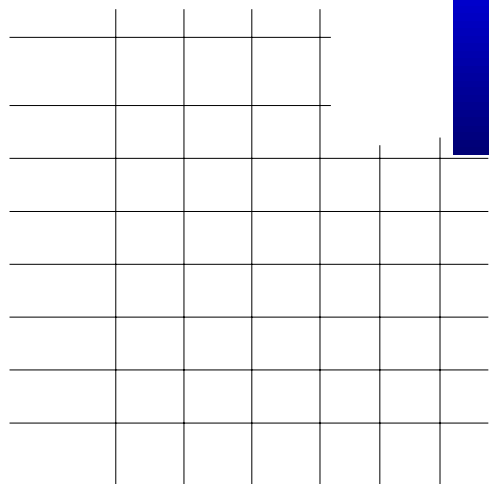


Training Guide On

Stigma and Discrimination
In Relation to HIV&AIDS



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List of Acronyms and Abbreviations

AIDS	Acquired Immunodeficiency Syndrome
AFRICASO	African Council of AIDS Service Organizations
ARVs	Anti-retroviral drugs
BCC	Behavior change communication
CBO	Community based organizations,
CEDAW	Convention on the Elimination of All forms of Discrimination Against Women
CSW	Commercial sex worker
FGM	Female Genital Mutilation
HBC	Home Based Care
HIV	Human Immunodeficiency Virus
HR	Human Rights
IDU	Intravenous Drug Users
ICASO	International Council of AIDS Service Organizations
KANCO	Kenya AIDS NGOs Consortium
MSM	Men who have sex with men
NACC	National AIDS Control Council
NASCOP	National AIDS and STD Control Program
NGO	Non-Governmental Organization
OI	Opportunistic infections
PLWHAs	People Living with HIV&AIDS
PMTCT	Prevention of Mother to Child Transmission of HIV
S&D	Stigma and Discrimination
STI	Sexually Transmitted Infections
UN	United Nations
VCT	Voluntary Counseling and Testing

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Allan Ragi

Executive Director

Kenya AIDS NGOs Consortium (KANCO)

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INTRODUCTION

This publication is intended to increase knowledge levels in the understanding of stigma and discrimination. The guide takes a participatory approach in discussing wide range of issues in HIV&AIDS related stigma and discrimination to get feedback from the participants. Lectures are used minimally. The guide covers: causes, forms, and contributing factors of stigma and discrimination. Issues of stigma in vulnerable groups, human rights, values, prejudices and core dimensions have also been examined. It is hoped that this guide will facilitate the learners to come up with strategies aimed at responding to stigma and discrimination at community levels.

The guide puts to task the participants to develop tentative work plans that will help in laying grounds for implementing practical stigma reduction strategies at community levels. Monitoring and evaluation of stigma reduction programs is still evolving, as yet no adequate tools allow us to argue convincingly about superior process and approaches. It is believed that inputs from participants will provide useful ideas to those grappling with the management of HIV-related stigma and discrimination.

The guide is designed for NGOs, CBOs, FBOs and PLWHAs organisations involved in HIV&AIDS, stigma and discrimination reduction activities. The training is scheduled to take a minimum of five days but leaves to the facilitators the discretion to modify the training schedules in accordance with participants level of training and experience in HIV&AIDS.

Aim

To increase the capacity of NGOs, CBOs, FBOs and PLWHAs organisations , to identify, document and address stigma and discrimination in accessing prevention and treatment services in HIV&AIDS.

Purpose

The purpose is to facilitate the training of stakeholders to increase their capacity in dealing with stigma and discrimination in the community as one of the strategies in HIV&AIDS fight. It will also act as an information pack on stigma and discrimination.

Specific objectives

- To identify the causes of stigma and discrimination in relation to HIV&AIDS.
- Document cases of stigma and discrimination in their communities.
- Relate stigma and discrimination to accessing prevention and treatment services in HIV&AIDS.
- To explore the various strategies in addressing stigma and discrimination.
- To define the role of PLWHAs in addressing stigma and discrimination.
- To formulate an action plan for community interventions to address social, cultural, political and economic barriers to addressing stigma and discrimination.

PART ONE

Outline of Training Guide on Stigma and Discrimination

Introduction

- Why stigma and discrimination.

Unit 1: Stigma and Discrimination –the differences and interrelationship

Specific objectives

- To define stigma.
- To define discrimination.
- To examine the differences and interrelationship between stigma and discrimination.
- To list the causes of stigma and discrimination.

Content

- What is stigma.
- What is discrimination.
- Differences and interrelationships between stigma and discrimination.
- Causes of stigma and discrimination.
- Factors that contribute to HIV&AIDS related stigma and discrimination.

Expected output

- To be able to define stigma and discrimination.
- To get a clear understanding of the relationship between stigma and discrimination.
- To identify some causes of stigma and discrimination.
- To give factors that contribute to HIV&AIDS related stigma.

Unit 2: Forms of HIV Related stigma and discrimination

Specific objective

- To list the common forms of stigma and discrimination in different settings.

Content

- Forms of HIV related stigma and discrimination.
- Family/immediate community.
- Workplace.
- Health services.
- Religious.
- Media.
- Country level.

Expected output

- To list the common forms of stigma and discrimination.

Unit 3: Stigma and discrimination in vulnerable groups

Specific objective

- To identify the most vulnerable groups in the society in relation to stigma and discrimination.
- To list forms of stigma and discrimination in vulnerable groups.
- To discuss the Human Rights of the vulnerable groups.

Content

- Stigma and discrimination on children.
- Stigma and discrimination in prisoners.
- Stigma and discrimination against Commercial Sex Workers.
- Stigma and discrimination among Intravenous Drugs Users.
- Stigma and discrimination in Men who have sex with men.

Expected output

- To list different reliable groups affected by stigma and discrimination in society.
- To understand and identify forums of stigma and discrimination to this group.
- To have a clear understanding on human rights issues associated with identified groups.

Unit 4: Stigma and discrimination in different context

Specific objectives

- To explore the values and prejudices involved in stigma and discrimination.
- To discuss the core dimensions involved in stigma and discrimination.
- To discuss the contextual perspectives in stigma and discriminations.

Content

- Exploration of values and prejudices.
- Core-dimensions involved in stigma and discrimination.
- Contextual perspective of stigma and discrimination in relation to HIV&AIDS.

Expected output

- To understand various values and prejudices related to stigma and discrimination.
- To come up with various core dimensions involved in stigma and discrimination.
- To be able to discuss various contextual perspectives of stigma and discrimination in relation to HIV&AIDS.

Unit 5: Impact of stigma and discrimination on accessing treatment and prevention services

Specific objective

- To examine the role of stigma and discrimination in people seeking treatment and prevention for HIV&AIDS and the role of the health worker.

Content

- Impact of stigma and discrimination on accessing treatment and prevention services.

Expected output

- To get a clear understanding on various forms of stigma and discrimination in accessing HIV&AIDS treatment and prevention services in the community.

Unit 6: Stigma and discrimination and Human rights

Specific objectives

- To examine the concept of Human Rights.
- To discuss the International Bill of Rights.
- To explain the challenges of the HIV&AIDS epidemic.
- To explain the relationship between Human Rights and HIV&AIDS.
- To understand the legal and ethical issues, around HIV&AIDS.
- To identify the human rights violations associated with HIV&AIDS
Vis a Vis the State duty.

Content

- Stigma and discrimination and Human Rights.
- Universal Declaration of Human Rights.
- Human rights and HIV&AIDS.

Expected output

- To get a clear understanding of Human Rights and its relation to HIV&AIDS in their communities.

Unit 7: Strategies in addressing stigma and discrimination

Specific objectives

- To explore the strategies in stigma reduction.
- To formulate plans in addressing the barriers to fighting stigma and discrimination in social, cultural, political and economic settings.
- To explore the strategies in fighting stigma and discrimination in PLWHAs.
- To explore the role of PLWHAs in fighting stigma and discrimination.

Content

- Measures to combat stigma and discrimination.
- Programs aimed at mitigating the effects of stigma and discrimination can benefit from the following principles (Dr. Peter Piot).
- Personal strategies for dealing with stigma and discrimination
- Key lessons learnt.
- Steps to address discrimination against PLWHAs.
- Tentative Work plan.

Expected output

- To come up with workable community level strategies aimed in addressing stigma and discrimination.
- To formulate plans in addressing the barriers to fighting stigma and discrimination in social, cultural, political and economic settings.
- Explore and identify ways in which PLWHAS can be involved in stigma reduction.
- Identify key lessons learnt in tackling stigma and discrimination in the community.
- Set workable steps to address discriminations against PLWHAs.

Unit 8:Monitoring stigma and discrimination

Specific objectives

- To list some of the indicators to be used in monitoring and evaluation of stigma and discrimination.

Content

- Community obligations.
- Strategies.

Expected output

- To get a clear understanding on ways of monitoring and evaluating stigma and discrimination in the community.

PART TWO

Why Stigma and Discrimination

" You are sinner". "Don't come so close". "With your lifestyle, this was bound to happen". "You've brought shame on our family." Shame on you." " We are no allowed to play with you." "You are already dead!" "You are a walking stick, don't touch me." "Stay away from my house". .. These among others are some of the most painful symptoms of HIV&AIDS.

In our communities issues of stigma and discrimination are still a challenge in the fight against HIV&AIDS.

Stigma and discrimination associated with HIV&AIDS are the greatest barrier to preventing further infections, providing adequate care support and treatment, and alleviating impact. HIV&AIDS-related stigma and discrimination are universal, occurring in every country and region of the world. They are triggered by many forces, including lack of understanding of the disease, myths about how HIV is transmitted, prejudice, lack of treatment, irresponsible media reporting on the epidemics, the fact that AIDS is incurable, social fears about sexuality, fears relating to illness and death, and fears about illicit drugs and injecting drug use.

People fear to go for HIV&AIDS tests because of associated stigma and discrimination to the disease. The struggle against HIV&AIDS will never succeed without addressing stigma and discrimination that can be more lethal than the virus. It not only kills, but it also perpetrates its own sort of emotional suffering. Stigma, unlike physical symptoms of AIDS has a way of obstructing the designs of health care providers and the international development community.

Education is strongly related to positive attitudes towards reduction of stigma and discrimination. This training guide is meant to raise the level of knowledge and understanding of stigma and discrimination in the community. The guide introduces stigma and discrimination and its relevance to HIV&AIDS. It seeks to get workable strategies and ideas on how to effectively reduce stigma and discrimination at community levels.

Stigma, Discrimination – the Differences and Interrelationships

This unit gives definitions of stigma and discrimination. Facilitators will guide in getting the definitions from the participants. The unit also brings out the differences between stigma and discrimination. Causes and factors that lead to stigma and discrimination are also discussed in this unit.

Specific objectives

- To define stigma.
- To define discrimination.
- To examine the differences and interrelationship between stigma and discrimination.
- To list causes of stigma and discrimination.

1.1 Definitions

1.1.1 Stigma

Stigma is referred to as the imposition of a special discrediting and unwanted mark on a person or persons in such a way that they are looked at fundamentally and shamefully different.

1.1.2 Self-stigma

This begins with a HIV positive individual looking at him/herself as unfortunate and his/her concerns and fears about what other people are going to think about her/him.

1.1.3 Discrimination

This occurs when a distinction is made against a person that results in their being treated unfairly and unjustly on the basis of their belonging, or being perceived as belonging to a particular group.

1.2 Differences and interrelationship between stigma and discrimination

Stigma automatically leads to discrimination. They are interrelated one to the other. No stigma. No discrimination.

Stigma is an imposition of a special discrediting and unwanted mark on a particular person or persons, which is actually a mark of shame.

Discrimination on the other hand is imposition of burdens, obligations, and disadvantages on such persons as above. As long as stigma remains at the level of negative thought it is possible that no harm is done to others. Acts of discrimination can be manifested when a person's prejudiced thoughts lead them to omit or do something that harms or denies services or entitlement of others.

Stigma is a powerful tool of social control. Stigma can be used to marginalize, exclude and exercise power over individuals who show certain characteristics. While the societal rejection of certain social groups (such as 'homosexuals, injecting drug users, and commercial sex workers') may predate HIV&AIDS, the disease has, in many cases, reinforced this stigma. By blaming certain individuals or groups, the society can excuse itself from the responsibility of caring for and looking after such groups of people. This is seen not only in the manner in which 'outsider groups,' are often blamed for bringing HIV into a country, but also in how such groups are denied access to the services and treatment they need.

1.3 Causes of stigma and discrimination

From early in the AIDS epidemic, a series of bad and powerful images were used that reinforced and tried to legitimize stigmatization. These immoral measures were in a way successful and persist up to date. These were:

- HIV&AIDS as punishment (e.g. for immoral behavior).
- HIV&AIDS as a crime (e.g. in relation to innocent and guilty victims).
- HIV&AIDS as war (e.g. in relation to a virus which need to be addressed).
- HIV&AIDS as horror (e.g. in which infected people are demonized and feared).
- HIV&AIDS as otherness (in which the disease is an affliction of those set apart- these were CSWs, IDUs, MSMs and promiscuous people).

1.4 Factors that contribute to HIV&AIDS related stigma

- HIV&AIDS is a life-threatening disease.
- People are scared of contracting HIV.
- The disease's association with behaviors (such as sex between men and injecting drug-users) that are already stigmatized in many societies.
- People living with HIV&AIDS are often thought of as being responsible for becoming infected.
- Religious or moral beliefs that lead some people to believe that having HIV&AIDS is the result of moral fault (such as promiscuity or 'deviant sex') that deserves to be punished.

- Stigma related to HIV feeds on well-established power relationships in a society- those associated with:
 - Race.
 - Ethnicity.
 - Economic status.
 - Sexual orientation.
 - Low women's status.
 - Injecting drug users.
 - CSW.
- It causes some groups to be devalued and ashamed while others feel superior.
- In most societies, women carry a greater burden of stigma attracting more contempt and rejection.
- PMTCT- Pregnant women with HIV suffer multiple layers of stigma. Breast feeding becomes an issue.

At the end of the session, the participants should be able to define stigma and discrimination and give examples from their communities. They will be buzzed into groups and discuss causes, effects and consequences of stigma.

Forms of HIV Related Stigma and Discrimination

This unit discusses forms of HIV&AIDS related stigma and discrimination in families, communities, workplace, health care services, churches, media and at the country level.

Specific objective

- To list the common forms of stigma and discrimination in different settings.

2.1 Forms of HIV related stigma and discrimination

Stigma manifests itself in a number of ways and at different levels. For example; Communications, Words and images.

Social relations such as within institutions, families, and communities; prejudice, avoidance, ostracism, hostility, violence, among others.

We may think and feel in the ways described above for instance perceived subjective stigma or we may act in ways that are keeping with our thoughts and feelings. This is referred to as enacted or objective stigma or discrimination.

Self- stigma: - that which HIV positive people may impose on themselves such as fears of exclusion, loss of proper employment, educational opportunities, eviction from rental houses, and abandonment by friends, families and communities.

Loss of rights and decision-making power.

2.2 Family/immediate community

The family is meant to be the immediate caregiver in the case of any illness. The social norms in the case of HIV&AIDS have broken down leading to:

- Isolation of both the infected and affected due to fears that HIV can be transmitted by casual contact.
- Restrictions on participation in local communal events.
- Refusal to allow infected and affected children in local schools.
- Lack of support for affected bereaved family members, including orphans.

2.3 Workplace

The work place was until recently a minefield for people with HIV&AIDS. Some examples of what happens in most workplaces are listed below:

- Mandatory testing before hiring /refusal to employ HIV positive people.
- Involuntary periodic testing/dismissal on grounds of HIV status.
- Violations of confidentiality.
- Refusal to work with infected colleagues out of fear of contagion.
- Refusal to go to school with infected schoolmates for fear of contagion.

2.4 Health services

The health sector has in some cases behaved in a very unprofessional manner. Some of these actions include:

- Refusal to treat HIV&AIDS patients.
- Violations of confidentiality.
- Provisions of care in specific establishments [such as STI clinics] that further stigmatize the clients.
- Behavior with clients that clearly identifies their HIV status instead of using universal precautions.
- Advice given or pressure applied to HIV positive persons to undergo treatment that would not be emphasized for others such as abortions, sterilization.

Many reports reveal the extent to which people are stigmatized and discriminated against by health care systems. Many studies reveal the reality of withheld treatment, non-attendance of hospital staff to patients, HIV testing without consent, lack of confidentiality and denial of hospital facilities and medicines. Also fuelling such responses are ignorance and lack of knowledge about HIV transmission.

2.5 Religion

Religious organizations are doing a lot especially caring for HIV&AIDS infected people and also caring for orphans. However, some have been involved in:

- Denial of traditional rituals such as funeral practices.
- Restricted access to marriage.
- Restrictions on participation in religious activities.

2.6 Media

The media can play a vital role in informing the public about HIV prevention and treatment. However, the media can be used for negative stereotyping and perpetuating fear and anxiety by depicting HIV as death.

2.7 Country level

At the country level, stigma and discrimination has led to some countries not enacting legislation to protect people infected or affected by HIV&AIDS. Lack of such legislation may lead to PLWHAs or the affected not being allowed to enter those countries or deportation of infected foreigners. This limits international travel and migration. In addition lack of the said legislation may give room to compelling screening of such groups thus perpetuating stigmatization of the said groups and creating a false sense of security among individuals who are not considered 'high risk. There are also countries that have laws that insist on compulsory testing for HIV cases and the restriction of persons right to anonymity and confidentiality as well as the right to movement of those infected. Though justified on the grounds that the disease is a public health risk, it enforces stigma and discrimination.

Nonetheless numerous countries have enacted legislation to protect the rights and freedoms of people living with HIV&AIDS and to safeguard them from discrimination. Much of this legislation has sought to ensure their right to employment, education, privacy and confidentiality. However, in some societies, laws, rules and policies can increase the stigmatization of people living with HIV&AIDS as well as the right to access information, treatment and support. Governments and national authorities sometimes cover up and hide cases, or fail to maintain reliable reporting systems. Ignoring the existence of HIV&AIDS, neglecting to respond to the needs of those living with HIV infection, and failing to recognize growing epidemics in the belief that HIV&AIDS 'can never happen to us' are some of the most common forms of denial. These denial fuels AIDS stigmas by making those individuals who are infected appear abnormal and exceptional.

At the end of the session, the participants will have a group discussion on the forms and levels of stigma and discrimination and their own personal experiences.

Stigma and Discrimination in Vulnerable Groups

This unit discusses various forms of stigma and discrimination in vulnerable groups.

Specific objectives

- To identify the most vulnerable groups in the society that experience stigma and discrimination.
- To list forms of stigma and discrimination in vulnerable groups.
- To discuss the Human Rights of the vulnerable groups.

3.1 Stigma and discrimination in children

Stigma and discrimination in children works at multiple levels of exclusion.

- School- Education.
- Health services.
- Economic
- Social.
- Family.
- Inheritance.

By 2001, AIDS had killed one or both parents of 13.4 million children under 15 years. The number is expected to double by 2010. Children suffer profoundly as their parents fall sick or die. They experience:

- Psychological distress- worsened by pervasive stigma and discrimination.
- Economic hardship.
- Withdrawal from school of especially the girl child, to take care of ailing parents or to look after younger siblings.
- Malnutrition and illness.
- Loss of inheritance.
- Fear and isolation.
- Increased risk of abuse.
- Increased risk of HIV.

The UN convention on the rights of children

The convention on the rights of the child is a universally agreed set of non-negotiable standards and obligations. It spells out the basic human rights

that children everywhere have, without discrimination. These include, the right to survive, to develop, protection from harmful influences, abuse and exploitation and to participate fully in family affairs, cultural and social functions. It sets standards in health care, education, legal and social services.

3.2 Stigma and discrimination in prisoners

Forms of stigma and discrimination in prisons

- Isolation in special cells.
- Name calling.
- Being denied food.
- Being denied access to treatment.
- Lack of access to pre and post-test counseling.
- Compulsory HIV testing.

Human rights of prisoners in relation to stigma and discrimination Statement of Fundamental Principles.

- People in prisons are part of our communities. After prison they return to the communities. Hence they should be included in the fight against stigma and discrimination.
- Prisoners living with HIV&AIDS have a right to live free from stigma and discrimination and violence.

Therefore States have a responsibility to:

- Prohibit mandatory HIV testing of prisoners.
- Provide access to voluntary, confidential HIV testing for prisoners.
- Ensure that proper pre-and post-test counseling is a mandatory component of HIV testing protocols and practice.
- Provide access to anonymous HIV testing to prisoners in countries where such testing is available in the community such as in Kenya.

The prisoner is in real danger of losing his life if he has engaged in sexual activity while in prison and then his HIV status is disclosed. There should be laid down systems to deal with matters of health including stigma and discrimination for prisoners.

3.3 Stigma and discrimination against Commercial Sex Workers

Sex workers perhaps bear the brunt of HIV related stigma and discrimination. Almost everywhere people who sell sex are stigmatized. Commercial sex work has been practiced for a long time and examples are found in both ancient Roman and Japanese cultures. Commercial sex occurs all over the world. In most of the Countries in Southern Africa, much as commercial sex workers exist they are criminalized and not recognized as a distinct work force. In Kenya, they

are usually arrested for “ Loitering with an intent to commit a felony” . Commercial sex raises complex moral and social problems. It is however true that the HIV prevalence is generally higher among sex workers than in the general population. When HIV was first identified, sex workers were immediately named as carriers of the disease.

Sex workers can be female, male or transgender. Men sell sexual services to men in most cultures although this is often denied. These men at times are married to women and have children. The potential for overlap between commercial sex, injecting drug use and men who have sex with men can fuel an explosive epidemic. Some individuals and organizations believe that commercial sex is wrong and should be legislated against. However, this will not wish away the problem. With less stigma and discrimination, specific programs that target this group of people can be set up.

At the policy level, governments should de-criminalize sex work and set up programs that provide alternative ways of income generation. This would also be a stigma reduction strategy. The most effective prevention programs for sex workers include condom distribution and easy access to diagnosis and treatment of sexually transmitted infections and HIV.

The policy of “100% condom use” among commercial sex workers has been highly effective in some countries. The female condom is another tool that would be highly effective for commercial sex workers but is under utilized.

The core values that should guide HIV prevention programs among sex workers include:

- A basic humane approach dealing with the essential dignity of a person.
- Absolute confidentiality.
- Respect to the needs of sex workers to earn income.
- Flexibility.
- Sex worker involvement at all levels.

(Adapted from principles that guide the HIV Intervention Project, Sonagachi, Calcutta India.)

3.4 Stigma and discrimination among Intra-venous Drug Users

Injecting drug use is the main or major mode of transmission of HIV in many countries in Asia, Europe, Latin America and North America. Intravenous drug use is a growing problem in Sub-Saharan Africa, which initially served as a transit hub for drugs. Sharing or using contaminated needles is a very efficient way of spreading HIV. HIV can spread very fast through drug using populations. There is an interphase between IDUs and high-risk behavior. IDUs may also

engage in transactional sex (or commercial sex) to finance their habit. Drug injecting also contributes to an increased incidence of HIV through transmission of the virus to the children of drug injecting mothers and through sexual contact between drug injectors and non-injectors. Because of stigma and discrimination, most of intravenous drug use occurs at the periphery of society. Intravenous drug use is a criminal offence in most countries thus making intervention difficult. Intravenous drug use is a form of drug abuse and is more of a psycho-medical problem. Drug trafficking on the other hand is a widely recognized criminal offence.

HIV prevention among intravenous drug users requires:

- Prevention of drug abuse.
- Provision of drug abuse treatment.
- Outreach services to locate drug users.

A comprehensive HIV prevention package among IDUs involves:

- Raising awareness among injectors and their sexual partners about HIV risks and safe practices.
- Providing sterile injecting equipment.
- Making available drug treatment programmes.
- Providing HIV infected drug injectors with care and support.

3.5 Stigma and discrimination in Men who have sex with men

Men who have sex with men account for up to 10% of HIV cases worldwide. Men who have sex with men may also have sex with women thus spreading HIV to that population. Men who have sex with men are a group that is highly stigmatized. There are also many countries where it is a criminal offence for men to have sex with men. Little is known about HIV prevalence in this population in Sub-Saharan Africa. In most parts of the world, there is not enough data to inform effective prevention programmes for men who have sex with men. Where data exists, HIV prevalence among men who have sex with men is higher than in the general population.

In many countries, there are social networks of men who have sex with men. In Kenya, such networks exist and are being targeted for prevention programmes. Peer based HIV prevention programmes that target this networks are very effective in some countries. At the policy level, it may make sense to de-criminalize homosexuality, so that they can be reached with effective prevention programmes.

At the end of the session, the participants will have a group discussion on the forms and levels of stigma and discrimination and their own personal experiences.

Stigma and discrimination in Different Context

The unit explores values and prejudices related to stigma and discrimination. Core dimensions and contextual perspectives are also discussed.

Specific Objectives

- To explore the values and prejudices involved in stigma and discrimination.
- To discuss the core dimensions involved in stigma and discrimination.
- To discuss the contextual perspectives in stigma and discriminations.

4.1 Exploration of values and prejudices

Human Beings naturally harbor prejudice, sometimes unknowingly. During workshops, topics on prejudice will be included and this will go a long way in reducing prejudice especially to PLWHAs and their relatives. Many people think wrongly due to ignorance and as result practice prejudice to PLWHA. They actually think they never be infected with the HIV. This call for a need to educate the community on facts about HIV&AIDS alongside teaching on stigma and discrimination. The lessons should include a lot of group discussions.

4.2 Core dimensions involved in stigma and discrimination

There are other dimensions of stigma and discrimination other than the forms and types mentioned earlier on, such as:

- Committing suicide or thinking about suicide.
- Wanting to die alone.
- Withdrawal from public activities (church activities, societies and others).
- Feeling unloved.
- Feel unproductive/useless/ not contributing.
- Forced to leave the community.
- Divorce or separation.
- Loss of scholarships.

The participants can come up with as many others as possible. Other considerations can be done for example:

- Superficial access to information.
- Violence.
- Compulsory testing-before and after employment.
- Compulsory testing-before marriage.
- Selective health services.
- Constrained fellowship and psychosocial support.

4.3 Contextual perspective in stigma and discrimination in relation to HIV&AIDS

HIV&AIDS has no barriers. It does not choose between tribe, race or otherwise. In other words it can affect anybody at any time. It affects all people and therefore all systems. It is for this reason that it must be addressed from all possible corners and by all who are able to do so. Stigma and discrimination as we have already seen is a big hindrance to HIV&AIDS fight. Once stigma and discrimination can be eliminated, then we can be sure to reduce numbers of new infections and HIV&AIDS related deaths. We can mention some of the contextual perspectives:

- Social setups – Family, marriage, and other intimate social settings
- Religious institutions-Concept of sin.
- Economic systems – Access to financial backups.
- Political systems -Resource prioritization.
- Legal Provisions – Rights and protection.
- Academic and Human Resource Development.

Participants to give different values and prejudices related to HIV&AIDS. They should discuss core dimensions and contextual perspectives in stigma and discrimination related to HIV&AIDS.

Impact of Stigma and Discrimination on Accessing Treatment and Prevention Services

The unit examines the impact of stigma and discrimination on accessing HIV&AIDS treatment and prevention services in the country. It also examines the roles of health care workers and those involved in home-based care at community levels.

Specific objective

- To examine the role and impact of stigma and discrimination in people seeking treatment and prevention for HIV&AIDS and the role of the health worker

5.1 Impact of stigma and discrimination on accessing treatment services

- Stigma may lead people to shun seeking treatment for STIs, which if left untreated increase the risk of contracting HIV.
- Stigma forces denial about ones own HIV status leading many to die prematurely without accessing treatment such as ARVs, drugs for opportunistic infections.
- Health workers inability to manage HIV&AIDS- they lack enough psychological resources to cope with terminal illnesses. This induces stigma and impacts negatively on care and treatment.
- Stigma by health workers impacts negatively on access to treatment in health centers- waiver system has discriminatory tendencies. Some health workers, in an attempt to avoid having to provide care for AIDS patients refer patients from hospital to hospital.
- Stigma and discrimination among families and relatives is a significant barrier to accessing proper treatment. Even though most HIV infected people receive loving care from their families, there are occasions when family members refuse to do so for fear of transmission, out of anger, judgment and moral condemnation, or a combination of these factors.

- Stigma and discrimination is a barrier to accessing treatment by fostering ignorance on care and support services available in the community.
- Stigma and discrimination affects access to treatment of PLWHAs— Health workers may be uncompassionate, not confidential and discriminatory.
- Stigma and discrimination reduces the quality of treatment programmes at health facilities with a possibility of increased rate of HIV transmission.
- Stigma and discrimination adds to the problem of transmission of drug resistant strains of HIV due to hampering treatment and care of PLWHAs on ARVs. One of the worst effects of continued stigmatization is the increasing resistance of ARVS. Due to stigma and discrimination some clients discontinue drugs, hiding their status to avoid disclosure. There is need to empower HIV care providers to provide access to low cost HIV testing and in assisting patients to monitor the effectiveness of HIV treatment.
- Stigma and discrimination has made the medical treatment of HIV&AIDS very stressful despite efforts to create more awareness and BCC interventions due to social stigmatization of the infected and affected. Social stigmatization of the disease frustrates efforts to apply the most effective medical interventions in the management of HIV&AIDS such as counseling, testing and treatment. PLWHAs shy away from tests due to stigma hence no start of treatment, no viral load test, no CD4 T cell count.
- Delayed treatment can contribute to the continued spread of HIV because people do not know their status.

5.2 Impact of stigma and discrimination on accessing prevention services

- Stigma and discrimination views HIV&AIDS as a disease of the outsiders which leads to exclusion from the community. This exclusion leads to lack of involvement and social inaction. This leaves individuals sheltering behind a wall of silence and preventing the social mobilization that has proved the most effective tool in fighting the epidemic.
- Stigma makes the uninfected deny their own risk of infection and perhaps not take adequate precautions to protect themselves.
- Stigmas hinders sex partners, including couples, discussing the use of condoms and hence rarely use them, use them incorrectly, or don't use them at all. Usually the stigma attached to the condom use is own infidelity or partner suspected infidelity.

- HIV&AIDS related stigma constantly reminds members of the discriminated groups that they are social outcasts or even deserve to be punished. If people are mocked or treated with hostility, they may feel uncared for and are therefore less likely to take steps to protect themselves.
- Stigma and discrimination associated with HIV&AIDS and community taboos restricts openness to HIV&AIDS Prevention activities at the community levels resulting in rise in new infections.
- Stigma and discrimination hinders prevention interventions by fostering ignorance about facts on HIV.
- Stigma and discrimination infringes not only on the rights of the clients in terms of safety and quality health services but also on the Health workers rights of safety from infections.
- HIV&AIDS related Stigma and discrimination discourages people from getting tested or when they get tested from returning for their results. Some avoid VCT centers or other clinics known to test for HIV. Some fear that the result test results will somehow eventually reach the community- self stigma.
- Self-stigma leads one to police her/his behavior resulting in withdrawal from the community and the available services. The fear of being stigmatized in the people of all ages leads to inability to look after their sexual and reproductive Health i.e. accessing sexual Health information on methods of HIV&AIDS prevention such as male and female condom and other prevention measures.
- Stigma and discrimination stops one from discussing their HIV status with others e.g. fear of disclosure affects the decisions that mothers with HIV&AIDS make about breast feeding. While exclusive formula feeding and exclusive breastfeeding are considered valid options for mothers with HIV, many find it difficult to use formula or avoid mixed feeding. In some cultures, the norm is breastfeeding. Not breastfeeding may be deemed as a sign that you are HIV positive.
- Some affected individuals may choose not to change or adapt their behavior to reduce the risk of HIV&AIDS transmission for fear that such change would arouse suspicion, stigma and discrimination.

This session should be aimed to get information from participants on various forms of stigma and discrimination experienced in their communities in accessing HIV&AIDS treatment and prevention services with practical examples.

Stigma and Discrimination and Human Rights

This unit examines the concept of Human Rights and its relationship to HIV&AIDS stigma and discrimination.

Specific objectives

- To examine the concept of Human Rights.
- To discuss the International Bill of Rights.
- To explain the challenges of the HIV&AIDS epidemic.
- To explain the relationship between Human Rights and HIV&AIDS.
- To understand the legal and ethical issues, around HIV&AIDS.
- To identify the human rights violations associated with HIV&AIDS vis-a-vis State duty.

6.1 Stigma and discrimination and Human Rights

What are Human Rights?

Human Rights are rights that belong to people simply because they are human beings. They are also described as being 'Universal moral rights' or 'generally accepted principles of fairness and justice.'

They are often called 'natural rights' as they are rights that each individual is entitled to by birth regardless of whether such rights are protected by law.

Examples of human rights

- The right to life.
- The right to human dignity.
- The right to equality.

Human Rights based approach to HIV&AIDS

Starts from the premise that human rights abusers contribute to spread of HIV and undermine attempts to protect people from becoming infected and once infected, from receiving needed treatment and care. The promotion and protection of Human Rights must therefore be at the center of all aspects of an effective response to HIV&AIDS.

Note: Where human rights are protected by the constitution then the courts can be used to enforce these rights.

Stigma leads to discrimination, where a distinction is made against a person

which results in their being treated unfairly or unjustly on the basis of being HIV positive or being perceived as such. Freedom from discrimination is a basic fundamental Human Right.

6.2 Universal Declaration of Human Rights (UDHR)

The first international codification of Human Rights took place in 1948 after the Second World War. The UDHR is universally accepted by all states. The UDHR (1948) provides that everyone:

- Is born free and should be treated in the same way.
- Is equal despite differences in language, sex, color etc.
- Has the right to life and to live in freedom and safety.
- Has the right not to be hurt or tortured.
- Has the right to be recognized before the law.
- Has a right to be treated as a person.
- Has a right to be treated equally before the law.
- Has a right to ask for legal help when the rights are not respected.
- Has a right not to be imprisoned unjustly.
- Has a right to a fair trial.
- Has a right to be presumed innocent until proved guilty.
- Has a right to privacy.
- Has a right to travel within and outside the country.
- Has a right to asylum.
- Has a right to nationality.
- Has a right to marry.
- Has the right to own property.
- Has a right to freedom of thought, conscience and religion.
- Has a right to freedom of opinion and expression.
- Has a right to meet with others.
- Has a right to take part in the government and vote.
- Has a right to social security.
- Has a right to work and join a trade union.
- Has a right to leisure.
- Has a right to adequate standard of living and medical assistance.
- Has a right to education.
- Has a right to participate in the community's cultural life.
- Is entitled to a social and international order.
- Must respect the rights of others.
- The rights in the declaration cannot be taken away by anybody.

6.3 Human Rights and HIV&AIDS

Human rights violations in the context of HIV&AIDS take place mainly because of ignorance about the disease and the people most affected by it.

UNAIDS and the United Nations Higher commissioner for Human Rights

published **international guidelines** on HIV&AIDS and Human Rights. These include:

- Human Rights of women.
- Criminal laws and correctional systems.
- Anti-discrimination and protective laws.
- Legal supportive services.
- Right to education.
- Freedom of assembly and association.
- Right to health.
- Right to work.
- The right to freedom from cruel inhuman or degrading treatment or punishment.

The legal and ethical issues relating to HIV&AIDS are brought about by:

- Fear and stigmatization.
- Breaches in confidentiality.
- Unethical research.
- Criminalization of HIV&AIDS infections.
- Illegal/ mandatory testing.
- Abuse of Human rights e.g. confinement.
- Right to life.
- HIV&AIDS in the workplace.

The Human Rights most relevant to HIV&AIDS include:

- Non-discrimination.
- Equality before the law.
- Right to liberty and security.
- Right to health.
- Right to freedom of expression.
- Right to freedom from inhuman and unjust treatment.
- Right to marry and found a family.
- Right to education.
- Right to work.
- Rights of children.

Participants to get a clear understanding of Human Rights and its relation to HIV&AIDS. Participants to be buzzed into groups and give various views on the relationship between human rights and HIV&AIDS in their communities. Participants to give various strategies of tackling human rights issues at the community level.

Strategies in addressing stigma and discrimination

The Unit seeks to explore various strategies in stigma and discrimination reduction. It also explores the role of PLWHAs in fighting stigma and discrimination.

Specific objectives

- To explore the strategies in stigma reduction.
- To formulate plans in addressing the barriers to fighting stigma and discrimination with clear consideration of social, cultural, political and economic issues.
- To explore the strategies in fighting stigma and discrimination in PLWHAs.
- To explore the role of PLWHAs in fighting stigma and discrimination.

Background

Tackling stigma and discrimination associated with HIV&AIDS can be an overwhelming task due to its complex nature. Nevertheless, it is verified that strategies that focus on assisting PLWHAs, have proved to be an effective and influential step in combating stigma and discrimination in the society as a whole.

Remember

That stigma leads to false belief about HIV&AIDS. Persons who retain stigmatizing attitudes engulf themselves with misconceptions and misinformation pertaining HIV&AIDS.

7.1 Measures to combat stigma and discrimination

- Promote and fulfill the rights of the most vulnerable by strengthening the capacity of governments at all levels to promote legal reforms-inheritance, property, adoption and fostering laws. Ensure access to social services for children.
- Create an enabling environment to combat S&D.
- Ensure school enrolment, access to shelter, nutrition health and social services.
- Strengthen community capacity to identify and monitor vulnerable households.
- Care and support of orphans and vulnerable children.
- Promote appropriate counseling and psychological support for orphans and vulnerable children.

- Protect orphans and vulnerable children from all forms of abuse, violence, exploitation, discrimination, trafficking and loss of inheritance.
- Education about stigma and discrimination should be introduced into all educational curricula especially for the youth.
- Media involvement.

7.2 Programs aimed at mitigating the effects of stigma and discrimination can benefit from the following principles.(Dr Peter Piot)

- Strengthen caring capacities of families through community based mechanisms.
- Strengthen the economic coping mechanisms of families and the community.
- Enhance the capacities of families and the community to respond to psychological needs of orphans and vulnerable children.
- Foster links between HIV prevention, HBC and efforts to support orphans and vulnerable children.
- Target vulnerable children.
- Gender mainstreaming.
- Make children part of the solution.
- Accelerate learning and information exchange.
- Strengthen the roles of schools and the education system.
- Encourage child and community centered approaches.
- Build partnerships.

7.3 Personal strategies for PLWHAs in dealing with stigma and discrimination

- Be aware of what your thoughts and feelings are towards people you suspect may be HIV positive, or are infected.
- Do these feelings and thoughts stay at a subjective level, or do you tend to act in discriminatory way towards people with HIV&AIDS?
- Try and understand why you behave in this way—identify what you are feeling and why.
- Are these thoughts and feelings appropriate or inappropriate in the context?
- Acknowledge these thoughts and feelings and try to ensure that they don't impact in a negative way in your interactions with people with HIV&AIDS.
- Know your rights and responsibilities as a person living with HIV. These responsibilities include knowing your HIV status, seeking competent health care, drug adherence (if you are on ART), practicing safer sex (to avoid re-infection and so that you don't infect others—positive prevention).
- Be assertive.
- Build self-esteem and self confidence.

7.4 Key lessons learnt

- Children and youth face stigma and discrimination due to their own infection and the infection of parents or care givers.
- Stigma and discrimination is widespread in communities, among service providers and it results in children being denied rights and services.
- Stigma is a mark on a person indicating that they are shamefully different.
- Discrimination is when a stigmatizing belief leads to an unfair act or distinctions being made against PLWHAs.
- We all harbor stigma and prejudice but we need to learn to deal with such views to prevent unfair discrimination. There are tools for assisting with this process.
- Using a human rights framework provides a basis for seeing each person as entitled to be treated with dignity and respect regardless of any differences they may possess e.g. being of a different race group, of a different culture, or being HIV+.

7.5 Steps to address discrimination against PLWHAs

- Leadership: political, religious and civic leaders should speak out.
- Support PLWHAs organizations.
- Document Human Rights violations by increasing the capacity of NGOs, CBOs to use a human rights based framework.
- Strong legislative environment to enact and enforce laws protecting the rights of PLWHAs.
- Health and social services must be trained to reduce stigma and discrimination based on age, gender, race, economic status and sexual orientation.
- Multi-sectoral approach at work, health care setting, schools, churches to protect PLWHAs.
- Responses to the AIDS epidemic should not inadvertently promote stigma- e.g. providing food for AIDS orphans.
- Although the media is a major instrument in fighting HIV&AIDS, it has been observed over time that it is also a major feeler of stigma and discrimination. Instead of continuing to blame the media for this, a strategic approach can be applied to now use it to fight stigma and discrimination.

Aims

- To generate informed knowledge among the media, PLWHAs, and community leaders on challenges and solutions to combat stigma and discrimination.
- To empower and equip the media, PLWHAs, and community groups with information and skills to be enable action against stigma and discrimination.

- Enhance a greater understanding of stigma and discrimination.
- Work within a cultural framework to address stigma.
- Meet the people in their communities to practice reduction of stigma and discrimination.

The program to fight stigma intends to:

- Establish a database to track actors, programmes and policies on HIV&AIDS-related stigma and discrimination in Kenya.
- To develop bodies of stigma fighters within target communities to act as role models and new leaders in the fight against AIDS.

Strengths

- There are already identified PLWHAs who have overcome stigma and discrimination who can be very good resource persons in fighting stigma and discrimination.
- Existing HIV&AIDS Programs with youths in and out of school.

7.6 Tentative Work plan

A baseline survey to determine key issues, factors and determinants of HIV related stigma and discrimination in Kenya. This involves a review of existing literature, registration, research studies, regarding S&D in Kenya and other applicable sub-regional and regional countries.

A content analysis of Media reports on HIV&AIDS. Three Daily's to be used such *The Daily Nation, the Standard, Kenya Times, and the People Daily.*

Consulting roundtables and capacity building Workshops are components of the project. The target groups are the stakeholders- PLWHAs, Media, Traditional leaders, heads of community institutions, and Policy Makers at community levels.

The consultative roundtables are designed as a one-day meeting, which helps to generate debates on stigma and discrimination in the workplace, and ways to address them. The workshops focus on skills building and knowledge exchange on stigma issues among the community members, Media and PLWHAs to create a platform for forging partnerships to reduce stigma and discrimination between them.

Participant to give workable strategies aimed at reduction of stigma and discrimination in their communities. The participants should be able to develop tentative work plans.

Monitoring Stigma and Discrimination

This unit seeks to list indicators to be used in monitoring and evaluation of stigma and discrimination programming.

Specific Objective

- To list some of the indicators to be used in monitoring and evaluation of stigma and discrimination.

8.1 Community obligations

Local communities can explore ways of combating S&D by:

- Civic education.
- Counseling.
- Greater involvement of PLWHAs.
- Teaching coping skills.

8.2 Strategies

- Monitor Human Rights violations.
- Enable people to challenge discrimination.
- Emphasize and respect human rights.
- Confront culture, class, gender and race in open debate.
- Skills acquisition.

Scheduled annual workshops and roundtables will aim at including as many members of the target groups as possible. The impact of the information and knowledge gained at these programs will be evidenced by: -

- The number of non stigmatizing stories published in selected media publications.
- Number of show case role models and PLWHAs living positively in their communities.

Note: - The above will be possible by having a media monitoring exercise in place.

The impact of stigma and discrimination reduction strategies can be determined on the basis of: -

- The number of PLWHAs who have been referred to stigma reduction activities [e.g. support groups for PLWHAs in communities].

- Number/percentage of editorials, commentaries and opinions on HIV&AIDS in the national editorial press.
- Number or percentage of Health care facilities that protect against stigma and discrimination identified in the communities (shown by people attending VCT Centres, receiving ART services and PMTCT services).

There is also need to identify and document the following: -

- Number/percentage of people e.g. journalists editors and media managers who are aware of policies guaranteeing the rights of PLWHAs.
- How many PLWHAs are aware of Anti discrimination policies.
- How many Prominent people have joined the anti-stigma campaign either by supporting the PLWHAs or declaring their HIV status.

The above data can be collected using questionnaires and interviews administered annually or bi annually.

8.3 Challenges

The most challenging aspect is that of getting PLWHAs who are intelligent, articulate, and self- motivated to speak out against stigma and discrimination and who are living openly with HIV positive status.

More PLWHAs are encouraged to publicly declare their status after being empowered with basic skills in information and communication. In so doing they help to dispel certain pre conceived notions about HIV&AIDS, and its consequent demystification. These results in eliminating most of the factors that fuel stigma and discrimination. A PLWHAs living positively can better change the attitude of another PLWHAs to stigma and discrimination especially self stigma.

8.4 Conclusion

The fight against HIV&AIDS will continue being difficult as long as stigma and discrimination against the affected and the infected continues at its current level. Stigma and discrimination reduction strategies should be mainstreamed into all HIV&AIDS prevention, care and mitigation efforts.

At the end of the session, participants will have a plenary brainstorming session on the way forward.

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