



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 PEOPLE LIVING WITH HIV



Acknowledgements

CARICOM/PANCAP takes this opportunity to thank the World Bank for funding this series of HIV and AIDS Anti stigma toolkits which have been developed for use by People Living with HIV (PLHIV), Health Workers, Private Sector, Tourism, Educators and Faith Based Organisations, respectively. Materials for two of the activities in Unit Four, Books 1 and 2 of this series were adapted from Bodywork II Positive Living, Care and Support: A Guide for Trainers of HIV Peer Educators written by Bonita Harris with funding from USAID. Texts were also taken from UNICEF, UNAIDS, UNDP, US Centers for Disease Control and Prevention, Human Rights Watch, and Family Health International websites, The University of the West Indies publication 'Guidelines on Law, Ethics, and Human Rights', Dr. Joseph Petraglia's Behaviour Change Model, and Eckhart Tolle's book 'A New Earth: Awakening to Your Life's Purpose'.

This toolkit was developed for use by Persons living with HIV (PLHIV) 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.



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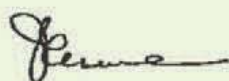
Foreword

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.

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 stakeholders including parliamentarians, policy makers in the fields of education and health,



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

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

ABC	Abstinence, Be faithful, Condomise
AIDS	Acquired Immune Deficiency Syndrome
ARVs	Anti-retrovirals
CAREC	Caribbean Epidemiology Centre
CARICOM	Caribbean Community
CD4	Cluster of Differentiation 4
CDC	Centers for Disease Control and Prevention
CHAA	Caribbean HIV&AIDS Alliance
CRN+	Caribbean Regional Network of People Living with HIV/AIDS
DFID	Department for International Development
DNA	Deoxyribonucleic Acid
HIV	Human Immunodeficiency Virus
ILO	International Labour Organization
IHAA	International HIV/AIDS Alliance
JIS	Jamaica Information Service
MARPs	Most-At-Risk Populations
NAP	National AIDS Programme
NNRTI	Non-nucleoside Reverse Transcriptase Inhibitors
PANCAP	Pan Caribbean Partnership Against HIV/AIDS
PLHIV	People Living with HIV
PMTCT	Prevention of Mother-to-Child Transmission
RNA	Ribonucleic Acid
S&D	Stigma and Discrimination

Acronyms *(continued)*

STIs	Sexually Transmitted Infections
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
VCT	Voluntary Counselling and Testing
WHO	World Health Organization

About the Toolkit



About the Toolkit

The HIV and AIDS epidemic is a major health crisis for the Caribbean. According to the latest indicators, outside of Sub-Saharan Africa, the Caribbean has the highest HIV rate globally. Approximately 440,000 people are living with HIV in the region. In the Caribbean Community (CARICOM) countries specifically, 240,000 people are currently living with HIV. Stigma is one of the key barriers to addressing HIV and AIDS. It manifests itself through denial, ostracism and rejection and often results in discrimination and human rights abuses against People Living with HIV.

Who is the toolkit for?

This toolkit was designed for People Living with HIV in Caribbean countries. It was created to help PLHIV and their families deal with stigma and discrimination and advocate for their rights and entitlements with respect to HIV.

How was the toolkit developed?

A preliminary literature review on HIV-related stigma and discrimination was conducted by the lead consultant. Regional consultants were contracted with responsibility for developing the toolkits. An Orientation Workshop was convened with the CARICOM/PANCAP, CHAA, CARICOM Steering Committee and the regional consultants to explore stigma and discrimination issues that may exist in each target group, discuss what data are required to inform preparation of the draft toolkits and the major components that should be included in each toolkit, review the project deliverables and agree on the work plan and time frames. At this workshop, agreement was reached on the contacts for field work, the framework for interim reports and the need for each regional consultant to conduct a literature review and summary of existing toolkits, develop and submit a research protocol for field work in selected countries and develop a proposal detailing the content of the toolkits. The literature review was conducted, the protocols were developed and reviewed and the field work conducted in Barbados, Jamaica and the Bahamas to inform the development of the PLHIV, Health Workers and Private Sector toolkits.

At a second workshop, which comprised the same individuals who participated in the Orientation Workshop, summary presentations were made on the interim report and draft outlines for the toolkits and instructional guides. Agreement was reached on modification of structure and content of the toolkits and on the deadlines for submission of draft reports, draft toolkits, draft instructional guidelines, reviews and guidance by the lead technical

About the Toolkit (continued)

consultant, consideration of feedback from members of CHAA's Technical Advisory Committee and CARICOM's Steering Committee and field testing via questionnaire.

The draft toolkits, instructional guides and list of champions/mentors were reviewed and approved by the lead consultant and the CARICOM Steering Committee. A Validation Workshop was conducted subsequently during which the findings from the field test via questionnaire and field test through the incorporation of specific activities from the toolkit into a two-day and three-day peer education training for PLHIV and FBO representatives, held in St. Lucia and Guyana, were presented. The toolkits were accepted with the agreement that adjustments be made based upon recommendations from the field tests and the Validation Workshop. The toolkits and instructional guidelines were subsequently amended to reflect the recommendations. Champions/mentors were trained in the use of the toolkits following the submission of the final documents.

How is the toolkit organised?

The toolkit comprises an introduction section and seven activity-based units. Some activities are accompanied by background reading materials located in the appendices.

- Introduction
- Unit 1: Fundamentals of HIV and AIDS
- Unit 2: Exploring Values and Diversity
- Unit 3: Success Stories and Best Practices
- Unit 4: Cultural Factors and Stigma
- Unit 5: HIV and Human Rights
- Unit 6: Empowerment of PLHIV and Their Families
- Unit 7: Advocacy
- Appendices (these can also be used as handouts)

About the Toolkit *(continued)*

Each activity consists of:

- Objective(s)
- Required materials
- Suggested timeframe
- Facilitator's instructions
- Facilitator's notes

Activities are designed to guide the facilitator on how to stimulate critical thinking and encourage interaction among the participants as they explore personal values and diversity, apply life skills and use emotional intelligence to examine their deeply-held beliefs with respect to stigma and discrimination and how these impact the lives of People Living with and affected by HIV.

This toolkit will enable PLHIV to explore what empowerment looks like for them and their families. Activities will lead participants to examine their current attitudes and behaviours and reflect on and draw strength from past negative experiences as part of the behaviour change process critical to overcoming self-stigma and coping with HIV. Activities will equip PLHIV with the tools needed to adopt and maintain a lifestyle of positive living, advocate for their meaningful involvement in the response to HIV and help reinforce their understanding of the roles of the networks and support groups.

The toolkit is produced for adaptation by countries to their own cultural context. It is hoped that groups such as indigenous people will be reached. Since activities build upon each other, it is recommended that, as much as possible, facilitators maintain the sequence. The acronym PLHIV was used throughout the toolkit, nonetheless facilitators are encouraged to use 'People Living with HIV' when facilitating the activities.

This toolkit should not be viewed as a solution to overcoming the challenges associated with encouraging behaviour change with respect to stigma and discrimination. Instead, it should be seen as a useful component of a wider framework on stigma and discrimination reduction and behaviour modification within the Caribbean.

Introduction



Introduction

i. Clarifying HIV-related Stigma and Discrimination

"HIV and AIDS-related stigma is a real or perceived negative response to a person or persons by individuals, communities or society. It is characterised by rejection, denial, discrediting, disregarding, underrating and social distance. It frequently leads to discrimination and violation of human rights....Stigma is the attitude. Discrimination is the behaviour." (CAREC 2004)

Stigma is also defined as either 'felt' – expectations of stigmatised individuals as to how others will react to their condition and 'enacted' or 'experienced stigma' – how the same individuals experience discriminatory acts. The consensus among researchers is that stigma is a negatively perceived defining characteristic, either tangible or intangible, (Population Council Inc. 1999) and is an attribute used to set the affected persons or groups apart from the normalised social order and this separation implies devaluation. (Gilmore and Somerville 1994)

ii. Historical and Current 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 homophobia in some territories is a significant factor that influences HIV-related stigma and impedes access to HIV prevention information, condoms and health care in the Caribbean. Studies identified a number of factors that contribute to homophobia in the Caribbean, including laws that criminalise sex among men, religious beliefs and more

Introduction (continued)

recently, the lyrics of dancehall and hip-hop music that reinforce hatred of Men who have Sex with Men (MSM).

iii. Stigma and Discrimination Issues Affecting PLHIV

Studies have found that the main types of HIV-related stigma experienced by People Living with HIV in the Caribbean are verbal stigma, neglect and differential treatment. The fear of voluntary disclosure of their HIV status and fear of having their HIV status exposed through breach of confidentiality were issues of felt stigma reported by PLHIV. The fear reported by PLHIV was rooted in personal and others' experiences of stigma and driven by the strong belief that they would be rejected and diminished by those who found out their HIV status.

Types of Experienced stigma

- Verbal stigma
- Neglect
- Differential treatment

Types of Felt stigma

- Fear of voluntary disclosure
- Fear of breach of confidentiality

Drivers of self-stigma towards PLHIV

- Personal and others' experiences of stigma
- Strong belief that they will be rejected
- Strong belief that they will be diminished by those who found out their status

iv. Challenges to Reducing Stigma and Discrimination Among PLHIV

- Self-stigma among PLHIV as a result of past experiences of discrimination towards them or others
- Public's awareness of the reluctance of PLHIV to seek recourse for violation of their rights because of the implication that their HIV status would be disclosed

Introduction (continued)

- The lack of understanding among many that the epidemiological evidence and the likely negative impact on society determine that some populations (vulnerable) need more assistance
- Perverse (vicious) homophobia in some territories

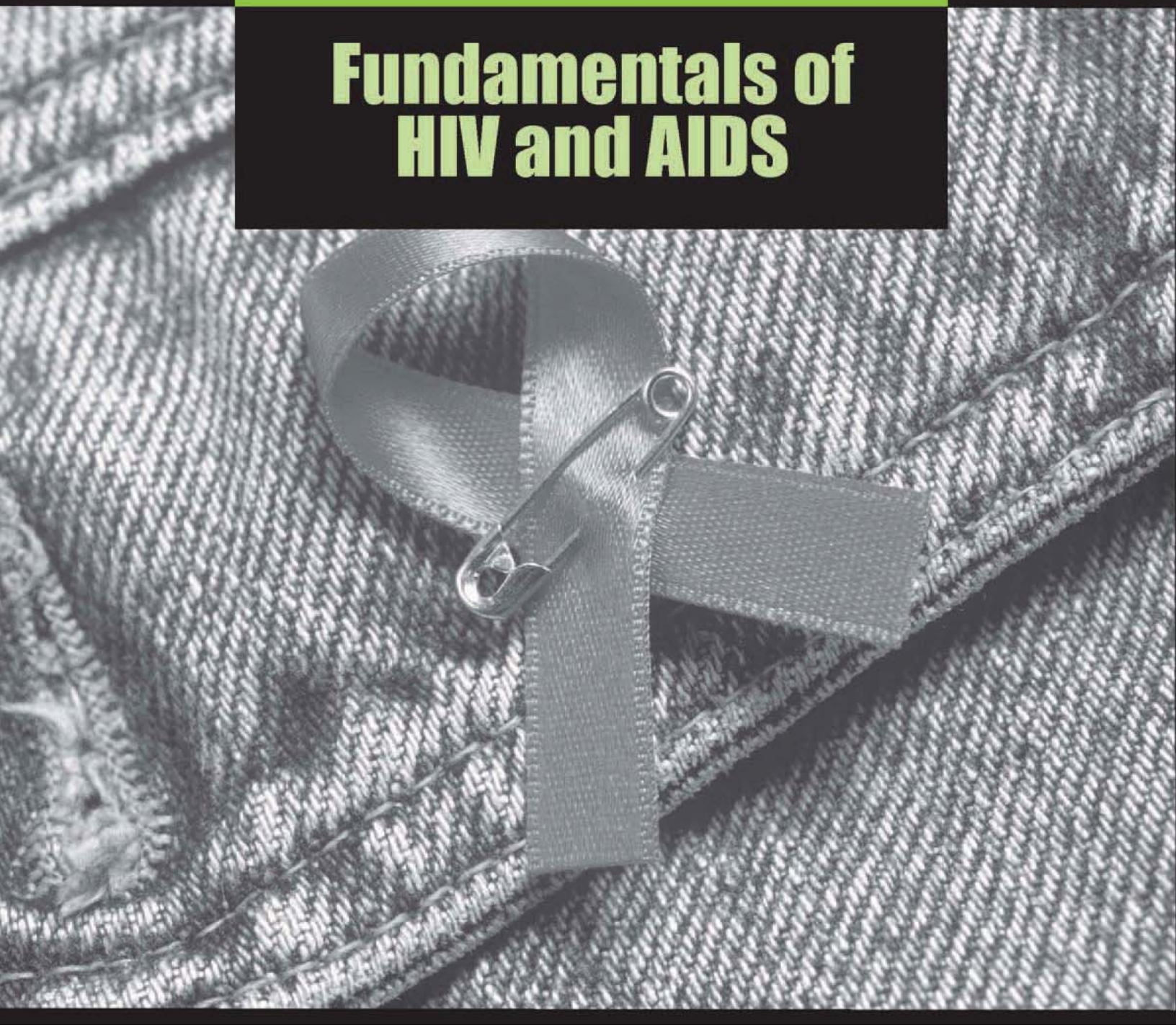
v. Stigma, Discrimination and Human Rights.

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, i.e. peace, security and self-control 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) Freedom from discrimination is a fundamental human right founded on principles of natural justice that are universal and perpetual. The UN Commission on Human Rights resolutions (1999/49 and 2001/51) state quite unequivocally that the term "or other status" in non-discrimination provisions in international human rights texts 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

Fundamentals of HIV and AIDS





Unit 1:

Fundamentals of HIV and AIDS

Purpose of the Unit

The purpose of the unit is to help PLHIV to learn the basic facts about HIV and AIDS and to be able to apply the information to their own lives.

Activities

Activities will enable participants to identify significant landmark events in the history of HIV and AIDS and increase their understanding of the global, regional and country-specific AIDS epidemics. Activities will help participants to discuss frequently asked questions in relation to HIV transmission and explore prevention strategies, including abstinence, being faithful, condom use, prevention for positives and universal precautions.

Activities in this unit will also enable participants to examine the HIV life cycle and the role of anti-retroviral therapy in slowing down the growth of HIV. Activities will also increase participants' understanding of the side effects of ARVs and how to document and report these side effects to their doctor.



Activity 1.1:

Brief History of the AIDS Epidemic

Objective:

By the end of the activity, participants will be able to identify key landmark events in the history of the AIDS epidemic.

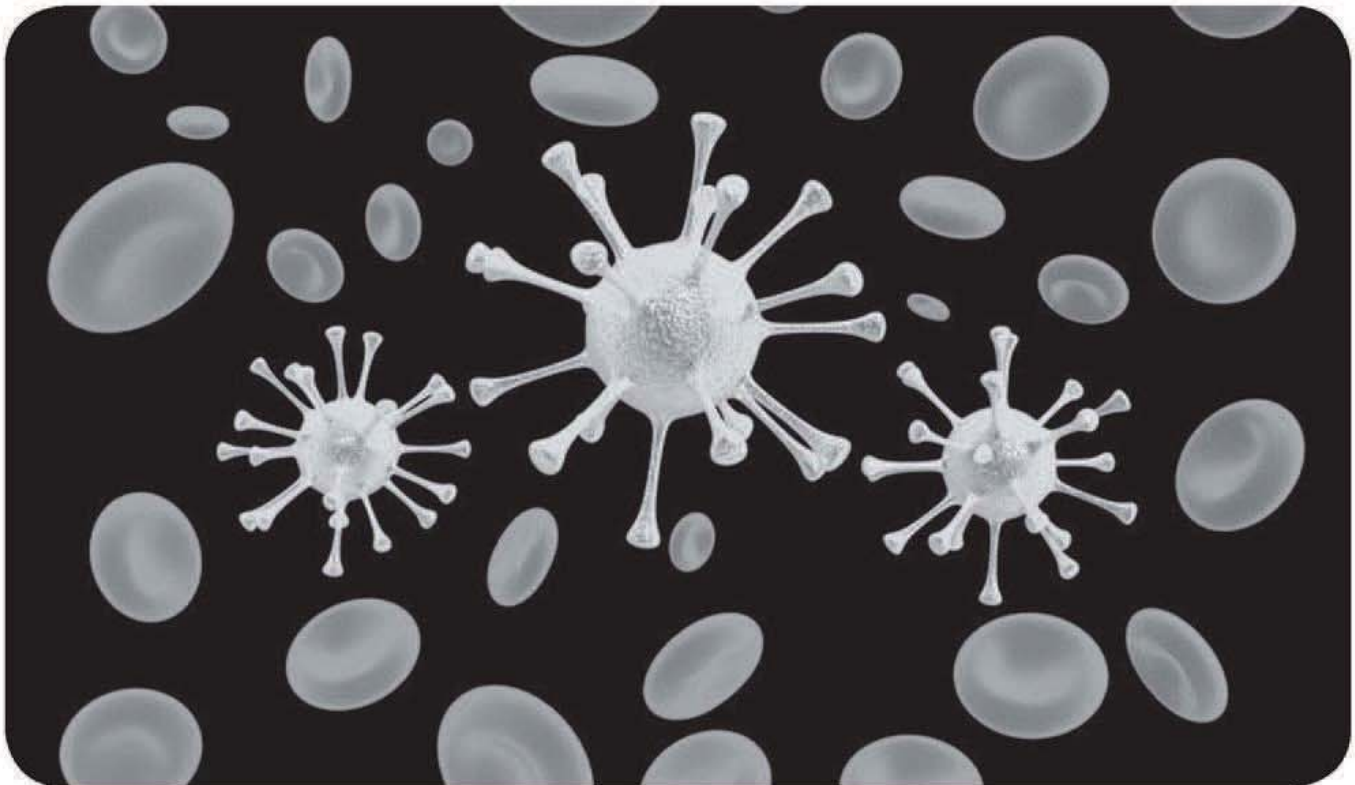
Materials

- Facilitator's Instructions
- Projector
- Laptop
- Handouts



Facilitator's Instructions

1. Welcome participants and introduce the toolkit. Explain that this toolkit was designed for People Living with HIV in Caribbean countries. It was created to help PLHIV and their families deal with stigma and discrimination and advocate for their rights and entitlements with respect to HIV.
2. Invite them to introduce themselves by stating their names and sharing the year in which they first heard the term 'HIV' or 'AIDS' and what they heard in relation to HIV or AIDS. Record participants' responses on a timeline. Ensure that you write the date nearest to 1982 on the left of the line and the most recent date on the right of the line.
3. Point out any observed differences in time in relation to age. It is more likely that older participants will report having heard about 'AIDS' and will share dates closer to 1982 while younger participants are more likely to report having heard about 'HIV' and will share more recent dates.
4. Display the timeline below either using a projector or flip chart. Let the group spend some time discussing each landmark event.





Activity 1.1: Brief History of the AIDS Epidemic

A Brief 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 MSM 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 Immuno deficiency 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 MSM demonstrates effectiveness of MSM 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.

5. End the activity and say that looking back at the history of HIV and AIDS enables us to observe how the epidemic changed from being confined among MSM to rapidly spreading among the general population, and that some populations have been more affected. Also point out that we have moved from having no treatment available to having universal access to life-saving ARV therapy.

Facilitator's Notes

You may wish to place the timeline on a flip chart if you do not have access to a projector or if there is a possibility that you may have power outage.



Activity 1.2: Frequently Asked Questions

Objective:

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

- discuss frequently asked questions
- clear up myths and misconceptions in relation to HIV transmission

Materials

- Facilitator's instructions
- Projector
- Laptop
- Handouts



Time

1 hour

Facilitator's Instructions

1. State the name and explain to participants that this activity will provide them with an opportunity to ask and discuss the answers to questions they have in relation to HIV.
2. Invite participants to ask their questions and list them on flip chart paper. Questions should include, but may not be limited to the following:

Frequently Asked Questions

What are the main routes of HIV transmission?

Can I be infected if my partner doesn't have HIV?

How safe is oral sex?

What are the chances of becoming infected with HIV if my partner does not come inside me?

Is deep kissing a route of HIV transmission?

Are lesbians or other Women who have Sex with Women at risk for HIV?

Is unprotected anal intercourse more of an HIV risk than vaginal or oral sex?

Does 'fingering' during sex carry a risk of HIV transmission?

Is there a connection between HIV and other STIs (Sexually Transmitted Infections)?

Can I become infected with HIV through everyday contact/activities such as shaking hands/toilet seats/swimming pools/sharing cutlery/kissing/sneezes and coughs?

Is there a risk of HIV transmission when having a tattoo, body piercing or visiting the barbers?

Are healthcare workers at risk from HIV through contact with HIV-infected patients?

Am I at risk of becoming infected with HIV when visiting the doctor or dentist?

If blood splashes into my eye, or I get some in my mouth, can I become infected with HIV?

Can I become infected with HIV through biting?

Can I get HIV from a mosquito?

Can HIV be transmitted in household settings?



Activity 1.2: Frequently Asked Questions

Can I become infected with HIV if I inject drugs and share the needles with someone else, without sterilising them?

Can I transmit HIV to my baby during pregnancy or breastfeeding?

Does donating blood or having a blood transfusion mean that I am putting myself at risk of HIV?

Can HIV be transmitted outside of the body?

Does circumcision protect against HIV?

If I am taking anti-retroviral drugs and have an 'undetectable' viral load, am I still infectious?

What is the window period?

3. Lead a discussion around the questions with a view to ensuring that participants receive correct answers to the questions asked. Please note that other participants may have the answers to many of these questions. However, you may need to clarify or correct responses provided.
4. End the activity by encouraging participants to continue to ask questions that might arise during other activities.

Facilitator's Notes

You may wish to familiarise yourself with the responses to the questions above. These are found in Appendix 1: HIV 101: Getting Down to Basics.



Activity 1.3: Anti-retroviral Therapy

Objective:

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

- explain what is anti-retroviral therapy
- identify the different classes of ARVs
- explain how the ARV drugs are used

Materials

- Facilitator's instructions
- Projector
- Laptop
- Handouts



1½ hours

Facilitator's Instructions

1. Share the name and objective of the activity. Ask participants to explain what anti-retroviral therapy is.
2. Explain that ARV therapy means treating viral infections like HIV with drugs. Emphasise that the drugs do not kill the virus, however, they slow down its growth. 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.
3. Tell participants that you will review the HIV Life Cycle, that is, what happens from the time the virus enters the body to when it reproduces and new viruses are assembled. Point out that there are several steps in the HIV life cycle. Review the life cycle slowly and allow time to answer participants' questions.

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.
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.

4. Explain that there are different classes or types of approved ARVs available and that each class acts upon a stage of the HIV life cycle by attacking HIV in a different way. Begin with the first class below.

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 (ZDV, zidovudine, Retrovir)
- ddI (didanosine, Videx)



Activity 1.3:

Anti-retroviral Therapy

- 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)

The second 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. Four NNRTIs have been approved:

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

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)

The fourth class and 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)



Activity 1.3: Anti-retroviral Therapy

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)

5. Explain that new drugs are being developed in all five of the existing classes. Researchers are also trying to develop new types of drugs, such as drugs that will block other steps in the HIV life cycle and drugs that will strengthen the body's immune defences.

What happens after a person is infected?

6. Explain that 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 may then remain free of HIV-related symptoms for ten years or more, despite continuous replication of HIV.

How are the drugs used?

7. Explain that when HIV multiplies, most of the new copies are mutations (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.

Can these drugs cure AIDS?

8. Explain that 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 all the viruses are 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 ARV Therapy?

9. Explain that 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?

10. Explain that each ARV drug has side effects. Some are serious. 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.
11. Close by recapping the session and ask participants to share how their knowledge of ARVs has changed as a result of the activity.

Facilitator's Notes

You may wish to spend some time becoming familiar with the information in this section before facilitating this activity. You may wish to keep the presentation simple and non-technical. If you are neither a medical doctor nor a pharmacist, you may wish to say so before you begin.



Activity 1.4:

Recording and Reporting Side Effects

Objective:

By the end of the activity, participants will be able to record and report ARV side effects to their doctor.

Materials

- Facilitator's instructions
- Projector
- Laptop
- Handouts



Time

1 hour

Facilitator's Instructions

1. Share the name and objective of the activity. Ask participants to explain what they understand by the term 'side effects'.
2. Explain that drugs are generally tested on and licensed to help with specific illnesses. However, when they affect the body in other ways, these are called side effects. 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?

3. Explain that 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.

General side effects

4. Ask participants to share any side effects they have experienced or have heard others experienced when using ARV and whether they had reported the side effects to their doctor.
5. Explain that 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

6. Explain to participants that 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:



Activity 1.4: Recording and Reporting Side Effects

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?

Why do I need to tell my doctor?

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 work or the shop.

When do I need to tell my doctor?

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.

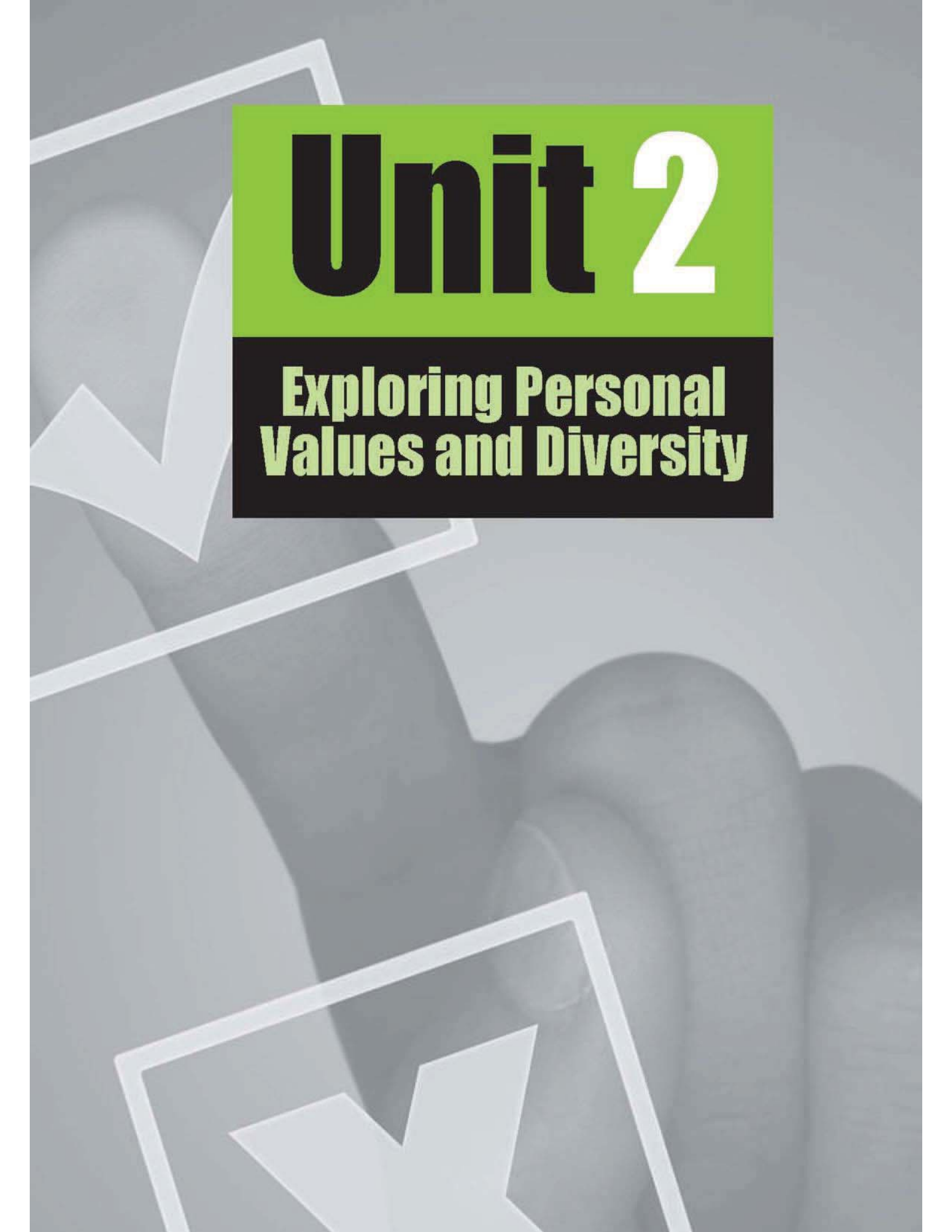
7. Close by asking each participant to share how this activity would help him/her.

Facilitator's Notes

You may wish to spend some time becoming familiar with the information in this section before facilitating this activity.

Unit 2

Exploring Personal Values and Diversity





Unit 2:

Exploring Personal Values and Diversity

Purpose of the Unit

The purpose of this unit is to enable PLHIV to explore personal values and diversity as well as attitudes towards differences.

Activities

Activities will enable PLHIV to become aware that while our values are shaped by family, society and culture, our individual set of values is separate. Activities will allow participants to recognise that values are not about right and wrong in the sense of a broad, cultural construct, but about what's right and wrong for us as individuals, since what we truly value is, by definition, right for us. Activities will help participants to realise that what we value may not be right for those close to us and may be a source of disagreement and dissatisfaction if others attempt to enforce their code of values on us.

Activities will help PLHIV increase their understanding of what diversity is and why it matters to all of us. This will enable them to experience the diversity amongst themselves and appreciate that they must not disrespect someone for their differences, no matter how great or small the difference. Activities will help participants to consider adopting positive attitudes to diverse social identities such as Men who have Sex with Men, Sex Workers, drug users and street people/ children.

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



Activity 2.1:

Understanding the Issue of Confidentiality

Objective:

By the end of the activity, participants will be able to identify the need for and challenges to, maintaining confidentiality.

Materials

-Facilitator's instructions



1 hour

Facilitator's Instructions

1. Ask each participant to say whether he/she is confidential. Share the following scenario with the group.

Scenario

You are attending a PLHIV support group meeting. The meeting is held at a multipurpose centre so no one knows which services individuals access when they enter the building. You look across the room and see someone who lives in your neighbourhood. He/she does not speak to you and your family and you believe that this is because the individual feels that he/she is better than you are. Your sister comes to pick you up after the meeting and asks you what the individual was doing in the building. What would you say and what would you do?

2. Give participants a few minutes to think and then ask them to share individually what they would say and do. Emphasise that you want to hear their gut response.
3. Encourage participants to come to a consensus about what they should do if faced with such a situation.
4. Have participants share what they learnt about themselves in relation to confidentiality.
5. Ask participants to share their opinions as to why people gossip.
6. Share the following taken from Eckhart Tolle's book, *A New Earth: Awakening to Your Life's Purpose*.

You are about to tell someone the news of what happened. "Guess what? You don't know yet? Let me tell you". If you are alert enough, you may be able to detect a momentary sense of satisfaction within yourself just before imparting the news, even if it is bad news. It is due to the fact that for a brief moment there is, in the eyes of the ego, an imbalance in your favour between you and the other person. For that brief moment you know more than the other. The satisfaction that you feel is of the ego. And it is derived from feeling a stronger sense of self relative to the other person. Even if he/she is the prime minister or a millionaire, you feel superior in that moment because you know more. Many people are addicted to gossiping partly for this reason.

7. Close by sharing that we should not disclose information that is shared with us directly or in a confidential setting such as a support group. We must consider how our actions would affect the lives of others when we disclose confidential information about them. Remind participants that they have a right to confidentiality, however, they must also remember that they have an obligation to maintain confidentiality in relation to each other.

Facilitator's Notes

You may wish to spend some time reflecting on a time in your life when you faced the dilemma of maintaining confidentiality.





Activity 2.2:

Values and Diversity

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
- explore the diversity of the group

Materials

- Facilitator's instructions
- Flip chart
- Markers
- Masking tape



Time
1 hour

Facilitator's Instructions

1. Share the name and objectives 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 you learn your values?	What values do you hold?
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 and religious leaders, other influential and powerful people and culture.	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. Explain when an individual acts in accordance with his/her values, he/she is becoming a person of character, irrespective of who he/she is. Share the quote below with the group.
"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
6. Continue by establishing common ground for the activity, for example, "We live in a diverse world." 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.
7. Say 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 labels and assumptions that we, as a product of our cultures, experience and hold.
8. Say to the group that you will ask them to gather on one side of the room and face towards its centre and that you will call out specific categories/labels/descriptions. Ask that all of those to whom this applies, walk to the other side of the



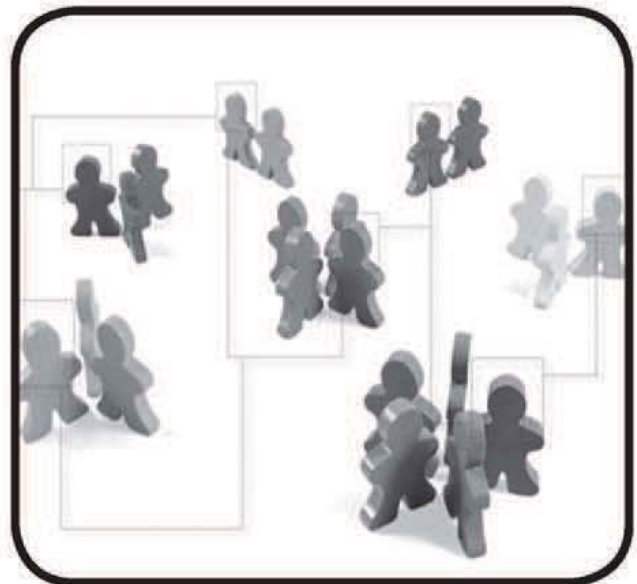
Activity 2.2: Values and Diversity

room. For example, you might request that anyone with glasses cross the room and if this describes them and they feel comfortable acknowledging it, they should walk to this side of the room (indicate).

9. Say that once there, they should turn and face the crowd they just left. Ask them 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, you will continue with a new category. A number of categories will be called out. Remember, they must cross the room if the category applies.
10. Explain that there is no pressure to cross the room if they don't feel comfortable doing so. They will need to make that decision. 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 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. Encourage them to remain in the room as an observer.

11. Begin the activity by asking questions from the list below:

- Anyone who has visited another country, cross the room
- Anyone who has never flown...
- Anyone who owns a car...
- Anyone who doesn't believe in God...
- Anyone who is of mixed race...
- Anyone who is the oldest child...
- Anyone who is the youngest child...
- Anyone who is divorced...
- Anyone who is adopted...
- Anyone who sometimes has low self-confidence...
- Anyone who sometimes feels lonely...
- Anyone whose parents have 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 an MSM, WSW, bisexual, or transgendered...
- Anyone who is choosing to abstain from sex until marriage...
- Anyone who has experienced the effects of alcoholism in the family...
- Anyone who has experienced the effects of drug addiction in the family...
- Anyone who has a friend or relative who has attempted suicide...
- Anyone who hasn't crossed the line...



12. 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?



Activity 2.2:

Values and Diversity

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

Facilitator's Notes

You may wish to clarify your own values before facilitating this activity. You may also wish to divide the room into two sections by placing masking tape on the floor. At the end of the activity you may need to explain that going on a date is not the same as being in a relationship.



Activity 2.3: Respect for Diversity

Objective:

By the end of the activity, participants will be able to identify prejudice in themselves and learn to respect diversity.

Materials

-Facilitator's instructions



Time

1 hour

Facilitator's Instructions

1. Ask participants to listen to and respond to the following questions:

- Agree or disagree: It's okay to insult or make fun of people, as long as they don't hear it
- What are some common signs of disrespect that you have encountered? How do you feel about that?
- What do you dislike most about the way people treat each other? Why do you feel that way?
- Do you have to like a person in order to be respectful, or can you be respectful to someone even if you don't particularly care for him/her?



- Do you think people are afraid of differences sometimes? Can you give some examples? Why do you think that's true?
- Is it harder to respect someone who is very different from us? Why?
- What are the benefits of having friends who are different from us?
- Have you ever learnt something new about a different culture from a friend?
- Is it ever okay to treat another person with disrespect?
- What are the benefits of treating people with respect?

2. Explain that while we classify all HIV-positive persons as People Living with HIV, in most cases, the only thing that they have in common is an HIV-positive status. Among PLHIV there is diversity that is reflected in their socio-economic status, ethnicity, marital status, etc.
3. Ask participants to take turns talking about how their understanding of diversity has been deepened by the activity.
4. Close by explaining that when we are respectful, we value and encourage others. We must help other people find value in themselves. We will become respected when we act with respect towards others. Respect is never demanded. Read the quote from Mother Teresa below.

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

Mother Teresa

Facilitator's Notes

You may wish to reflect on your own attitude in relation to diversity before facilitating this activity.



Activity 2.4:

Attitudes Towards Men Who Have Sex With Men

Objective:

By the end of the activity, participants will be able to reflect on their attitudes towards Men who have Sex with Men and how these impact homophobia.

Materials

-Facilitator's instructions



Time

1 hour

Facilitator's Instructions

1. Ask participants to share their feelings about Men who have Sex with Men. What does homophobia mean to them? What is their attitude towards MSM? Why do they feel the way they do?
2. Summarise the discussion and explain that homophobia may be defined as an irrational fear of same-sex relationships that becomes overpowering to the person. Homophobia may be experienced by heterosexuals, as well as by MSM and lesbians. Homophobia is shown at the personal level, as well as being widely embedded within our society.



3. Tell participants that you are going ask them to think about and respond to some questions to help them explore their personal experience of homophobia.
 - i. Have you ever stopped yourself from doing or saying something because of a concern that someone might think you are an MSM or a lesbian?
 - ii. How did you respond the last time that someone around you told a joke about "battyman", "bullers", or "dykes", or made a derogatory comment about MSM or lesbians?
 - iii. Have you ever intentionally done or said something so that someone will think you are not an MSM or a lesbian?
 - iv. Do you believe that MSM or a lesbian can influence heterosexuals to change their sexual orientation?



Activity 2.4:

Attitudes Towards Men Who Have Sex With Men

- v. Do you believe someone could influence you to change your sexual orientation?
 - vi. How would you feel about having a son who is an MSM or a daughter who is a lesbian? How would you feel about having your son's/daughter's same-sex partner in your home? How would you feel about introducing your son/daughter and his/her partner at your church or at your place of employment?
 - vii. How would you feel if one of your parents, or one of your siblings came out to you as an MSM or a lesbian?
 - viii. How would you react if the person you are in a relationship with reveals that he/she is an MSM, lesbian, bisexual or transgendered?
 - ix. Are there any jobs or professions which you think MSM and lesbians should be barred from holding? What is your reason for this belief?
 - x. Have you ever been to an MSM or lesbian bar, social club, party? If not, what has kept you away?
4. Ask participants to talk about what they were thinking and feeling as they responded to the questions.
 5. Explain that prejudice is not about homophobia but that homophobia is about prejudice and power dynamics.
 6. Close by asking participants to share what they learnt about themselves as a result of this activity.

"If God, as they say, is homophobic, I wouldn't worship that God."

Archbishop Desmond Tutu

Facilitator's Notes

You may wish to reflect on your own attitude towards Men who have Sex with Men.



Activity 2.5: Attitudes Towards Differences

Objective:

By the end of the activity, participants will be able to identify their attitudes towards Sex Workers, drug users and street people/children.

Materials

-Facilitator's instructions



1½ hours

Facilitator's Instructions

1. Share the name and the objective of the activity with participants.
2. Divide participants into three groups. Ask each group to select a facilitator, note-taker and someone who will report. Tell them that they have twenty minutes for discussion in each group and five minutes to present what came up in the group.
3. Explain that group one will discuss Sex Workers; group two, drug users and group three, street people/children using the questions below to guide the discussion. Ask them to begin the discussion.

Group 1: Sex Workers



- What comes to mind when you think of Sex Work?
- How do you feel about Sex Work?
- Do you believe that Sex Workers have values?
- Do you respect the values of Sex Workers? If yes, why? If no, why not?

Group 2: Drug users



- What comes to mind when you think of illegal drug use?
- How do you feel about drug users?
- Do you believe that drug users have values?
- Do you respect the values of drug users? If yes, why? If no, why not?

Group 3: Street people/children



- What comes to mind when you think of street people/children?
- How do you feel about street people/children?
- Do you believe that street people/children have values?
- Do you respect the values of street people/children? If yes, why? If no, why not?



Activity 2.5: Attitudes Towards Differences

4. Ask each group to share what came up at the end of the group discussion. Invite other groups to share additional points before moving on to the next group.
5. After the groups have shared, draw attention to similarities and differences in attitudes reported by each group towards Sex Workers, drug users and street people/children and any gender differences.
6. Ask participants to share what they learnt about themselves as it relates to their attitudes towards differences.
7. Close by reminding participants that everyone has values, irrespective of how those values are different from ours. We must, therefore, work towards valuing the diversity of all people and see them as a valid part of that diversity. In so doing, we are demonstrating that we are willing to address the prejudice in ourselves and others.

Facilitator's Notes

You may wish to reflect on your own attitude towards differences.



Activity 2.6:

My Behaviour Change

Objective:

By the end of the activity, participants will be able to assess their ability to change and identify the steps for changing behaviour.

Materials

-Facilitator's instructions
-Handouts



1½ hours

Facilitator's Instructions

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 1 to 10, how important behaviour change is to them. Discuss the responses.
3. Ask participants on a scale of 1 to 10, how confident they are that they can change their behaviour. Discuss the responses.
4. Ask participants to reflect silently on a 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?
 - Did you try 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, 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 that participants shared.
8. Ask participants to share what they learnt about behaviour change from this activity and what behaviour they wish to change.
9. End the session by sharing the quote below with the group.



Activity 2.6:

My Behaviour Change

**"Learning is not just learning things, but learning the meaning of things.
If learning does not lead to change, then there is no learning."**

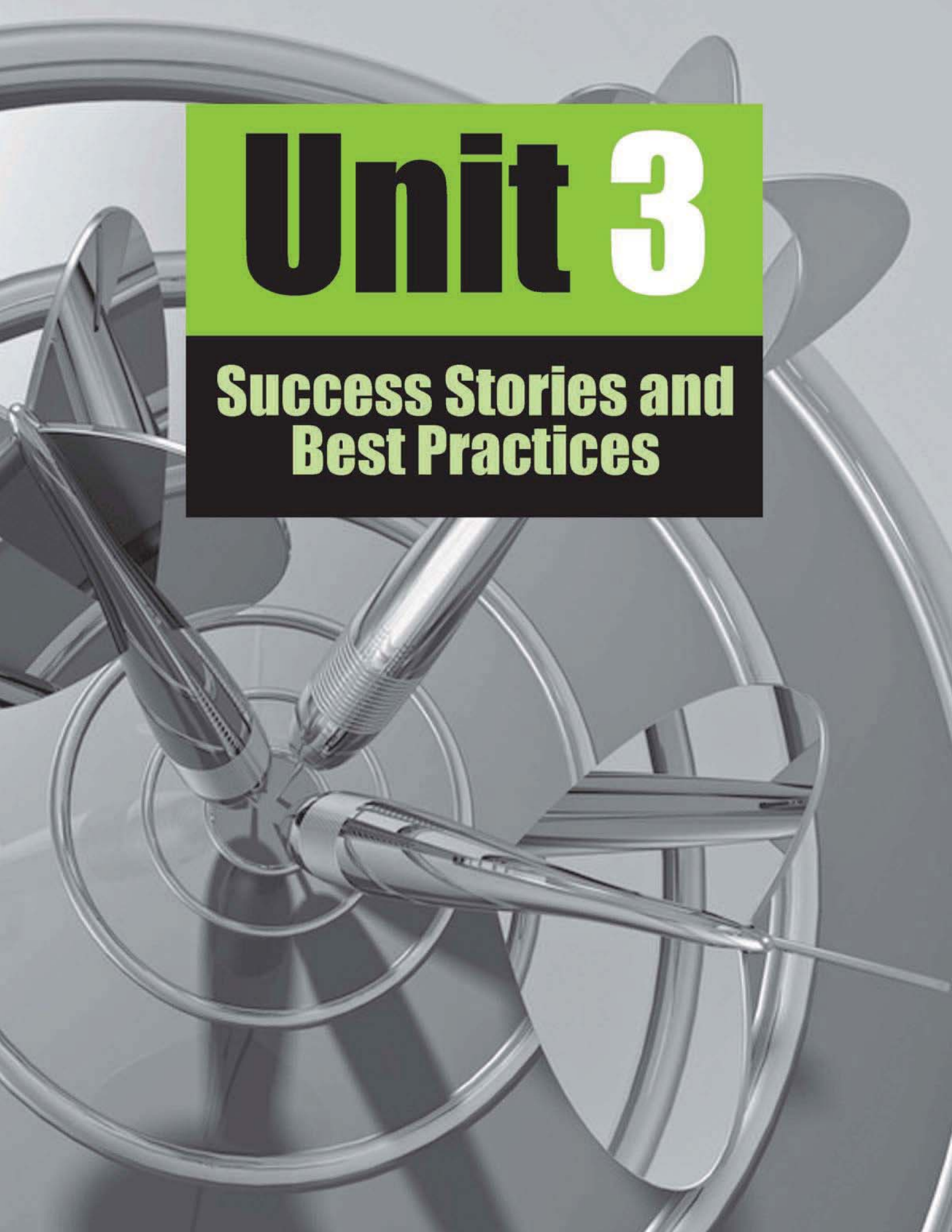
John Dewey

Facilitator's Notes

You may wish to reflect on a behaviour you have changed or tried to change before facilitating this activity, and familiarise yourself with the information on Behaviour Change in Appendix 5.

Unit 3

Success Stories and Best Practices





Unit 3:

Success Stories and Best Practices

Purpose of the Unit

The purpose of this unit is to highlight success stories and best practices as a means of countering past negative stories and experiences of HIV-positive persons in relation to stigma and discrimination.

Activities

Three success stories are included in this unit for the facilitator to share with PLHIV who will also be encouraged to share their stories and the stories of others. Such stories may include personal testimonies regarding changes in others' attitudes towards PLHIV or those championing their rights.



Activity 3.1: Success Stories

Objective:

By the end of the activity, participants will learn more about how other PLHIV are coping with stigma.

Materials

-Facilitator's instructions
-Success stories & best practices



Time

1 hour

Facilitator's Instructions

1. Ask participants to reflect on and share their experiences with stigma and discrimination.
2. After participants have shared, summarise and explain that negative stories and experiences help to reinforce fear among People Living with HIV – fear of disclosure and fear of breach of confidentiality – and in turn prevent many from seeking prevention, care and support services.
3. Highlight any positive stories shared and explain that one way of countering those negative stories is to draw attention to positive stories and best practices. Explain that you will now share some stories of how People Living with HIV are coping with and overcoming stigma. Share the stories below and any others you are aware of.

Success Story 1: Jamaican Health Ministry Launches HIV Anti-Stigma Campaign

Tuesday, September 19, 2006

KINGSTON, Jamaica (JIS): The Jamaican Ministry of Health has launched an HIV anti-stigma campaign, which is aimed at reducing the discrimination that is associated with the disease.

The campaign dubbed *Getting on with Life* will involve the use of television and radio advertisements, posters and billboards, to combat discrimination. Two HIV-positive Jamaicans, Annesha Taylor and Ainsley Reid, have bravely come forward to participate in the campaign and will speak publicly about their experiences living with the disease.





Activity 3.1: Success Stories

"The anti-stigma campaign will be supported by a public relations programme offering an opportunity to hear from Annesha and Ainsley, their stories and how they have come to terms living with HIV," informed Professor Peter Figueroa, Chief of Epidemiology and AIDS in the Ministry of Health, at the launch of the campaign at the Hilton Kingston hotel.

He noted that the campaign represented an important milestone in Jamaica's response to the HIV and AIDS epidemic.

"Jamaicans must understand that the growing number of persons living with HIV and AIDS are real people with families, friends, co-workers and neighbours. These persons are like you and me, who have their lives to live and wish to do so free from the stigma of HIV and free from any discrimination that may arise due to their HIV status," he stated.

"I am encouraging persons who are living with HIV to disclose their status to more friends and co-workers. All of us have a responsibility to make our community and workplace supportive of persons living with HIV," he stated.

In a February 2009 interview with Ainsley Reid and Annesha Taylor, both reported that the campaign had propelled them to fame and given them celebrity status.

Success Story 2: Modelling Acceptance

"We (PLHIV) also need to avoid self-stigma because they (family and community) feed off of it and stigmatise and discriminate against us. They see us as victims to be pitied and feared because we lose our self-esteem and confidence. We begin behaving as though we are different and they treat us like we are. The family and the community draw from our fears and they become even more frightened. If we take control of our lives and treat ourselves right, and we act confidently, they will treat us differently. That's how I dealt with stigma." (Jamaican Female Living with HIV)

Success Story 3: Lorna's Story: "I feel as if I have really empowered myself."

Lorna Henry was diagnosed with HIV in 2001. She is married with two children and is working hard to overcome stigma and discrimination (UNAIDS: *Keeping Score II*)

"By coming out openly at the beginning of 2008, I feel as if I have really empowered myself. It's been a weight off my shoulders and I have found a lot of support, sometimes in the most unlikely places. My mind is a little more at ease now and my health is better as I don't have the stress of hiding any more and hoping that no one will find out. Before when I was depressed I had to stay in depression alone, except for my husband. But now I have plenty of people who are there to hold my hand."

"Going public with my status has not been the easiest thing, though. Discrimination is still very much out there. My husband, who's negative, used to be really sociable and have a lot of friends but not so many come around now. If someone is difficult with me he'll challenge them. He loves me and always puts me first."

"My openness about my status has also affected our income as I lost my job in a supermarket and it's harder to make ends meet. My children have been barred from a particular nursery school even though they are not living with the virus. The teacher told me point blank that she didn't want my kids in her school. I am leaving her to God. It hurts me that my family has suffered like this."

"But I know that people can change. My mother reacted badly when she first found out and told me to leave the house but she has a really different attitude now and she asked me to come back. She loves being with her grandchildren. Some of the people who I thought would run away from me have shown they are there for me. They tell me how brave I am. They're standing behind me."



Activity 3.1:

Success Stories

"I can see why people choose not to disclose their status. It's not an easy road to take. But I'm glad I did. I feel stronger and calmer. I'm happy, though I have down days where I just want to cry all the time. I'm teaching my kids to be stronger, too, in the midst of all of this. I am standing on my own two feet. I want to be treated like everyone else and have the same opportunities. I'm not a special case and I don't want anyone's pity or sorrow. Yes it's true I have HIV and too bad if that means you don't like me. I'm here to stay."

4. Ask participants the following questions:
 - I. What did you learn from these experiences?
 - II. If you were asked to share your story with the public, which other information might you include?
5. Close by asking a few participants to share how this activity has changed the way they see themselves in relation to stigma and discrimination.

Facilitator's Notes

You may wish to include other success stories and best practices and ask participants to share those they are aware of. You may wish to point out, if it is not mentioned, that participants should also share the changes they had to make in their lives because of HIV as a means of encouraging HIV-negative persons to protect themselves.

Unit 4

Cultural Factors & Stigma





Unit 4:

Cultural Factors & Stigma

Purpose of the Unit

The purpose of this unit is to help participants explore cultural factors that fuel stigma and examine the consequences of stigma.

Activities

Studies suggest that HIV-related stigma in the Caribbean is shaped primarily by fear of contamination, homophobia, prejudicial attitudes to prostitution and Sex Work, about injecting drug use and ignorance reinforced by religious beliefs. Activities will enable participants to differentiate between sex and gender and examine sexuality within the context of HIV and its influence on stigma and explore the double role of religion as it relates to underpinning stigma and assisting People Living with HIV to cope.

Activities will help participants to think critically about stigma and its influence on behaviour and enable them to recognise that stigma and discrimination require more than education to correct; it requires “cultural work” to address deeply entrenched notions of religious beliefs and sexuality.



Activity 4.1:

Causes and Effects of Stigma and Discrimination

Objective:

By the end of the activity, participants will be able to increase their understanding of stigma, its causes and effects

Materials

-Facilitator's instructions



1½ hours

Facilitator's Instructions

1. Tell participants the name and objective of this activity.
2. Warm up the group by asking them why they think that a pregnant schoolgirl faces stigma and the schoolboy who is expecting a child, the father-to-be, does not have to deal with stigma. In fact, he might even walk taller.
3. Ask participants what they understand by the word stigma, then explain that stigma is a real or perceived negative response to a person or persons by individuals, communities or society. It is characterised by rejection, denial, discrediting, disregarding, underrating and social distance. Stigma is the attitude.
4. Divide the group in half. Half of the group will be looking at HIV and stigma and the other, AIDS and stigma. Organise participants into pairs.
5. Have HIV pairs spend ten minutes discussing why there is stigma attached to HIV. AIDS pairs should do likewise where AIDS is concerned. Each pair should try to come up with at least five reasons.
6. Have representatives from each pair share the reasons for stigma.
7. Did the following points come up – fear, blame, various types of sex, not enough information on HIV and AIDS, dying and death?
8. What were the differences between HIV stigma and AIDS stigma?
9. Now have the pairs discuss the consequences and effects of stigma. Each pair should aim to think of at least eight points.
10. Begin with the pairs with the shortest lists. Other pairs should add only new points.
11. End by asking each person to say what he/she can do to help reduce the stigma associated with HIV and AIDS.

"We are not our labels."

Eckhart Tolle

Facilitator's Notes

You may wish to spend some time becoming familiar with the causes and effects of stigma before you facilitate this activity.





Activity 4.2:

Why Do People Discriminate?

Objective:

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

- share reasons why people discriminate
- say what is good about discrimination
- say what is bad about discrimination

Materials

-Facilitator's instructions



Time

1 hour



Facilitator's Instructions

1. Share the name of the activity with the group and ask participants to share their understanding of discrimination.
2. Explain that discrimination is the behaviour or the action that people take as a result of stigma (the attitude).
3. Ask participants to think and talk about a time when they discriminated and why.
4. Ask participants to think and talk about what is good about discrimination. If participants seem unsure, you may begin by saying, "When someone has to take a long taxi ride in the middle of the day he/she may choose a driver who has air condition in his/her car. Is he/she discriminating? Yes. But the choice he/she makes ensures that he/she has a comfortable ride." Encourage participants to share.
5. Ask participants to think and talk about what is bad about discrimination. When participants have finished sharing, explain that discrimination is not a bad thing, however, when we discriminate with prejudice, we cause someone to feel diminished, alienated, disconnected or cut off. This causes loneliness, isolation, lack of self-esteem, anti-social behaviour and depression, just to name a few. Each of us needs to feel a sense of belonging and love.
6. Explain that in the example you provided earlier, the taxi driver could choose to put AC into his/her car, but in the case of someone who is HIV positive, he/she cannot change his/her status. We can choose not to discriminate against him/her by not allowing his/her HIV status to become an issue of discomfort for us.
7. Explain that people living with and affected by HIV also discriminate against each other on the grounds of how they contracted HIV, social and economic status, sexual orientation, Sex Work, etc.
8. Close by asking participants to share how their understanding of discrimination has deepened as a result of this activity.

Facilitator's Notes

You may wish to prepare yourself for this activity by thinking about times when you discriminated, why you did so, what was good about it and what was bad about it.



Activity 4.3: Religion and HIV

Objective:

By the end of the activity, participants will be able to identify the dual role of religion in relation to PLHIV

Materials

- Facilitator's instructions
- Flip chart
- Markers



Time

1 hour

Facilitator's Instructions

1. Divide participants into three groups and ask each group to select a facilitator and someone who will report on their behalf.
2. Ask group one to discuss the first statement; group two, the second and group three, the third, with respect to stigma:
 - i. "Our hearts are open to those poor AIDS sufferers."
 - ii. "Those terrible things do not happen here with us."
 - iii. "What can we do for the innocent AIDS babies?"
3. Ask the groups to discuss the statements with the following considerations:
 - Which groups of persons are likely to make these statements?
 - Which words are caring?
 - Which words are judgemental?
 - What conclusions can they draw from these statements?
4. After the groups have concluded their discussions, state the name and objective of the activity and ask each group to share.
5. Summarise the points and explain that the feeling about the intention is good but the language, 'those' and 'sufferers' suggests distance. While the feeling is caring, the choice of a word like 'innocent' exposes an underlying belief that somehow, someone had been guilty and those guilty adult(s) should not expect a kind welcoming from the religious community.
6. Invite a few participants to share experiences they have had in relation to stigma within the religious community. These experiences are likely to show the contrasting role of religion in relation to PLHIV.
7. Ask participants to reflect on the experiences they shared and say whether religion sends different messages in relation to stigma and PLHIV.
8. Close by explaining that religion has a contradictory influence in relation to HIV. On the one hand, it is the source and ultimate cause of the stigma. On the other hand, religion also holds the key to move people to a real position of non-discrimination and holistic acceptance of People Living with HIV.



Facilitator's Notes

You may wish to reflect on a time when religion had a contradictory influence on your life or the life of a loved one.



Activity 4.4: Gender Versus Sex

Objective:

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

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

Materials

- Facilitator's instructions
- Flip chart
- Markers



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 make a list again 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. Emphasise that 'Sex' refers to the biological characteristics that define humans as female or male and 'Gender' refers to the economic, social and cultural attributes and opportunities associated with being male or female at a particular point in time.
9. Close by asking participants to share what they learnt about themselves in relation to gender and sex.

Facilitator's Notes

You may wish to prepare yourself 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 behaviours and roles according to his/her biological sex.

Source: This activity was adapted from IRH/Georgetown University VCT Training Manual, 2006.



Activity 4.5: Sexuality, PLHIV and Sexual Matters

Objective:

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

- identify ways of disclosing their HIV status to regular and new partners
- identify appropriate birth control methods for women living with HIV

Materials

-Facilitator's instructions

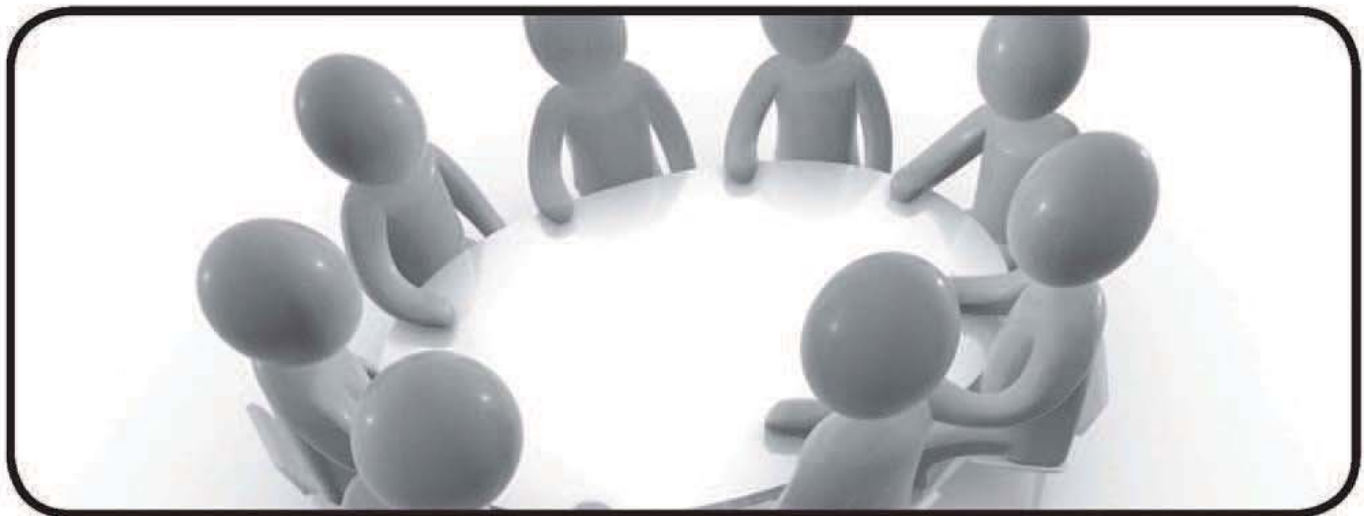


Time

1 hour

Facilitator's Instructions

1. Share the name and the objectives of the activity with participants. Divide participants into two groups and tell them they have twenty minutes for discussion and five minutes to report. Ask each group to select a facilitator, note-taker and a presenter.
2. Tell Group One members that you would like them to imagine that they are in a relationship and that they found out that they are HIV-positive. They do not know their partner's HIV status. Discuss how they would tell their partner.
3. Tell Group Two members that you would like them to imagine that they are HIV-positive and have just started a relationship with someone whose HIV status they do not know. They would like to share their HIV status with this new partner. Discuss how they would tell their partner.



4. After the discussions end, ask Group One to share what came up. The following may come up:
 - Decide when and where would be the best time and place to have a conversation. Choose a time when you expect that you will both be comfortable, rested and as relaxed as possible
 - Think about how your partner may react to stressful situations. If there is a history of violence in your relationship, consider your safety first and plan the situation with a case manager or counsellor
 - Imagine several ways in which your partner might react to the news that you are HIV-positive. Write down what he/she might say, then think about what you might say in response



Activity 4.5:

Sexuality, PLHIV and Sexual Matters

5. Ask Group Two to share what came up and point out that the issues are similar. However, in the case of a new partner, don't assume that your partner is negative. He/she also may be wondering, "Is this the right time to say that I have HIV?"
6. Explain that HIV-positive persons and their partners will have to decide what they are comfortable doing sexually in relation to safer sex. This applies to concordant couples (with the same status) and discordant couples (one partner is HIV-positive and the other is HIV-negative). If you aren't used to talking openly about sex, this could be hard to get used to. Ask persons who are comfortable to share how they approach this issue with their partner. You could also provide them with the following tips:

Tips

- Find a time and place outside the bedroom to talk
 - Decide what your boundaries, concerns and desires are before you start to talk
 - Make sure you clearly state what you want. Use only "I" statements, for example: "I want to use a condom when we have sex"
 - Make sure you don't do, or agree to do anything that you're not 100 percent comfortable with
 - Listen to what your partner is saying. Acknowledge your partner's feelings and opinions. You will need to come up with solutions that work for both of you
 - Be positive. Use reasons for safer sex that are about you, not your partner
7. Ask participants to brainstorm birth control options that DO protect against HIV:
 - abstinence (not having sex)
 - male condom
 - female condom
 8. Ask participants to brainstorm birth control options that DO NOT protect against HIV:
 - oral contraceptive ("the pill")
 - Depo-Provera (shot)
 - emergency contraception ("morning-after pill")
 - Norplant
 - IUD (intrauterine device)
 - diaphragm, cap and shield
 - vasectomy (getting your tubes tied, if you are a man)
 - tubal ligation (getting your tubes tied, if you are a woman)
 - withdrawal



Activity 4.5:

Sexuality, PLHIV and Sexual Matters

Considerations for HIV-positive women

9. Emphasise that HIV-positive women and men **have the right to have children**. HIV-positive persons wishing to have children should discuss this with their doctor or healthcare provider who will provide them with the necessary guidance.
10. Share with participants that an HIV-positive woman in a monogamous relationship with a partner who is also HIV-positive, may decide to use a birth control method other than condoms. Emphasise that these methods won't protect against other STIs or reinfection.

Safe methods of birth control for HIV-positive women with an HIV-positive partner include:

- using a diaphragm
- tubal ligation (getting your tubes tied)

Use only after checking with your provider (these may interact with your anti-HIV medications):

- birth control pills
- Depo-Provera
- Norplant

Not recommended (may cause irritation and infection – something you want to avoid):

- IUD (intrauterine device)

11. Close by asking participants to share how they would use the information learnt during this activity.

Facilitator's Notes

You may wish to familiarise yourself with the information in this activity before facilitating.



Activity 4.6:

Words Have Power!

Objective:

By the end of the activity, participants will be able to share their experiences with language that stigmatises.

Materials

-Facilitator's instructions



Time

1 hour

Facilitator's Instructions

1. Ask the whole group to close their eyes and think of a time when a family member used stigmatising language to them or about them. Give some examples: skin colour, hair texture, body size or appearance, achievements or failures, potential or lack of potential.



2. Tell participants you want them to think about the words and language used against them along the following lines:
 - What was said
 - Who said it
 - When
 - Where (privately, publicly, at home or abroad)
 - Why
 - What feelings and thoughts followed, then and now
 - How it affected life, then and now
3. Have participants take turns talking about their experiences using the outline above. After each participant has shared ask the group to say how the experience relates to stigma and discrimination in relation to HIV.
4. After everyone has shared, return to feelings people mentioned. If feelings of disrespect did not come up, ask about them. What was disrespectful about the language and its tone? When a young person feels disrespected, what is the effect? When a child feels disrespected, what is the effect?
5. Get participants thinking and talking about the following:
 - Why can language wound deeply, sometimes more deeply, than a physical blow?
 - How can the power of negative words affect our sanity, faith and sense of security, especially in the context of the family?
6. Bring the exercise to an end by asking persons to share insights about stigma that they gained from the activity.

**"It isn't for the moment that you are struck that you need courage,
but for the long, uphill climb back to sanity and faith and security."**

Anne Morrow Lindbergh

Facilitator's Notes

You may wish to reflect on past experiences when a family member used stigmatising language to you before the activity.



Activity 4.7:

Past Experiences with Disclosure

Objective:

By the end of the activity, participants will be able to increase their understanding of stigma and connect disclosure to stigma.

Materials

-Facilitator's instructions

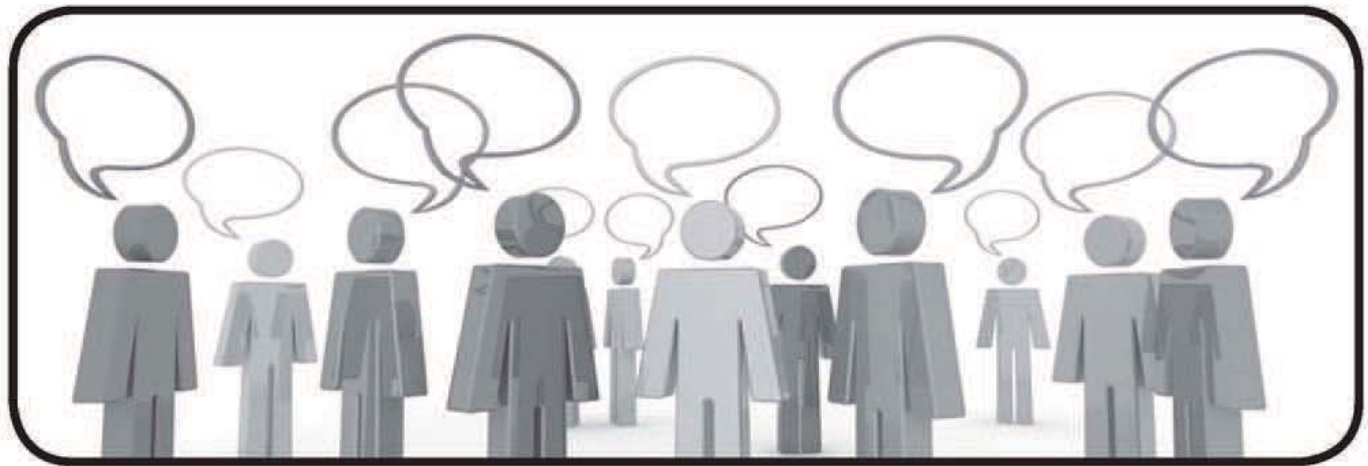


Time

1 hour

Facilitator's Instructions

1. Ask participants to spend a few minutes thinking of personal experiences with telling (disclosure) or not telling (non-disclosure) family members something that involved the fear of rejection or other negative consequences. It should not be about HIV.
2. Have participants consider, for example, the first menstruation, getting pregnant or getting someone pregnant, a drug problem, an inter-ethnic relationship, a relationship with a big age or faith difference, a consensual same-sex relationship, incest, sexual abuse, contracting an STI that is not HIV, failure, loss, or any experience likely to be seen as shameful or disgusting.
3. Ask persons who wish to share good, bad and really ugly experiences with disclosing or not disclosing 'personal stuff' to blood relations.
4. Tell participants the name and objective of the activity.





Activity 4.7:

Past Experiences with Disclosure

5. After everyone has had a chance to share (some persons may want to share experiences they know of, in addition to those they have experienced), have the group look at what came up with respect to:

Blood	Disgrace	The number of disclosures that had a positive effect compared to those with negative effects, that is, compare good to bad and 'uglies'.
Fear	Ignorance	The number of non-sex-related disclosures compared to sex-related disclosures.
Shame	Sex	The number of people who were actually surprised by the responses.
Blame	Trust	Feeling judged.

6. Have participants share what the benefits of disclosure are in relation to HIV.
7. Close by sharing the quote below and asking participants to take turns talking about how their understanding of stigma has been deepened by the activity.

**"Trouble is a part of life, and if you don't share it,
you don't give the person who loves you a chance to love you enough."**

Dinah Shore, American Singer & Actress, 1920

Facilitator's Notes

You may wish to spend some time reflecting on situations in your own life when you had to deal with disclosure.

Unit 5

HIV and Human Rights





Unit 5:

HIV and Human Rights

Purpose of the Unit

The purpose of this unit is to create awareness among participants about human rights within the legal and institutional framework for 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, the Group argues, is necessary to attain universal access to HIV prevention, treatment, care and support, itself a human rights imperative.

The activities are aimed at sensitising participants to the rights and in-country mechanisms available to protect and provide them with recourse for infringement of those rights. Participants will also explore human rights and HIV within the context of the workplace.



Activity 5.1:

What are Human Rights?

Objective:

By the end of the activity, participants will be able to identify their human rights and how these rights are expressed.

Materials

-Facilitator's instructions



Time

1 hour

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, 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.



Facilitator's Notes

You may wish to read the notes on HIV and Human Rights (Appendix 2) to familiarise yourself with the Treaties and Conventions.

Activity 5.2:

What are my Human Rights with Respect to HIV?

Objective:

By the end of the activity, participants will be able to identify their rights and entitlements in relation to HIV.

Materials

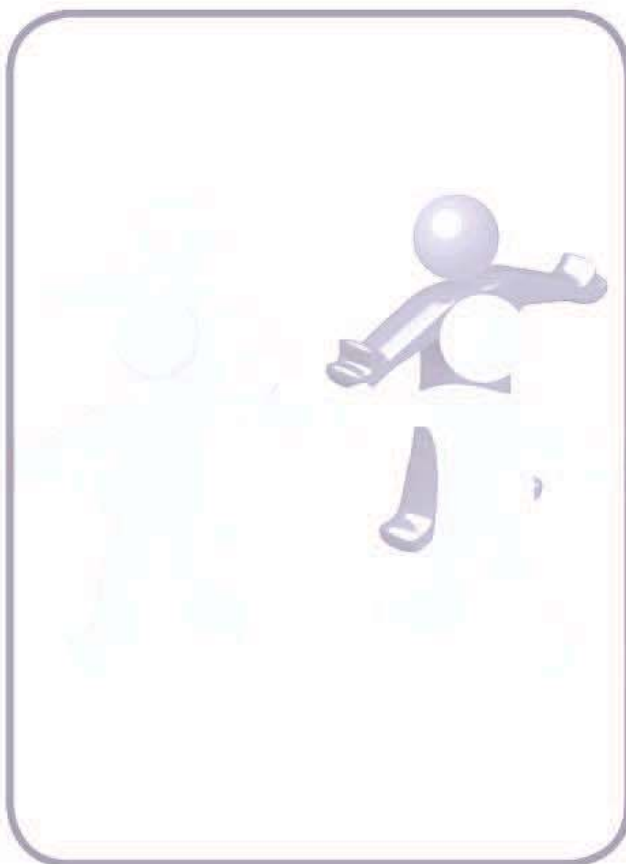
- Facilitator's instructions
- Projector
- Laptop
- Handouts



1 ½ hour

Facilitator's Instructions

1. Share the objective of this activity with the group.
2. Inform participants that the Political Declaration on HIV, 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.
3. You may 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.
4. You may 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.
5. Begin the presentation.



How do some of the relevant rights apply?

Rights Holders

6. Explain that in order 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.
- **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 to male and female condoms





Activity 5.2:

What are my Human Rights with Respect to HIV?

PLHIV

7. Explain that 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

Vulnerable Populations

8. Explain that 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 and prisoners.

These groups should have equal access to HIV prevention information, education and commodities and to HIV care, support and anti-retroviral treatment; should not be subject 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
9. Close by inviting participants to share how this activity helped them to understand the application of human rights to HIV.

Facilitator's Notes

You may wish to prepare copies of the presentation for participants to follow even if you are using an overhead projector. You may also wish to review Appendix 2: HIV and Human Rights.



Activity 5.3:

In-country Mechanisms for Protecting the Rights of PLHIV

Objective:

By the end of the activity, participants will be able to identify the in-country mechanisms for protecting their rights.

Materials

-Facilitator's instructions
-In-country mechanisms



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? and Activity 4.2: What are my rights in relation to HIV?
3. Ask participants to think and talk about how they can access those rights in their country. 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 PLHIV to report acts of discrimination and seek redress through in-country mechanisms in the event that they believe that their rights have been infringed.

Facilitator's Notes

You may wish to prepare copies of a list of in-country mechanisms for distribution to participants.





Activity 5.4:

Human Rights and HIV Workplace Policy

Objective:

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

- identify the ten key principles of the Code of Practice
- discuss the process for developing a workplace policy

Materials

- Facilitator's instructions
- Code of Practice
- Projector
- Laptop
- Handouts



Facilitator's Instructions

1. Explain to participants that a policy is a deliberate plan of action to guide decisions and achieve reasonable results. For example, HIV workplace policy provides the framework for action to reduce the spread of HIV and AIDS and manage how it affects the workplace.
2. Ask participants what is the purpose of an HIV workplace policy. Record their responses and add to the list any of the points below that were not mentioned.

A workplace:

- makes a clear commitment to company/agency action and ensures that they are in line with appropriate national laws
 - lays down a standard of behaviour for all employees (whether infected or not)
 - gives guidance to supervisors and managers
 - helps employees living with HIV or AIDS to understand what support and care they will receive, so they are more likely to come forward for voluntary testing
 - helps to stop the spread of the virus through prevention programmes
 - assists an enterprise/agency to plan for HIV and AIDS and manage its likely effect and in so doing save money
3. Explain that the policy provides the basis for putting in place a comprehensive workplace programme, combining prevention, care and the protection of rights. Depending on the particular situation, it may consist of a detailed document just on HIV and AIDS, setting out programmes, as well as policy issues, or it may be part of a wider policy or agreement on safety, health and working conditions and it may be a short statement of principle.





Activity 5.4:

Human Rights and HIV Workplace Policy

4. Explain that the International Labour Organization (ILO) developed a Code of Practice that forms the framework for action related to the workplace. This Code of Practice contains ten key principles for policy development and practical guidelines for programmes at enterprise, community and national levels. It covers the following main areas:
 - prevention of HIV
 - management and efforts to reduce the effects of AIDS on the world of work
 - care and support of workers infected with and affected by HIV and AIDS
 - removal of stigma and discrimination on the basis of someone's real or perceived HIV status
5. Spend some time discussing each of the above areas to ensure that participants fully understand what each is about.
6. Lead a discussion on the process (see below) that needs to be undertaken when developing the Workplace Policy.
 - General statement
 - Policy framework and general principles
 - Specific provision
 - Implementation and monitoring
 - Budget and finance
7. Ask each participant to share how he/she can contribute to either developing or implementing a workplace policy.
8. Close by sharing that an HIV workplace policy will also outline the responsibilities, rights and expected behaviour for management and employees.

Facilitator's Notes

You may wish to read Appendix 3: HIV and AIDS Workplace Policy before facilitating this activity. You may also wish to find out whether the workplace already has a policy and if it is being implemented. This will enable you to determine whether you need to focus on policy development or implementation. Management should be encouraged to implement and enforce the policy while employees should be encouraged to support its implementation.

Unit 6

Empowerment of PLHIV and Their Families





Unit 6:

Empowerment of PLHIV and Their Families

Purpose of the Unit

This purpose of this unit is to facilitate the empowerment of people living with and affected by HIV and to enable them to cope with their HIV status or the status of their loved one.

Activities

A common understanding of empowerment is necessary to enable us to know empowerment when we see it in people with whom we are working. As a general definition, empowerment is a multi-dimensional social process that helps people gain control over their own lives. It is a process that fosters power (that is, the capacity to implement) in people, for use in their own lives, their communities and in their society, by acting on issues that they define as important. (*Extension Journal Inc.*)

This unit provides a series of activities aimed at helping PLHIV and their families explore issues of self-stigma, positive living, life skills and emotional intelligence. It will help them identify their strengths by exploring past negative experiences, dealing with acceptance and exploring the process of behaviour change. Ultimately, the unit is aimed at facilitating empowerment of people living with and affected by HIV to enable them to cope with stigma and embrace positive living.



Activity 6.1: Positive Living

Objective:

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

- list the main elements of positive living

Materials

- Facilitator's instructions
- Pens/pencils
- Sheets of writing paper



1½ hours

Facilitator's Instructions

1. Share the name and objective of the activity with the group.
2. Ask participants to think about what positive living means to them and list six things that would make their lives better and help them live longer.
3. Ask each participant to share the six things with the group. Add elements of positive living not mentioned by participants. Some elements are listed below.
 - Acceptance of HIV status
 - Disclosure
 - Relationships with partner, children, parents, siblings, relatives, co-workers and friends
 - Future goals
 - Healthy body
 - Healthy mind
 - Healthy spirit
 - Exercise
 - Good nutrition
 - Care and support
 - Treatment adherence
 - Being alcohol free
 - Being drug free
 - Being tobacco free
4. Ask participants to say which elements would be feasible in their own lives and why.
5. Ask participants to give examples of changes they could make in order to incorporate aspects of healthy living into their own lives (e.g. giving up smoking/drinking, doing more exercise, etc.).
6. Ask participants to brainstorm the things that they should not do to ensure positive living. For example, taking herbal treatment as an alternative to conventional medicine.
7. Now ask participants who provide care for fellow PLHIV to indicate by a show of hands. Ask those participants to share what it means to provide care and support to PLHIV.





Activity 6.1: Positive Living

8. After each participant has shared, explain that some HIV-positive caregivers may feel a great need to be 'super heroes' and in so doing may not be taking care of themselves. Explain that it is therefore necessary for all such persons to take care of themselves because if they fail to do so they will suffer burnout and will not be in a position to help others. Share the Caregivers' Bill of Rights below as a means of emphasising the need for PLHIV caregivers to take good care of themselves.

Jo Horne: Author of *Caregiving: Helping an Aging Loved One*

I have the right:

To take care of myself. This is not an act of selfishness. It will enable me to take better care of my loved one or client.

I have the right:

To seek help from others even though my loved one/client may object. I recognise the limits of my own endurance and strength.

I have the right:

To maintain facets of my own life that do not include the person/client I care for, just as I would if he/she were healthy. I know that I do everything that I reasonably can for this person and I have the right to do some things for myself.

I have the right:

To get angry, be depressed and express other difficult emotions occasionally.

I have the right:

To reject any attempt by my loved one/client (either conscious or unconscious) to manipulate me through guilt, anger or depression.

I have the right:

To receive consideration, affection, forgiveness and acceptance from my loved one/client for as long as I offer these qualities in return.

I have the right:

To take pride in what I am accomplishing and to applaud the courage it sometimes takes to meet the needs of my loved one/client.

I have the right:

To protect my individuality and my right to make a life for myself that will sustain me when my loved one/client no longer needs my full-time help.

I have the right:

To expect and demand that as new strides are made in finding resources to aid physically and mentally impaired persons in our country, similar strides will be made toward aiding and supporting caregivers.



Activity 6.1:

Positive Living

9. Close by sharing with the group that HIV-positive persons are living longer, because of new and effective treatments. Positive living is a lifestyle adopted by a person with HIV in order to live life as fully as possible while slowing the progression of the disease. It is made possible when we move away from the idea that HIV is an immediate and inevitable death sentence.

Facilitator's Notes

You may wish to think about what positive living means for you, even in the absence of HIV.



Activity 6.2: Life Skills

Objective:

By the end of the activity, participants will be able to identify and use life skills for positive living.

Materials

- Facilitator's instructions
- Flip chart
- Markers
- Projector
- Laptop
- Handouts



1½ hours

Facilitator's Instructions

1. Ask a few participants to take turns sharing what preparations they made prior to coming to the workshop.
2. Ask those who shared to state their reasons for doing what they did if this was not already mentioned.
3. Point out that persons were in fact making decisions, for example, what to cook, what to wear, when to leave home, or which route to take. Some persons might have made decisions about what to cook based upon the time they had available and this would suggest critical thinking.
4. Share the name and the objective of the activity and ask the group whether they were aware that they were using life skills.
5. Spend some time discussing their responses and ask participants to define life skills and share any life skills they know. Add those not mentioned and group them according to the following three categories: **social skills**, **cognitive skills** and **emotional coping skills**. Explain that whether or not we are aware of them, we use life skills everyday for communicating, decision-making, problem-solving and managing stress.
6. Write the WHO definition of life skills (below) on a flip chart.



"Abilities for adaptive and positive behaviours that enable individuals to deal effectively with the demands and challenges of everyday life." (WHO 1993)

7. Encourage a few participants to share situations in which they have used life skills. Ask them to identify each of the life skills used. Request other participants to share additional life skills that could have been used in each of the situations described and to say whether the use of those skills might have resulted in another outcome and what that outcome might have been.
8. Remind participants about the activity on confidentiality and ask them to think about the life skills they had used during the activity but might not have been aware of (Critical thinking, decision-making, refusal skills, empathy).



Activity 6.2: Life Skills

9. Explain that the choice of and emphasis on different skills, will vary according to the topic and conditions (e.g. decision-making may feature strongly in HIV prevention, whereas conflict management may be more prominent in a peace education programme). Though the list suggests these categories are distinct from each other, many skills are used simultaneously in practice. For example, decision-making often involves critical thinking ("What are my options?") and values clarification ("What is important to me?"). In the end, the interplay between the skills is what produces powerful behavioural outcomes, especially where this approach is supported by other strategies such as media, policies and health services.
10. End the activity by encouraging participants to be aware of life skills and how they can apply them to enhance their lives.

"A key life skill is the ability to see Beauty where it is and not where you want it to be, where you hoped it would be, or where your parents told you it would be. The same applies to Love, Truth and Joy."

Source: Early Morning Conversation

Facilitator's Notes

You may wish to familiarise yourself with the UNICEF-suggested Life Skills in Appendix 4.



Activity 6.3:

Emotional Intelligence

Objective:

By the end of the activity, participants will be able to develop an understanding of emotional intelligence and how they can apply it to their everyday life.

Materials

- Facilitator's instructions
- Projector
- Laptop
- Handouts

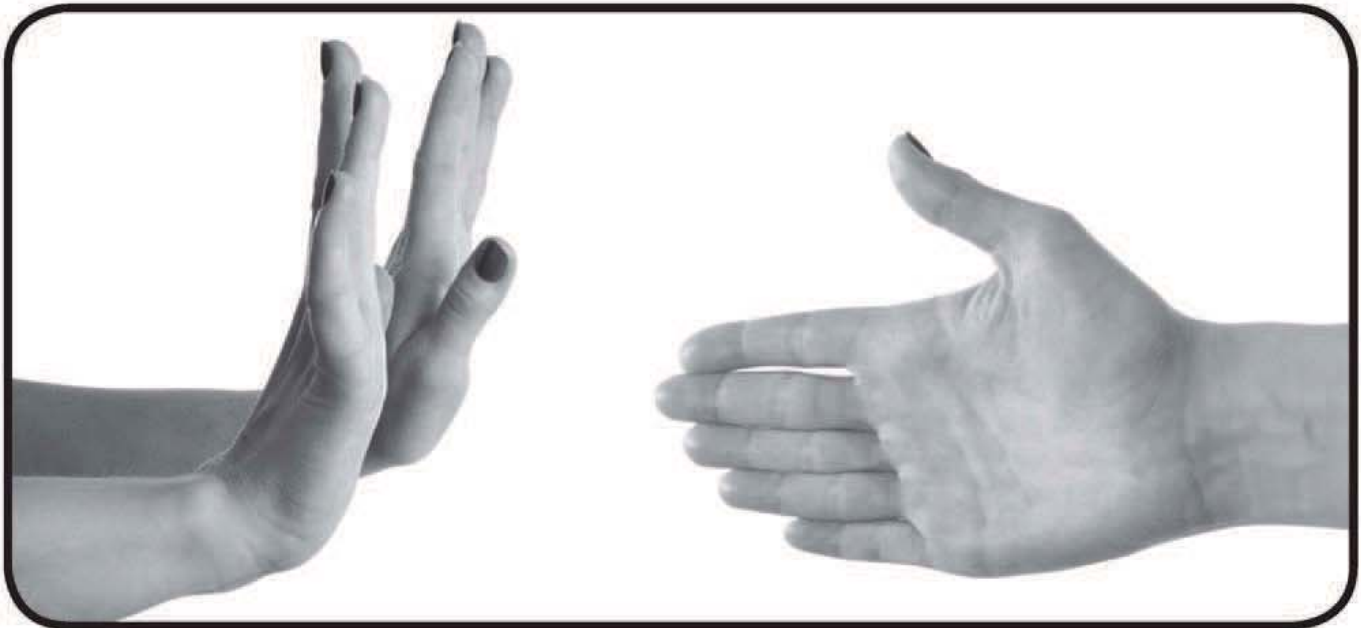


Time

1 hour

Facilitator's Instructions

1. Share the name and the objective of the activity with the group and present the following scenario to participants.



Scenario

A friend has borrowed something small but high in sentimental value. You've asked your friend to return the item, but your friend has failed to bring it back. Which of the following responses would you choose?

- a) You let it go. Friendship is more important than material items.
- b) You give your friend the cold shoulder until he/she returns your item.
- c) You admit to your friend how important the item is to you and why you would like it back and ask your friend to return the item to you.
- d) You end the friendship. You don't need a friend who disrespects you and your feelings.



Activity 6.3:

Emotional Intelligence

2. Ask participants to share their reasons for choosing the response they did.
3. Explain that when we handle situations smartly, ensuring that no one is damaged or relationships do not suffer, we are using emotional intelligence. Ask participants if they had heard the term 'emotional intelligence' before and if they understood what it meant.
4. Share that emotional intelligence includes the following five characteristics and abilities below:
 - Self-awareness – knowing your emotions, recognising feelings as they occur and discriminating between them
 - Mood management – handling feelings so they're relevant to the current situation and so that you react appropriately
 - Self-motivation – "gathering up" your feelings and directing yourself towards a goal, despite self-doubt, inertia, and impulsiveness
 - Empathy – recognising feelings in others and tuning into their verbal and non-verbal cues
 - Managing relationships – handling interpersonal interaction, conflict resolution and negotiations
5. Ask participants to define emotions. Eckhart Tolle defines emotions as "our response to a situation or event".
6. Ask participants to share situations where they used emotional intelligence and what the outcome was.
7. Share with the group that developing emotional intelligence in the home/workplace/etc. means acknowledging that emotions are always present and doing something intelligent with them. People vary enormously in the skill with which they use their own emotions and react to the emotions of others.
8. Explain that relationships have to be managed and that we manage them by the way we manage our conversations in those relationships. What we say and how we say it are both important.
9. Conclude the activity by saying that people derail because of the lack of life skills to deal with their emotions intelligently, not the lack of technical skills.

Facilitator's Notes

You may wish to spend some time reflecting on situations in your own life when you used emotional intelligence and what the outcomes were.



Activity 6.4:

Turning Negative Experiences into Positives

Objective:

By the end of the activity, participants will be able to identify their strengths by exploring past negative experiences.

Materials

- Facilitator's instructions
- Flip chart
- Markers



Time

1 hour

Facilitator's Instructions

1. Write the statement below by Maya Angelou on the flip chart and ask participants to spend ten minutes thinking about past negative experiences in their lives in relation to the statement.
2. Ask participants to form themselves into pairs and share the experiences that came. Each participant will share for five minutes.

"Someone was hurt before you, wronged before you, hungry before you, frightened before you, raped before you; yet, someone survived."

Maya Angelou

3. Invite participants who are comfortable sharing in the large group to share and say what they discovered about themselves in relation to their strengths. They can share what they discovered without sharing the actual experiences.
4. Close by drawing participants' attention to the quote below and saying when adversity appears in our lives, we often feel victimised, alone and helpless. A very deep look at the lives of successful people shows that misfortunes do not just strike selected individuals. It is inevitable in all our lives. The big challenge is how we choose to handle the situations and what we can learn from it.

"Do not grieve. Misfortunes do not flourish particularly in our path. They grow everywhere."

These words spoken by Omalia Indian Chief Big Elk in 1815

Facilitator's Notes

You may wish to spend sometime reflecting on past negative experiences you have had and what strengths you gained from them before facilitating the activity.





Activity 6.5:

Acceptance: Getting in Touch with the I Am-ness

Objective:

By the end of the activity, participants will be able to develop an understanding of how acceptance enables them to cope with HIV.

Materials

-Facilitator's instructions



Time

1 hour

Facilitator's Instructions

1. Tell participants that you want them to think about anything that they have lost. It could be a ring, a friendship, home, job, or HIV status. Ask them to think about the loss and how it felt then and now and about how important the thing or person was to them.
2. Ask participants to share their loss and the feeling around such loss.
3. When participants have finished sharing, say: "I am going to ask you a few questions, but instead of answering them now, see if you can find the answers within you. I will pause briefly after each question. When an answer comes, it may not necessarily come in the form of words."
 - i. Do you realise that you will have to let go of the feelings that you have in relation to the loss?
 - ii. For those of you who have not yet let go of the loss, how much more time will you need before you will be ready to let go of those feelings?
 - iii. Will you become less when you let go of it?
 - iv. Has who you are become diminished (a lesser person) by the loss?
4. Ask participants to share their feelings with the group. If any of them share that they felt diminished, ask them why they thought or felt so. Explain that thinking occurs in the mind, but we feel with our entire body.
5. Now ask participants who said that they still feel diminished to try answering the last question again but this time try to feel, rather than think. To help them, you may need to lead them in taking a few deep breaths and ask them to feel the air as it enters the lungs and the oxygen as it enters the blood.
6. Now share the name and objective of the activity. Tell participants that if they can feel the "I Am" strongly, then who I am has not been diminished at all.
7. Tell participants that the "I Am" is the joy of "being," and that you can only feel it when you get out of your head. Being must be felt. It cannot be thought. The loss was really in your head as a thought that you confused with the sense of I Am. You thought that the I Am or a part of it was in the loss. Whenever you completely accept a loss, you go beyond the ego and who you are, the I Am, which is consciousness itself, emerges. Practise becoming conscious each day by breathing in deeply and feeling the I Am. This helps you to separate your loss from who you are.



Activity 6.5:

Acceptance: Getting in Touch with the I Am-ness

8. Close by sharing that one thing we do know is that life will give us whatever experience is most helpful for the evolution of our consciousness. How do you know this is the experience you need? Because this is the experience you are having at this moment.

Facilitator's Notes

You may wish to do this activity yourself and face your own truths before you facilitate it. Insight for this activity came from Eckhart Tolle's book *A New Earth: Awakening to Your Life's Purpose*.



Activity 6.6:

Stigma: Real or Imagined?

Objective:

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

- reflect on situations in which they stigmatised themselves
- distinguish between real and imagined stigma

Materials

- Facilitator's instructions
- Flip chart
- Markers



1½ hours

Facilitator's Instructions

1. Ask each participant to share any situation in which they felt stigmatised or discriminated against. Ask them to reflect on the situation with the following considerations:
 - What happened?
 - What was said or done that made them feel that they were stigmatised or discriminated against?
 - How did they feel at the time?
 - How did they deal with the situation?
2. Listen very carefully to participants as they share. Make note of participants who shared that they were stigmatised or discriminated against by people who are unlikely to know their HIV status. Ask those participants the following questions after all participants have shared.
 - Did you know the person prior to this incident?
 - Do you know whether the person knew you?
 - Do you believe that the person knew that you are HIV-positive?
 - How would they have known that you are HIV-positive?
3. Share the name and objectives of the activity with participants and ask them to share their understanding of self-stigma. Self-stigma refers to the ways that stigmatised people in turn stigmatise themselves.
4. Explain that some People Living with HIV become weighed down and obsessed with feelings of guilt and fear that they will be judged. They may even worry that they pose a health threat to those around them, thus avoiding or sacrificing meaningful relationships in the process.
5. Say to participants that now that they know what self-stigma is, can they think of a time when they might have stigmatised themselves? Give them some time to think before sharing.
6. Explain that in many such situations the other individual might be having a bad day or might be just downright rude. The individual's attitude or behaviour may not be in any way connected or the result of your HIV status. This awareness will greatly help to deal with self-stigma.
7. Ask participants who have been able to overcome self-stigma to share how they were able to do so for the benefit of those who may still be dealing with it.



Activity 6.6:

Stigma: Real or Imagined?

8. Close by saying that the best way for someone living with HIV to overcome self-stigma is to become empowered. Counselling, support groups, public disclosure, being up-to-date with HIV-related matters, seeking and maintaining treatment, peer support and participation in HIV activities are some of the highly effective ways to become empowered and deal with self-stigma.

Facilitator's Notes

You may also wish to tell participants that if they are able to overcome self-stigma, they are more likely to influence the way others treat them.



Activity 6.7:

Understanding the Role of the Multi-disciplinary Team

Objective:

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

- discuss the role of the multi-disciplinary team
- discuss what is shared confidentiality

Materials

- Facilitator's instructions
- Projector
- Laptop
- Handouts



1½ hours

Facilitator's Instructions

1. Begin by asking the group to brainstorm what needs PLHIV and their families might have. When participants have finished brainstorming, ask them to help you place the issues raised under the four categories below:
 - Clinical management
 - Nursing care
 - Counselling
 - Social support
2. Explain that the needs which participants identified form the basis of the essential care elements listed above. Clarify what those elements mean.

Essential Care Elements

- Clinical management – providing early diagnosis, including HIV testing, rational treatment and follow up care
 - Nursing care – promoting and maintaining hygiene and nutrition; palliative care; home care and education to care providers at home and to family; as well as promoting observance of Universal Precautions
 - Counselling – providing psychosocial and spiritual support, including stress- and anxiety-reduction; risk-reduction planning and enabling coping; accepting HIV status and disclosure to important others; positive living and planning of the future for the family
 - Social support – providing welfare services; spiritual support and legal advice; providing information and referrals to such services and facilitating peer support
3. Divide participants into three groups and ask them to discuss the types of services that would be provided and by whom, under the categories of care listed below. Tell the groups to select a facilitator, notetaker and a presenter. Let them know that they have twenty minutes for the discussion and write up and five minutes to present.



Activity 6.7:

Understanding the Role of the Multi-disciplinary Team

Group 1: Community, Home and Palliative Care – self-care and skilled health personnel drawn from primary healthcare facilities or from the community itself

Group 2: Primary Healthcare – primary care facilities may include clinics and pharmacies

Group 3: Secondary Healthcare – typically includes a district or regional hospital

4. At the end of the group discussion, ask each group to present. Allow five minutes after each presentation for questions and additions to the group's list of points.
5. Fill in any information left out and share the objectives of the activity.
6. Inform participants about the issue of shared confidentiality and encourage them to think about the issue and its importance in relation to access to prevention, care and treatment services.

Shared confidentiality in relation to HIV refers to the sharing of information about the client among the multi-disciplinary team, that is, persons directly responsible for the client's care. These persons include but are not limited to doctors, nurses, counsellors, pharmacists and medical technologists. It does not include the cleaner or healthcare staff, who are in no way responsible for the client's care.

7. Emphasise that participants need to combine their knowledge of the role of the multi-disciplinary team and their increased self-confidence to engage in discussion with their healthcare provider. Participants must see it as their right to ask questions when they are unclear about their medications, diagnosis in relation to opportunistic infections, or wish to share concerns that they have regarding their care.
8. Close by asking participants to share what new information they learnt as a result of the activity and how they can use this information to increase their access to services.

Facilitator's Notes

You may wish to prepare yourself for this activity by reading Appendix 6: The Multi-disciplinary Prevention, Care and Treatment Team and familiarise yourself with the essential care elements available in your country.

Unit 7

Advocacy





Unit 7:

Advocacy

Purpose of the Unit

The purpose of this unit is to enable participants to increase their understanding of advocacy and their role as advocates for change.

Activities

The previous units provided persons living with and affected by HIV with some of the tools they need for empowering themselves and beginning the journey to behaviour change. 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 their rights.

Activities will help participants to identify and discuss the roles of PLHIV networks and support groups, since the development of strong networks among PLHIV has helped them to overcome social and cultural barriers. Additionally, it is hoped that both individually and collectively, PLHIV will work towards reducing stigma and discrimination and in so doing, increase their access to care and treatment services and ultimately to achieving improved quality of life and longevity.



Activity 7.1:

What is Advocacy?

Objective:

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

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

Materials

- Facilitator's instructions
- Projector
- Laptop
- Handouts



Time

1 hour

Facilitator's Instructions

1. Ask participants to share their understanding of advocacy.
2. Ask participants to identify the types of situations in which advocacy may be able to assist them. Participants should come up with scenarios such as the following:
 - Other people (including service providers) have an obligation to you that they are not fulfilling
 - Your rights are being ignored or violated
 - You have a responsibility that is particularly difficult for you to carry out
 - You 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 important:
 - Advocacy makes sure that there is recognition of the rights of people with HIV and other groups
 - 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 others
 - 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.



Facilitator's Notes

You may wish to deepen your understanding of advocacy before facilitating this activity.



Activity 7.2:

Who is an Advocate?

Objective:

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

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

Materials

- Facilitator's instructions
- Projector
- Laptop
- Handouts



Time

1 hour

Facilitator's Instructions

1. Ask participants who an advocate is. An advocate is someone who campaigns on your behalf on an issue.
2. Ask participants to share what are some of the roles and responsibilities 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





Activity 7.2:

Who is an Advocate?

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. Ask participants to discuss whether they believe that they can advocate for themselves.
5. Close by sharing that each person can be an advocate for himself/herself. Identifying and utilising their own strengths and skills are talents in themselves and can create a real sense of empowerment and achievement.

Everyone can work to reduce stigma and discrimination by being constantly aware of our feelings and thoughts, by not being judgemental, by not blaming, by becoming informed and educated about HIV and AIDS, by teaching others about HIV and AIDS, by not engaging in stigmatising thoughts or talk and by correcting those who do.



Activity 7.3:

The Role of PLHIV Networks

Objective:

By the end of the activity, participants will be able to identify and discuss the different roles of the PLHIV network.

Materials

- Facilitator's instructions
- Projector
- Laptop
- Handouts



Time
1 ½ hours

Facilitator's Instructions

1. Share the name and the objective of the activity with participants.
2. Ask participants to choose a partner and spend three minutes each talking about the role of PLHIV networks.
3. Ask participants from each pair to share what they came up with and record their responses on the flip chart. Responses should include, but not be limited to the following:

- 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 partnering 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 access to prevention, care and treatment services

4. Summarise the discussion and share the following roles:

- The network should provide a platform where the issue of HIV and AIDS is addressed and capacity-building of PLHIV is achieved for effective response to HIV and AIDS and the needs of PLHIV
- The network should 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
- The network should create opportunities for the provision of enhanced social support to PLHIV, including the reduction of stigma and discrimination against them





Activity 7.3: The Role of PLHIV Networks

5. Now help participants to understand the advocacy role of the networks by sharing and clarifying the following:

Role of PLHIV Networks at the Policy Level

- Advocate for Universal Access to generic anti-retroviral drugs as a means of increasing access for PLHIV and vulnerable populations
- Advocate for proper nutritional support, crucial for effective treatment for PLHIV
- Advocate for the rights of women and 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 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

6. Ask participants to take turns sharing how they will use the information they learnt about PLHIV networks.
7. Close by sharing the quote below from Credo.

**"We need not walk alone...
We reach out to each other with love and understanding and with hope...
We come together from all walks of life,
from many different circumstances...
We need not walk alone."
Credo, The Compassionate Friend**



Activity 7.3:

The Role of PLHIV Networks

Facilitator's Notes

You may wish to familiarise yourself with the role of PLHIV networks before facilitating this activity. You may wish to make copies of Appendix 7: Roles of PLHIV Networks for distribution to participants.

This activity was adapted from Christopher Dorset's (Chairman CRN+) presentation on the Role of CRN+.



Activity 7.4:

The Role of PLHIV Support Groups

Objective:

By the end of the activity, participants will be able to identify and discuss the role of PLHIV support groups.

Materials

- Facilitator's instructions
- Projector
- Laptop
- Handouts



1½ hours

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 are part of a support group.
2. Ask a few participants who raised their hands to share on what a support group is and what it does. 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 that 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 share why they joined a support group and why others should. Summarise their responses and share the following:

Why join 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-generation activities, nutritional support, day care, legal aid, etc.



Activity 7.4:

The Role of PLHIV Support Groups

4. Ask participants who are not part of a support group if they know how to find a support group. After they have responded, share the following:

How to find a support group?

- Ask your healthcare provider. This person could be your doctor, counsellor or nurse, etc.
 - Contact your National AIDS Programme (NAP)
 - Contact the Human Rights Advocate, oftentimes located at the NAP
 - Check your local telephone directory. The front pages of most directories usually provide such information
 - Ask another PLHIV to recommend a support group
5. Have two participants share good experiences that they have had being part of a support group. Have two others share any bad experiences they have had. Ask them not to share the names of and location of the support groups. You don't want to appear to be singling out any particular support group.
 6. After they have shared, ask participants to brainstorm what a good support group should look like. Record their responses on the 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 requests for assistance and queries
- Regular meetings at convenient times
- Access to professional support (for example, doctors, counsellors 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 welcomed
- 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



Activity 7.4:

The Role of PLHIV Support Groups

7. Tell participants to take turns sharing what they learnt as a result of this activity.
8. Explain to participants that the activities in the toolkit could be used within their support group to help facilitate empowerment of their members. Emphasise that a support group is very diverse and consists of persons who have had similar experiences and many whom have learnt how to cope. Explain that the answers to many of the questions raised in relation to coping with HIV reside with members of the group.
9. 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 provide the necessary information that allows them to meet their own needs.

Facilitator's Notes

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 8: Roles of Support Groups for distribution to participants.

Appendices



Appendix 1:

HIV 101: Getting Down to Basics

UNAIDS AIDS Epidemic update 2009

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

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

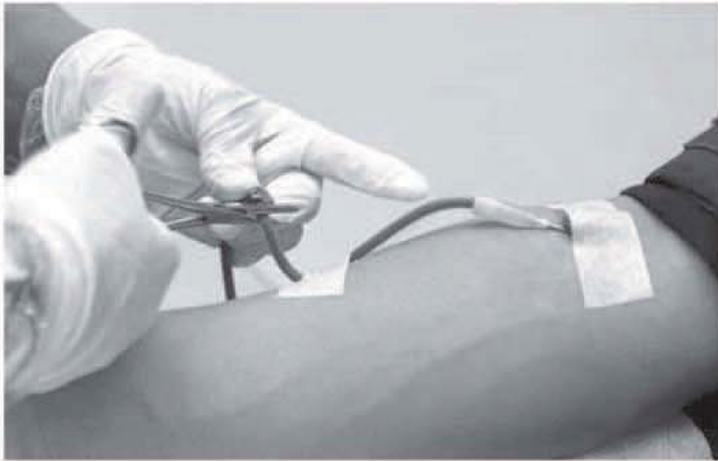
Tips for the Facilitator

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.



Appendix 1:

HIV 101: Getting Down to Basics



Answers to Frequently Asked Questions

Avert. Last updated September 04, 2009. <http://www.avert.org/faq1.htm>

What are the main routes of HIV transmission?

These are the main ways in which someone can become infected with HIV:

- Unprotected penetrative sex with someone who is infected
- Injection or transfusion of contaminated blood or blood products, donations of semen (artificial insemination), skin grafts or organ transplants taken from someone who is infected
- From a mother who is infected to her baby. This can occur during pregnancy, at birth and through breastfeeding
- Sharing unsterilised injection equipment that has previously been used by someone who is infected

Appendix 1:

HIV 101: Getting Down to Basics

Can I be infected if my partner doesn't have HIV?

No. Like all Sexually Transmitted Infections, HIV cannot be 'created', only passed on. If you are sure that your partner does not have HIV, then there is no risk of acquiring it, even if you do have unprotected sex (whether it be vaginal, anal or oral). However, pregnancy and other Sexually Transmitted Infections (if your partner has one) remain a risk, so you should still use a condom or other suitable form of birth control wherever possible.

How safe is oral sex?

Although it is possible to become infected with HIV through oral sex, the risk of becoming infected in this way is much lower than the risk of infection via unprotected sexual intercourse with a man or woman.

When giving oral sex to a man (sucking or licking a man's penis) a person could become infected with HIV if infected semen came into contact with damaged and receding gums, or any cuts or sores that might be present in his/her mouth.

Giving oral sex to a woman (licking a woman's vulva or vagina) is also considered relatively low-risk. Transmission could take place if infected sexual fluids from a woman got into the mouth of her partner. The likelihood of infection might be increased if there is menstrual blood involved or if the woman is infected with another Sexually Transmitted Infection.

The likelihood of either a man or a woman becoming infected with HIV as a result of receiving oral sex is extremely low, as saliva does not contain infectious quantities of HIV.

More information can be found on our oral sex & HIV page.

What are the chances of becoming infected with HIV if he doesn't come inside me?

Whilst research suggests that high concentrations of HIV can sometimes be detected in pre-cum, it is difficult to judge whether HIV is present in sufficient quantities for infection to occur. To guard against the possibility of infection with HIV or any other Sexually Transmitted Infection it is best to practise safer sex, i.e. sex with a condom.

Is deep kissing a route of HIV transmission?

Deep or open-mouthed kissing is a very low-risk activity in terms of HIV transmission. HIV is only present in saliva in very minute amounts, insufficient to cause infection with HIV.

There has been only one documented case of someone becoming infected with HIV through kissing – a result of exposure to infected blood during open-mouthed kissing. If you or your partner have blood in your mouth, you should avoid kissing until the bleeding stops.

Are lesbians or other Women who have Sex with Women at risk for HIV?

Lesbians/bisexual women are not at high risk of contracting HIV through woman-to-woman sex. Very few women are known to have passed HIV on to other women sexually, though it is theoretically possible if infected vaginal fluids or blood from an HIV-positive partner enter the other woman's vagina (perhaps on fingers or sex toys).

AVERT has more information about lesbians, bisexual women and HIV.



Appendix 1:

HIV 101: Getting Down to Basics

Is unprotected anal intercourse more of an HIV risk than vaginal or oral sex?

Unprotected anal intercourse does carry a higher risk than most other forms of sexual activity. The lining of the rectum has fewer cells than that of the vagina and therefore can be damaged more easily, causing bleeding during intercourse. This can then be a route into the bloodstream for infected sexual fluids or blood. There is also a risk to the insertive partner during anal intercourse, though this is lower than the risk to the receptive partner.

Does 'fingering' during sex carry a risk of HIV transmission?

Inserting a finger into someone's anus or vagina would only be an HIV risk if the finger had cuts or sores on it and if there was direct contact with HIV infected blood, vaginal fluids or semen from the other person. There might also be a risk if the person doing the fingering had HIV and their finger was bleeding.

Is there a connection between HIV and other STIs (Sexually Transmitted Infections)?

HIV and other Sexually Transmitted Infections can impact upon each other. The presence of these in an HIV infected person can increase the risk of HIV transmission. This can be through a genital ulcer, which could bleed, or through increased genital discharge.

An HIV-negative person who has a Sexually Transmitted Infection can be at increased risk of becoming infected with HIV through sex. This can happen if the STI causes ulceration or breaks in the skin (e.g. syphilis or herpes), or if it stimulates an immune response in the genital area (e.g. chlamydia or gonorrhea). HIV transmission is more likely in those with ulcerative STIs than non-ulcerative.

Using condoms during sex is the best way to prevent the sexual transmission of diseases, including HIV. AVERT.org has more information on STIs.

Can I become infected with HIV through everyday social contact/activities such as shaking hands/toilet seats/swimming pools/sharing cutlery/kissing/sneezes and coughs?

No. HIV is not an airborne, water-borne or food-borne virus and does not survive for very long outside the human body. Therefore ordinary social contact such as kissing, shaking hands, coughing and sharing cutlery does not result in the virus being passed from one person to another.

Is there a risk of HIV transmission when having a tattoo, body piercing or visiting the barber?

If instruments contaminated with blood are not sterilised between clients, then there is a risk of HIV transmission. However, people who carry out body piercing or tattooing should follow procedures called 'Universal Precautions', which are designed to prevent the transmission of blood-borne infections such as HIV and Hepatitis B.



Appendix 1:

HIV 101: Getting Down to Basics

When visiting the barber, there is no risk of infection unless the skin is cut and infected blood gets into the wound. Traditional 'cut-throat' razors used by barbers now have disposable blades, which should only be used once, thus eliminating the risk from blood-borne infections such as Hepatitis and HIV.

Are healthcare workers at risk from HIV through contact with HIV-infected patients?

The risk to healthcare workers being exposed to HIV is extremely low, especially if they follow universal healthcare precautions. Everyday casual contact does not expose anyone, including healthcare workers, to HIV. The main risk is through accidental injuries from needles and other sharp objects that may be contaminated with HIV.

It has been estimated that the risk of infection from a needlestick injury is less than one per cent. In the UK for instance, there have been five documented cases of HIV transmission through occupational exposure in the healthcare setting, the last being in 1999. In the US, there were fifty-seven documented cases of occupational HIV transmission up to 2006.

The risk posed by a needlestick injury may be higher if it is a deep injury; if it is made with a hollow bore needle; if the source patient has a high viral load; or if the sharp instrument is visibly contaminated with blood. For further information, see our HIV and healthcare workers page.

Am I at risk of becoming infected with HIV when visiting the doctor or dentist?

Transmission of HIV in a healthcare setting is extremely rare. All health professionals are required to follow infection control procedures when caring for any patient. These procedures are called Universal Precautions for infection control. They are designed to protect both patients and healthcare professionals from the transmission of blood-borne diseases such as Hepatitis B and HIV.

If blood splashes into my eye, or I get some in my mouth, can I become infected with HIV?

Research suggests that the risk of HIV infection in this way is extremely small. A very small number of people – usually in a healthcare setting – have become infected with HIV as a result of blood splashes in the eye.

Blood in the mouth carries an even lower risk. The lining of the mouth is very protective, so the only way HIV could enter the bloodstream would be if the person had a cut, open sore or area of inflammation somewhere in their mouth or throat (if the blood was swallowed). Even then, the person would have to get a fairly significant quantity of fresh blood (i.e. an amount that can be clearly seen or tasted) directly into the region of the cut or sore for there to be a risk. HIV is diluted by saliva and easily killed by stomach acid once the blood is swallowed.

Can I become infected with HIV through biting?

Infection with HIV in this way is unusual. There have only been a couple of documented cases of HIV transmission resulting from biting. In these particular cases, severe tissue tearing and damage were reported in addition to the presence of blood.

Appendix 1:

HIV 101: Getting Down to Basics

Can I get HIV from a mosquito?

No, it is not possible to get HIV from mosquitoes. When taking blood from someone, mosquitoes do not inject blood from any previous person. The only thing that a mosquito injects is saliva, which acts as a lubricant and enables it to feed more efficiently.

Can I become infected with HIV if I inject drugs and share the needles with someone else, without sterilising them?

There is a possibility of becoming infected with HIV if you share injecting equipment with someone who has the virus. If HIV infected blood remains within the bore (inside) of the needle or in the syringe and someone else then uses it to inject himself/herself, that blood can be flushed into the bloodstream. Sharing needles, syringes, spoons, filters or water can pass on the virus. Disinfecting equipment between uses can reduce the likelihood of transmission, but does not eliminate it. More information can be found on our injecting drugs, drug users and HIV page.

Can I transmit HIV to my baby during pregnancy or breastfeeding?

An HIV-infected pregnant woman can pass the virus on to her unborn baby either before or during birth. HIV can also be passed on during breastfeeding. If a woman knows that she is infected with HIV, there are drugs she can take to greatly reduce the chances of her child becoming infected. Other ways to lower the risk include choosing to have a Caesarean section delivery and not breastfeeding. Read more about HIV and pregnancy.



Does donating blood or having a blood transfusion mean that I am putting myself at risk of contracting HIV?

Some people have been infected through a transfusion of infected blood. In most countries, however, all the blood used for transfusions is now tested for HIV. In those countries where the blood has been tested, HIV infection through blood transfusions is now extremely rare. Blood products, such as those used by people with haemophilia, are now heat-treated to make them safe.

Donating blood at an approved donation centre should carry no risk, as all equipment should be sterile and blood collection needles are not reused.

Can HIV be transmitted outside of the body?

Whilst HIV may live for a short while outside of the body, HIV transmission has not been reported as a result of contact with spillages or small traces of blood, semen or other bodily fluids. This is partly because HIV dies quite quickly once exposed to the air and also because spilled fluids would have to get into a person's bloodstream to infect them.

Scientists agree that HIV does not survive well in the environment, making the chance of environmental transmission remote. To obtain data on the survival of HIV, laboratory studies usually use artificially high concentrations of laboratory-grown virus. Although these concentrations of HIV can be kept alive for days or even weeks under controlled conditions, studies have shown that drying of these high concentrations of HIV reduces the amount of infectious virus by 90 to 99 per cent within a few hours.

Appendix 1:

HIV 101: Getting Down to Basics

Since the HIV concentrations used in laboratory studies are much higher than those actually found in blood or other specimens, the real risk of HIV infection from dried bodily fluids is probably close to zero. Incorrect interpretation of conclusions drawn from laboratory studies have unnecessarily alarmed some people. AVERT.org has additional facts about HIV and AIDS.

Does circumcision protect against HIV?

There is very strong evidence showing that circumcised men are about half as likely as uncircumcised men to acquire HIV through heterosexual sex. However, circumcision does not make a man immune to HIV infection, it just means that it's less likely to happen. Male circumcision probably has little or no preventive benefit for women. Read more about HIV and circumcision.

If I am taking anti-retroviral drugs and have an 'undetectable' viral load, am I still infectious?

Even if your tests show that you have very low levels of HIV in your blood, the virus will not have been totally eradicated and you will still be capable of infecting others. Some drugs do not penetrate the genitals very well and so do not disable HIV as effectively there as they do in the blood. This means that while you may have little active virus showing up on blood tests, there may still be quite a lot of HIV in your semen or vaginal fluids. Transmission may be less likely when you have a low viral load, but it is still possible so you should always take appropriate precautions.

For more information on this issue, read AVERT's HIV transmission and anti-retroviral therapy briefing sheet.

What is the window period?

The 'window period' is a term used to describe the period of time between HIV infection and the production of antibodies. During this time, an antibody test may give a 'false negative' result, which means the test will be negative, even though a person is infected with HIV. To avoid false negative results, antibody tests are recommended between six weeks and three months after potential exposure to HIV infection.

A negative test at three months will almost always mean a person is not infected with HIV. It is very important to note that if a person is infected with HIV, they can still transmit the virus to others during the window period.

HIV 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:

Human – Meaning only humans can contract this strain of the virus

Immunodeficiency – Affecting the immune system and causing it to weaken

Virus – A micro-organism that multiplies inside a host organism's cell



Appendix 1:

HIV 101: Getting Down to Basics

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:

Acquired – It happens to people who have already been infected with HIV

Immune – Affecting the immune system

Deficiency – Weakening

Syndrome – 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

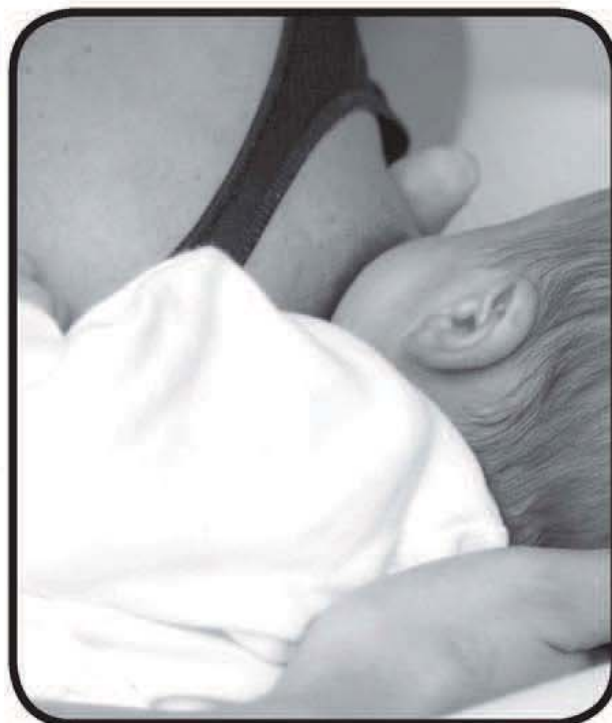
Some people fear that HIV might be transmitted in other ways, however, no scientific evidence to support any of these fears has been found. If HIV were being transmitted through other routes (such as through air, water, or insects), the pattern of reported AIDS cases would be much different from what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

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.



Appendix 1:

HIV 101: Getting Down to Basics

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.

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.

Appendix 1:

HIV 101: Getting Down to Basics

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.

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. They 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. Universal Precautions 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:

HIV and Human Rights

Human Rights Watch

Additional information can be found on the UNAIDS webpage *Human Rights and HIV*

<http://www.unaids.org/en/PolicyAndPractice/HumanRights/default.asp>

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.



Appendix 2:

HIV and Human Rights

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 on 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 giving 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 of 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."

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.

Appendix 2:

HIV and Human Rights

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, legitimise stigma and discrimination.

Ensuring the protection, respect 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 3:

HIV and AIDS Workplace Policy

Adapted from ILO Workplace Policy Guidelines

For more information visit <http://www.ilo.org/public/english/protection/trav/aids/steps/index.htm>

Why have a Workplace Policy?

A workplace policy provides the framework for action to reduce the spread of HIV and AIDS and manage its impact. A workplace policy:

- makes an explicit commitment to corporate action and ensures consistency with appropriate national laws
- lays down a standard of behaviour for all employees (whether infected or not)
- gives guidance to supervisors and managers
- helps employees living with HIV or AIDS to understand what support and care they will receive, so they are more likely to come forward for voluntary testing
- helps to stop the spread of the virus through prevention programmes
- assists an enterprise to plan for HIV and AIDS and manage its impact, so ultimately saving money

It provides the basis for putting in place a comprehensive workplace programme, combining prevention, care and the protection of rights. Depending on the particular situation, it may consist of a detailed document just on HIV and AIDS, setting out programmes, as well as policy issues, it may be part of a wider policy or agreement on safety, health and working conditions and it may be a short statement of principle.

Key Principles of the Code of Practice

The Code of Practice is the framework for action related to the workplace. It contains key principles for policy development and practical guidelines for programmes at enterprise, community and national levels. It covers the following main areas:

- prevention of HIV
- management and mitigation of the impact of AIDS on the world of work
- care and support of workers infected with and affected by HIV and AIDS
- elimination of stigma and discrimination on the basis of real or perceived HIV status.

1. Recognition of HIV and AIDS as a Workplace Issue

HIV/AIDS is a workplace issue, not only because it affects the workforce, but also because the workplace can play a vital role in limiting the spread and effects of the epidemic.

2. Non-discrimination

There should be no discrimination or stigmatisation of workers on the basis of real or perceived HIV status.

3. Gender Equality

More equal gender relations and the empowerment of women is vital to successfully preventing the spread of HIV infection and enabling women to cope with HIV and AIDS.



Appendix 3:

HIV and AIDS Workplace Policy

4. Healthy Work Environment

The work environment should be healthy and safe and adapted to the state of health and capabilities of workers.

5. Social Dialogue

A successful HIV and AIDS policy and programme requires co-operation and trust between employers, workers and governments.

6. Screening for Purposes of Employment

HIV screening should not be required of job applicants or persons in employment and testing for HIV should not be carried out at the workplace, except as specified in this code.

7. Confidentiality

Access to personal data relating to a worker's HIV status should be bound by the rules of confidentiality consistent with existing ILO codes of practice.

8. Continuing the Employment Relationship

HIV infection is not a cause for termination of employment. Persons with HIV-related illnesses should be able to work for as long as medically fit in appropriate conditions.

9. Prevention

The social partners are in a unique position to promote prevention efforts through information and education and support changes in attitudes and behaviour.

10. Care and Support

Solidarity, care and support should guide the response to AIDS at the workplace. All workers are entitled to affordable health services and to benefits from statutory and occupational schemes.

Developing the Workplace Policy

- General statement
- Policy framework and general principles
- Specific provision
- Implementation and Monitoring
- Budget and Finance

Steps to Developing a Workplace Policy

Step 1. Set up an HIV and AIDS committee with representatives of top management, supervisors, workers, trade unions, the human resources department, training department, industrial relations unit, occupational health unit, health and safety committee. In smaller workplaces, an existing committee may be given this responsibility.

Step 2. Decide on the reference and decision-making powers and responsibilities. These must be approved by existing decision-making bodies to ensure support for implementation.



Appendix 3:

HIV and AIDS Workplace Policy

Step 3. Review of national laws and their implications. This should go beyond any specific laws on HIV and AIDS and could include anti-discrimination laws, etc. and international treaties to which the country is a signatory.

Step 4. Assess the impact of the HIV epidemic on the workplace and the needs of workers by carrying out a confidential baseline study. This is important for planning a programme and for monitoring its effectiveness.

Step 5. Determine what health and information services are already available, both at the workplace and in the local community. This is useful to avoid duplication and essential to ensuring no- or low-cost response where resources are few.

Step 6. Draft a policy and circulate for comment then revise and adopt. Note that the wider the consultation, the fuller the sense of 'ownership' and support.

Step 7. Develop a budget for implementation of the policy. This will be used to mobilise funding.

Step 8. Draw up a plan of action with timetable and lines of responsibility to implement policy. Identify at least one named co-ordinator/focal point to ensure implementation.

Step 9. Disseminate policy and plan of action widely through notice boards, mailings, pay slip inserts, special meetings, and training sessions. Put in place programmes of information, education and care.

Step 10. Monitor the impact of the policy and revise it as necessary. The HIV epidemic is evolving rapidly and so is the response, therefore workplace policies and programmes must not stand still.

Checklist for HIV and AIDS Policy

Compliance with national laws	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Confidentiality and privacy ensured	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Protection of employees affected by HIV against discrimination, victimisation and harassment	<input type="checkbox"/> Yes	<input type="checkbox"/> No
No HIV screening of employees or job applicants	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Entitlement to company/statutory benefits and services	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Equal terms and conditions for women at work and protection where necessary (e.g. against sexual harassment)	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Protection of workplace safety and health accommodation	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Information and education on HIV and AIDS for employees and their families	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Provision of condoms free or at affordable prices	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Training for managers, workers' representatives, peer educators and others if relevant, e.g. safety and health officers	<input type="checkbox"/> Yes	<input type="checkbox"/> No

Appendix 4: Life Skills

UNICEF

Visit http://www.unicef.org/lifeskills/index_whichskills.html



There is no definitive list of life skills. The list below includes the psychosocial and interpersonal skills generally considered important. The choice of and emphasis on different skills will vary according to the topic and local conditions (e.g. decision-making may feature strongly in HIV and AIDS prevention whereas conflict management may be more prominent in a peace education programme). Though the list suggests these categories are distinct from each other, many skills are used simultaneously in practice. For example, decision-making often involves critical thinking ("What are my options?") and values clarification ("What is important to me?"). Ultimately, the interplay between the skills is what produces powerful behavioural outcomes, especially where this approach is supported by other strategies such as media, policies and health services.

Communication and Interpersonal Skills

Interpersonal communication skills

- Verbal/non-verbal communication
- Active listening
- Expressing feelings; giving feedback (without blaming) and receiving feedback

Negotiation/refusal skills

- Negotiation and conflict management
- Assertiveness skills
- Refusal skills

Empathy

- Ability to listen and understand another's needs and circumstances and express that understanding

Appendix 4:

Life Skills

Co-operation and Teamwork

- Expressing respect for others' contributions and different styles
- Assessing one's own abilities and contributing to the group

Advocacy Skills

- Influencing skills and persuasion
- Networking and motivation skills

Decision-Making and Critical Thinking Skills

Decision-making/problem-solving skills

- Information-gathering skills
- Evaluating future consequences of present actions for self and others
- Determining alternative solutions to problems
- Analysis skills regarding the influence of values and attitudes of self and others on motivation

Critical-thinking skills

- Analysing peer and media influences
- Analysing attitudes, values, social norms and beliefs and factors affecting these
- Identifying relevant information and information sources

Coping and Self-Management Skills

Skills for increasing internal locus of control

- Self-esteem/confidence-building skills
- Self-awareness skills including awareness of rights, influences, values, attitudes, rights, strengths and weaknesses
- Goal-setting skills
- Self-evaluation/Self-assessment/Self-monitoring skills

Skills for managing feelings

- Anger management
- Dealing with grief and anxiety
- Coping skills for dealing with loss, abuse, trauma

Skills for managing stress

- Time management
- Positive thinking
- Relaxation techniques

Appendix 5: Behaviour Change

Dr. Joseph Petraglia, Behaviour Expert, USA

Stages of Change

Pre-Contemplation	Contemplation	Preparation	Action	Maintenance
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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 5:

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 6:

The Multi-disciplinary Prevention, Care & Treatment Team

Family Health International 2009

The multi-disciplinary team model of HIV care evolved out of necessity due to the diverse characteristics and needs of People Living with HIV disease and is now accepted as the international standard of care, though it represents a significant departure from methods of care for other infectious diseases. This model of care allows for health services to be tailored to the express needs of patients and this leads to better care and improved health outcomes. (PubMed, 2002)

These needs form the basis of the essential care elements as follows:

- Clinical management – providing early diagnosis, including HIV testing, rational treatment and follow-up care
- Nursing care – promoting and maintaining hygiene and nutrition; palliative care; home care and education to care providers at home and family and promoting observance of universal precautions
- Counselling – providing psychosocial and spiritual support, including stress- and anxiety-reduction, risk-reduction planning and enabling coping, accepting HIV status and disclosure to important others; positive living and planning of the future for the family
- Social support – providing welfare services; spiritual support and legal advice; providing information and referrals to such services and facilitating peer support

The composition of and emphasis within such a comprehensive approach will change over time between the phase of suspicion of infection or early HIV-related illnesses and late-stage disease. For example, when infection is suspected, emphasis will be on meeting anxiety needs through counselling, followed at a later stage by meeting clinical needs through managing opportunistic infections. At later stages of the disease, palliative care, combined with social support to ensure a future for the family, become the most pressing needs.

At any moment in time, however, the different elements of comprehensive care complement and even potentiate each other and if provided well will result in a better quality of life for affected people. Managing a clinical condition, for example, will be easier and better appreciated if worries about being infected and what will happen in the future can be dealt with through referral to a counsellor and to services dealing with social or legal support.



Appendix 6:

The Multi-disciplinary Prevention, Care & Treatment Team

For care to be comprehensive, it must comprise a wide range of support services. These need not necessarily be provided by the same individual or institution but can be provided through networking in partnership with other services, institutions, or projects. Comprehensive care should also include timely referrals between home or community and the hospital and vice versa, effective discharge planning and follow up at each level.

The essence of “comprehensive care across a continuum” provides a unique opportunity to respond to the wide range of medical, emotional and social support needs of People Living with HIV and AIDS and their families. To enter a care continuum, a diagnosis has to be made in such a way that it allows further care-seeking and support. Experience so far has shown that voluntary counselling and testing (VCT) sites at hospitals or clinics, or even free-standing sites, serve the purpose of helping people know about and accept their serostatus or diagnosis and learn where to go for care. During the course of HIV illness, PLHIV will have different needs and care may need to be provided away from hospitals and closer to home or within the home. Teamwork and referral mechanisms will allow providers to offer a continuum of care and thus avoid parallel and isolated care efforts.

The principle of a care continuum applicable to most, if not all health issues, is particularly critical to HIV/AIDS for several reasons. First, HIV infection is a chronic state, which may extend over a long period of time if opportunistic infections are prevented or promptly treated. This situation requires that there be a strong synergy between various levels of the care systems, as some infections may be diagnosed and treated at the local level, while others may require effective referral to care institutions. Second, because of the ongoing fear and stigma associated with HIV infection, many people are forced to seek care far from home. This occurs despite the fact that optimal care involves access to care where it is most convenient and cost-effective and where people benefitting from such care can pursue their professional and personal lives with minimum disruption and without fear. As a general rule, the farther a person has to travel from home to receive care, the greater the personal cost (for example, economic cost of arranging travel time away from home and work and costs of time lost).

The various stages across the continuum are:

Home and Community Care

Self-care requires skills in prevention and early presumption and treatment of some opportunistic infections and other conditions, such as diarrhoea, headaches, or dermatosis. These skills may be acquired by the Person Living with HIV and/or by his/her relatives or friends who may also provide needed social support. Peer support groups are very important in supporting and helping them update and exchange information on optimal self-care and care-seeking.

Self-care may not always be possible or sufficient. Skilled health personnel, drawn from primary healthcare facilities or from the community itself, may be trained to provide such forms of care as palliative and nursing care. Some forms of home-based care will require that outreach programmes be created. Other forms of home-based care will build on the strength of community support structures with trained volunteers supervised by the primary healthcare level. At the home level, social support is often provided by the community itself, with or without external help.

Appendix 6:

The Multi-disciplinary Prevention, Care & Treatment Team

Primary Health Care

Depending on the strength of the national or regional health system and the private and traditional sector, primary care facilities may include clinics and pharmacies, traditional healers, health posts or dispensaries operated by health assistants, health centres managed by trained healthcare providers, or medically trained personnel, including clinical nurses and physicians. The human resources, skills, collaboration, equipment, supplies and other resources available at this level will determine the type and quality of services locally available and the criteria for referral of patients to secondary or tertiary care levels.

Secondary Health Care

This typically includes a district or regional hospital (public, private, or non-profit), such as tuberculosis treatment centres, HIV clinics, VCT centres, rehabilitation centres, or social and welfare services. At this level, human resources, biomedical technology and physical facilities are available to provide complex inpatient, outpatient and social services. Inpatient facilities for terminal care for those who do not benefit from such support at home may be available at this level in separate units such as day care centres or hospices for the chronically ill.

Tertiary Health Care

Regional, national, or university hospitals (public or private) are expected to offer the highest level of care. This care is often provided by multi-disciplinary teams and combined with research. Attendance at tertiary care facilities may evolve with the stage of maturity of the HIV and AIDS epidemic. Such facilities may see and admit most people diagnosed with HIV or AIDS at an early stage of the epidemic.

Living with HIV or AIDS implies obtaining medical and other types of support from the most convenient and effective sources of care. The continuum of care will therefore require defining roles and functions within each of the elements of the care continuum; creating services and securing the resources adequate to perform these roles and functions and building the bridges between each of the elements of the continuum so that referral and return home coincide with the corresponding level of care provision and capacity for any point of the evolution of HIV infection.

Appendix 7:

Role of PLHIV Networks

Role of the PLHIV 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
- Network and partner with agencies to mobilise technical and financial support for the community
- Build local capacity and sensitise stakeholders/partners
- Advocate locally, regionally and internationally for the integration and reinforcement of policies that ensure access to prevention, care and treatment services
- Provide a platform where the issue of HIV and AIDS is addressed and capacity-building of PLHIV is achieved, for effective response to HIV and AIDS 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 access for PLHIV and vulnerable populations
- Advocate for proper nutritional support, crucial for effective treatment for PLHIV
- Advocate for the rights of women and 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 or 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 PLHIV 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 8:

Role of PLHIV Support Groups

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 off-load
- When searching for a support group, the single most important thing to remember may be that if the group doesn't feel right for you or doesn't match your needs, try a different group. There are many options available

Why join 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.

How to find a support group

- Ask your healthcare provider. This person could be your doctor, counsellor or nurse, etc.
- Contact your National AIDS Programme (NAP)
- Contact the Human Rights Advocate, oftentimes located at the NAP
- Check your local telephone directory. The front pages of most directories usually provide such information
- Ask another PLHIV to recommend a support group

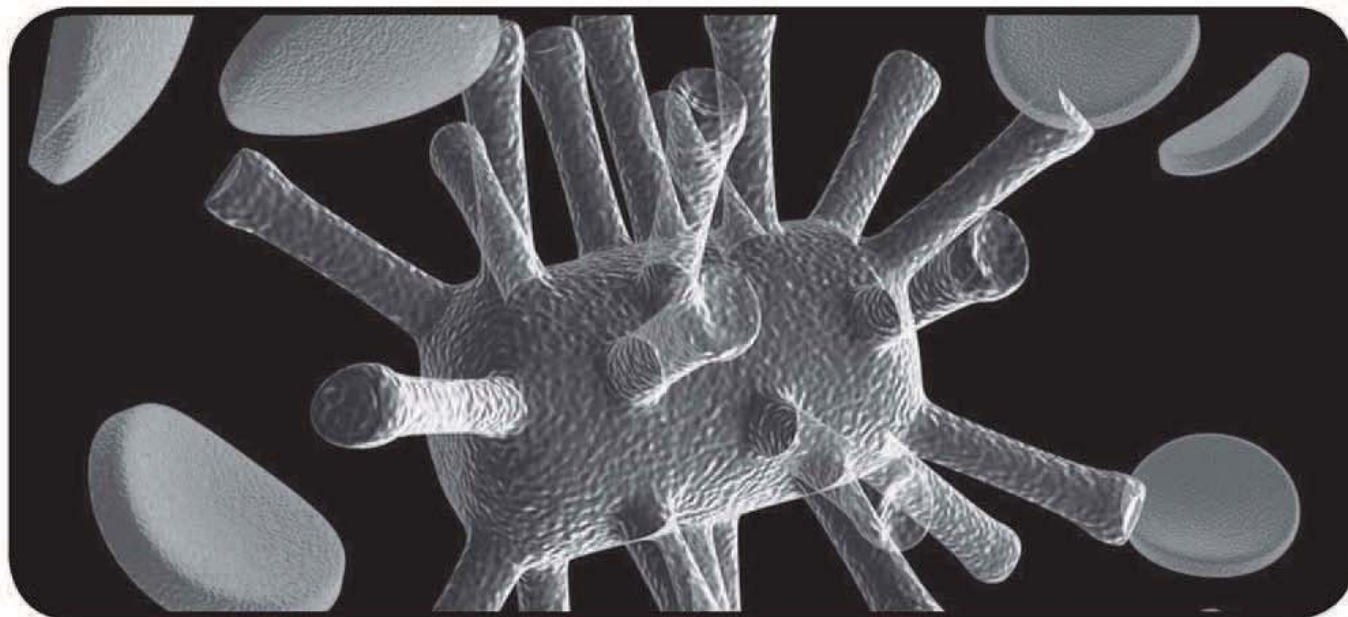
What to look for in a good support group

- A clearly stated confidentiality policy
- Provision of up-to-date, reliable information
- Prompt response to requests for assistance and queries
- Regular meetings at convenient times
- Access to professional support (for example, doctors, counsellors 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 welcomed
- 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



Appendix 9:

Key Findings of a Participatory Study on Stigma and Discrimination Among PLHIV in Selected Caribbean Countries



Conducted by Dereck Springer, Regional Consultant, CARICOM-PANCAP Anti-stigma Toolkit Project, February-March, 2009

- The study found that fear of voluntary disclosure of their HIV status and fear of having their HIV status exposed through breach of confidentiality were issues of stigma and discrimination (S&D) reported by PLHIV and that these were rooted in personal and others' experiences of stigma
- Homophobia was found to be a significant driver of stigma in the study countries and varied from tolerance to perverse in some territories. Societies were more accommodating of Men who have Sex with Men (MSM) from the higher socioeconomic stratum, even in countries where homophobia is perverse and the data suggests that it is the behaviour of MSM, rather than their sexual orientation that fuels homophobia
- The provision of ARVs has resulted in some reduction in S&D but some people are still reluctant to access them because of concerns about S&D. A minority of informants held the view that ARVs would increase the vulnerability of HIV-negative persons
- The study found that policy has not brought about significant changes in relation to reduction of S&D. While workplace policy has been developed by many private-sector agencies, there was intransigence in relation to its implementation
- The data revealed that in one country where there was non-discrimination legislation, the lack of interest in disseminating the legislation failed to provide PLHIV with the protection and recourse that was intended. This finding suggests that legislation is not necessarily the solution to reducing S&D

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