruits of your labour be reflected in the improved quality of life of all stigmatised and discriminated populations in the Caribbean.





# Foreword


Stigma and discrimination are pervasive features of society. In the context of HIV and AIDS, stigma and the consequent discrimination remain major barriers for People Living with HIV and AIDS - including being able to access treatment and care. These remain impediments in the Caribbean's response to reverse the spread of the epidemic.

PANCAP sought to address these impediments through the Champions for Change initiative. Champions for Change was conceived as a "brand" or approach for promoting the reduction of stigma and discrimination and was intended to complement other approaches.

The Champions for Change initiative, launched at the first conference in November 2004, in St. Kitts and Nevis, brought together a cross-section of stakeholders including parliamentarians, policy makers and practitioners in the fields of education and health, representatives of youth organisations, Faith-Based Organisations, the Private Sector and civil society, sport and cultural icons and People Living with HIV and AIDS (PLHIV) to address issues of stigma and discrimination. It is therefore appropriate that the first comprehensive set of HIV and AIDS anti-stigma and discrimination toolkits for the region has been developed specifically to assist these population groups to address stigma and discrimination in their respective spheres.

The toolkits in this series have been developed for Educators, Health Workers, PLHIV, Faith-Based Organisations, the Private Sector and the Tourism Sector: key population groups in critical sectors of the society influencing and impacting on development. These groups can, by their own attitudes, help to reduce AIDS-related stigma and discrimination as well as play a major role in advocating for the rights and entitlements of People Living with HIV and AIDS.

We trust that the spirit of hope, understanding, acceptance and expectation for a better world for people living with and affected by HIV and AIDS that permeated the workshops convened and other activities undertaken in the development of the toolkits, will live on and come alive each time the toolkits are used.



EDWARD GREENE  
ASSISTANT SECRETARY GENERAL  
CARICOM SECRETARIAT



# The Pan Caribbean Partnership against HIV and AIDS (PANCAP)

PANCAP was created in 2001 with a specific mandate to co-ordinate the Caribbean's response to HIV and AIDS. This creation, which is multi-country and cross-sectoral, brings together a wide spectrum of partners each with its own mandate, institutional arrangements and organisational culture. These partners include: Caribbean States, UN/multilateral agencies, bilateral agencies, regional NGOs, academic organisations, regional Private Sector organisations, youth, Faith-Based Organisations, labour, and People Living with HIV/AIDS.

PANCAP is guided by a Caribbean Regional Strategic Framework (CRSF) which is organised around six priority areas and defines the strategic objectives for the HIV response in the region, as well as the regional goods and services that will be available to support country programmes. These six priority areas are:

1. An enabling environment that fosters universal access to HIV prevention, treatment, care and support services
2. An expanded and co-ordinated multi-sectoral response to the HIV epidemic
3. Prevention of HIV transmission
4. Treatment, care and support
5. Capacity development for HIV and AIDS services
6. Monitoring, evaluation and research

An underlying principle of this framework is support for national HIV programmes through, *inter alia*, the provision of regional public goods and services that can be more cost-effectively provided from the regional rather than the national level. A novel initiative of PANCAP's efforts to reduce HIV and AIDS stigma and discrimination against People Living with HIV resulted in three conferences, in 2004, 2005 and 2006 and plans of action/work programmes.

In essence, the Champions for Change initiative seeks to address the issue of stigma and discrimination through key advocates who are leaders in their communities and willing to be forerunners of the effort to change attitudes. Champions for Change was conceived as a "brand" or approach for promoting the reduction of stigma and discrimination and was intended to complement other approaches. It was felt that given the sensitivities involved in stigma and discrimination, the use of "Champions" to advocate for a change in attitudes could have a positive impact. The first of three major interventions was made in 2004 when, venturing into uncharted waters, a conference - the first of its kind in the region - was organised as a brainstorming, agenda-setting activity, bringing together a cross-section of



## **The Pan Caribbean Partnership against HIV and AIDS (PANCAP) (continued)**

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stakeholders including parliamentarians, policy makers in the fields of education and health, representatives of youth organisations, Faith-Based Organisations, the Private Sector and civil society, sport and cultural icons and PLHIV. Its stated objectives were: to review the factors underlying stigma and discrimination associated with HIV and AIDS and their impact; identify best practices and models of stigma and discrimination reduction; recommend policy options and develop a framework for a plan of action by which regional leaders could advocate for stigma reduction as Champions for Change.

Declared an international best practice for its governance structure by the United Nations in 2004, the benefits of PANCAP to all partners are mainly due to its focus on the delivery of regional public goods such as building institutional and human resource capacity, research, training, advocacy, the provision of model legislation and increased access to treatment, care and support services for PLHIV.



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# Acronyms

<b>ABC</b>	<b>Abstinence, Be faithful, Condomise</b>
<b>AIDS</b>	<b>Acquired Immune Deficiency Syndrome</b>
<b>ART</b>	<b>Anti-retroviral Therapy</b>
<b>ARVs</b>	<b>Anti-retrovirals</b>
<b>BCC</b>	<b>Behaviour Change Communication</b>
<b>CARICOM</b>	<b>Caribbean Community</b>
<b>CHAA</b>	<b>Caribbean HIV&amp;AIDS Alliance</b>
<b>FBO</b>	<b>Faith-Based Organisation</b>
<b>GIPA</b>	<b>Greater Involvement of People Living with or affected by HIV/AIDS</b>
<b>HIV</b>	<b>Human Immunodeficiency Virus</b>
<b>IHAA</b>	<b>International HIV/AIDS Alliance</b>
<b>ILO</b>	<b>International Labour Organization</b>
<b>MSMs</b>	<b>Men who have Sex with Men</b>
<b>PANCAP</b>	<b>Pan Caribbean Partnership against HIV/AIDS</b>
<b>PLHIV</b>	<b>People Living with HIV</b>



## Acronyms *(continued)*

<b>S&amp;D</b>	<b>Stigma and Discrimination</b>
<b>STIs</b>	<b>Sexually Transmitted Infections</b>
<b>SWs</b>	<b>Sex Workers</b>
<b>UNAIDS</b>	<b>Joint United Nations Programme on HIV/AIDS</b>
<b>UNESCO</b>	<b>United Nations Educational, Scientific and Cultural Organization</b>
<b>UNICEF</b>	<b>United Nations Children's Fund</b>
<b>VCT</b>	<b>Voluntary Counselling and Testing</b>
<b>WHO</b>	<b>World Health Organization</b>



# About the Toolkit



## About the Toolkit

HIV-related stigma and discrimination have been identified as major barriers to effectively responding to the situation of HIV and AIDS in the Caribbean. Best practice indicates that a multi-sectoral approach is essential to addressing this phenomenon in the region. Faith-Based Organisations can provide a unique and effective approach to this problem by applying key religious principles and values to educate, support and advocate. The aim of this toolkit is to enable Faith-Based Organisations to provide quality HIV spiritual guidance, support and care to all PLHIV and other marginalised groups in a manner that acknowledges their needs and rights to compassion, dignified treatment and genuine respect. The toolkit seeks to build on the Faith-Based Organisations' principles of care and compassion. It does not attempt to change the religious principles of Faith-Based Organisations.

### Who is this resource guide for?

This toolkit is intended for two audiences. The first group includes religious leaders and key decision-makers within Faith-Based Organisations. The second group comprises members of Faith-Based Organisations and the larger religious community.

### How is it organised?

- This toolkit has seven sections: Introduction, Basics of HIV and AIDS, Exploring Values and Attitudes, Gender and Sexuality, Human Rights, Advocacy, Care and Support
- This toolkit is accompanied by a Facilitator's Guide, which provides helpful information for conducting the sessions. In addition to providing helpful techniques and ideas for the facilitator, the guide also provides information on how to conduct the evaluation
- Each section includes objectives, important information, activities, materials needed, suggested time frame and facilitator's instructions
- This toolkit is designed to be a guide that can be adapted to the specific needs of different populations within different settings. Facilitators must keep in mind that the toolkit is only 50 percent of the facilitation – 25 percent is personal style while the other 25 percent is "playing it by ear" or making adjustments according to the group dynamics, mood and immediate needs of the group



## **About the Toolkit (continued)**

### **Why is this toolkit needed?**

Faith-Based Organisations are poised in key positions to effect attitudinal and behavioural change among their members and the larger community. Attitudinal and behavioural changes are important elements in the fight against stigma and discrimination. By exploring moral values and beliefs that sometimes perpetuate stigma and discrimination against PLHIV and other vulnerable groups, Faith-Based Organisations can play a leading role in eliminating this barrier that fuels stigma with respect to the epidemic in the region. This toolkit is specifically designed to provide opportunities for reflection and discussion on attitudes towards differences, the psychosocial impact of discrimination and exploration of stigma and discrimination from a scriptural perspective.



# Introduction



## Introduction

### i. Clarifying the Concept of Stigma and Discrimination

Stigma is the setting apart of individuals or groups through the attachment of heightened negative perceptions and values. It is a process that occurs at the individual level, which is influenced by social processes related to assumptions, stereotypes and labelling of people. Stigma involves the social expression of negative attitudes and beliefs. (Parker and Birdsall 2005). "When stigma is acted upon, the result is discrimination. Discrimination consists of actions or omissions that are derived from stigma and directed towards those individuals who are stigmatised. Discrimination refers to any form of arbitrary distinction, exclusion, or restriction affecting a person, usually but not only by virtue of an inherent personal characteristic or perceived belonging to a particular group." (UNAIDS 2002). Thus, stigma is the attitude that leads to the discriminatory behaviour.

### ii. Historical Perspective of Stigma and Discrimination in the Caribbean

The PANCAP (2007) *Survey of HIV/AIDS Stigma and Discrimination in Six Caribbean Countries* found that stigma and discrimination are historically and inextricably part of the Caribbean culture. Historically, the plantation systems, indentured labour, waves of imported labourers and migrants were arranged according to a hierarchical structure that allowed order and exclusion. These factors were used to exclude some groups and order the colonies, therefore the roots of stigma and discrimination are deep within the Caribbean psyche. This issue is now related to other factors such as race, ethnicity, colour, economic status, politics and religion.

HIV-related stigma is based on "a particularly Caribbean cocktail of fear of contamination, homophobia, religious beliefs and ignorance". (Anderson M. et al. 2008). All over the world, and especially in Latin America and the Caribbean, it has systematically played to and reinforced existing prejudices and anxieties about homosexuality and bisexuality, about prostitution and sex work and about injecting drug use. (Aggleton et al. 2003). A refusal to "take time to understand" was felt to be specifically a Caribbean phenomenon. (Anderson M. et al. 2008). Pervasive and virulent homophobia in some territories is a significant factor that influences HIV-related stigma and impedes access to HIV prevention information, condoms and healthcare in the Caribbean. Studies identify a number of factors that contribute to homophobia in the Caribbean, including laws that criminalise sex among men, religious beliefs and more recently, the lyrics of dancehall and hip-hop music that reinforce hatred of gay men.

### iii. Causes and Effects of Stigma and Discrimination within FBOs

One of the major stigma and discrimination issues within the Faith-Based Organisation sector is the association of HIV infection with immoral behaviour and the reluctance to





## Introduction (continued)

openly discuss the true root causes underpinning HIV transmission. Religion can sometimes contribute to the situation of stigma through taboos, sanctions and silences about human sexuality, much of it based on religious morals and values. This results in an alienation of marginalised populations who feel threatened, judged, rejected and unwelcomed within organised religions.

### iv. Challenges to Reducing Stigma and Discrimination among FBOs

Studies have found that there is a willingness to engage in discussions on the topic of stigma and discrimination with a focus on compassion and care for the individual as a human being. There still remains, however, reluctance to address the issue from a human sexuality and human rights perspective. Even though the response of the Faith-Based Organisation sector in the Caribbean has increased over recent years, there is a need to focus efforts on working with marginalised populations in a manner that is objective and non-judgemental.

### v. Stigma, Discrimination and Human Rights

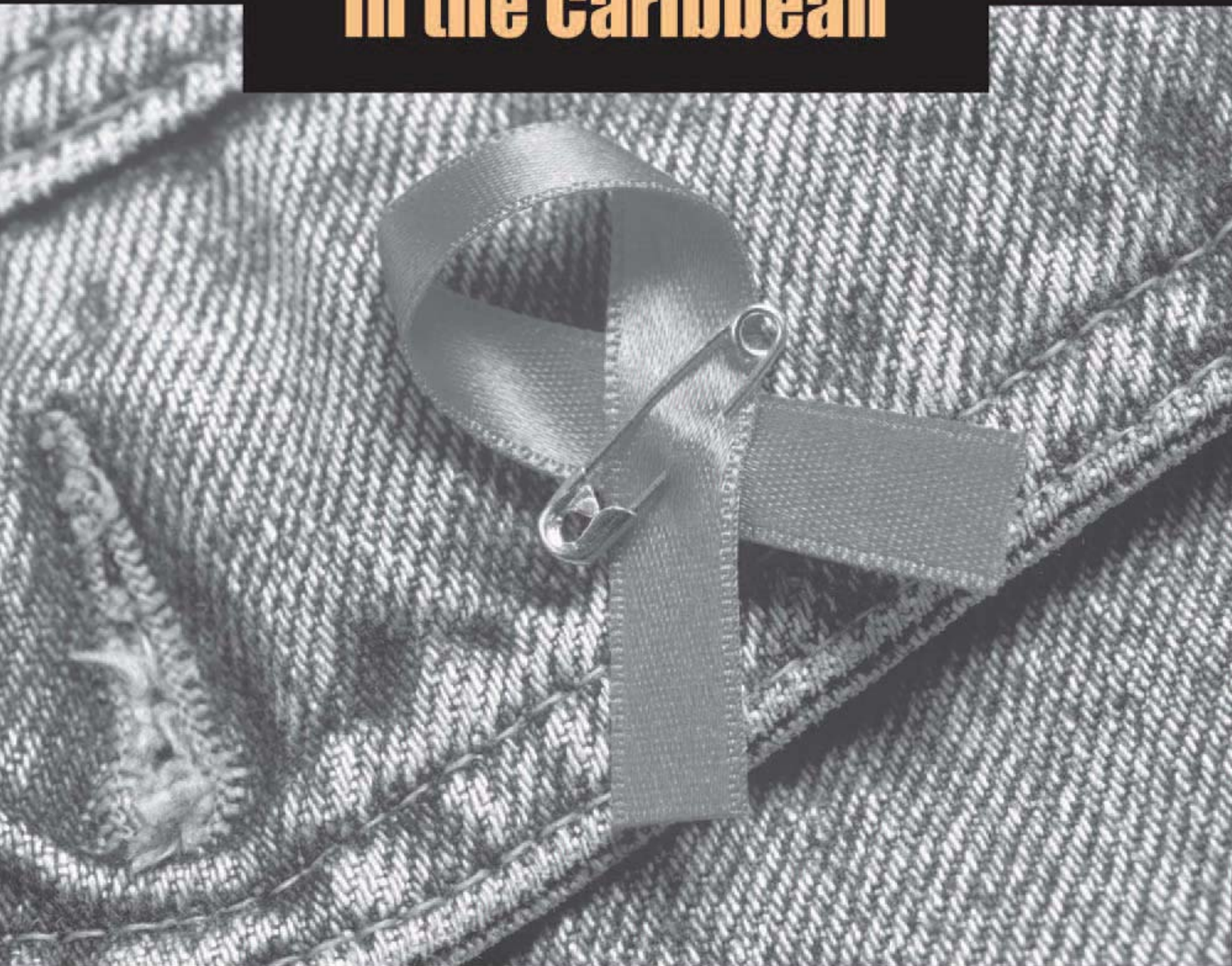
Human rights are defined as those rights that belong to every individual. Human rights are not given or bestowed upon people by individual governments or societies but are earned by virtue of being born human. (WHO, 2002). These embody the basic standards without which people cannot realise their inherent human dignity as reflected in the Declaration of Human Rights (1948) and more recently, in the Vienna Declaration and Programme of Action of the World Conference on Human Rights 2003. International human rights instruments play an important role with respect to HIV and AIDS and human rights since their norms may guide the establishment of procedural, institutional and social mechanisms to counteract the HIV and AIDS epidemic. (Theodore 2007).

In the vicious cycle of stigma, discrimination and the violation of rights, stigma causes discrimination that leads to violation of human rights, which in turn legitimises stigma. (Parker and Aggleton 2003). Stigma leads to discrimination and other violations of human rights that affect the well-being of People Living with HIV and other marginalised groups in deep-seated ways. The UN Commission on Human Rights resolutions (1999/49 and 2001/51) state quite unequivocally that the term "or other status" in non-discrimination should be interpreted to cover health status, including HIV and AIDS. These resolutions have, moreover, confirmed that "discrimination on the basis of HIV status, actual or presumed, is prohibited by existing human rights standards." Discrimination against People Living with HIV, or those thought to be infected, is therefore a clear violation of their human rights.



# Unit 1

## Basics of HIV and AIDS in the Caribbean





## Unit 1:

# The Basics of HIV and AIDS in the Caribbean

### Materials

- Facilitator's guide
- Flip chart paper
- Markers
- Paper and pens for participants



Time

8 hours

### Purpose

The purpose of this unit is to provide participants with an overview of the basics of HIV and AIDS within the Caribbean context. This will ensure that they have the knowledge of HIV necessary to engage in discussions on HIV and other related topics.

### Activities

The activities within this unit will familiarise participants with the profile of HIV and AIDS in the Caribbean by helping them understand the situation within their national context. By learning the epidemiological profile of HIV in their countries they have an appreciation of the severity of the situation and the urgent need to be a part of the multi-sectoral response in a manner that is effective. The HIV 101 activity presents basic information on HIV and AIDS such as the difference between the virus and the disease. It includes discussion on the three main modes of transmission, as well as the ways in which transmission cannot occur. It also includes discussions on the modes of prevention, which are abstinence, being faithful and condom use. It includes information on signs and symptoms of HIV and AIDS, as well as diagnosis. It also provides information on what a negative or positive test result means, as well as emphasises the importance of getting tested early. An important activity focuses on myths and misconceptions. This section addresses common myths and misconceptions about HIV such as modes of transmission and prevention. It especially highlights the fact that myths and misconceptions contribute to stigma and discrimination, as well as place persons at more risk and increase HIV infection. The unit will conclude with a 'Wildfire Simulation Exercise'. This activity provides participants with an opportunity to appreciate the psychosocial experience of HIV. This activity seeks to sensitise participants in preparation for the other units in the toolkit.

**Duration: Total of 8 Hours**





## Activity 1.1:

# Profile of HIV and AIDS in the Caribbean

### Objectives:

By the end of the activity, participants :

- will understand the history of HIV and AIDS
- will be familiar with the global HIV situation
- will be knowledgeable about HIV in the Caribbean

### Materials

- Facilitator's guide
- Important information
- Flip chart paper
- Markers

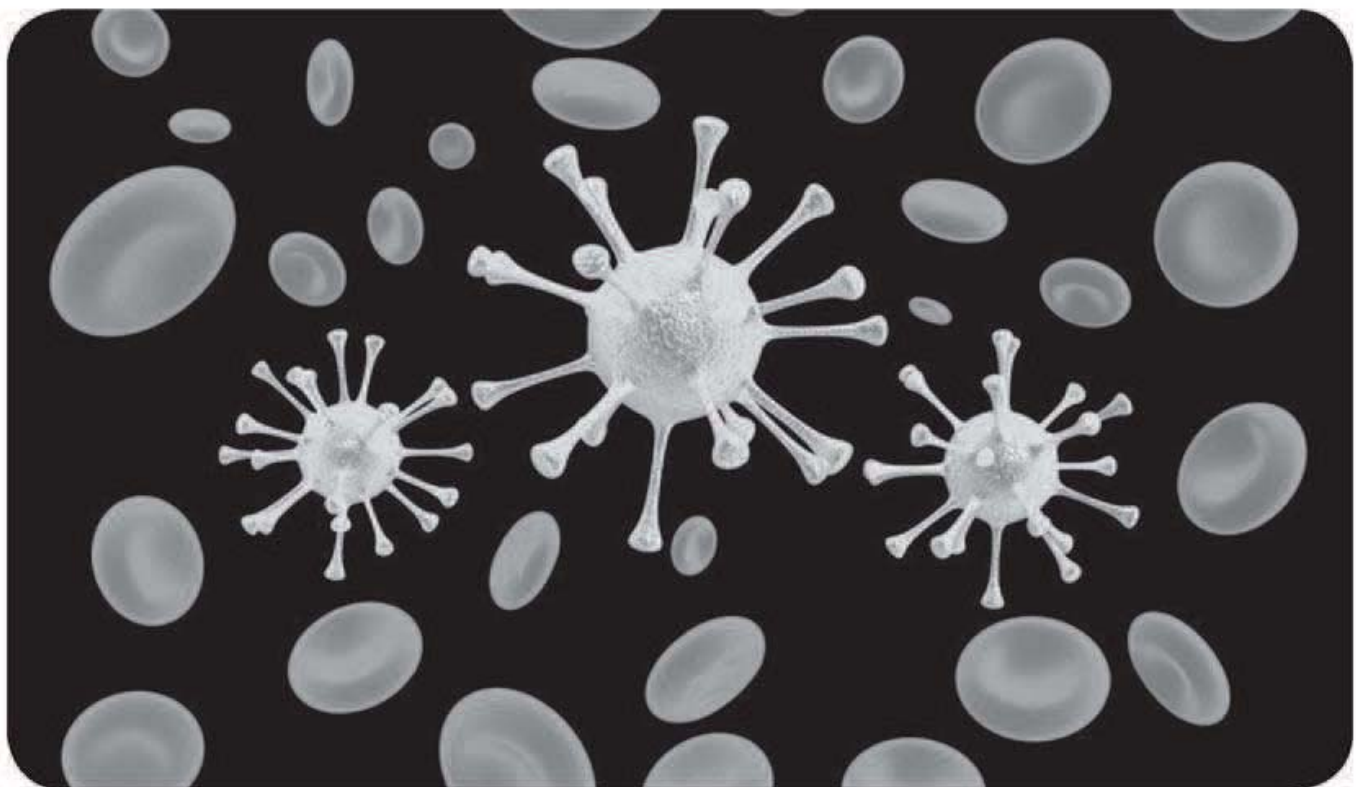


1½ hours

Source: UNAIDS Epi\_Briefs 2008

### Facilitator's Instructions

1. Prepare flip chart paper or slides with the following information beforehand.
2. Present the following important information to the participants.
3. Allow time for questions and discussions.





## Activity 1.1:

# Profile of HIV and AIDS in the Caribbean

### Important Information:

### History of HIV and AIDS

#### Early 1980s

New illness first identified in San Francisco as GRID (Gay-Related Immune Deficiency). No treatment available.

#### Mid-1980s

Name changed to Acquired Immune Deficiency Syndrome (AIDS) as populations other than gay men affected. Worldwide pandemic declared with particularly high numbers of infection in sub-Saharan Africa. UNAIDS founded to respond. As no effective treatment yet discovered, massive prevention efforts undertaken including screening blood supply for HIV (begins 1985 in Canada).

#### Late 1980s

Human Immunodeficiency Virus (HIV) identified by French and American scientists as virus that leads to AIDS. AZT and DDI identified as treatment options.

#### Early 1990s

Decrease of new HIV infections among gay men demonstrates effectiveness of gay community prevention efforts.

#### Mid to late 1990s

Significant increase in HIV incidence among injecting drug users, aboriginal populations, women and street-involved youth.

HAART (Highly active anti-retroviral therapy) emerges and is touted as a precursor to a cure for AIDS.

No one is certain where HIV came from. HIV may have been around for years before it was discovered and, like many viruses, simply needed the right combination of factors to emerge as a global health threat.





## Activity 1.1:

# Profile of HIV and AIDS in the Caribbean

### UNAIDS AIDS Epidemic update 2009

People newly infected with HIV in 2008	Number of people living with HIV in 2008	AIDS deaths in 2008
Total 2.7 million [2.4–3.0 million] Adults 2.3 million [2.0–2.5 million] Children under 15 years 430,000 [240,000– 610,000]	Total 33.4 million [31.1–35.8 million] Adults 31.3 million [29.2–33.7 million] Women 15.7 million [14.2–17.2 million] Children under 15 years 2.1 million (1.2–2.9 million)	Total 2.0 million [1.7–2.4 million] Adults 1.7 million [1.4–2.1 million] Children under 15 years 280,000 [150,000–410,000]

### The Caribbean Region

- The region has been more heavily affected by HIV than any region outside of Sub-Saharan Africa
- The Caribbean has the second highest level of adult HIV prevalence at 1.0% [0.9%–1.1%] in 2008 with a total of 240,000 [220,000 – 260,000] PLHIV
- An estimated 12,000 [9,300–14,000] people in the Caribbean died of AIDS in this year and AIDS remains one of the leading causes of death among persons aged 25 to 44 years.
- The primary mode of HIV transmission in this region is sexual intercourse
- Women account for approximately half of all infections in the Caribbean

#### Tips for the Facilitator:

1. Remember to always answer questions as best as you can and when you do not have the answer, refer participants to where they can get this information e.g. <http://www.unaids.org> or the Ministry of Health.
2. This information is for 2008 and should be updated on an annual basis.



## Activity 1.2:

# HIV 101: Getting Down to Basics

### Objective:

By the end of the activity, participants will:

- understand the difference between HIV and AIDS
- identify modes of HIV transmission and how HIV is not transmitted
- identify modes of prevention
- learn about HIV testing

### Materials

- Facilitator's guide
- Important information
- Flip chart



Time

1½ hours

### Facilitator's Instructions

- Prepare flip chart paper or slides with the important information
- Go over each of the steps and ask to provide answers
- After each question share the Important Information

**Step 1: Ask participants to define HIV and AIDS and list their responses on flip chart paper.**

### Important Information

Acquired Immune Deficiency Syndrome or AIDS is caused by a tiny organism called a virus. This virus is called HIV, or Human Immunodeficiency Virus. HIV lives in the blood of an infected person. The virus affects the body's immune system so that the body cannot fight certain infections that it would normally be able to fight. When people become infected with HIV, they do not become sick with AIDS immediately.

A person may be infected for many years with HIV and look and feel completely healthy. During this time he/she can spread the virus to other people.

**Step 2: Ask participants to brainstorm the ways that HIV can be passed from one person to another (modes of transmission). List responses on a flip chart; be sure that all of the following are included:**

### Important Information

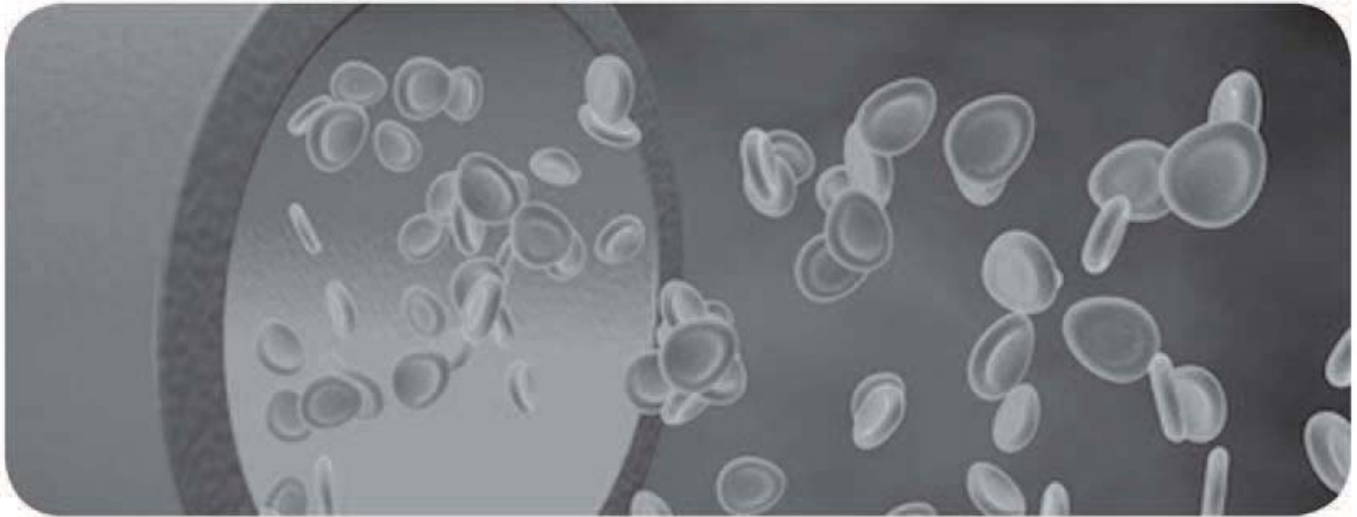
- Sexual intercourse (includes oral, anal or vaginal sex) with an infected person
- The use of needles, syringes, knives and blades that have been used on an infected person and have not been properly cleaned. This includes instruments used for circumcision, tattooing, skin piercing and traditional healing
- Transfusion of blood products from an infected donor
- From an infected mother to her unborn or newborn child if no ART is involved
- Emphasise that blood, semen, vaginal fluids and breast milk are the body fluids capable of transmitting the virus





## Activity 1.2:

# HIV 101: Getting Down to Basics



**Step 3:** Tell participants that HIV is transmitted more easily when genital ulcers and sores caused by some Sexually Transmitted Infections (STIs) are present.

**Step 4:** Ask participants to discuss how HIV is not transmitted.

### Important Information

Possible responses: Mosquito bites, hugging, touching, sharing food, shaking hands with an infected person. Explain that kissing is generally safe unless it is very hard “french kissing” and draws blood, or either partner has open sores, wounds, or infections in or around the mouth.

**Step 5:** Ask a participant to explain the difference between HIV and AIDS.

### Important Information

HIV is the virus that causes the disease AIDS. HIV slowly destroys a person’s immunity. A person infected with HIV is considered HIV-positive. This person may look and feel healthy for many years. Normally, the body can fight diseases. HIV weakens the body’s ability to fight diseases. A person who is infected with HIV will eventually get sicker and sicker unless he/she receives treatment. When a person infected with HIV begins to get many sicknesses, we say that he/she has AIDS. Most people who are infected with HIV will eventually get AIDS.

**Step 6:** Emphasise that a person with HIV who looks and feels healthy can still spread the infection to others.

### Important Information

The person may not even know he/she has the infection. There is no way to tell by looking at somebody if he/she has HIV or AIDS or not. The only way to tell if a person is HIV-positive is for the person to have a blood test.





## Activity 1.2:

# HIV 101: Getting Down to Basics

**Step 7:** Explain to participants what a negative and positive HIV result means.

### Important Information

**A negative result means:** that at this moment there are no HIV antibodies detected in the blood due to the following reasons:

1. The person has not been infected with the virus.
2. The person has come in contact with HIV but has not been infected. More contacts with the virus increase the possibility of infection.
3. The person is infected but antibodies have not developed as yet. Generally, antibodies will develop two to eight weeks after infection has occurred and sometimes up to six months. For other persons, many years can pass before any antibodies develop.

**A positive result means:**

1. That HIV is in the person's body and that he/she can infect others.
2. In all cases when the result is positive, a confirmatory test must be carried out. If the second test is positive as well, another test called "Western Blot" can be done to be totally sure of the result.
3. In case the first test is positive and the second test comes up negative, it could mean that the person has other antibodies but is not infected with HIV.

**Step 8:** Discuss the minor and major signs and symptoms of AIDS.

MINOR Signs of AIDS	MAJOR Signs of AIDS
<ul style="list-style-type: none"> <li>• Persistent cough for more than one month, not related to smoking or other causes</li> <li>• Itchy skin rashes</li> <li>• Cold sores all over the body</li> <li>• Recurrent herpes zoster (shingles)</li> <li>• Swollen lymph glands at two or more sites for more than three months</li> </ul>	<ul style="list-style-type: none"> <li>• Loss of greater than 10% of body weight</li> <li>• Fever for more than one month</li> <li>• Persistent, severe fatigue</li> <li>• Severe night sweats</li> <li>• Diarrhoea for longer than one month (on and off or all the time)</li> </ul>

**Remember:** These signs are common in many illnesses and cannot be used to diagnose AIDS. The only way to tell for sure if somebody is infected with HIV is through a blood test.

**Step 9:** Ask participants to brainstorm how people can protect themselves from HIV/AIDS.

### Important Information

Possible responses: Having only one sexual partner who is faithful to you; using condoms every time you have sex; avoiding injections from unskilled workers and being sure that instruments used to pierce the skin are sterilised between uses on other persons. It's as easy as ABC: Abstinence, Being faithful and using a Condom every time one engages in sexual relations. (Practice Universal Precautions. See Appendix 7 to learn ways of avoiding accidental infection within your Faith-Based Organisation setting.)





## Activity 1.3:

# Addressing Myths and Misconceptions

### Objective:

By the end of the activity, participants will:

- address common myths and misconceptions about HIV
- discuss how myths and misconceptions contribute to stigma and discrimination

*Source: Peace Corp Life Skills Manual 2001*

### Materials

- Facilitator's guide
- Bag or bowl with statements
- Coloured cards



Time

1½ hours

## Facilitator's Instructions

- Prepare slips of paper with the true and false statements
- Fold these and place them in a bag or bowl
- Give each participant cards of two different colours, e.g., blue and red
- Explain that one card (blue) means TRUE and one card (red) means FALSE
- Have participants choose one slip of paper and read it out aloud to the group
- Ask participants to indicate if the statement is TRUE or FALSE by showing the card and to share their reasons for choosing that card

## True Statements

1. The Caribbean has the second highest rate of HIV infection in the world.
2. In the Caribbean, heterosexuals make up the majority of known HIV cases.
3. Although treatments to slow the progression of AIDS exist, there is still no cure for HIV.
4. Although HIV transmission is a risk for everyone, women and girls are more vulnerable to HIV infection.
5. There is an incubation period of 3-6 months before the HIV antibody shows in an HIV test.

## False Statements

1. HIV is a disease that mostly affects foreigners and immigrants.
2. Since everyone dies of AIDS, it is better not to know if you have it.
3. You can be cured of HIV by having sex with a virgin.
4. People in the Caribbean have access to herbal medicines that can cure them of AIDS.
5. Mosquitoes can transmit HIV.
6. There is scientific evidence that shows that HIV can be cured through spiritual healing.





## Activity 1.4:

# Psychosocial Impact of HIV

### Objective:

By the end of the activity, participants will:

- have an opportunity to experience the emotions of someone receiving an HIV-positive diagnosis
- discuss the issues related to HIV risk-taking and infection at a personal level

### Materials

- Facilitator's guide
- Jelly beans or beads for results
- Paper and pen for participants



1½ hours

Source: Africa Consultants International UNDP Facilitator's Manual

### Activity 1.4.1: Wildfire Simulation Exercise

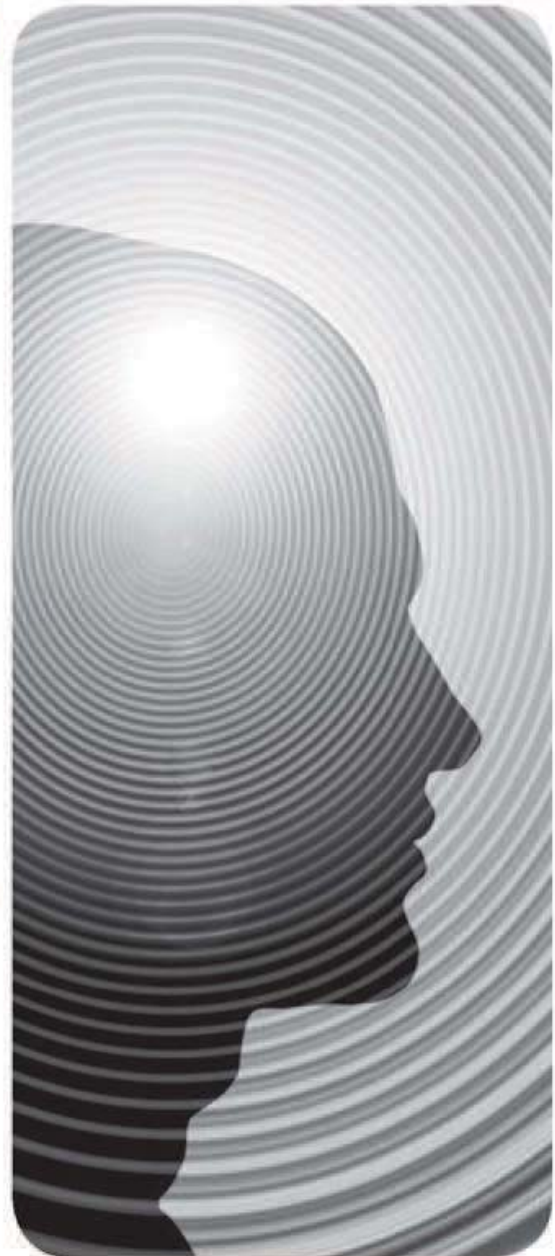
Source: Africa Consultants International UNDP Facilitator's Manual

#### Facilitator's Instructions

- Talk to the group about the game. Explain that this is a simulation designed to get them to feel what it might be like to discover you are HIV-positive. Let participants know that if they feel uncomfortable, they don't have to participate but need to leave the room for a while as no observers are allowed
- Begin by reading out the following statement:

The wildfire exercise is designed to give you an opportunity to experience what it might feel like to discover that you have been exposed to HIV. This is a simulation for learning purposes only and in no way implies or suggests anything about peoples' real lives and HIV status.

1. Explain that one person in the room will get a handshake that is different from a normal handshake. When shaking hands with someone else they must use the index finger of their right hand to scratch the palm of the person they are introducing themselves to. Demonstrate with a volunteer and then get the participants to practise with the person next to them.
2. Explain that the person who received the 'different' handshake should only scratch the palm of one other person in the room (or two people depending on the number of people in the group) and everyone else that he/she introduces himself/herself to gets a normal handshake.





## Activity 1.4: Psychosocial Impact of HIV

3. Two rules: no one is to indicate that he/she is passing on the 'different' handshake and no one is to indicate that he/she has received a 'different' handshake.
4. Allow a sufficient period of time for the participants to introduce themselves (usually 3-5 minutes depending on the size of the group).
5. Once you have called time, ask the group to form a circle.
6. Ask all those who have had their palms scratched to come into the middle of the circle.
7. Ask them to form one side of the circle and those who have not had their palms scratched to form the other side to complete the circle.
8. Explain that those who had their palms scratched are now potentially HIV-positive.
9. Ask those who have had their palms scratched if they would like to be tested to find out whether they are HIV-positive.
10. Hand out little squares of paper (or jellybeans, whatever you would like to use) to only two to three people who have had their palms scratched. Tell them that their tests have come back and they are HIV-negative.
11. Ask them to go to the side of the circle with those who did not have their palms scratched. Ask them how they feel right now?
12. Tell all those who have had their palms scratched and did not receive a piece of paper/jellybean that their tests have come back and they are all HIV-positive.
13. Ask them how they feel right now? How do those who did not have their palms scratched feel about those who did? How do the people whose tests came back negative feel about those who are now positive?
14. Ask them how they feel after discussing what it might be like to be a Person Living with HIV. They might come up with words like helpless, angry, desolate, etc... be sure to allow them to explore the hope at the end of the simulation. Ask them what can be done.
15. Remember to allow enough time for each question so that participants can think out their responses carefully. Do not be uncomfortable with moments of silence after questions. This means that the participants are reflecting on the question.

### Additional Activity

#### Special Preparation:

If you are not a trained counsellor, invite one to be present in case personal issues arise. Wildfire is a very powerful exercise that needs to be guided by a trained facilitator; some participants may feel varying degrees of distress at being put in the role of an HIV-positive person. It is recommended that two facilitators be present.





## Activity 1.4: Psychosocial Impact of HIV

### Activity 1.4.2: The Loss Exercise

#### Facilitator's Instructions

1. Ask participants to number one to five on their sheet of paper. Explain that you are going to read five statements and that they will respond to those statements on their papers. It is very important to emphasise that no one else in the room will see their papers – they will not be collected. They will not be used at any later time – the papers are their own personal property.
2. You should do this exercise slowly and seriously. Participants should feel the full impact of this discussion. One by one, read off the statements and tell the participants to write their responses on their papers. Reinforce that it will not be shared with others. If there are participants who don't know how to write, you can assist them by writing their answers for them.

The statements are:

- Write down the name of the **personal possession that you love the most**
- Write down the **part of your body that you need the most**
- Write down the name of the **activity you most enjoy doing**
- Write down **one secret or very confidential thing about yourself** that no one else in the world, or only one other person knows about
- Lastly, write down the **name of the person whose love and support means the most to you in the world**

1. After everyone has finished, explain that you will now go through the list again. As you go through each statement, they should imagine that they are living through what you are saying.
2. Imagine that something terrible happens that causes you to lose the material possession that you love the most. Either a theft occurs or a loss of some kind that takes this thing away from you completely. You will never again see the thing listed on #1. Take your pen/pencil and cross out #1 now.
3. Imagine that an accident or other unfortunate occurrence causes you to lose the part of your body that you need the most. You will never again see have what you listed on #2. Take your pen/pencil and cross out #1 now.
4. Imagine that this same accident or unfortunate occurrence makes it impossible for you to do your favourite activity ever again. You will never again, in your entire life, be able to do the activity that you wrote on #3. Cross out #3 with your pen/pencil now.
5. Imagine that because of all of the above situations, your secret has been exposed. Everyone now knows what you wrote on #4. It has become public knowledge. Everyone in the town, Faith-Based Organisation and community knows about what you wrote on #4. Circle #4 with your pen/pencil now.
6. Lastly, because of all these changes (losing your possession, losing your body part, not being able to do your favourite activity and everyone knowing your secret), the person that you love the most in the world leaves you forever. You will never again see this person that you love and who is your most important source of support. Cross out #5 with your pen/pencil now.
7. Allow a few silent moments for the participants to truly feel what you have just said. People are usually a bit upset and uncomfortable at this point. Give them some time to think about this.





## Activity 1.4: Psychosocial Impact of HIV

8. Now, ask the participants to describe in one word or phrase the emotions they are feeling. Write the words on the blackboard. Keep brainstorming until all of the possible ideas are exhausted. (The list may include: sadness, grief, depression, anger, blame of others, no reason to continue.)
9. Ask the participants to take a look at the list that you have created. Ask them to imagine how these feelings might relate to testing positive for HIV.
10. Discuss the links between this exercise and testing positive. Remind the group that they have placed themselves in the position of a person living with HIV and this allowed them to experience the very powerful emotions that such a person might be living with every day.
11. Discuss what this might mean for the support that they could give to People Living with HIV. How can they help someone in this situation? How would they feel if they or someone they love were involved in this situation?
12. Provide a few minutes' break after these sessions since students might need to deal with some of the emotions that will have arisen from these activities.

### Tips for the Facilitator: Special Preparation

If you are not a trained counsellor, invite one to be present in case personal issues arise. Wildfire is a very powerful exercise that needs to be guided by a trained facilitator; some participants may feel varying degrees of distress after completing this exercise. It is recommended that two facilitators be present.

# Unit 2

**Exploring Values,  
Attitudes and  
Diversity**





## Unit 2:

# Exploring Values, Attitudes and Diversity

### Materials

- Facilitator's guide
- Flip chart paper
- Markers
- Paper and pen for participants



Time  
5 hours

### Purpose

The purpose of this unit is to provide participants with an opportunity to explore personal values and attitudes and learn how these influence stigma and discrimination.

### Activities

Activities will help participants explore the origins of values and attitudes by understanding the influence of family, religion, society and culture. They have an opportunity to reflect on their personal values and attitudes and how these affect the way they view and treat persons whose values and beliefs differ from ours. Activities provide participants with an opportunity to explore their own experiences and feelings in instances when they have felt stigmatised and discriminated. By identifying scriptures and readings from scriptural books, participants have an opportunity to explore stigma and discrimination from a scriptural perspective. The activities are also designed to help participants understand the diversity and its importance. Activities provide participants with opportunities for reflecting on attitudes towards diversity by allowing them to place themselves on the Riddle Scale. Participants will also learn and have an opportunity to portray basic principles of counselling and helping through role-playing and triads practice.

This unit forms the foundation for the remaining activities in the toolkit since the values promoted by social inclusion and respect for diversity sets the groundwork for a rights-based approach to HIV and life in general.

**Duration: Total of 5 Hours**







## Activity 2.1:

# The Sources and Origins of Values

### Objective:

By the end of this activity, participants will be able to:

- define values
- understand where and from whom they get their values
- identify and share their values

### Materials

- Facilitator's guide
- Flip chart
- Markers

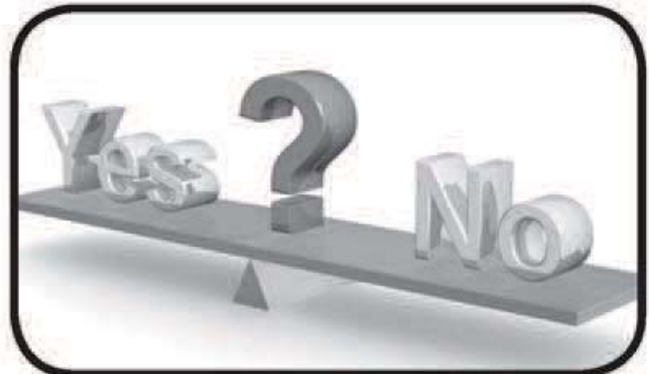


Time

2 hours

### Facilitator's Instructions

1. Share the name and objective of the activity. Divide a flip chart into three columns: What are values? Where do you learn your values? What values do you hold?
2. Ask the group to define values, identify where they learn their values and identify specific values they hold. Record their responses as shown in the matrix below.



What are values?	Where do we learn our values?	Which values are important to you?
Values are deeply held beliefs about what is good, right and appropriate. Values are deep-seated and may remain constant or change over time.	We accumulate our values from childhood based on teachings and observations of our parents, teachers, religion and other influential and powerful people in our lives.	Record values stated.

3. Have participants discuss the similarities and differences in the values expressed.
4. Ask participants to say what they learnt about themselves and others with respect to values.
5. End the activity by impressing upon participants the idea that when individuals act in accordance with their values they are persons of character, irrespective of who they are.

### Tips for the Facilitator

Share the following quote and ask for comments.

**"Live by your personal code of values to get the most out of life.  
Life is fulfilling and free of stress when we live in accordance to our own personal values."**

Jerry Lopper





## Activity 2.2:

# Values Clarification on Stigma and Discrimination

### Objective:

By the end of this activity, participants will:

- learn how values contribute to stigma and discrimination
- discuss the effects of stigma and discrimination
- identify stigmatising and discriminatory messages

Source: CDC PMTCT Training Manual

### Materials

- Facilitator's guide
- Flip chart paper
- Markers
- Important information



1½ hours

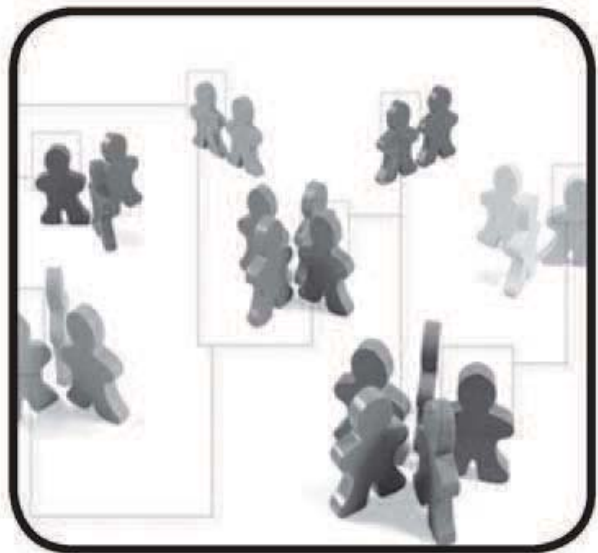
### Facilitator's Instructions

- Share the important information with participants
- Start by asking participants to define the difference between "STIGMA" and "DISCRIMINATION"

### Important Information

Stigmatisation reflects an attitude but discrimination is an act or behaviour. Discrimination is a way of expressing, either on purpose or inadvertently, stigmatising thoughts.

Stigma and discrimination are linked. Stigmatised individuals may suffer discrimination and human rights violations. Stigmatising thoughts can lead a person to act or behave in a way that denies services or entitlements to another person.



### The face of stigma

HIV and AIDS-related stigma is complex, dynamic and deeply ingrained.

### Attitudes and actions are stigmatising

People are often unaware that their attitudes and actions are stigmatising. A word, action or belief may be unintentionally stigmatising or discriminatory toward an individual who is HIV-infected. People often exhibit contradictory beliefs and behaviours.

For example, consider the following.

- A person who is opposed to stigmatisation or discrimination may simultaneously believe that PLHIV indulge in immoral behaviours, deserve what they get, or are being punished by God for their sins
- A person who claims to know that HIV cannot be transmitted through casual contact may still refuse to buy food from a vendor who is HIV-infected or allow his family to use utensils once used by a PLHIV



## Activity 2.2:

# Values Clarification on Stigma and Discrimination

### Choice of language may express stigma

Language is central to how stigma is expressed. People may not realise that they are stigmatising with their choice of words in referring to HIV disease or PLHIV. One way that language can be stigmatising is in the use of derogatory references to those with HIV and AIDS. In some countries, people refer to persons with HIV as “hopeless cases”.

### Lack of knowledge and fear foster stigma

Knowledge and fear interact in unexpected ways that allow stigma to continue. Although most people have some understanding of HIV transmission and prevention, many lack in-depth or accurate knowledge about HIV. For example, many do not understand the difference between HIV and AIDS, how the disease progresses, the life expectancy of PLHIV, or that AIDS-related opportunistic infections (such as tuberculosis) are treatable and curable. Others equate an HIV-positive test result with death. The fear of death is so powerful that many people will avoid individuals suspected to have HIV – even though they know that HIV is not transmitted through casual contact.

### Shame and blame are associated with HIV and AIDS

Sexuality, morality, shame and blame are associated with HIV and AIDS. Stigmatisation often centres on the sexual transmission of HIV. Many people assume that individuals who are HIV-infected must have been infected through sexual activities deemed socially or religiously unacceptable. People who are HIV-infected are often presumed to be promiscuous, careless, or unable to control themselves and therefore responsible for their infection.

### Stigma makes disclosure more difficult

Disclosure, the sharing of HIV status with others, is advocated but often difficult and uncommon in practice. Most people believe that disclosure of HIV infection should be encouraged. Yet many people infected with HIV avoid disclosing their HIV status for fear that doing so will subject them to unfair treatment and stigma. Some of the benefits of disclosure are the following:

- Disclosure can encourage partner(s) to be tested for HIV
- Disclosure can help prevent the spread of HIV to partner(s)
- Disclosure allows individuals to receive support from partner(s), family, and/or friend(s)

### Stigma can exist even in environments that should be caring

Care and support can co-exist with stigma. Caregivers who offer love and support to family members living with HIV and AIDS may also exhibit stigmatising and discriminatory behaviour (such as blaming and scolding). In many cases, the caregivers don't recognise this behaviour as stigmatising.

- Stigmatising attitudes exist even among those individuals, communities and healthcare workers who are opposed to HIV and AIDS-related stigma
- People can have both correct and incorrect information about HIV at the same time. For example, an individual's understanding of the routes of HIV transmission may be accurate in some respects but inaccurate in others
- People express both sympathetic and stigmatising attitudes toward PLHIV
- Families that provide genuine and compassionate care may sometimes stigmatise and discriminate against a family member with HIV or AIDS





## Activity 2.2:

# Values Clarification on Stigma and Discrimination

### Discrimination Exercise

#### Facilitator's Instructions

- Step 1:** Ask all participants with a certain characteristic to leave the circle and go stand in a corner. (A characteristic should be chosen that only a few participants have, for example, a particular hairstyle, eye glasses, a certain height etc.) Instruct the group that leaves that they are not to talk or move from their corner.
- Step 2:** Lead the remaining participants in a song or other enjoyable activity. After a few minutes, call the other participants back to the group. Ask them to discuss how they felt about being asked to leave the group.
- Step 3:** Instruct the "excluded" group to imagine that from now on, all people with the selected characteristic would be fired from their jobs, shunned by their families and rejected by their communities.

Discuss the following questions:

- How would you feel about this?
- What would you do?
- Would you try to hide this characteristic?

- Step 4:** Relate the discussion to STIs, HIV and AIDS by discussing how people with HIV are stigmatised and shunned in your community.

Possible responses: PLHIV may lose their jobs, may be forced to leave school, may be shunned by their family and may be made to feel ashamed, immoral and "dirty."

Next,

- Ask participants to share with the person next to them what they believe are the effects and consequences of stigma and discrimination
- Share the important information

### Important Information

#### Effects of stigma

Stigma is disruptive and harmful at every stage of the HIV continuum, from prevention and testing to treatment and support. For example, people who fear discrimination and stigmatisation are less likely to seek HIV testing, while persons who have been diagnosed may be afraid to seek necessary treatment, care and support. Also, PLHIV may receive sub-optimal care from workers who stigmatise them.

- Stigma may reduce an individual's choices in healthcare and family/social life
- Stigma may limit access to measures that can be taken to maintain health and quality of life





## Activity 2.2: Values Clarification on Stigma and Discrimination

### HIV/AIDS-related stigma fuels new HIV infections

- Stigma may discourage people from getting tested for the disease
- Stigma may make people less likely to acknowledge their risk of infection
- Stigma may discourage those who are HIV-infected from discussing their HIV status with their sex partners and/or those with whom they share needles
- Stigma may discourage PLHIV from adopting risk-reduction practices that may label them as HIV-infected
- Stigma may discourage PLHIV from seeking spiritual support and guidance for fear of judgement

### Secondary stigma (stigma by association)

The effects of stigma often extend beyond the infected individual to stigma by association also known as secondary stigma. Secondary stigma is evidenced in statements like, "If I sit near someone with AIDS, others will think that I have AIDS, too" or, "If I welcome homosexuals into my Faith-Based Organisation, people will think that I am a homosexual, too".

### Tips for the Facilitator

Encourage discussions that are based on personal experience within the participant's specific settings, e.g. their Faith-Based Organisation, school, workplace or community.

### Small Group Exercise

- Divide the participants into groups of five or six
- Ask participants to share examples of stigmatising and discriminatory messages or attitudes that they have seen in each of the following places: workplace, religious institutions and schools
- Provide each group with flip chart paper and markers
- Ask them to divide the flip chart paper into three columns – one column for each of the places: workplace, religious institutions and schools and write down their examples of stigmatising and discriminatory messages
- Allow about twenty minutes for discussion, then ask each group to share their messages
- Share the following examples, if they were not included in the groups' messages





## Activity 2.2:

# Values Clarification on Stigma and Discrimination

### Some Examples of Stigmatisation and Discrimination

#### In the Workplace

- Requiring testing before employment
- Refusing to hire people who are HIV-infected and HIV-affected
- Mandating periodic HIV testing
- Being dismissed because of HIV status
- Violating confidentiality
- Refusing to work with colleagues who are HIV-infected because of fear of contagion

#### In the Context of Religion

- Denying participation in religious/spiritual traditions and rituals (such as funerals) for PLHIV
- Restricting access to marriage for PLHIV
- Restricting participation of PLHIV in religious activities
- Expecting homosexuals and Sex Workers to change their lifestyles before being accepted in the Faith-Based Organisation

#### In Schools

- Isolating students who are HIV-infected
- Restricting participation of children with HIV in school events
- Refusing to allow children who are HIV-infected or HIV-affected to attend school
- Ostracising children of PLHIV
- Denying support for teachers who are living with HIV
- Refusing to hire or dismissing teachers because of HIV status
- Refusing to work with colleagues who are PLHIV

#### Tips for the Facilitator

Encourage discussion and debate but ask everyone to respect opinions which are different from theirs.





## Activity 2.3:

# Stigma, Discrimination and Scripture

### Objective:

By the end of the activity, participants will:

- deepen their awareness of challenges and opportunities in addressing stigma and discrimination within their Faith-Based Organisations
- discuss stigma and discrimination from a scriptural perspective

### Materials

- Facilitator's guide
- Slips of paper with quotes



1½ hours

Source: ICASA Kenyatta International Conference Report

### Facilitator's Instructions

- Start the session by reading the following quotation:

"Religious leaders have a unique catalytic role to play in addressing stigma and discrimination within communities. Religious leaders can influence a community's response. Unfortunately, many religious leaders have spoken in judgement against HIV/AIDS equating it to sin that afflicts unbelievers and those who have fallen short in their morals. Ironically, religion is full of hope for those who suffer and this can be translated into action to support those infected and affected by HIV/AIDS." (ICASA Satellite Session on The Role of Religious Leaders)

- Then, ask participants to provide comments on what you just read. They should state if they agree or not and why
- Divide the participants into small groups of five to six
- Give each group one of the quotations below to discuss

### Quotations

Source: ICASA Kenyatta International Conference Report

1. "Theologians need to review scriptural literature so as to show some loving and care to people who are infected and affected with HIV or AIDS."
2. "FBOs need to understand issues that drive the HIV epidemic such as gender inequality, social injustice and denial of rights of PLHIV and other marginalised groups such as MSMs and sex workers."
3. "Religion needs to address women as a social category of the population that is more affected by HIV and AIDS. Religious writings predominantly come from a patriarchal culture, a fact that disadvantages women because it leads to gender inequality"
4. "There is no doubt that silence around HIV and AIDS fuels stigma, but the question is how can religious leaders help to break the silence?"
5. "Religious leaders should talk about AIDS in a language of compassion and support."
6. "Religious leaders need to avoid inspiring fear in people; they need to develop a scripture of respect of human dignity, compassion, solidarity and mercy that inspires hope in the person. They need to revisit scriptural thinking."





## Activity 2.3:

# Stigma, Discrimination and Scripture

### Facilitator's Instructions

- Ask participants to identify quotations from their religion's scriptures that speak against stigma and discrimination, and speak of compassion, caring and non-judgemental attitudes. For example: "Let he who is without sin cast the first stone."
- Write these down on flip chart paper then have them posted on the walls where everyone can see them
- Next, ask each group to choose one of the quotations or scriptures and present it in the form of a role-play

### Some Suggestions

1. Address HIV and AIDS as a disease like any other, don't create unnecessary fear in people or feed the attitudes that stigmatise people.
2. Revisit and make use of the sacred texts and other scriptural language that can provide more support of People Living with HIV. Simple and compassionate language is very essential, as is the careful use of all language to provide positive reinforcement.
3. Address sexuality in scriptural language.
4. Share information on how different Faith-Based Organisations are addressing HIV-related stigma within their organisations.

### Tips for the Facilitator

Encourage discussion and debate but ask everyone to respect opinions that are different from theirs. End the session with the following quotation.

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**"If you judge people, you have no time to love them."**

Mother Teresa of Calcutta

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## Activity 2.4: Attitudes Towards Differences

### Objective:

By the end of this activity, participants will:

- measure their attitudes towards difference on a continuum
- discuss attitudes towards persons that are different
- reflect on how their values influence their attitudes

*Source: Dr. Dorothy Riddle's Scale of Homophobia*

### Materials

- Facilitator's guide
- Flip chart
- Markers
- Riddle Scale



Time

1½ hours

### Activity 2.4.1 Crossing the Line

#### Facilitator's Instructions

1. Begin by establishing common ground for the activity, for example, "We live in a diverse world" and "What a boring world it would be if human beings were all the same." Explain that the activity will allow us to explore the diversity among the group and that we might even discover that this group which might seem alike, is much more diverse than any of us would assume.
2. Share with participants that the activity will involve labelling and personalising some of this diversity. This personalisation (relating to self) might prove uncomfortable at times. Eventually, however, it might empower us to break down some of the stereotypes and assumptions that we, as a product of our cultures and experiences, hold.
3. Ask the group to gather on one side of the room and face towards its centre. State that different categories/labels/descriptions will be called out. Say that if the specific category applies to them, they should walk to the other side of the room. For example, the facilitator might ask that anyone wearing glasses cross (indicate).
4. Say to participants that once they are there, they should turn and face the crowd they just left. They should try to get in touch with their feelings and think about those people on both sides of the room – then return to the side they started from. After a few seconds, continue with a new category. A number of categories will be called out.
5. Explain that there is no pressure to cross the room if they don't feel comfortable doing so. There may be times when this activity makes them feel slightly uncomfortable. Say that you would urge them to lean into that discomfort since it may mean that they are about to gain an important learning or insight. However, if the discomfort becomes intense, they may stop participating at any time. No questions will be asked and their decision will be respected.
6. Begin the activity by asking questions from the list below:
  - Anyone who has visited another country, cross the room
  - Anyone who has never flown in a plane...
  - Anyone who owns a car...





## Activity 2.4:

## Attitudes Towards Differences

- Anyone who believes in a Supreme Being...
- Anyone who is of mixed race...
- Anyone who is the oldest child...
- Anyone who is the youngest child...
- Anyone who is adopted...
- Anyone who sometimes has low self-confidence...
- Anyone who sometimes feels lonely...
- Anyone whose parents are divorced...
- Anyone who has had a parent who has passed away...
- Anyone who believes it is alright for someone to have a date of the same sex at a social event...
- Anyone who has a family member who is gay, lesbian or bisexual...
- Anyone who has experienced the effects of alcoholism or drug addiction in the family...
- Anyone who believes that AIDS is a punishment from God...
- Anyone who has a friend or relative who has attempted suicide...
- Anyone who hasn't crossed the line...

7. Now invite the group to form a circle and lead a discussion about the activity. As much as possible focus on values.

- What did you learn?
- What kind of feelings did you have as you participated?
- How did you feel when there were very few of you on one side?
- Did you find yourself making judgements of others?
- Through this activity, intentionally or not, did you share your values?
- Through this activity, intentionally or not, do you think that you learnt about the values of others?
- If this activity is about values, then how do we use this experience to remove the labels we give to others?
- How do values represent themselves in everyday life?
- Are there times in life when values are ignored?
- What is the result when values are ignored, forgotten or thrashed about?

8. End the activity by asking participants to embrace each other if they are comfortable doing so.





## Activity 2.4: Attitudes Towards Differences

**Tips for the Facilitator: Read the following and ask participants to discuss**

Past studies suggest that “HIV-related stigma in the Caribbean is shaped primarily by fear of contamination, homophobia and prejudicial attitudes to Sex Work, injecting drug use and ignorance. Studies have shown that religion serves a double role: underpinning stigma and assisting People Living with HIV in coping. Therefore, tackling stigma and discrimination requires more than education; it requires cultural work to address deeply entrenched notions of religious beliefs and sexuality.”

### Activity 2.4.2 Riddle Scale

#### Facilitator’s Instructions

1. Present slides or flip chart paper with the following attitudes and characteristics.
2. Read each one carefully so participants have time to think about them.

Attitude	Characteristics
<b>Repulsion</b>	People who are different are strange, sick and crazy. Anything that will change them to be more normal or a part of the mainstream is justifiable.
<b>Pity</b>	People who are different are somehow born that way and that is pitiful. Being different is definitely immature and less preferred. To help these poor individuals, one should reinforce normal behaviour.
<b>Tolerance</b>	Being different is just a phase of development that most people ‘grow out of’. Thus, they should be protected and tolerated as one does a child who is still learning.
<b>Acceptance</b>	Implies that one needs to make accommodations for another’s differences; does not acknowledge that another’s identity may be of the same value as their own.
<b>Support</b>	Works to safeguard the rights of those who are different. Such people may be uncomfortable themselves, but they are aware of the climate and the irrational unfairness in our society.
<b>Admiration</b>	Acknowledges that being different in our society takes strength. Such people are willing to truly look at themselves and work on their own personal biases.



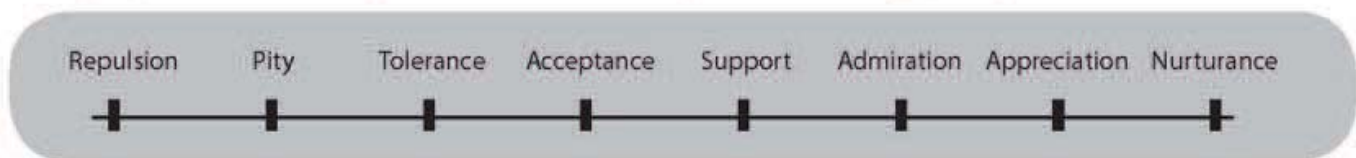


## Activity 2.4: Attitudes Towards Differences

Attitude	Characteristics
<b>Appreciation</b>	Values the diversity of people and is willing to confront insensitive attitudes.
<b>Nurturance</b>	Assumes the differences in people are indispensable in society. They view differences with genuine affection and delight and are willing to be advocates of those differences.

Ask participants to identify where they are on the Riddle Scale below based on their attitude towards persons that have different values and lifestyles from their own, e.g. Men who have Sex with Men, Sex Workers, street people and drug users.

Invite participants to share, if they choose to do so. Encourage discussions among participants.





## Activity 2.5:

# Basic Principles of HIV Counselling and Helping

### Objective:

By the end of the activity, participants will:

- know the basic principles of HIV counselling
- learn important characteristics of a counsellor
- understand how failure to apply these principles can result in discrimination towards the client

### Materials

- Facilitator's guide
- Flip chart paper
- Markers
- Important information
- bristol board



1½ hours

### Facilitator's Instructions

- Share the important information with the participants

### Important Information

### Principles of HIV Counselling

**Objectivity:** There should be neutral and genuine desire to help. The counsellor's opinions or views should not be imposed on the client.

**Privacy:** The information shared in a counselling session should be kept private so as to protect the client's right to intimacy and respect.

**Confidentiality:** Absolute discretion about the information shared in the interview.

- Ask participants to identify the principles that they have used when offering counselling to someone before
- Ask them to identify which of these they use less or have never used



### Characteristics of a Good Counsellor

#### Group Exercise

- Organise the participants into groups in a creative and fun manner
- Give each group some markers, a sheet of bristol board and ten strips of bristol board and ask them to draw a counsellor on the sheet of bristol and on each of the strips to write one characteristic of a good counsellor
- When they have finished, ask each group to put its finished project on the wall so that the others can observe their counsellor and the characteristics
- Next, using flip chart paper or slides make a brief presentation on the characteristics which a good counsellor should possess, emphasising how important it is for the counsellor to have these characteristics





## Activity 2.5:

# Basic Principles of HIV Counselling and Helping

### Important Information

#### Characteristics of a Good Counsellor

**Empathy:** To be able to put oneself in another's place or shoes. It is to experience how the other person feels in the specific situation.

**Unconditional Positive Regard:** To be able to transmit acceptance without judgement even though you may not be in agreement with the attitude or behaviour of the client.

**Respect:** To allow the freedom of expression, not to impose, invade or force one's own opinion or points of view.

**Discretion:** To maintain all information shared by the client in the strictest confidentiality at all times with the exception of suicide, homicide or some form of abuse.

**Understanding:** To accept the different values and attitudes of clients who have different backgrounds and experiences.

**Sociability:** To respond warmly to the needs of the other persons and to relate with a level of personal satisfaction with the different types of clients, ages, backgrounds and personalities.

**Flexibility:** To be open to the unexpected, to changes in opinion or decisions on the part of the client and to be tolerant of different behaviours.

#### In Summary, a Good Counsellor:

- Is open-minded (does not condemn or judge): Accepts the clients without prejudice or judgement
- Is honest: Tells the client the truth. Does not try to ease the pain by lying to the client
- Is discreet (confidential): Respects the privacy and confidentiality of information shared
- Is empathetic: Has the capacity to see situations from different perspectives; can put himself/herself in the place of another
- Is responsible: Commits to the client and the counselling relationship to offer quality service and to help the client make the best, informed decisions

#### Tips for the Facilitator

Emphasise that there is a difference between advice-giving and counselling. Advice-giving is not a good counselling practice. Persons need to be empowered to come up with their own solutions to their problems.

#### Confidentiality Issues in HIV Counselling

**Start off this session by explaining the following:** People Living with HIV (PLHIV) often face discrimination, stigmatisation and isolation. They may lose their jobs or be rejected by their families. This is why confidentiality in HIV counselling is so vital. This session enables participants to become aware of the discrimination that may affect People Living with HIV and the importance of maintaining client confidentiality.





## Activity 2.5: Basic Principles of HIV Counselling and Helping

**Step 1:** Ask participants to brainstorm about what is meant by the term “confidentiality.” Possible responses: secret, private matters, firm trust.

**Step 2:** Ask participants to think about an incident in their own life when somebody failed to keep a secret of theirs or broke a promise.

**Step 3:** Ask for a volunteer to share this experience with the group. Ask the volunteer to reflect on how this betrayal of confidence felt.

- What was the promise that was broken or the secret that was betrayed?
- How did you feel about what happened?
- What did you feel about the person who told the secret or broke the promise? Did the person apologise?
- Would you confide in the same person again?

**Step 4:** Discuss the following questions:

- If you were diagnosed with HIV, would you want other people to know about it? Why or why not?
- What would happen if there were NO one whom you trusted?
- What could be some of the consequences if a counsellor talked to others about a client’s HIV status?
- Why is confidentiality so important in HIV counselling?

**Step 5:** Emphasise that information that is shared between counsellor and client must never be shared with another person unless the client gives you the authority to do so. Present the following scenario:

*“The husband of one of the regular members of your Faith-Based Organisation tells you that he recently found out that he is HIV-positive. He doesn’t want to tell his wife about his HIV status and doesn’t want to use condoms with her because he is afraid that will make her suspicious. You are worried that he will give HIV to his wife if she doesn’t already have it. As a counsellor, you have a professional obligation to maintain the confidentiality of the husband. Should you tell the wife that her husband is HIV-positive?”*

Discuss strategies for handling this type of situation.

There is no “correct” answer for how to handle this difficult situation. A counsellor could work on convincing the husband of the importance of protecting his wife. He/she could introduce him to somebody who is HIV-positive who has infected a family member and have this person share how this made them feel.

**Step 6:** Summarise the session by re-emphasising the importance of confidentiality in the counsellor-client relationship.



# Unit 3

## Gender, Sex and Human Sexuality







## Unit 3:

# Gender, Sex and Human Sexuality

### Materials

- Facilitator's guide
- Flip chart paper
- Markers
- Paper and pen for participants



Time

5½ hours

### Purpose

The purpose of this unit is to provide participants with an opportunity to explore gender, sex and sexuality and how perceptions of these contribute to stigma and discrimination.

### Activities

This unit provides activities that explain the difference between gender and sex. Activities also highlight how religious, cultural and traditional beliefs contribute to gender stereotyping and lead to stigma and discrimination. They also provide opportunities to discuss the link between gender and HIV. This section also includes discussions on the different components of human sexuality using the Circle of Sexuality diagram, which shows that sex is only one component of human sexuality. The unit concludes with a discussion on religion and sexuality, which provides an opportunity to explore human sexuality from a religious perspective. Studies have shown that some religious organisations are reluctant to address the issue of HIV from a gender and human sexuality perspective.

This unit opens an opportunity to begin this very important dialogue in addressing HIV and AIDS and the factors that contribute to stigma and discrimination within religious settings and the larger community as a whole.

**Duration: Total of 5½ Hours**





## Activity 3.1: Gender Versus Sex

### Objective:

By the end of the activity, participants will:

- understand the difference between gender and sex
- learn how stereotypes lead to stigma and discrimination

### Materials

- Facilitator's guide
- Flip chart
- Markers
- Important information



1½ hours

Source: IRH/Georgetown University VCT Training Manual, 2006

### Facilitator's Instructions

1. Make three columns on a large sheet of paper. Label the first column 'Woman' and leave the other two blank.
2. Ask participants to identify personality traits, abilities and roles (attributes) that are often associated with women. These may include stereotypes that are common in the participants' communities or their own ideas.
3. Next, label the third column 'Man' and ask participants to again make a list of personality traits, abilities and roles that are often associated with men.
4. If participants do not give any negative or positive traits, abilities or roles for either sex, add some to ensure that both columns include positive and negative words.
5. If the participants do not mention any biological characteristics, (such as breasts, beard, penis, vagina, menopause) add some to the two columns.
6. Now, reverse the headings of the first and third columns by writing 'Man' above the first column and 'Woman' above the third column. Working down the list, ask the participants whether men can exhibit the characteristics and behaviours attributed to women and whether women can exhibit those attributed to men. Those attributes usually not considered interchangeable are placed into the middle column that is then labelled 'Sex'.
7. To save time, it is not necessary to discuss each term separately. Participants can simply be asked whether there are any terms in the lists which cannot be reversed. However, make sure that all the words that belong in the 'Sex' column are discussed.
8. Expect participants to debate the meanings of some words – one of the goals of this exercise is to demonstrate that people assign different meanings to most characteristics that are gender-based. So don't feel surprised or frustrated by the debates that occur.

### Tips for the Facilitator

Be prepared to handle discussions on different types of sexuality. It can be useful to distinguish 'sexual orientation' from gender. If necessary, provide simple definitions related to sexual orientation, using a large sheet of paper or the overhead transparency. Point out that no matter what a person's sexual orientation is, he/she is influenced by social expectations regarding his/her behaviour and roles according to his/her biological sex.





## Activity 3.1: Gender Versus Sex

### Important Information

1. Share the important information.

**Sex** refers to the biological characteristics that define humans as female or male.

**Gender** refers to the economic, social and cultural attributes and opportunities associated with being male or female at a particular point in time.

### What are Gender Roles?

- They are ideas about how men and women should behave
- They are created by society, culture and traditions
- As they grow up, girls and boys learn about how women and men should behave from their parents, community, religious institutions, schools and media
- Gender roles are given differently for people of different ages – for example young girls may be given very different tasks and levels of responsibility from their grandmothers
- Gender roles vary from one society to another and change as society changes
- Because gender roles are created by society, it is possible to change them

### Why are Gender Roles Important?

- Ideas of gender roles – how girls and boys, men and women should behave – affect all our relationships, especially our sexual ones
  - Gender roles affect if and when persons have sex, whom they have sex with and if they protect themselves against pregnancy and Sexually Transmitted Infections
2. Use examples to illustrate how gender roles are assigned by society and how they can be unfair at times. For example, women and girls are supposed to be weak and submissive, while boys are supposed to be strong and in control. Many times this leads to abuse of girls and women by men.
  3. Next, divide the group into small groups of five to six.
  4. Once you have the groups divided, ask them to sit in a circle. Then, provide each group with two flip chart papers and markers. They should use one sheet of paper to write all the tasks that they know are done by girls and women. On the other paper they should write all the roles they know for boys or men.
  5. After all the groups have finished, have them share their lists with the large group. Have a discussion on gender roles and how sometimes these can be unfair and discriminatory of one gender or the other and make women more vulnerable to HIV.





## Activity 3.2: Let's Talk About Sexuality

### Objective:

By the end of the activity, participants will:

- deepen their understanding of human sexuality
- discuss human sexuality, HIV and stigma

Source: *Life Planning Education, 1996*

### Materials

- Facilitator's guide
- Important information
- Flip chart and markers



Time

1½ hours

### Activity 3.2.1 Sexuality 101

#### Facilitator's Instructions

- Explain that in this session participants will explore definitions of and messages about sexuality. Let them know that it is normal for some persons to feel embarrassed and uncomfortable. Point out that in our society we hear about sexuality all the time on the television, radio, magazines and movies, but people don't often have serious discussions about the subject
- Write the word "Sexuality" on the board or on flip chart/chalkboard paper. Make sure you write it as large as possible
- Divide the participants into three groups. Tell them that they will spend some time talking about what they have heard about sexuality. Provide each group with flip chart/chalkboard paper and markers
- Give the following directions:

1. Group 1 will list what their parents told them about sexuality.
2. Group 2 will list what their friends told them about sexuality.
3. Group 3 will list what they have heard about sexuality in their Faith-Based Organisations (FBOs).

After about fifteen minutes, ask participants to post their flip chart papers on the wall and share their lists with the group.

- Conclude the activity by discussing the following points in a large group

#### Discussion Points

- How are the messages from family, friends and religion different? Why do you think that is so?
- Which messages do you agree with? Disagree with?
- Can you think of any sexuality messages you have heard somewhere else, for example, teachers, religious teachings or media?
- Which of these messages would make a person feel uncomfortable talking about sexuality?





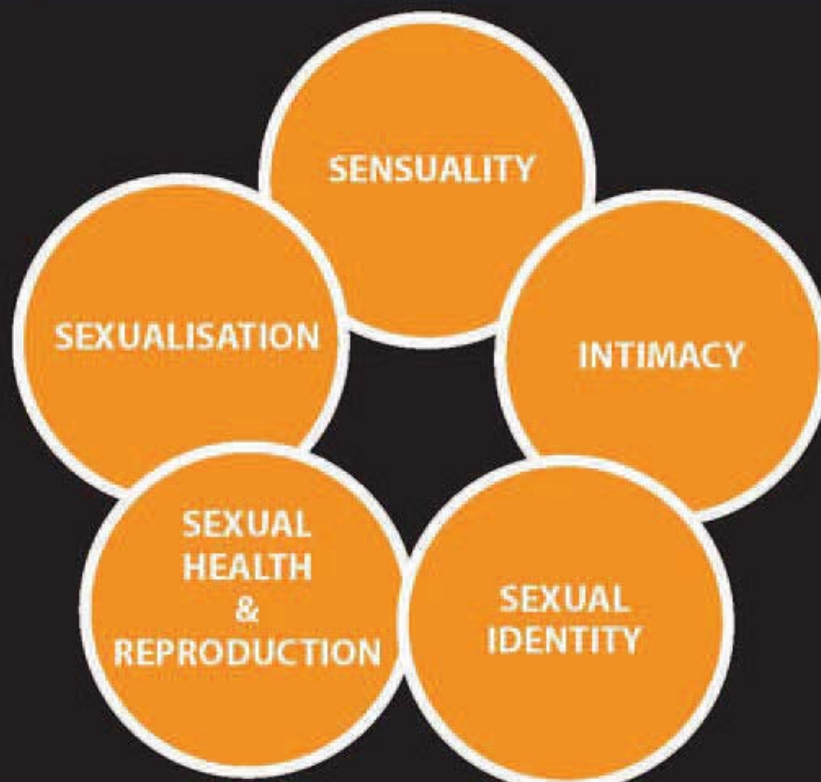
## Activity 3.2: Let's Talk About Sexuality

### Activity 3.2.2: The Circles of Sexuality

#### Facilitator's Instructions:

- Make a generalisation about the points that the participants presented in the previous activity. If many of the messages were about genital sexual behaviour, (such as intercourse, reproduction or contraception) make a note of that
- Explain that many times when people think of sexuality they think of 'Sex' or some sexual activity. Tell them that sexuality is more than just sexual intercourse and sexual feelings. Sexuality is an important part of who a person is and will become. We are all sexual beings. Sexuality includes all feelings, behaviour, thoughts of being male and female, being attractive, being in a relationship, being in love, as well as being in a relationship that includes physical sexual activity and intimacy
- Next, write the word "Sexuality" on a flip chart/chalkboard paper or on the board and draw a box around the letters S- E -X. Point out that S, E and X are only three letters in the word "Sexuality." Display the circles of sexuality and give each participant one of the handouts. Explain that sexuality is made up of five different components: sensuality, intimacy, identity, reproduction and "sexualisation". Everything related to sexuality fits into one of these circles
- Beginning with the circle labelled "sensuality", explain each circle briefly. Take five minutes to read the definition of each circle and explain its elements and ask for examples that would fit in the circles. Write them in the circles and ask the participants to write them on their handouts

#### Circles Of Sexuality





## Activity 3.2:

# Let's Talk About Sexuality

### Important Information

#### Sensuality

Awareness, acceptance of and comfort with one's own body; physiological and psychological enjoyment of one's body and the bodies of others.

This involves: body image, human sexual response cycle, skin hunger, and fantasy.

#### Intimacy

The ability and need to experience emotional closeness to another person and have it returned.

This involves: caring, sharing, loving, liking, risk-taking and vulnerability.

#### Sexual Identity

The development of a sense of who one is sexually, including a sense of femaleness and maleness.

This involves: bias, gender identity, gender role and sexual orientation.

#### Sexual Health and Reproduction

Attitudes and behaviours related to producing children, care and maintenance of the sex and reproductive organs and health consequences of sexual behaviours.

This involves: Factual information, feelings and attitudes, intercourse, physiology, anatomy and sexual and reproductive health.

#### Sexualisation

The use of sex to influence, control or manipulate others.

This involves: rape, incest, sexual harassment, withholding sex, seduction, flirting.

End the activity with the following discussion points:

- Which of the five circles seems the most familiar? Why do you think that is so?
- Is there any part of these circles that you never thought of as being sexual?
- Which circle is most important for you and your friends to know about?
- Which circle would you like to discuss with your parents?





## Activity 3.2: Let's Talk About Sexuality

### Adolescent Sexual and Reproductive Health

Share the following information with the participants and encourage discussions.

#### Sexual development:

- Is a normal part of adolescence
- Fortunately, most adolescents go through these changes without significant problems. Nonetheless, all adolescents need support and care during this transition to adulthood and some need special help

#### The main issues in adolescent sexual and reproductive health are:

- Sexual development and sexuality (including puberty)
- Sexually Transmitted Infections, HIV and AIDS
- Unwanted and unsafe pregnancies

#### The reasons that adolescents are at risk include:

- Social and economic environment
- Information and skills
- Access to health services

#### Social and economic environment:

- For many adolescents, sex is linked with violence and abuse – sometimes even by family members or adults who should be trustworthy
- In some communities, women are conditioned to be submissive to men and they find it difficult or impossible to refuse early marriage, to space births, or to refuse to have unprotected sex with an unfaithful spouse or partner

#### Information and skills:

Many adolescents are poorly informed about sexuality and reproduction.

Often policy-makers, religious leaders and parents believe that withholding information about sexuality and reproduction from young people will dissuade them from becoming sexually active.

#### Access to health services:

Most adolescents (boys and girls, married and unmarried) become sexually active before the age of 20, but generally lack access to family planning services (including appropriate contraceptives), prevention and care of Sexually Transmitted Infections, or pregnancy care.

### Tips for the Facilitator

End off this session by emphasizing that all young persons have sexual and reproductive rights but young persons must be reminded that with rights come responsibilities.





## Activity 3.3:

# Cultural Beliefs: Gender and Sexuality

### Objective:

By the end of the activity, participants will:

- increase their understanding of the influence of culture on gender and sexuality
- discuss how this perception leads to discrimination

### Materials

- Facilitator's guide
- Important information
- Flip chart paper
- Markers



Time

1½ hours

**Start off the session by sharing the following important information with participants:**

### Important Information

Cultural beliefs and traditional practices many times influence the way people behave towards persons that are different from the "norm". Persons who do not fit into the expectations of society and culture are many times marginalised, discriminated and labelled as "abnormal".

Many times these cultural and traditional expectations are based on beliefs that are not grounded in the reality of human sexuality and human rights to freedom of expression. Persons who refuse to fit into the "mould" which society has created for them as men or women, for example, are seen as "outcasts." Gender stereotypes and roles assigned by society lead to discrimination against persons who do not abide by these expectations. When it comes to HIV, marginalised populations such as MSM and Sex Workers, who are most times stereotyped and discriminated against, will not access life-saving information and services for fear of discrimination and rejection.

### Facilitator's Instructions

- Ask participants to get back into their groups (as previous small group activity). Provide each group with flip chart paper. Ask them to make a copy of the matrix "How do we become men?" or "How do we become women?" using their flip chart paper
- Ask participants to discuss the questions and fill in the matrix on the basis of their own experiences and observations. For example, did anyone ever tell them, "Big boys don't cry!" or, "Nice girls don't sit like that," or were car keys and late curfews given to adolescent boys while girls were not allowed out of the house at night?
- Participants should compare the expectations placed on a thirty-year-old woman (which might include that she should be married and raising children) versus a man of the same age (which might include that he should be earning money or establishing a career)

The groups have twenty minutes to fill out the matrix on a flip chart paper and prepare to present it to the group.







### Activity 3.3:

## Cultural Beliefs: Gender and Sexuality

### Messages and Teachings Influenced by Culture

Life Stage	Biological characteristics that mark us as men	Messages and teachings we received from our families and communities so that we become men
Childhood		
Adolescence		
Adulthood		
Life Stage	Biological characteristics that mark us as women	Messages and teachings we received from our families and communities so that we become women
Childhood		
Adolescence		
Adulthood		



## Activity 3.4: The Heterosexual Questionnaire

### Objective:

By the end of the activity, participants will:

- be sensitised to the feelings of sexually diverse groups by responding to questions about their heterosexuality

### Materials

- Facilitator's guide
- Copies of heterosexual questionnaire



1 hour

**Provide participants with a copy of the questionnaire and ask that they answer as honestly as possible.**

1. What do you think caused your heterosexuality?
2. When and how did you first decide you were a heterosexual?
3. Is it possible your heterosexuality is just a phase you may grow out of?
4. Is it possible your heterosexuality stems from a neurotic fear of others of the same sex?
5. Isn't it possible that all you need is a good gay lover?
6. If you've never slept with a person of the same sex, how do you know you wouldn't prefer that?
7. To whom have you disclosed your heterosexual tendencies? How did they react?
8. Your heterosexuality doesn't offend me, as long as you don't try to force it on me.
9. The great majority of child molesters are heterosexuals. Do you really consider it safe to expose your children to heterosexual teachers?
10. Why do you insist on being so obvious and making a public spectacle of your heterosexuality? Can't you just be what you are and keep it quiet?
11. How can you ever hope to become a whole person if you limit yourself to a compulsive, exclusive heterosexual object choice and remain unwilling to explore and develop your normal, natural, healthy, God-given homosexual potential?
12. With all the societal support marriage receives, the divorce rate is spiralling. Why are there so few stable relationships among heterosexuals?
13. There seem to be very few happy heterosexuals. Have you considered aversion therapy?
14. Do heterosexuals hate and/or distrust others of their own sex? Is that what makes them heterosexual?

- Ask participants how they felt being asked the question. Did they find the questions to be silly, unnecessary and ridiculous? Encourage discussions
- Explain to participants that these are questions that many times are asked of gays, lesbians, bisexuals and transgendered persons. Encourage discussion



# Unit 4

## HIV and Human Rights





## Unit 4:

# HIV and Human Rights

### Materials:

- Facilitator's guide
- Flip chart paper
- Markers
- Paper and pen for participants



Time

4 hours

### Purpose

The purpose of this unit is to provide participants with an opportunity to learn about human rights and how violation of these leads to discrimination against marginalised populations, such as People Living with HIV.

### Activities

According to UNAIDS Reference Group on HIV and Human Rights, for many reasons, now more than ever, greater attention to human rights is essential to an effective response to HIV. Such increased attention, it argues, is necessary to attain universal access to HIV prevention, treatment, care and support, itself a human rights imperative.

The activities in this unit seek to create awareness about human rights within the legal and institutional framework for People Living with HIV and other marginalised groups. They seek to familiarise participants about in-country mechanisms available to protect and provide recourse for infringement of those rights. The unit calls attention to the fact that the human rights of marginalised groups (Sex Workers, people who use drugs, Men who have Sex with Men, prisoners, street walkers, etc.) must also be respected and fulfilled for the response to HIV to be effective. The activities specifically focus on human rights from a scripture perspective looking at how, sometimes, religious taboos and sanctions infringe on these rights. It provides an opportunity for participants to reflect on this reality and identify ways in which their beliefs and religious practices might be violating the rights of others. Participants also have an opportunity to discuss how rights and responsibilities can be presented to the larger society from a religious perspective.

This unit forms the foundation for the remaining activities in the toolkit since a rights-based approach to HIV and life in general is a key component in the multi-sectoral response to HIV in the region.

**Duration: Total of 4 Hours**





## Activity 4.1:

# What are Human Rights?

### Objective:

By the end of the activity, participants will:

- develop an understanding of human rights
- learn how these rights are expressed

### Materials

- Facilitator's guide
- Important information
- Flip chart paper and markers



1½ hours

### Facilitator's Instructions

1. Ask each participant to list the things they need to live and record their responses.
2. Review the list and ask participants to separate their needs from their rights; for example, someone needs a car and someone has the right to clean water. Include rights not mentioned.
3. Ask each participant to identify the rights that are not accessible to them and share what it means to him/her if he/she is unable to access these rights.
4. Have participants talk about the things that prevent them from obtaining these rights.
5. Have participants take turns talking about what are the most important rights for them.
6. Tell the group that the rights that they identified are called human rights, which are rights inherent to all human beings, whatever our nationality, place of residence, sex, national or ethnic origin, colour, religion, language, or any other status. We are all equally entitled to our human rights without discrimination.
7. Have participants think and talk about how human rights are expressed.
8. Summarise and explain that Universal Human Rights are often expressed and guaranteed by law, in the forms of treaties, customary international law, general principles and other sources of international law. International human rights law lays down obligations of governments to act in certain ways or to refrain from certain acts, in order to promote and protect human rights and fundamental freedoms of individuals or groups.
9. Share with the group that human rights are inalienable (absolute). They should not be taken away, except in specific situations and according to due process. For example, the right to liberty may be restricted if a person is found guilty of a crime by a court of law.
10. Close by asking participants to think and talk about how the awareness of these rights has helped them to deal with stigma and discrimination.



### Tips for the Facilitator

Emphasise the point that with rights come responsibilities. In the same manner that all human beings can exercise their rights, they also must be responsible for their actions and their consequences.





## Activity 4.2:

# Human Rights from a Scriptural Perspective

### Objective:

By the end of the activity, participants will:

- have an opportunity to discuss human rights and entitlements in relation to HIV from a scriptural perspective

### Materials

- Facilitator's guide
- Flip chart paper
- Markers



Time

1½ hours

## Facilitator's Instructions

### How do some of the relevant rights apply?

- Share the objective of this activity with the group. Mention that participants will have an opportunity to discuss the different human rights from their scriptural perspectives
- Inform participants that the Political Declaration on HIV and AIDS, United Nations 2006, provides guidance about how the relevant rights must be applied. Tell them that you will present this activity in the form of an interactive presentation
- You might wish to use an overhead projector, or provide participants with copies of the presentation for them to follow if you do not have access to a projector
- You might encourage participants to stop and ask questions or seek clarification as you make the presentation. You can also employ adult teaching methodology by asking participants to read some sections of the presentation



## Rights Holders

To empower rights holders to claim their rights, to protect human dignity and to prevent the transmission of HIV, the following rights should be protected so that people will come forward for HIV information, education and means of protection and will be supported to avoid risky behaviour:

- **Non-discrimination:** protected against discrimination if seeking help or are HIV-positive
- **Right to privacy:** protected against mandatory testing; HIV status kept confidential
- **Right to liberty and freedom of movement:** protected against imprisonment, segregation, or isolation in a special hospital ward
- **Right to education/information:** access to all HIV prevention education and information, and sexual and reproductive health information and education
- **Right to health:** access to all healthcare prevention services, including for Sexually Transmitted Infections, tuberculosis, voluntary counselling and testing, as well as male and female condoms



## Activity 4.2:

# Rights of Vulnerable Populations

Divide the large group into five groups and assign one HIV right to each of the groups. Have each group discuss the right assigned to them from an HIV perspective and then from a scriptural perspective. Participants can discuss what scripture says about the right.

### PLHIV

For those living with HIV or otherwise affected by it, the following rights should be protected:

- **Non-discrimination and equality before the law:** right not to be mistreated on the basis of health status, i.e. HIV status
- **Right to health:** right not to be denied healthcare/treatment on the basis of HIV status
- **Right to liberty and security of person:** right not to be arrested and imprisoned on the basis of HIV status
- **Right to marry and found a family:** regardless of HIV status
- **Right to education:** right not to be expelled from school on the basis of HIV status
- **Right to work:** right not to be fired on the basis of HIV status
- **Right to social security, assistance and welfare:** right not to be denied these benefits on the basis of HIV status
- **Right to freedom of movement:** regardless of HIV status
- **Right to seek and enjoy asylum:** regardless of HIV status

In a large group read each right and ask participants to discuss each right based on their scriptural beliefs and practices.

### Vulnerable Populations

Depending on the legal and social situation and the nature of the epidemic in-country, some groups may be more vulnerable to infection and impact because of their legal status or lack of human rights protection, e.g. women, children, minorities, indigenous people, poor people, migrant-workers, refugees, Sex Workers, people who use drugs, Men who have Sex with Men, street people including street children and prisoners.

These groups should have equal access to HIV prevention information, education and commodities, as well as to HIV care, support and anti-retroviral treatment; should not be subjected to sexual violence or coercion, where applicable and should be able to participate in the formulation and implementation of HIV and AIDS policies that affect them.

- **Non-discrimination/equality before the law:** same access as others to services
- **Rights to education and health:** same access to HIV prevention education and information and healthcare services, including STI services and condoms
- **Liberty, security of person and freedom from cruel, inhuman and degrading treatment:** freedom from violence, including sexual violence, freedom from mandatory testing
- **Right to participate in public life:** participation in the formulation and implementation of HIV policy

In a large group read each right and ask participants to discuss each right based on their scriptural beliefs and religious practices. Participants should be encouraged to express their opinions freely.

Close by inviting participants to share how this activity helped them to understand the application of human rights to HIV and overall scriptural view of rights.





## Activity 4.3:

# In-Country Mechanisms for Protection of Rights

### Objective:

By the end of the activity, participants will:

- be able to identify the in-country mechanisms for protecting rights of PLHIV

### Materials

- Facilitator's guide
- Important information
- Flip chart paper
- Markers



Time

1 hour

### Facilitator's Instructions

1. Share the objective of the activity with the group.
2. Ask participants to reflect on Activity 4.1: "What are Human Rights?"
3. Ask participants to think and talk about how they can access those rights in their countries. Participants should mention in-country mechanisms available if they are aware of their existence.
4. Ask if anyone in the group had reported acts of discrimination and sought redress through any of the mechanisms and encourage them to share their experiences, if they are comfortable doing so.
5. After participants have shared, add any mechanisms available in-country that participants left out or might not be aware of. Ensure that you tell them where these mechanisms are located and how they can access them. At this time you could also provide participants with copies of a list of in-country mechanisms. These may include the following:
  - Human Rights desks
  - Workplace policy
  - Legislation – non-discrimination provision within the employment law
  - HIV-related reporting and redress system
  - Formal legal services
  - Programmes to ensure adequate training in non-discrimination
  - Informed consent and confidentiality for healthcare workers
6. Close by emphasising that it is the right of participants to report acts of discrimination and seek redress through in-country mechanisms in the event that they believe that their rights have been infringed.

### Tips for the Facilitator

Mention to participants that HIV anti-stigma toolkits have been developed to inform and sensitise policy-makers and legislators to the needs of People Living with HIV and other marginalised groups.





# Unit 5

## Advocacy





## Unit 5:

# Advocacy

### Materials

- Facilitator's guide
- Flip chart paper
- Markers
- Paper and pen for participants



4 hours

### Purpose

The purpose of this unit is to familiarise participants with the process of advocacy. The unit seeks to motivate them to become advocates by supporting and enabling marginalised populations to express their views and concerns, access information and services, defend and promote their rights and responsibilities and explore choices and options.

### Activities

The activities in this unit seek to enable participants to better understand advocacy, the different forms that it can take and identify the types of advocacy to facilitate their meaningful involvement in claiming and protecting the rights of PLHIV and other vulnerable populations. Participants have an opportunity to understand the concept of advocacy and learn practical ways in which they and their Faith-Based Organisations can be HIV advocates in their community setting. The activities explore the Faith-Based Organisation and AIDS paradigm. This provides an opportunity for exploring the role of the Faith-Based Organisations in the field of HIV which is many times equated with sin. It will especially provide an opportunity for religious leaders to compare how far they will go in HIV advocacy. This discussion will allow them to appreciate that Faith-Based Organisations will be different in the level of involvement that they are prepared to exercise in the area of HIV advocacy. It will especially highlight how far they will go to advocate on behalf of PLHIV and Most-At-Risk Populations.

The unit also familiarises participants with the Faith-based Response HIV Guidelines developed by the Caribbean Conference of Churches. This document provides Faith-Based Organisations with practical guidelines for developing and/or reviving HIV action plans and policies.

### Duration: Total of 4 Hours





## Activity 5.1:

# The FBO and AIDS Paradigm

### Objective:

By the end of the activity, participants will:

- deepen their understanding of HIV and the FBO
- discuss the challenges of embracing HIV from an FBO perspective

### Materials

- Facilitator's guide
- Quotations
- Flip chart paper
- Markers



1½ hours

Source: Arnau van Wyngaard Swaziland Reformed FBO, 2006

### Facilitator's Instructions

- Place a chair in the front of the room and ask each participant to describe what it is. Explain that each participant was looking at the same chair and describing it in their own way based on their experiences, opinions and point of view. Explain that with HIV it's the same way. Different persons see it from different perspectives. FBOs also view HIV from a specific perspective and thus, respond and deal with it accordingly. A paradigm is a mental map. It's a lens through which reality is viewed
  - Divide the large group into four groups. Assign one quotation to each of the groups. Explain to participants that the quotations are taken from an article entitled the *Scripture of HIV/AIDS*
  - Ask each group to assign a leader and a reporter. Each group should read and discuss the quotation and decide as a group if they agree or not with the quotation and provide reasons for their decision. Groups can also report that they were divided in their opinions
1. "We could not have designed a more frightening disease if we had tried. If we could play at being Satan for the day, charged with the task of designating an epidemic to undermine the developed and underdeveloped countries of the world at the end of the 20th century, then the blueprint for the design would incorporate many of the features of AIDS." (Connor & Kingman, quoted in Saayman & Kriel 1991:154).
  2. "... we cannot speak of Africa without speaking about HIV. I want to go one step further and say that we can no longer speak about the FBO without speaking about HIV. This then forms the motivation for the theme of this paper: Towards a Scripture of HIV and AIDS. Why a scripture of HIV and AIDS? Is it justified to formulate a scripture for every crisis with which the world is faced? Obviously not. However, at times a crisis develops which has the potential for such devastating consequences throughout the world that it becomes necessary for the FBO to respond to that crisis, not only practically, but also scripturally. Throughout history there have been times when the FBO has had to respond in a special way to a particular crisis." (Arnau van Wyngaard Swaziland Reformed FBO, 2006).
  3. McDonagh (1994:3) argues that "HIV and AIDS raise no new questions about God. However, it raises old questions in a new form on the relation between human suffering and God's presence. Some people consider HIV and AIDS simply as God's punishment for mankind's sin." (Van der Walt 2004:6-8; Douma 1987:31-34; Clifford 2004:3). "From Biblical times the question has been raised whether sickness or suffering could somehow be the direct result of sin."
  4. During the Global Consultation on AIDS (World Council of FBOs 2001:2) it was said: "Our difficulty in addressing issues of sex and sexuality has often made it painful for us to engage in any honest and realistic way with issues of sex education and HIV prevention. For years the FBO has warned against the evil of sexual immorality, of pre- and extra-marital sexual relations, but perhaps too little has been done to enable Christians to celebrate the gift of human sexuality that God has given to us."





## Activity 5.2:

# What is Advocacy?

### Objective:

By the end of the activity, participants will be able to:

- define what advocacy is
- identify what forms it can take
- determine what the best ways are to go about it

### Materials

- Facilitator's guide
- Important information
- Flip chart
- Markers



1½ hours

### Facilitator's Instructions

Ask three volunteers to pretend that they are standing in line to pay a bill or purchase something. Another volunteer is asked to just arrive and move to the front of the line. Ask participants to state how they would deal with this person. Explain that they can all do some form of advocacy on behalf of the person who should have been at the front of the line, as well as for themselves.

1. From the scenario presented, ask participants to share what they understand advocacy to be.
2. Ask participants to identify the types of situations in which advocacy may be able to assist People Living with HIV and other marginalised groups. Participants should come up with scenarios such as the following:

- Other people (including service providers) have an obligation that they are not fulfilling
- Persons rights are being ignored or violated
- Persons have a responsibility that is particularly difficult for them to carry out
- They are being misunderstood or are having trouble understanding others

3. Ask each participant to share why advocacy is important. Summarise and clarify participants' responses. Here are some more reasons why advocacy is so important:

- Advocacy makes sure that there is recognition of the rights of People Living with HIV and other Most-At-Risk populations
- Advocacy can change community attitudes and misconceptions
- Advocacy can help you have control over your situation
- It ensures that you have a voice and that it will be heard
- It can also promote positive change to the structure and policy of organisations, which will be of benefit to people with HIV and other Most-At-Risk populations
- Advocacy can help make service providers and organisations accountable, ensuring there is transparency in their actions and decisions
- It can assist people to gain access to resources, funding and information

4. Close by asking participants to share how the activity deepened their understanding of advocacy.

### Tips for the Facilitator

Emphasise that Faith-Based Organisations can serve as advocates for People Living with HIV in addition to providing them with care, support and spiritual guidance.





## Activity 5.3: Who is an Advocate?

### Objective:

By the end of the activity, participants will be able to:

- understand the role of an advocate
- identify the different types of advocacy

### Materials

- Facilitator's guide
- Flip chart paper
- Markers



### Facilitator's Instructions

1. Ask participants to say who an advocate is. An advocate is someone who campaigns on your behalf on an issue.
2. Ask participants to share what some of the roles and responsibilities are that an advocate would undertake. Participants' responses should include:
  - To speak on your behalf, or to help you speak for yourself
  - An advocate has no interest in telling you what to do, but will aim to help you identify what you want and how best to get it
  - An advocate can help you get the information you want or need
  - An advocate may be able to help you challenge people who make unfair assumptions about you, or who treat you with disrespect
  - An advocate can help you recognise and make good use of your own skills and strengths, while also providing help in areas where you may require it
3. Share with the group that there are three main types of advocacy.
  - **Individual Advocacy** is when the advocate concentrates his/her efforts solely on advocating for one or two people. The advocate could be a staff member of an organisation, a caregiver, family member, friend or volunteer. This type of advocacy is focused on the specific needs or situation surrounding the individual or person with a disability
  - **Systemic Advocacy** is primarily concerned with influencing and changing the 'system' in general (such as legislation, policy and practices) in ways that will benefit people with a disability as a group. Systemic advocates will encourage overall changes to the law, service policies, government and community attitudes. This form of advocacy does not usually involve individual advocacy, as it can cause a conflict of interest around the resources that are being generated and the purpose of the advocacy in general
  - **Self Advocacy** is similar to individual advocacy, except it is undertaken by a person or group of people on behalf of themselves. If it is a group of people self-advocating, they typically share the same characteristics, interests, or needs
4. Divide the large group into three groups and ask them to present a role-play depicting one of the types of advocacy. They may be encouraged to use other creative ways and not just role-plays.
5. Close by sharing that each person can be an advocate for himself/herself. Identifying and utilising your own strengths and skills is a talent in itself and can create a real sense of empowerment and achievement.

### Tips for the Facilitator

Ask participants if they feel they could be advocates for People Living with HIV, as well as other marginalised groups.





## Activity 5.4:

# FBOs as Advocates: Practical Guidelines

### Objective:

By the end of the activity, participants will:

- learn about the important role of FBOs as advocates
- become familiar with the Caribbean Conference of FBOs' guidelines for policies and action plans
- determine what their FBO is prepared to do

Source: Caribbean Conference of FBOs, 2005

### Materials

- Facilitator's guide
- Flip chart
- Markers
- Important information



1½ hours

## Facilitator's Instructions

- Start off by sharing the important information on the Caribbean Conference of FBOs

The Caribbean Conference of Churches (CCC) is the regional ecumenical organisation formed by Faith-Based Organisations in the Caribbean. Its role is to serve the Faith-Based Organisations in the cause of unity, renewal and joint action. The CCC is also one of the major development agencies at work in the region today.

The Caribbean Conference of Churches (CCC) spearheads the regional faith-based response to HIV and AIDS in the region. The CCC has conducted consultations with Faith-Based Organisations (FBOs) on an HIV and AIDS Policy and Action Plan document entitled, *Guidelines for Caribbean Faith-Based Organisations in Developing Policies and Action Plans to Deal with HIV and AIDS*.

- Mention to the participants that this document focuses on priority areas of HIV and provides guidelines for Faith-Based Organisations' involvement and participation
- Read this section which focuses on guidelines on human rights and advocacy and encourage discussions among the participants

## Human Rights and Advocacy

1. Take a lead role in the discussions in the society at large, on ethical issues posed by HIV and AIDS.
2. Support members who face difficult ethical choices in the areas of prevention and care.
3. Outline, study and promote the human rights of People Living with HIV through mechanisms at the national, regional and international levels.
4. Help safeguard the rights of persons affected by HIV and AIDS.
5. Agitate for workplace policies which do not discriminate negatively against people affected by and infected with HIV
6. Lobby for the implementation of laws which protect those infected with and affected by HIV and AIDS.
7. Advocate for justice, removal of stigma and discrimination, through Faith-Based Organisations' action and examples.
8. Advocate for access to medical care and treatment.
9. Advocate for increased spending by governments and medical facilities to find solutions to the problems – both medical and social, raised by the pandemic.





## Activity 5.4:

# FBOs as Advocates: Practical Guidelines

10. Recognise the linkage between AIDS and poverty and advocate measures to promote just and sustainable development.
11. Condemn discrimination and stigmatisation of PLHIV.
12. Involve PLHIV in management of the organisation and the development of programmes.
13. Care for PLHIV.

Now, engage the participants in a discussion based on these questions for consideration.

### Leadership

1. Does your Faith-Based Organisation have any established programmes for the education of its leaders on HIV issues?

### Prevention

1. Is your Faith-Based Organisation actively seeking to prevent the spread of HIV among its membership?
2. Do you have a stated responsibility for such prevention in the wider community?

### Care, Support and Counselling

1. Does your Faith-Based Organisation have a policy on confidentiality, including the question of disclosure of HIV and AIDS statuses of persons who are part of its membership?
2. Does your Faith-Based Organisation have any established programmes for the training of its leaders on HIV and AIDS issues, including care and support and counselling?

### Human Rights and Advocacy

1. Does your Faith-Based Organisation advocate for the rights of HIV-positive persons in the work place and in the wider society?
2. Does your organisation's policy on death and final rites consider the right of people with HIV to dignified final rites?
3. Does your Faith-Based Organisation address issues of gender relations, particularly as related to women and their vulnerability to HIV?

### Education

1. Does your Faith-Based Organisation have a policy on sex education and specifically on matters pertaining to HIV?



# Unit 6

## Empowerment







## Unit 6:

# Empowerment

### Materials:

- Facilitator's guide
- Flip chart paper
- Markers
- Paper and pen for participants



7 hours

### Purpose

The purpose of this unit is to equip participants with the knowledge and skills to work towards the empowerment of marginalised populations.

### Activities

There are a number of social and economic factors that increase people's vulnerability to HIV infection and put certain groups at greater risk, especially Men who have Sex with Men, Sex Workers and people who use injecting drugs. Stigma and discrimination, poverty, lack of HIV awareness and access to education, health and other services are all factors that make these populations engage in risky behaviours, such as unprotected sex or exchange of contaminated needles that put them at higher risk of becoming infected. This section provides an opportunity to discuss documented stories and best practices of the work of Faith-Based Organisations in addressing the issue of HIV stigma and discrimination in the region and the world. Participants have an opportunity to discuss the different approaches taken by these Faith-Based Organisations to overcome the challenge of addressing stigma and discrimination within the Faith-Based Organisation sector, as well as learn ways in which they can replicate this success within their own Faith-Based Organisations.

The activities in this unit also seek to enable participants to better understand the value of empowerment. They have an opportunity to understand the different components of empowerment for vulnerable populations. This section specifically focuses on methods of assessing needs and providing support to PLHIV and other vulnerable populations. The activities in this section look at bridging the gap between knowledge and behaviour change; setting up a support group, providing care and support to PLHIV, as well as providing skills training for vulnerable populations. These activities also include a focus on caring for the caregiver, which helps persons within Faith-Based Organisations who are providing care to deal with "burn-out". This section especially highlights the GIPA approach, which includes the greater involvement of PLHIV as empowered individuals who can make decisions for themselves and moves away from the misconception of PLHIV as helpless victims. Faith-Based Organisations can empower PLHIV to make their own choices and decisions and help them find solutions to their health and social problems independently. Additionally it is hoped that both individually and collectively they will work toward reducing stigma and discrimination. This unit identifies vulnerable populations as People Living with HIV, Men who have Sex with Men, Sex Workers, drug users and street walkers.

**Duration: Total of 7 hours**





## Activity 6.1:

# Best Practices and Success Stories

### Objective:

By the end of the activity, participants will be:

- familiar with some FBO best practice cases
- learn best approaches from success stories in the region that can be adapted within their FBOs

### Materials

- Facilitator's guide
- Flip chart
- Markers
- Important information



Time

1½ hours

## Facilitator's Instructions

Explain to participants that much can be learnt from the successful initiatives undertaken by other Faith-Based Organisations. Best practices provide ideas, insight and motivation for other Faith-Based Organisations to become involved in addressing stigma and discrimination.

Divide the group into four and assign each of them one of the best practices or success stories below. Ask each group to review the best practice or success story and identify ways in which they can adapt the best practice into the work of their Faith-Based Organisations. Have each group present a summary of their discussions to the larger group.

## Best Practices

### Case #1

**Source** Abstract Booklet of Best Practices – SANASO Conference

**Country** South Africa

**Subject group** Stigma and Faith-Based Organisation

**Organisation** Christian Health Care

**Title** Reduction of Stigma and Discrimination associated with HIV using Biblical Principles.

### Objectives

- To provide spiritual, medical care and appropriate support to those infected and affected by HIV and AIDS
- To provide advocacy to those who cannot speak for themselves for the rights of all who are infected and affected by HIV and AIDS
- To encourage greater involvement of people living with AIDS in community activities
- To collaborate/network with individuals, groups, companies or government whose actions or policies affect those infected and affected by HIV and AIDS

### Methods

- Psychosocial and spiritual counselling: Using examples from the Bible on how Jesus interacted with people who had similar diseases, such as leprosy
- Advocacy: Speaking up on behalf of those with HIV who are being stigmatised or discriminated against





## Activity 6.1: Best Practices and Success Stories

### Methods (continued)

- Capacity-building: Encouraging people to take action on reducing stigma and discrimination by empowering them with adequate information and appropriate skills
- Campaigning: Telling others about the situation in a way that encourages them to take action, e.g. through preaching the Word of God
- Prayer: Praying for God to change the hearts and attitude of people towards those infected and setting time at regular intervals to look back and consider how effective our actions have been

### Results

- 50 home-based care providers have been trained
- 250 homes have been visited over a period of one year
- 50 HIV-positive clients have been visited and counselled
- No cases of separation or divorce associated with HIV and AIDS have been reported

### Conclusion

The problem of stigma and discrimination against HIV continues to be source of worry in our community. Unless people are fully aware of the mode of transmission and prevention and begin to talk about it freely and take bold steps to know their HIV status, all efforts aimed at reducing stigma and discrimination will prove difficult.

### Case #2

<b>Source</b>	Caribbean Conference of Churches, 2005
<b>Country</b>	Caribbean Region
<b>Subject group</b>	Faith-Based Organisations and HIV
<b>Organisation</b>	Caribbean Conference of Churches

A project undertaken with the financial support of the Government of Canada provided through the Canadian International Development Agency (CIDA) ESAC Programme implemented by the Caribbean Conference of Churches (CCC).

### Background

The Caribbean Conference of Churches (CCC) is engaged in a collaborative relationship with the Canadian International Development Agency (CIDA), in the implementation of a three-year regional HIV Project entitled: "Building a Faith-Based Response to HIV/AIDS in the Caribbean". The goal of the project is to mobilise and enhance the response of Caribbean Faith-Based Organisations (FBOs) to the HIV epidemic.

Through this project, the CCC seeks to facilitate the formation of a strategic alliance among Caribbean FBOs to combat HIV/AIDS. The countries engaged in the project are Antigua and Barbuda, Anguilla, Barbados, Bahamas, Belize, Dominica, Grenada, Guyana, Jamaica, St. Kitts and Nevis, St. Vincent and the Grenadines, Suriname and Trinidad and Tobago.

Aspects of the project include: Baseline study and assessment of existing FBO HIV initiatives in each of the 14 target countries, workshops to educate Caribbean Clergy and lay persons on HIV issues, establishment of home-based care models in selected countries; creation of a seed fund to support FBO work in HIV and the development of the guidelines for the preparation of policies and action plans to deal with HIV and AIDS.





## Activity 6.1: Best Practices and Success Stories

The Policy and Action Plan Document entitled, *Guidelines for Caribbean Faith-Based Organisations in Developing Policies and Action Plans to Deal with HIV and AIDS*, was presented to 83 participants from Faith-Based Organisations throughout the 14 Caribbean countries. The consultation was held at the Umana Yana, Georgetown, Guyana during the period January 17-19, 2005. Participants in their debate agreed that there was the need for broader engagement on issues related to HIV and AIDS by religious leaders and theologians and that collaboration among leaders of all Faith-Based Organisations needs to take place.

### Case #3

<b>Source</b>	Abstract Booklet of Best Practices – SANASO Conference
<b>Country</b>	Zambia
<b>Subject group</b>	Stigma and Faith-Based Organisations
<b>Organisation</b>	Reformed FBO in Zambia
<b>Title</b>	Stigma and Faith-Based Organisations
<b>Objectives</b>	To reduce stigma and discrimination experienced by PLHIV and those affected within the FBO and communities at large.
<b>Methods</b>	<ul style="list-style-type: none"><li>• Promote a wide distribution of creative education and training programmes designed to combat the attitudes associated with stigma and discrimination with a view to bringing understanding and acceptance</li><li>• Promote counselling skills training for leaders</li><li>• To promote language which is non-discriminatory and non-judgemental</li></ul>
<b>Results</b>	<ul style="list-style-type: none"><li>• People Living with HIV will not encounter fear, discrimination and rejection</li><li>• Protection of PLHIV human rights</li></ul>

### Conclusions

The FBO as the Faith-Based Organisation is there to see to it that PLHIV and the affected are not discriminated against, stigmatised and blamed on the basis of behaviour.

### Case #4

<b>Source</b>	Nancy Muturi International Journal of Communication 2 (2008)
<b>Country</b>	Jamaica
<b>Subject group</b>	Faith-Based Organisations and HIV
<b>Title</b>	FBO HIV Initiatives in Jamaica





## Activity 6.1:

# Best Practices and Success Stories

### Background

FBOs play a major role in healthcare, providing care and support for those with health and medical needs in their communities. Many of them have responded to the HIV/AIDS epidemic through various ways in recent years and others struggle with the impact of the epidemic.

FBO contributions in Jamaica range from offering prayers and other spiritual or psychological support through counselling and other forms of communication for prevention and behavioural change, to direct care and support through medical support and other forms of assistance in meeting the basic needs among those infected with and affected by the AIDS virus. Respondents interpreted this role of FBOs as caring for body and soul, which is a more comprehensive way of dealing with the epidemic. However, as Green (2003) points out, most of the FBO efforts are not systematically documented.

### Social and Psychological Support

Jamaican FBOs have been central in the provision of physical, social, and psychological support to those affected by HIV and AIDS and other illnesses. In all the focus group discussions, members indicated going to their religious leaders and asking for prayers once diagnosed with any kind of illness. PLHIV focus groups stressed the role of prayers in helping them cope particularly in the early days post-diagnosis. This statement implies the role of spirituality in diverting destructive behaviour, whether directed to oneself or others by failing to reveal their status or to use protection. These findings support what Duggan (2006) argues, that enacted social support, or intentional acts conveying concern, aid, or information can buffer individuals from negative effects or stress and enhance health and well-being.

### Spiritual Healing

In addition to prayer, spiritual or faith healing is one of the FBO initiatives for Jamaica and practiced widely across the wider Caribbean. This practice is deeply rooted in the Jamaican culture where the crucial role spirituality plays in people's health is widely acknowledged within FBOs. A majority of respondents emphasised the power of prayer and faith in healing regardless of the nature of the disease demonstrating the role of prayer in AIDS cure.

Though the island is predominantly Christian, faith healing exists across religions. Embedded within Jamaican folk religions is the belief in spiritual healing and the supernatural powers that reside within their spiritual leaders (Obeah men and women), root doctors and herbalists, especially within practices derived from African rituals carried over from Africa through slavery and by African immigrants (Barrett, 1976; Patrick & Payne-Jackson, 1996). The Jamaican practices of Myal, Kumina, Pukumina, Convince and the Zion Revivalists utilise faith healing widely. The Rastafarians, a Jamaican folk religion that believes in the Bible, also practise spiritual healing. Healing in these religions takes the form of music, drumming and exorcism, prayers, laying-on of hands, and baptism (Barrett, 1976; Chevannes, 1995).

Traditional healers use magic, herbs, and exorcism in the treatment of HIV and AIDS, but the Christians rely on prayer and spiritual healing by the anointed leaders. The general view was that religious leaders had a role in the healing process. There is, however, recognition that not all leaders have been "anointed" or have the healing power and not everyone believes in faith healing. Several leaders acknowledged their lack of power, but they indicated their strong beliefs in the role spirituality plays in healing.





## Activity 6.2:

# Empowerment of Vulnerable Populations

### Objective:

By the end of the activity, participants will:

- understand what vulnerability is
- identify vulnerable populations to HIV
- discuss ways of reducing vulnerabilities

### Materials

- Facilitator's guide
- Flip chart
- Markers
- Important information



Time

1 hour

### Facilitator's Instructions

1. Ask participants what the word 'vulnerable' means to them. Possible responses are: capable of being physically or emotionally wounded; open to attack or damage. (Webster's Dictionary)
2. Ask participants to define the term 'population'. Possible responses are: the whole number of people or inhabitants in a country or region; the total of individuals occupying an area or making up a whole and a body of persons or individuals having a quality or characteristic in common. (Webster's Dictionary)
3. Ask participants to share what circumstances can make individuals vulnerable. These may include:
  - financial circumstances, including collapse of the world's economy
  - place of residence
  - illegal residence in another's country
  - state of health
  - age
  - inability to communicate effectively
  - presence of chronic or terminal illness or disability
  - personal characteristics
  - populations less able than others to safeguard their own needs and interests adequately
  - natural disasters such as hurricanes, earthquakes and floods
  - ethnicity
  - fire
  - loss
4. Have participants spend time discussing the circumstances above and then share their thoughts in relation to them. If it is not mentioned, share that unexpected circumstances can change our lives forever. Therefore, anyone of us can become vulnerable, whether HIV-positive or -negative people, gay or straight, Sex Worker or sexually active person, alcoholic or social drinker, street walker or homeless. We are vulnerable to the declining socioeconomic situation in the world.
5. Say to participants that having established that all of us are vulnerable, we must decide what can be done to to reduce vulnerability.
6. Divide participants into three groups and have them think and talk about vulnerability and what they can do about it. Ask each group to appoint a facilitator, scribe and a presenter. Tell them they have thirty minutes for the activity and five minutes each for presentations. Have each group present. Allow ten minutes for questions at the end of all of the presentations.





## Activity 6.3: The Role of PLHIV Support Groups

### Objective:

By the end of the activity, participants will:

- identify and discuss the role of the PLHIV Support Groups
- gather ideas for establishing support groups within their FBOs

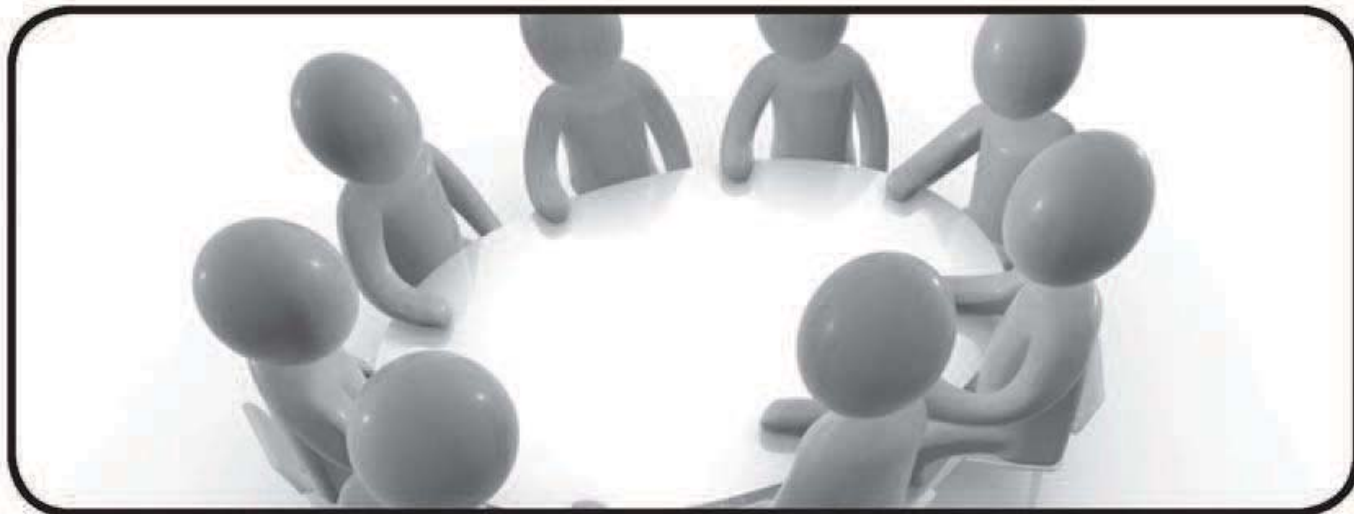
### Materials

- Facilitator's guide
- Flip chart
- Markers
- Important information



Time

1½ hour



### Facilitator's Instructions

1. Share the name and the objective of the activity with participants. Ask participants to indicate by a show of hands whether they know what the purpose of a support group is.
2. Ask a few participants who raised their hands to share what a support group is; what they do and if they have established a support group for PLHIV within their organisations. Summarise participants' responses and share the following.

### Support Groups: What they are and what they do

- Support groups are a place for people to give and receive both emotional and practical support, as well as to exchange information
  - People with health conditions, as well as their families and friends, find support groups to be a valuable resource – a place where people can share medical information, get confirmation that their feelings are "normal", educate others, or just offload
  - When searching for a support group, the single most important thing to remember may be; if the group doesn't feel right for you or doesn't match your needs, try a different group. There are many options available
3. Have a few participants state why they believe PLHIV should join a support group. Summarise their responses and share the following.





## Activity 6.3:

# The Role of PLHIV Support Groups

### Why should PLHIV be a part of a support group?

- Support groups are made up of people with common interests and experiences. People who have been through, or are going through, a similar circumstance can do more than sympathise with you – they can relate to what you are going through and keep you from feeling like you are alone
- However, many people are unaware of the additional benefits of joining a support group – support groups can be a great place to find practical tips and resources. At many support groups you can find:
  - Information about medical treatments, research and strategies (through brochures, booklets, websites, telephone help lines and person-to-person sharing in the group meetings)
  - Information about public policy, legal resources, privacy laws and protection from discrimination
  - Social support, including vocational skills training, income-generating activities, nutritional support, day care, legal aid, etc.

After they have shared, ask participants to brainstorm what a good support group should look like. Record their responses on flip chart. Summarise, then add any points left out from the list below.

### What to look for in a good support group

- A clearly stated confidentiality policy
  - Provision of up-to-date, reliable information
  - Prompt response to request for assistance and queries
  - Regular meetings at convenient times
  - Access to professional support (for example, doctors, counsellor for emotional support, or employment attorneys for workplace discrimination)
  - Strong leadership
  - Particular qualities the individual is seeking (for example, a group for PLHIV, or a group that includes affected family and friends)
  - A place where you feel welcome
  - A place where people talk about issues and feelings rather than about each other's business
  - A place where you feel empowered
  - A place where your contributions are listened to and respected
4. Tell participants to take turns sharing what they learnt as a result of this activity and if this activity has encouraged and motivated them to establish support groups for PLHIV in their organisations.
  5. Close by sharing that active participation and a sense of self-belonging are fundamental for the success of a PLHIV support group. Furthermore, PLHIV are the ones to decide the best direction for the group. Instead of traditional health education programmes designed by medical doctors, peer PLHIV add the necessary information that allows them to meet PLHIV's own needs.

### Tips for the Facilitator

You may wish to familiarise yourself with the role of PLHIV support groups before facilitating this activity. You may wish to make copies of Appendix 5: Roles of PLHIV Support Groups for distribution to participants. Remind participants that confidentiality is important in a support group among members and others providing support.







## Activity 6.4:

# Knowledge and Behaviour Change: Bridging the Gap

### Objective:

By the end of the activity, participants will be able to:

- assess their ability to change and identify the steps for changing behaviour
- discuss ways in which they can make changes based on what has been learnt about stigma and discrimination

### Materials

- Facilitator's guide
- Flip chart
- Markers
- Important information



Time

1½ hours

1. Inform participants that this activity will give them an opportunity to think about and assess their ability to change any given behaviour. This will require that participants assess the importance of changing their behaviour and their confidence that they can do so.
2. Ask participants, on a scale of one to ten, how important behaviour change is to them. Discuss the responses.
3. Ask participants, on a scale of one to ten, how confident they are that they can change their behaviour. Discuss the responses.
4. Ask participants to reflect silently on behaviour that they had tried to change and formulate silent responses to the following questions:
  - What was the habit or behaviour you tried to change?
  - What made you decide to change that behaviour?
  - Were there good things you thought would happen if you did change? What were they?
  - What steps did you take to change your behaviour?
  - Had you tried to change this behaviour before? What happened then?
  - Were there things that made it hard to change? (barriers)
  - Were there things that made it easier? (facilitators)
  - Were you successful in changing behaviour, and if so, how long did it take?
5. After participants have reflected on the questions, ask one or two participants who are comfortable sharing to tell the group which behaviour they had changed or attempted to change. Ask them to share in relation to the questions above.
6. Explain that there are five stages of behaviour change and ask participants to identify them: pre-contemplation, contemplation, preparation, action and maintenance.
7. Share that there are both barriers and facilitators to change and that these can be personal, social and environmental, and provide examples from the experiences participants shared.
8. Ask participants to share what they learnt about behaviour change from this activity.





## Activity 6.5:

# Caring for the Caregiver

### Objective:

By the end of the activity, participants will:

- realise that sometimes caregiver burn-out can lead to discrimination
- understand the importance of caring for the caregiver

### Materials

- Facilitator's guide
- Flip chart paper
- Markers
- Important information



Time

1½ hours

### Facilitator's Instructions

Share with participants that as caregivers it is important that they also take care of themselves. Share the following important information with them. Provide opportunity for feedback and discussions.



### Important Information:

#### The Concept of Caring

This concept is exemplified by doing "the little things that mean a lot".

- Take time to show that you care. Give support; touch, talk to your client
- Keep the client informed about matters pertaining to his/her care
- Be cheerful and approachable
- Greet and address your client by name when you want to carry out a procedure
- Be aware of the client's emotional and spiritual needs and allow time to ventilate them
- Do unto others as you would have them do unto you

#### On Entering the Client's Home

The client's home is not a general healthcare facility. Conduct yourself as a guest in the home.

- Call your client by name, e.g. Miss/Mrs./Mr. Smith not "darling", "sweetheart", etc. The same respect is due to the client's family
- Always maintain confidentiality
- Avoid giving your client's telephone number to anyone and do not use your client's telephone to make personal calls
- Avoid confrontation, do not argue with your client or family and use reasoning as appropriate
- When speaking to your client or the client's family, do not become familiar by "swapping experiences"
- Avoid gossiping with other family helpers and family members. Do not join in family misunderstandings





## Activity 6.5:

# Caring for the Caregiver

### Confidentiality

Confidentiality in client care has to do with restricting the use of personal information gained while interacting with the client, as care is delivered. It is the obligation owed by one person to another not to disclose information obtained by or about another, or the obligation to disclose it only in limited circumstances.

Breaching of confidentiality for People Living with HIV carries serious consequences such as stigmatisation, isolation, job and housing loss and financial stress.

In small, close-knit societies such as exist in the Caribbean, where everybody seems to know his/her neighbour's business, the caregiver must strive to protect the right to confidentiality of the client and the family.

### Suggestions for the Caregiver

1. Choose to take charge of your life and don't let your client's illness or disability always take centre stage.
2. Remember to be good to yourself. Love, honour and value yourself. You're doing a very hard job and you deserve some quality time, just for you.
3. Watch out for signs of depression and don't delay in getting professional help when you need it.
4. When people offer to help, accept the offer and suggest specific things that they can do.
5. Educate yourself about the client's condition. Information is empowering.
6. There's a difference between caring and doing. Be open to technologies and ideas that promote your client's independence.
7. Trust your instincts. Most of the time they'll lead you in the right direction.
8. Grieve for your losses and then allow yourself to dream new dreams.
9. Stand up for your rights as a caregiver and a citizen.
10. Seek support from other caregivers. There is great strength in knowing you are not alone. Join a local support group for caregivers.

### Coping with Fears

- Deal with personal fears related to the job. Confront your fears and talk about them in a supportive environment
- Fear of infection – obtain accurate information about infection, cross-infection and infection control and practise the measures identified
- Fear of burn-out – seek counsel and support. Find time for rest, recreation and spiritual sustenance
- Fear of a dying or dead person – ask for help, give excellent care to your client, especially in the area of personal hygiene and spiritual support; encourage friends and family who want to be a part of this significant moment in the client's life, to be present for the transition



# Appendices



# Appendix 1:

# HIV 101: Getting Down to Basics

US Centers for Disease Control & Prevention

## What's the Difference Between HIV and AIDS?

HIV stands for Human Immunodeficiency Virus. Let's break it down:

**H**uman – Meaning only humans can contract this strain of the virus

**I**mmunodeficiency – Affecting the immune system and causing it to weaken

**V**irus – A microorganism that multiplies inside a host organism's cell

HIV is a virus that we know causes AIDS. It enters the body and infects immune system cells, as well as other cells in the body, causing more copies of the virus to be produced. By contrast, AIDS stands for Acquired Immune Deficiency Syndrome:

**A**cquired – It happens to people who already have been infected with HIV

**I**mmune – Affecting the immune system

**D**eficiency – Weakening

**S**yndrome – A collection of symptoms that indicate a disease

An AIDS diagnosis is given by a doctor. People get an AIDS diagnosis only when they meet a specific set of criteria. For example, their white blood cell (CD4+ cells) count is below 350 or they have been diagnosed with several opportunistic infections.

Not everyone with HIV has AIDS. But everyone diagnosed with AIDS has HIV.

## How is HIV Transmitted?

- HIV is spread by sexual contact with an infected person
- by sharing needles and/or syringes (primarily for drug injection) with someone who is infected
- through transfusions of infected blood or blood clotting factors
- Babies born to HIV-infected women may become infected before or during birth or through breastfeeding after birth

Some people fear that HIV might be transmitted in other ways, however, no scientific evidence to support any of these fears has been found. If HIV were being transmitted through other routes (such as through air, water, or insects), the pattern of reported AIDS cases would be much different from what has been observed. For example, if mosquitoes could transmit HIV infection, many more young children and preadolescents would have received a positive diagnosis.



# Appendix 1:

# HIV 101: Getting Down to Basics

## Which Body Fluids Contain HIV?

HIV is found in varying concentrations or amounts in the following:

- Blood
- Semen
- Vaginal fluid
- Breast milk

HIV has been found in saliva and tears in very low quantities from some persons with AIDS. It is important to understand that finding a small amount of HIV in a body fluid does not necessarily mean that HIV can be transmitted by that body fluid. Contact with saliva, tears, or sweat has never been shown to result in transmission of HIV. HIV has not been recovered from the sweat of HIV-infected persons.

## How Can HIV Transmission Be Prevented?

### Abstinence

An abstinence-based approach to sex education focuses on teaching young people that abstaining from sex until marriage is the best means of ensuring that they avoid infection with HIV, other Sexually Transmitted Infections and unintended pregnancy.

### Be faithful

The practice of fidelity within marriages and other sexual relationships. However, both partners need to be faithful.

### Condom use

The proper and consistent use of latex or polyurethane (a type of plastic) condoms when engaging in sexual intercourse – vaginal, anal, or oral – can greatly reduce a person's risk of acquiring or transmitting Sexually Transmitted Infections, including HIV infection. For condoms to provide maximum protection, they must be used consistently (every time) and correctly.

### Kissing

Casual contact through close-mouthed or social kissing is not a risk for transmission of HIV. Because of the potential for contact with blood during "French" or open-mouthed kissing, this should be avoided with persons whose HIV status you do not know.

### In Households

Although HIV has been transmitted between family members in a household setting, this type of transmission is very rare. These transmissions are believed to have resulted from contact between skin or mucous membranes and infected blood. To prevent even such rare occurrences, precautions, as described in previously published guidelines, should be taken in all settings – including the home – to prevent exposures to the blood of persons who are HIV-infected, at risk for HIV infection, or whose infection and risk status are unknown. For example:



## Appendix 1:

# HIV 101: Getting Down to Basics

- Gloves should be worn during contact with blood or other body fluids that could possibly contain visible blood, such as urine, faeces, or vomit
- Cuts, sores, or breaks on both the caregiver's and patient's exposed skin should be covered with bandages
- Hands and other parts of the body should be washed immediately after contact with blood or other body fluids and surfaces soiled with blood should be disinfected appropriately
- Practices that increase the likelihood of blood contact, such as sharing of razors and toothbrushes, should be avoided
- Needles and other sharp instruments should be used only when medically necessary and handled according to recommendations for healthcare settings. (Do not put caps back on needles by hand or remove needles from syringes. Dispose of needles in puncture-proof containers out of the reach of children and visitors.)

### Businesses and Other Settings

There is no known risk of HIV transmission to co-workers, clients, or consumers from contact in industries such as food service establishments. Food service workers known to be infected with HIV **need not be restricted from work** unless they have other infections or illnesses (such as diarrhoea or Hepatitis A) for which any food service worker, regardless of HIV infection status, should be restricted. CDC recommends that all food service workers follow recommended standards and practices of good personal hygiene and food sanitation.

In 1985, CDC issued routine precautions that all personal service workers (such as hairdressers, barbers, cosmetologists, and massage therapists) should follow, even though there is no evidence of transmission from a personal service worker to a client or vice versa. Instruments that are intended to penetrate the skin (such as tattooing and acupuncture needles as well as ear-piercing devices) should be used once and disposed of or thoroughly cleaned and sterilised. Instruments not intended to penetrate the skin but which may become contaminated with blood (for example, razors) should be used for only one client and disposed of or thoroughly cleaned and disinfected after each use. Personal service workers can use the same cleaning procedures that are recommended for healthcare institutions.

### HIV Cannot Be Transmitted by Insects

From the onset of the HIV epidemic, there has been concern about transmission of the virus by biting and bloodsucking insects. However, studies conducted by researchers at CDC and elsewhere have shown no evidence of HIV transmission through insects, even in areas where there are many cases of AIDS and large populations of insects. Lack of such outbreaks, despite intense efforts to detect them, supports the conclusion that HIV is not transmitted by insects.

The results of experiments and observations of insect biting behaviour indicate that when an insect bites a person, it does not inject its own or a previously bitten person's or animal's blood into the next person bitten. Rather, it injects saliva, which acts as a lubricant or anticoagulant so the insect can feed efficiently. Such diseases as yellow fever and malaria are transmitted through the saliva of specific species of mosquitoes. However, HIV lives for only a short time inside an insect and unlike organisms that are transmitted via insect bites, HIV does not reproduce (and does not survive) in insects. Thus, even if the virus enters a mosquito or another sucking or biting insect, the insect does not become infected and cannot transmit HIV to the next human it feeds on or bites. HIV is not found in insect faeces.



## Appendix 1:

# HIV 101: Getting Down to Basics

### What About HIV's Survival in the Environment?

Scientists and medical authorities agree that HIV does not survive well in the environment, making the possibility of environmental transmission remote. No one has been identified as infected with HIV due to contact with an environmental surface. Additionally, HIV is unable to reproduce outside its living host (unlike many bacteria or fungi, which may do so under suitable conditions), except under laboratory conditions, therefore, it does not spread or maintain infectiousness outside its host.

### Prevention for HIV-Positive Persons

Taking responsibility for preventing HIV transmission is an important concern for most people with HIV, as well as for their healthcare providers.

- Disclosing HIV status
- Reducing the number of sex partners
- Using condoms, particularly for anal or vaginal intercourse (insertive or receptive)
- Having sex only with other HIV-infected partners (sero-sorting)
- Avoiding drug use in conjunction with sex
- Using adequate lubrication to avoid trauma to genital or rectal mucosa
- Maintaining maximal suppression of HIV through anti-retroviral therapy

### Universal Precautions

Universal Precautions, as defined by CDC, are a set of precautions designed to prevent transmission of Human Immunodeficiency Virus (HIV), Hepatitis B Virus (HBV) and other blood-borne pathogens when providing first aid or healthcare. Under Universal Precautions, blood and certain body fluids of all patients are considered potentially infectious for HIV, HBV and other blood-borne pathogens. Universal Precautions apply to blood, other body fluids containing visible blood, semen, and vaginal secretions. Universal Precautions also apply to tissues and to the following fluids: cerebrospinal, synovial, pleural, peritoneal, pericardial and amniotic fluids. Universal Precautions do not apply to faeces, nasal secretions, sputum, sweat, tears, urine and vomit unless they contain visible blood. They do not apply to saliva except when visibly contaminated with blood or in the dental setting where blood contamination of saliva is predictable. Universal Precautions involve the use of protective barriers such as gloves, gowns, aprons, masks, or protective eyewear, which can reduce the risk of exposure of the healthcare worker's skin or mucous membranes to potentially infective materials. In addition, under Universal Precautions, it is recommended that all healthcare workers take precautions to prevent injuries caused by needles, scalpels and other sharp instruments or devices.





## Appendix 2:

# How Do Anti-retrovirals Work?

National Institute of Allergy and Infectious Diseases (NIAID)

### What is ARV Therapy?

ARV therapy means treating viral infections like HIV with drugs. The drugs do not kill the virus. However, they slow down the growth of the virus. When the virus is slowed down, so is HIV disease. Anti-retroviral drugs are referred to as ARV. ARV therapy is referred to as ART.

### What is the HIV Life Cycle?

There are several steps in the **HIV life cycle**.

1. Free virus circulates in the bloodstream.
2. HIV attaches to a cell.
3. HIV empties its contents into the cell (infects the cell).
4. The HIV genetic code (RNA) is changed into DNA (genetic material) by the reverse transcriptase enzyme.
5. The HIV DNA is built into the infected cell's DNA by the integrase enzyme.
6. When the infected cell reproduces, it activates the HIV DNA, which makes the raw material for new HIV viruses.
7. Packets of material for a new virus come together.
8. The immature virus pushes out of the infected cell in a process called "budding".
9. The immature virus breaks free of the infected cell.
10. The new virus matures. Raw materials are cut by the protease enzyme and assembled into a functioning virus.

### Approved Drugs

Each type, or "class", of ARV drugs attacks HIV in a different way. The first class of anti-HIV drugs was the nucleoside reverse transcriptase inhibitors, also called "nukes". These drugs work by blocking Step 4, where the HIV genetic material is converted from RNA into DNA. Drugs in use in this class include:

- AzT (SDV, zidovudine, Retrovir)
- ddI (didanosine, Videx)
- d4T (stavudine, zerit)
- 3TC (lamivudine, Epivir)
- Abacavir (ziagen)
- Tenofovir (Viread)
- Combivir (AzT/3TC combination)
- Trizivir (AzT/3TC/Abacavir combination)
- Emtricitabine (FTC, Emtriva)
- Epzicom (3TC/abacavir combination)
- Truvada (tenofovir/emtricitabine combination)

Another class of drugs blocks the same step of the life cycle, but in a different way. This class is the **non-nucleoside reverse transcriptase inhibitors**, or **NNRTIs**. These NNRTIs have been approved:

- Nevirapine (NVP, Viramune)
- Delavirdine (DLV, Rescriptor)
- Efavirenz (EFV, Sustiva, Stocrin)
- Etravirine (ETV, Intelence)



## Appendix 2:

# How Do Anti-retrovirals Work?

The third class of anti-retroviral drugs block Step 10, where the raw material for new HIV is cut into specific pieces. Ten protease inhibitors are being used:

- Saquinavir (SQV, Invirase)
- Indinavir (IDV, Crixivan)
- Ritonavir (RTV, Norvir)
- Nelfinavir (NFV, Viracept)
- Amprenavir (APV, Agenerase)
- Lopinavir (LPV, Kaletra, Aluvia)
- Atazanavir (ATV, Reyataz)
- Fosamprenavir (FPV, Lexiva)
- Tipranavir (TPV, Aptivus)
- Darunavir (DRV, Prezista)

A newer class of ARV drugs is **fusion and attachment inhibitors**. They prevent HIV from attaching to a cell by blocking Step 2 of the life cycle. Two drugs of this type have been approved:

- Enfuvirtide (Fuzeon or T-20)
- Maraviroc (MVC, Selzentry, Celsentri)

The newest type of ARV drug is the integrase inhibitor. It prevents HIV from combining its genetic code with the infected cell in Step 5 of the life cycle. The first drug of this type is:

- Raltegravir (RGV, Isentress)

### What's Next?

- New drugs are being developed in all five of the existing classes. Researchers are also trying to develop new types of drugs, such as ones that will block other steps in the HIV life cycle and drugs that will strengthen the body's immune defences.
- When a person is infected with HIV, the virus replicates rapidly during the first few weeks of infection and disseminates throughout the body, especially to the lymph nodes and related organs. The body's immune system fights back with killer T cells (CD8+ T cells) and antibodies, which dramatically reduce HIV levels. A person might then remain free of HIV-related symptoms for ten years or more, despite continuous replication of HIV.
- Researchers know that a number of factors can boost HIV replication during the course of HIV infection. Dr. Fauci's group and others have shown that other infections such as *M. tuberculosis*, as well as immunisations, activate immune system cells and increase production of the virus in HIV-infected people. Chronic immune activation due to persistent infections or the cumulative effect of multiple episodes of immune activation and bursts of virus production, likely contribute to the progression of HIV disease.

### How Are the Drugs Used?

When HIV multiplies, most of the new copies are mutations – they are slightly different from the original virus. Some mutations keep multiplying even when you are taking an ARV drug. When this happens, the drug will stop working. This is called “developing resistance” to the drug. If only one ARV drug is used, it is easy for the virus to develop resistance. But if two drugs are used, a successful mutant would have to “get around” both drugs at the same time. And if three drugs are used, especially if they attack HIV at different points in its life cycle, it's very hard for a mutation to show up that can resist all three drugs at the same time. Using a triple-drug combination means that it takes much longer for resistance to develop. For this reason, using just one ARV drug (monotherapy) or two drugs is not recommended.



## Appendix 2:

# How Do Anti-retrovirals Work?

### Can These Drugs Cure AIDS?

A blood test called the “viral load” measures the amount of HIV in your bloodstream. People with lower viral loads stay healthier longer. Some people’s viral load is so low that it is “undetectable” by the viral load test. This does not mean that the entire virus is gone. Researchers used to believe that ARV therapy could eventually kill off the entire HIV in the body. Now this seems unlikely. The drugs do not “cure” AIDS. However, they make it possible for people with AIDS to live a long time.

### When Do I Start?

There is not a clear answer to this question. Most doctors will consider three things: 1) your viral load; 2) your CD4 cell count; and 3) any symptoms you’ve had. ART is usually started if your viral load is over 100,000, if your CD4 cell count is below 350, or if you’ve had any symptoms of HIV disease.

### Which Drugs Do I Use?

Each ARV drug has side effects. Some are serious. Refer to the fact sheet for each individual drug. Some combinations of drugs are easier to tolerate than others and some seem to work better than others. Each person is different and you and your doctor will have to decide which drugs to use. The viral load test is now being used to see if ARV drugs are working. If the viral load does not go down, or if it goes down but comes back up, it might be time to change ARV drugs.

### ARV Side effects

National Institute of Allergy and Infectious Diseases (NIAID)

### Introduction

Treatment for most people can become an easy, routine part of life, so long as any side effects are managed effectively. This can involve treatment for the side effects, dose adjustments or changing to alternative HIV drugs. To get this you need to take your quality of life seriously and may need to become active in your own care. A minority of side effects can be extremely serious, so it is important to be able to know which of these are associated with different drugs.

### What are Side Effects?

Drugs are generally tested and licensed, to help with specific illnesses. When they affect the body in other ways, these are called side effects. They are also called adverse events or drug toxicity. The focus here is on unwanted side effects of HIV treatments. It is important to realise that many of the symptoms of side effects are similar to symptoms of illnesses. Different treatments are needed when related to illnesses.

### Do All Drugs Have Side Effects?

Most drugs have side effects of some sort, although in the majority of cases they are mild and easily manageable. All drugs have side effects, but not all people taking drugs will experience the same effects and to the same extent. Sometimes side effects are so mild that they are rarely noticed. Sometimes they only affect a small proportion of people that use the drug. Sometimes side effects only become apparent after the drugs have been licensed and approved, when many more people use them over a much longer period than the original studies.



## Appendix 2:

# How Do Anti-retrovirals Work?

### General Side Effects

Nausea (feeling sick), diarrhoea and tiredness are the most common side effects. These often become easier after the first few weeks. Very rarely, nausea and tiredness can be very serious. This is why you should tell your doctor of any problems. Ask your doctor or pharmacist for anti-nausea and diarrhoea medications when you first start therapy so you can use these if you need them. If these medications aren't effective, ask your clinic for stronger or more effective drugs. If this still doesn't help, you may be able to change your treatment.

### How to Report Side Effects

If you want your doctor to be able to understand your side effects and how they are affecting you, you will need to be able to describe them very clearly. This will be important for your doctor to check for other causes, (e.g. that diarrhoea is not related to food poisoning or low sex drive to low testosterone levels). The best way to do this is to keep a side effects diary from when you start a new treatment until you next see your doctor. You can keep a diary of your symptoms. The diary should include information about the following areas:

### Frequency

- How often do you get symptoms?
- Once or twice a week? Once every day or five to ten times a day etc?
- Do they occur at night, as well as during the day?

### Duration

- How long do the symptoms last?
- If you feel sick or get headaches, do they last for twenty minutes or for three to four hours, or for different times?
- Do they occur when you take your medications or at a regular time afterwards?

### Severity

- How bad are the symptoms?
- Often it helps to rate them on a scale (from 1 for very minor to 10 for very severe).
- A scale is a useful tool for describing anything that involves pain.
- Recording how severe side effects are when they occur is better than doing so later.
- Have you noticed anything that helps to reduce or stop them?

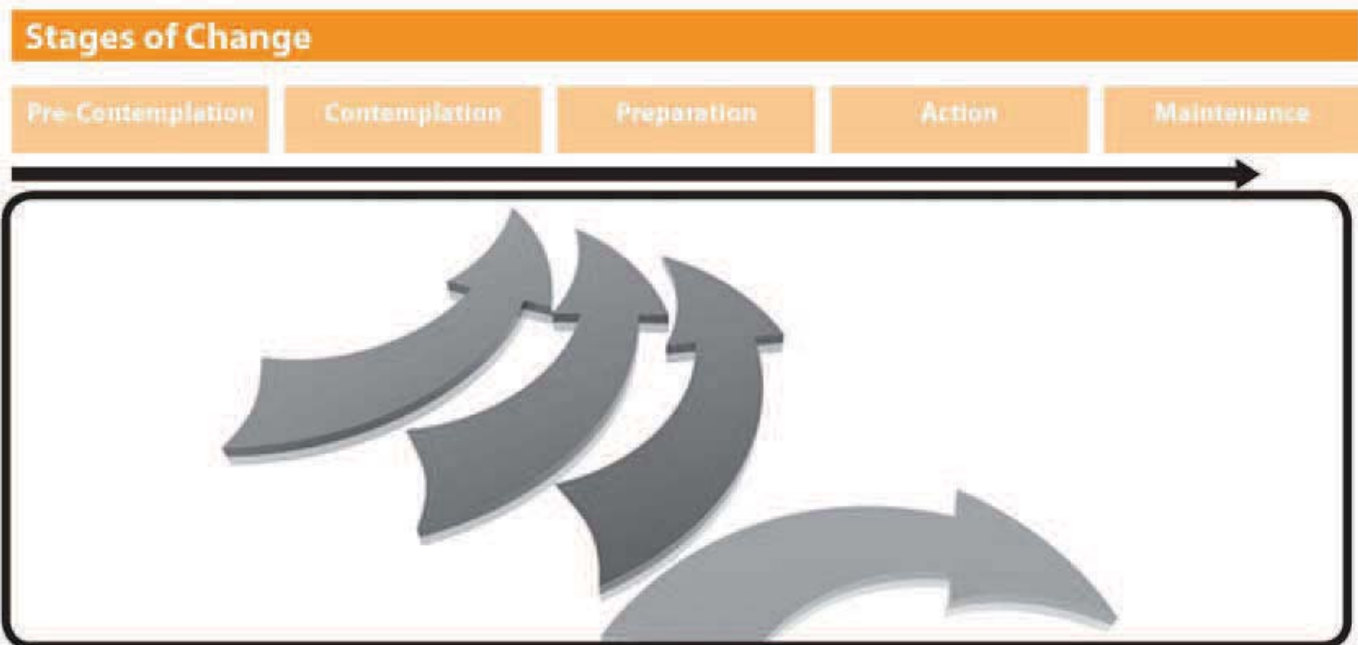
### Quality of Life

This can really help your doctor understand how difficult the side effects are for you. Many people put up with chronic diarrhoea without explaining to their doctor that it stops them even from going to the pub or the cinema. If you are feeling more anxious or nervous, are not sleeping properly, have a lower sex drive, have experienced taste changes, or are too nauseous to eat proper meals, it is important that your doctor understands this. If side effects are affecting adherence, i.e. you are not taking all your medication at the correct time and how you take your treatment, you must tell your doctor about this.



# Appendix 3: Behaviour Change

Dr. Joseph Petraglia, Behaviour Expert, USA



There are both barriers to and facilitators of behaviour change. Barriers and facilitators can be classified as personal, social and environmental.

- Knowledge
- Attitudes
- Beliefs
- Perceptions

**Self-efficacy:** is the belief in one's ability to perform a specific behaviour, as this belief, or lack thereof, will greatly influence success.

## Example

**High Self-efficacy:** "I know that if I put my mind to it, I can overcome self-stigma."

**Low Self-efficacy:** "I know that even if I tried, I could not overcome self-stigma."

**Self-efficacy** is behaviour-specific. High self-efficacy in terms of one behaviour does not mean high self-efficacy for other behaviours.

The outcome expectancy is another strong influence in the process of change. It is an individual's beliefs about the consequences of adopting a particular behaviour.



# Appendix 3:

## Behaviour Change

### Example

**Positive outcome expectancy:** "If I overcome self-stigma, I will be able to access care and treatment."

**Negative outcome expectancy:** "Even if I overcome self-stigma, I will be discriminated against, so why bother?"

An individual's risk perception is another factor that influences success or failure.

An individual's belief that a particular behaviour puts his/her health and well-being at risk.

### Example

**If one perceives risk:** "Not adhering to my treatment will cause me to experience treatment failure and will put my life at risk."

**If one does not perceive risk:** "Even if I don't adhere to my treatment, I will not get sick."

Like personal barriers, social and environmental barriers are influenced by a number of factors.

### Social Barriers and Facilitators

- Family
- Friends and peers
- Others in the community

### Environmental Barriers and Facilitators

- Availability of healthcare services
- Economic circumstances
- Mass media



# Appendix 4:

# HIV and Human Rights

Human Rights Watch

## What are Human Rights?

Human rights are rights inherent to all human beings, whatever our nationality, place of residence, sex, national or ethnic origin, colour, religion, language, or any other status. We are all equally entitled to our human rights without discrimination. These rights are all interrelated, interdependent and indivisible.

Universal human rights are often expressed and guaranteed by law, in the forms of treaties, customary international law, general principles and other sources of international law. International human rights law lays down obligations of governments to act in certain ways or to refrain from certain acts, in order to promote and protect human rights and fundamental freedoms of individuals or groups.

## Universal and Inalienable

The principle of universality of human rights is the cornerstone of international human rights law. This principle, as first emphasised in the Universal Declaration of Human Rights in 1948, has been reiterated in numerous international human rights conventions, declarations, and resolutions. The 1993 Vienna World Conference on Human Rights, for example, noted that it was the duty of States to promote and protect all human rights and fundamental freedoms, regardless of their political, economic and cultural systems. All States have ratified at least one and eighty per cent of States have ratified four or more of the core human rights treaties, reflecting consent of States, which creates legal obligations for them and gives concrete expression to universality. Some fundamental human rights norms enjoy universal protection by customary international law across all boundaries and civilisations.

## Interdependent and Indivisible

All human rights are indivisible, whether they are civil and political rights, such as the right to life, equality before the law and freedom of expression. Economic, social and cultural rights, such as the rights to work, social security and education, or collective rights, such as the rights to development and self-determination, are indivisible, interrelated and interdependent. The improvement of one right facilitates advancement of the others and likewise, the deprivation of one right adversely affects others.

## Equal and Non-discriminatory

Non-discrimination is a cross-cutting principle in international human rights law. The principle is present in all the major human rights treaties and provides the central theme of some international human rights conventions such as the International Convention on the Elimination of All Forms of Racial Discrimination and the Convention on the Elimination of All Forms of Discrimination against Women.

The principle applies to everyone in relation to all human rights and freedoms and it prohibits discrimination on the basis of a list of non-exhaustive categories such as sex, race, colour and so on. The principle of non-discrimination is complemented by the principle of equality, as stated in Article 1 of the Universal Declaration of Human Rights: "All human beings are born free and equal in dignity and rights."



# Appendix 4:

# HIV and Human Rights

## Both Rights and Obligations

Human rights entail both rights and obligations. States assume obligations and duties under international law to respect, to protect and to fulfil human rights. The obligation to respect means that States must refrain from interfering with or curtailing the enjoyment of human rights. The obligation to protect requires States to protect individuals and groups against human rights abuses. The obligation to fulfil means that States must take positive action to facilitate the enjoyment of basic human rights. At the individual level, while we are entitled our human rights, we should also respect the human rights of others.

## Legal and Institutional Framework for PLHIV

Stigmatising and discriminatory actions therefore, violate the fundamental human right to freedom from discrimination. In addition to being a violation of human rights in itself, discrimination directed at People Living with HIV or those believed to be HIV-infected, leads to the violation of other human rights, such as the rights to health, dignity, privacy, equality before the law and freedom from inhuman, degrading treatment or punishment. A social environment which promotes violations of human rights may, in turn, legitimate stigma and discrimination.

Ensuring the protection, respecting and fulfilment of human rights is one important way of combating AIDS-related stigma and discrimination. AIDS-related stigma and discrimination and their consequential human rights violations may be addressed through the use of existing human rights mechanisms. This existing framework provides a basis for accountability and an avenue for recognising and enforcing the rights of People Living with HIV who suffer discrimination on the basis of their actual or presumed HIV-positive status, to challenge such action through procedural, institutional and monitoring mechanisms for enforcing human rights and have recourse for countering and redressing discriminatory action.

International human rights principles, provide a coherent, normative framework within which to analyse and redress AIDS-related discrimination. States are responsible and accountable, not only for the direct or indirect violation of rights, but also for ensuring that individuals can realise their rights as fully as possible. The International Guidelines on HIV/AIDS and Human Rights (UNAIDS), published in 1998 by UNAIDS and the Office of the United Nations High Commissioner for Human Rights, clarify the obligations of States contained in existing human rights instruments (Universal Declaration of Human Rights) and how they apply in the context of AIDS.

## In-country Mechanisms for Protecting the Rights of PLHIV

Countries adopt both human rights and legal approaches to protecting the rights of people living with and affected by HIV. Human rights approaches include instituting legal action to challenge discrimination and other violations of human rights in various arenas; ensuring access to redress and conducting rights-awareness campaigns, including promoting understanding among People Living with HIV of their rights.





# Appendix 5:

## Role of PLHIV Support Groups

### Role of the Network

- Identify the needs of HIV and AIDS services
- Design and implement programmes that meet those needs
- Evaluate the effectiveness of such programmes
- Provide guidance and support to PLHIV support groups
- Networking and partner with agencies to mobilise technical and financial support for the PLHIV community
- Build local capacity and sensitise stakeholders/partners
- Advocate locally, regionally and internationally for the integration and reinforcement of policies that ensure PLHIV access to prevention, care and treatment services
- Provide a platform where the issue of HIV is addressed and capacity-building of PLHIV is achieved, for effective response to the HIV issue and the needs of PLHIV
- Strive to improve the quality of life for PLHIV through the provision of quality care and support (including meeting their medical, social and material needs) and ensuring a secure environment for all people infected with and affected by HIV and AIDS
- Create opportunities for the provision of enhanced social support to PLHIV, including the reduction of stigma and discrimination against them

### Role of PLHIV Networks at the Policy Level

- Advocate for Universal Access to generic anti-retroviral drugs as a means of increasing PLHIV and vulnerable populations access
- Advocate for proper nutritional support crucial for effective treatment for PLHIV
- Advocate for the rights of women, young girls and for scale-up of services to prevent Mother-To-Child Transmission
- Advocate for the rights of PLHIV in the workplace and the development of national workplace policies
- Advocate for adequate services for the prevention, treatment and management of opportunistic infections
- Advocate for governments to allocate adequate funding in health and social budgets to support activities geared towards Universal Access

### Role of PLHIV Networks at the General Population Level

- Assist National AIDS Programmes and other authorities/agencies in sensitising the general public about the negative impact of stigma and discrimination on People Living with HIV and AIDS
- Work towards a reduction of stigma and discrimination as a means of encouraging more individuals to access testing and care and treatment

### Role of PLHIV Networks at the Community Level

- Encourage PLHIV to become part of support groups
- Remind each other that HIV is a virus not a moral condition
- Encourage positive living through adherence to medication, nutritional regimen, positive prevention and maintaining good emotional health
- Mobilise PLHIV to advocate for greater access to effective care, support and treatment



## Appendix 6:

# Role of FBOs in the Response to HIV

Source: Guidelines for Caribbean Faith-based Organisations in developing Policies and Action Plans to deal with HIV/AIDS, Caribbean Conference of Churches

### Introduction

Faith-Based Organisations (FBOs) represent a major resource in the effort to prevent the spread of HIV and AIDS in the Caribbean. They are being called upon (directly and indirectly), by the wider society to help to address the multi-faceted issues confronting the society in the context of the HIV and AIDS epidemic. It would be ideal if these organisations could collaborate in order to address these issues by mutual exchanges of resources, learning and experience. As we work together, we must ask and answer many questions seriously and urgently. The leadership of Faith-Based Organisations should thus take the lead on the issue of HIV and AIDS and be open to training. The following are some guidelines for consideration:-



### Leadership

- Identify and access specialised training to meet new demands including internal expertise and skills to share with the membership
- Educate current and new leadership in Faith-Based Organisations as a whole, in their sub-groups and communities
- Prepare women's groups, men's groups, volunteers, youth and children to lead in the struggle
- Recognise and address the issues of gender and power relations, especially as they pertain to sexual relations

### Prevention

- Speak messages of abstinence, chastity and fidelity in marriage, clarifying what each means in practice
- Promote responsible sexual behaviour within Faith-Based Organisations and in the general population
- Promote and support Voluntary Counselling and Testing (VCT) for persons at opportune moments
- Establish opportunities for sharing information with and among membership on the issues of stigma and discrimination and how this fuels the spread of HIV
- Encourage reinforcement of safe behaviour and behaviour change where necessary, at individual and community level



## Appendix 6:

# Role of FBOs in the Response to HIV

### Care, Support and Counselling

- Emphasise listening, reconciliation, forgiveness
- Visit the sick and provide support for community and home-based care
- Address substance abuse and the role it plays in the spread of HIV and develop relevant responses and terms of care, rehabilitation and prevention
- Provide basic and advanced training for counsellors
- Pay particular attention to the conditions of orphans and survivors of the HIV and AIDS pandemic and seek ways to build a supportive environment
- Encourage the development and observance of strict codes of confidentiality for those affected by disclosure whether affected with or infected by HIV and AIDS
- Provide bereavement counselling
- Give referral to specialised agencies
- Encourage and actively facilitate adherence to medical recommendations, including adherence to anti-retroviral treatment

### Human Rights and Advocacy

- Take a lead role in the discussion in society at large, on ethical issues posed by HIV and AIDS
- Support members who face difficult ethical choices in the areas of prevention and care
- Outline, study and promote the human rights of People Living with HIV through mechanisms at national, regional and international levels
- Help safeguard the rights of persons affected by HIV and AIDS
- Agitate for workplace policies that do not discriminate negatively against people affected by and infected with HIV and AIDS
- Lobby for the implementation of laws that protect those infected with and affected by HIV and AIDS
- Advocate for justice, removal of stigma and discrimination through Faith-Based Organisations' action and examples
- Advocate for access to medical care and treatment
- Advocate for increased spending by governments and medical facilities to find solutions to the problems – both medical and social, brought about by the pandemic
- Recognise the linkage between AIDS and poverty and advocate measures to promote just and sustainable development
- Condemn discrimination and stigmatisation of PLHIV
- Involve PLHIV in management of the organisation and the development of programmes
- Care for PLHIV



## Appendix 6:

# Role of FBOs in the Response to HIV

### Death and Burial

- Observe the right of PLHIV to dignified final rites

### Education

- Promote the sharing of accurate information about HIV and AIDS to facilitate an environment of open discussion and work against the spread of misinformation and fear, especially within the family
- Pay particular attention to the issues of human sexuality, power and gender relations, with the goal of character-building
- Establish and utilise curricula in denominational schools, utilising age-appropriate content
- Establish and utilise curricula in training at religious institutions
- Educate all members, especially involving youth, men and PLHIV in activities aimed at preventing the spread of HIV
- Seek to understand more fully the gift of human sexuality in the contexts of personal responsibility, relationships, family life and faith
- Equip a new generation of religious leaders to engage the Faith-Based Organisations on issues related to HIV and AIDS and other Sexually Transmitted Infections

### Gender

- Pay attention to the impact of gender relations (sexual and interpersonal power relations), on women and their vulnerability to HIV and act accordingly
- Create special opportunities to educate men to change their behaviour and take responsibility for containing the spread of HIV
- Address and respond to the challenges of changing gender relations



# Appendix 7:

## Universal Precautions and FBOs

### Universal Precautions and Checklist of Precautions to Prevent HIV Transmission

extracted from the ILO Code of Practice, Appendix II

#### A. Universal Blood and Body-fluid Precautions

Universal blood and body-fluid precautions (known as “Universal Precautions” or “Standard Precautions”) were originally devised by the United States Centers for Disease Control and Prevention (CDC) in 1985, largely due to the HIV and AIDS epidemic and an urgent need for new strategies to protect hospital personnel from blood-borne infections. The new approach placed emphasis for the first time on applying blood and body-fluid precautions universally to all persons regardless of their presumed infectious status. Universal Precautions are a simple standard of infection control practice to be used in the care of all patients at all times to minimise the risk of blood-borne pathogens. Universal Precautions consist of:

- careful handling and disposal of sharps (needles or other sharp objects)
- hand-washing before and after a procedure
- use of protective barriers – such as gloves, gowns, masks – for direct contact with blood and other body fluids
- safe disposal of waste contaminated with body fluids and blood
- proper disinfection of instruments and other contaminated equipment
- proper handling of soiled linens

### Additional Checklist of Precautions to Prevent HIV Transmission

#### 1. First Aid Kits

- Store first aid kits in designated rooms in the Faith-Based Organisation
- Ensure that the first aid kits contain at least four disposable single-use latex gloves, gauze, scissors and materials to help heal the wound
- Check the contents of first aid kits every week
- Ensure that the responsible persons know where the first aid kits are stored

#### 2. Emergencies and Mouth-to-Mouth Resuscitation

- If you are trained to do so, perform mouth-to-mouth resuscitation in emergencies with People Living with HIV
- Although saliva has not been implicated in HIV transmission, to minimise the need for contact with the mouth, you may use mouth-pieces, or other ventilation devices

# Appendix 7:

# Universal Precautions and FBOs

## 3. How to Manage Injuries Involving Blood

- Put on your gloves
- Cover any abrasions or cuts on your arms with a waterproof dressing
- Clean the wound
- Remove the gloves and place in a resealable bag
- Do not touch your eyes before washing up
- Wash hands immediately after touching blood, body fluids and contaminated items, whether or not gloves had been worn
- Wash hands with soap and water for at least fifteen to twenty seconds
- Change any bloodstained clothes as quickly as possible
- Immediately discard contaminated sharps and materials in resealable bags

## 4. Disinfecting

- Prior to disinfecting, ensure that adherent blood is scraped from surfaces and objects
- HIV does not survive in the environment. Nonetheless, potentially contaminated spills should be disinfected by using household bleach, one part bleach to ten parts water. Pour the solution around the periphery of the spill
- Ensure that mops, buckets and other cleaning equipment are disinfected with fresh bleach solution

## 5. Cleaning Staff

- Inform all cleaning staff about the Universal Precautions for handling bodily fluids









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