

KENYA AIDS NGOS CONSORTIUM (KANCO)

HIV&AIDS, Human Rights and The GIPA Principle

Information Pack for PLWHAs and Human Rights

Published by:-

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ACKNOWLEDGEMENT

This information pack would not have been possible without financial support from International Humanistic Institute for Cooperation with Development Countries (HIVOS). We are truly grateful for their willingness to support this information pack under the project “Strengthening the Capacity of NGOs, CBOs and Religious Institutions addressing legal and human Rights issues relating to HIV&AIDS.”

Particular gratitude goes to KANCO staff: Jennifer Chege, Margaret Mbugua and Rachel Karanja, who, under the leadership of Miano Munene, researched and developed this information pack. Sincere gratitude goes to Mrs. Winfred Lichuma for ensuring that the legal and human rights issues are well repackaged.

Special thanks go to Elizapharn Ombui and Pauline Irungu for their relentless effort in editing, layout and designing of this publication.

Finally, our thanks go to Jane Mwangi, Programme Director and Allan Ragi, Executive Director without whose leadership and direction, this programme would not have been possible to implement.

To you all we say thank you.

Kenya AIDS NGOs Consortium

ABBREVIATIONS

AIDS	-	Acquired Immunodeficiency Syndrome
ARV	-	Anti-Retro Viral
APN+	-	The Asian Pacific Network of People Living with HIV&AIDS
CAT	-	Convention Against Torture
CSW	-	Commercial Sex Workers
CEDAW	-	Convention on the Elimination of All forms of Discrimination against Women
GIPA	-	Greater Involvement of People Living with HIV&AIDS
HIV	-	Human Immuno Deficiency Virus
HIVOS Countries	-	Humanistic Institute for Cooperation with Development
ICCPR	-	International Convention on Civil and Political Rights
IEC	-	Information Educational and Communication
ILO	-	International Labour Organization
ICERD	-	International Convention on the Elimination of All forms of Racial Discrimination
ICESCR	-	International Covenant on Economic, Social and Cultural Rights
KANCO	-	Kenya AIDS NGOs Consortium
MMAAK	-	Movement of Men Against AIDS in Kenya
MSM	-	Men who have Sex with Men
NGO	-	Non - Governmental Organization
OVC	-	Orphans and Vulnerable Children

PLWHAs	-	People Living with HIV&AIDS
RBA	-	Rights Based Approach
UDHR	-	Universal Declaration of Human Rights
UN	-	United Nations
UNAIDS	-	Joint United Nations Programme on HIV&AIDS
VCT	-	Voluntary Counselling and Testing
WHO	-	World Health Organization
UNGASS	-	United Nations General Assembly Special Session on AIDS

Introduction

Human rights violations fuel HIV&AIDS pandemic. This connection was explicitly recognized by the United Nations General Assembly Special Session (UNGASS) in its 2001 Declaration of commitment on HIV&AIDS. Gross HIV&AIDS human rights abuses and violations are occurring in Kenya to PLWHAs at an alarming rate with very little documentation. Most of this goes unpunished.

“The full realization of human rights and fundamental freedoms for all is an essential element in a global response to HIV&AIDS pandemic; including the areas of prevention, care, support and treatment, and that it reduces the vulnerability to HIV&AIDS and prevents stigma and related discrimination against people living with or at risk of HIV&AIDS”.

This information pack seeks to raise the level of knowledge and understanding of legal, ethical, human rights and HIV&AIDS issues among PLWHAs organizations. The information pack introduces HIV&AIDS and the concept of human rights. It moves to discuss gender and the impact of discrimination and stigma related to HIV&AIDS. It outlines the legal and Ethical issues in respect to HIV&AIDS. It further discusses Greater Involvement of People infected and affected with HIV, the Rights Based Approach to programming and finally GIPA and Advocacy process.

Purpose

The purpose of the information pack is to promote knowledge, skills and understanding of HIV&AIDS related legal, ethical and human rights issues and to demonstrate that HIV&AIDS and human rights are interrelated; and that the very problem of HIV&AIDS is indicative of existence of human rights violations.

People living with HIV are some of the greatest champions of HIV prevention. The epidemic prevention strategies have been more effective when they have meaningfully involved people living with HIV in their design, implementation and evaluation. HIV prevention strategies have, however, often failed to address the distinct prevention needs of people diagnosed with HIV or build capacity for their meaningful participation. Their involvement has often been relegated to little more than tokenism. An effective response requires that this should change.

Although the GIPA principle itself is a giant, progressive step for those infected and affected by HIV&AIDS, active involvement of people living with HIV in decision-making is still far from universal. Furthermore, involvement of HIV-positive women, youth and children has lagged far behind that of men in most parts of the world. Most people are unable to be open about their status because of the fear to face discrimination and stigma.

On the other hand, human rights are fundamental to any response to HIV&AIDS. As the number of people living with HIV&AIDS continues to grow in developing countries faced with unstable economic conditions and social structures, so does human rights violations related to HIV&AIDS become increasingly diverse and apparent. For a long time, human rights violations related to HIV&AIDS in Kenya have not received much attention and recognition. People living with HIV&AIDS often fail to act and speak out on human rights violations related to HIV&AIDS. Social, cultural and political environments are often characterized by high levels of denial,

fear and stigmatization not conducive to the involvement of PLWHAs. These places PLWHAs in difficult situations without mechanisms that can enable them contribute to policy changes. So far very little has been done about raising awareness on making the GIPA principle a reality.

PLWHAs need information and support to enable them participate more actively. This is especially necessary if more HIV-positive women and young people, traditionally excluded from decision making processes, are to be empowered to contribute in a meaningful way. Involvement of networks and organizations of PLWHAs is essential in implementing the GIPA principle in a sustainable manner.

The aim of this information pack is to promote greater and meaningful involvement of PLWHAs in prevention, care and support by combating stigma, discrimination and abuse of legal and human rights associated with HIV&AIDS in programming.

Specifically the information pack:

- Discusses HIV&AIDS and Human Rights.
- Discusses HIV and Gender dimensions.
- Examines stigma and discrimination as a human rights violation.
- Explores GIPA Principle and the Rights based approach to programming.
- Gives tips for involving PLWHAs in advocacy.

1. Introduction

HIV&AIDS continue to spread throughout the world at an alarming rate. The widespread abuse of human rights and fundamental freedoms associated with HIV&AIDS has emerged in all parts of the world in the wake of the epidemic.

Protection of human rights is essential in safeguarding human dignity in the context of HIV&AIDS and ensures an effective rights-based response to HIV&AIDS. An effective response puts into consideration of all human rights, civil and political, economic, social and cultural and fundamental freedoms of all people in accordance with existing international human rights standards.

It has been recognized that when human rights are protected, fewer people become infected and both the infected and affected cope better with HIV&AIDS.

2. What are human rights?

Human rights are universal legal guarantees protecting individuals and groups against actions and omissions that interfere with fundamental freedoms, entitlements and human dignity. Human rights law obliges Governments (principally) and other duty-bearers to do certain things and prevents them from doing others.

Some of the most important characteristics of human rights include:

- Are universal-the birthright of all human beings.
- Focus on the inherent dignity and equal worth of all human beings.
- Are equal, indivisible and interdependent.
- Cannot be waived or taken away.
- Impose obligations of action and omission, particularly on States and non-State actors.
- Have been internationally guaranteed.
- Are legally protected.
- Protect individuals and, to some extent, groups.

Human rights standards have become increasingly well defined in recent years. Codified in international, regional and national legal systems, they constitute a set of performance standards against which duty -bearers at all levels of society but especially organs of the State-can be held accountable. The fulfilment of commitments under international human rights treaties is monitored by independent expert committees called "treaty bodies" which also help clarify the meaning of particular human rights.

Among the rights guaranteed to all human beings under international treaties, without any discrimination on grounds such as race, colour, sex, language,

political or other opinion, national or social origin, property, birth or other status, are:

- The right to life, liberty and security of person.
- Freedom of association, expression, assembly and movement.
- The right to the highest attainable standards of health.
- The right to a fair trial.
- The right to just and favourable working conditions.
- The right to adequate food, housing and social security.
- The right to education.
- The right to equal protection of the law.
- Freedom from arbitrary interference with privacy, family, home or correspondence.
- Freedom from torture and cruel, inhuman or degrading treatment or punishment.
- Freedom from slavery.
- The right to a nationality.
- Freedom of thought, conscience and religion.
- The right to vote and take part in the conduct of public affairs.
- The right to participate.

3. Hierarchy among Human Rights

All human rights are equally important. The 1948 *Universal Declaration of Human Rights* (UDHR) makes it clear that human rights of all kinds; economic, political, civil, cultural and social are of equal validity and importance. This fact has been reaffirmed repeatedly by the international community.

The Vienna Declaration and Programme of Action, adopted at the world Conference on Human Rights in June 1993, affirmed that all human rights are universal, indivisible, interdependent and interrelated. States are duty bound to promote and protect human rights.

The principle of their *indivisibility* recognizes that no human right is inherently inferior to any other. Economic, social and cultural rights must be respected, protected and realized on an equal footing with civil and political rights. The principle of their *interdependence* recognizes the difficulty (and, in many cases, the impossibility) of realizing any one human right in isolation. For instance, it is futile to talk of the right to work without a certain minimal realization of the right to education. Similarly, the right to vote may seem of little importance to somebody with nothing to eat or in situations where people are victimised because of their skin colour, sex, language or religion. Taken together, the indivisibility and interdependence principles mean that efforts should be made to realize *all human rights together*, allowing for prioritization as necessary in accordance with human rights principles.

4. Kinds of Human Rights Obligations

Obligations are generally of three kinds: to respect, to protect and to fulfil human rights:

- To *respect* human rights means simply not to interfere with their enjoyment. For instance, States should *refrain* from carrying out forced evictions and not *arbitrarily* restrict the right to vote or the freedom of association.
- To *protect* human rights, means to take steps to ensure that third parties do not interfere with the enjoyment of these rights. For example, States must protect the accessibility of education by ensuring that parents and employers do not stop girls from going to school.

- To *fulfil* human rights means to take steps progressively to realize the right in question. These obligations sometimes subdivided into obligations to *facilitate* and to *provide* for its realization. The former refers to the obligation of the State to engage proactively in activities that would strengthen people’s ability to meet their own needs, for instance, creating conditions in which the market can supply the healthcare services that they demand. The obligation to “provide” goes one step further, involving direct provision of services if the right(s) concerned cannot be realized otherwise, for example to compensate for market failure or to help groups that are unable to provide for themselves.

Human rights law recognizes that lack of resources can impede the realization of human rights. Accordingly, some human rights obligations are of a progressive nature, while others are *immediate*. For economic, social and cultural rights, States have a core obligation to satisfy the *minimum* essential level of each right. This level cannot be determined in the abstract; it is a national task, to be undertaken in accordance with human rights. However, in any situation where a significant number of people are being deprived of their right to health, housing food and so forth, the State has a duty to show that all its available resources—including through requests for international assistance, as needed are being called upon to fulfil these rights.

Taking the rights to health as an example, it is not permissible for available resources to be devoted exclusively to first-rate services for only half the population or only those living in urban areas. Available resources should be dedicated to ensuring that the standard of health of the entire population is progressively improved, with immediate planning towards that objective, and effective mechanisms for monitoring progress and, as necessary, redress.

Human rights treaties also set certain limits on human rights obligations:

- The enjoyment of some international human rights can be limited in line with legitimate requirements of national security, “public order” (although this does not offer complete freedom to abrogate human rights) or public health. Examples include the right to peaceful assembly and freedom of movement under the International Covenant on Civil and Political Rights.
- Quite a number of human rights can lawfully be *derogated* from, or suppressed, in times of public emergencies, such as a security crisis. Examples include freedom of expression and freedom of association, although not rights basic to immediate human survival. To be lawful, derogations must be issued according to pre-established constitutional procedures, be publicly notified, and be strictly necessary and in proportion to severity of the crisis.
- At the time of ratifying or acceding to human rights treaty, States may also submit what is known as a *reservation*, limiting or modifying the treaty’s effect, provided the reservation is consistent with the treaty’s overall object and purpose.

5. Individuals, as well as States’ Obligations

Human rights obligations can also attach to private individuals, international organizations and other non-state actors. Parents, for example, have explicit obligations under the Convention on the Rights of the Child (CRC) and States are obliged to cooperate with each other to eliminate obstacles to development. Moreover, individuals have general responsibilities towards the community at large and, at a minimum, must respect the human rights of others.

However, States remain the primary duty-bearers under international law, and cannot abrogate its duty to set in place and enforce an appropriate regulatory environment for private sector activities and responsibilities. National legislation and policies must detail how the States human rights obligations will be discharged at national, provincial and local levels, and the extent to which individuals, companies, and local government units, NGOs or other organs of society will directly shoulder responsibility for implementation.

6. Realization of Human Rights with Limited Funds

In many situations the obligations to respect a given right (non-interference) may require more in the way of political will than financial resources. Even for obligations requiring positive action by the state, rapid progress may be possible by using the available funds more efficiently. For example, by scaling down expenditure on unproductive activities and by reducing spending on activities whose benefit goes disproportionately to the privileged groups of society. Some interventions important for human rights, such as tackling corruption, in fact save public money.

7. Differences between individuals' rights and collective rights

Sometimes the equal worth and dignity of all can be assured only through the recognition and protection of *individuals rights as members of a group*. The term *collective rights or group rights* refers to the rights of such peoples and groups, including ethnic and religious minorities and indigenous peoples, where the individual is defined by his or her ethnic, cultural or religious community.

Human rights claims are generally made most effectively by people acting together as a group. Collective rights are reflected strongly in some regional human rights regimes. The African Charter on Human and Peoples' Rights, for example defines "peoples' rights" to embrace the right to existence and determination, the right to economic, social and cultural development, and the right to a general satisfactory environment favourable to their development.

8. Human Rights and Culture

International human rights are universally recognised regardless of cultural differences, but their practical *implementation* does demand sensitivity to culture.

International human rights standards enjoy a strong claim to universality, with considerate adaptability to different cultural contexts. Article 1 of the Universal Declaration of Human Rights states;

"All human beings are born free and equal in dignity and rights. Human rights are inherent and inalienable in human beings, simply by the fact of their being human. The human person in whom they inhere cannot voluntarily give them up nor can others take them away".

9. Human Rights and Domestic Law

Kenya is a dualistic State. Upon ratification of international treaties, the human rights principles have to be domesticated before they can be recognised in the courts of the law.

Chapter V of the Kenyan Constitution provides for the fundamental rights and freedoms of the individual. It entails protection of right to life, right to personal liberty, protection from slavery and forced labour, inhuman treatment, protection of property, arbitrary search or entry, secure

protection of law, freedom of conscience, freedom of expression, freedom of assembly and movement, and protection from discrimination on the ground of race, colour among other grounds.

However the Kenyan Constitution does not make provisions for the Economic, Social and Cultural rights. Other statutes protect specific rights in Kenya such as Children's Rights, Sexual Offences Act, Employment Act among others.

10. HIV&AIDS Human Rights Issues

It has been recognized that human rights violations fuel HIV&AIDS pandemic as recognized by the UNGASS Declaration in 2001.

Key human rights principles which are essential to effective state responses to HIV&AIDS are found in existing international instruments such as the UDHR, International Convention on Economic, Social and Cultural Rights (ICESCR), the International Convention on Civil and Political Rights, the International Convention on Elimination of All Forms of Racial Discrimination, the Convention on the Elimination of All Forms of Discrimination Against Women, the Convention Against Torture and other Cruel, Inhuman or Degrading Treatment or punishment and the Convention on the Rights of the Child including the Regional instruments like the African Charter on Human and people's Rights. In addition, a number of conventions and recommendations of the International Labour Organization (ILO) are particularly relevant to the problem of HIV&AIDS, such as ILO instruments concerning discrimination in employment and occupation, termination of employment, protection of workers, privacy and safety and health at work.

HIV&AIDS and Human Rights International Guidelines have identified the following rights as particularly relevant in the context of HIV&AIDS:

- Non-discrimination and equality before the law.
- Human rights of women.
- Human rights of children.
- Right to marry and found a family, and protection of the family.
- Right to privacy.
- Right to enjoy the benefits of scientific progress and its applications.
- Right to liberty of movement.
- Right to seek and enjoy asylum.
- Rights to liberty and security of person.
- Right to education.
- Freedom of expression and information.
- Freedom of assembly and association.
- Right to the highest attainable standards of living and social security services.
- Freedom from cruel, inhuman or degrading treatment or punishment.

Initial responses to HIV&AIDS were often reactionary involved in the name of Public Health and frequently at the expense of human rights. This created discrimination of PLWHAs and failed to reduce the spread of HIV infection over a long time. With time, it has been realized that classification of "us" and "them" is counter productive. Promotion and protection of human rights in the context of HIV&AIDS is therefore important. The **legal ethical issues** recognised are discussed below:

1. Testing for HIV&AIDS

Testing has to be voluntary. Mandatory testing violates an individual's rights. Mandatory testing is only recommended in cases of rape and defilement where it is legally important to establish the

status of the offender and the victim. It is necessary since the victim will require to be placed on Post exposure prophylaxis. Indirect testing such as pre-natal testing may be allowed as long as the results remain anonymous. Testing for purposes of insurance cover, marriage or admission in any institution of learning is illegal.

2. Right to privacy and confidentiality

Privacy and confidentiality is a human right principle that has to be adhered to strictly. Confidentiality has to be observed in doctor patient relationship, at the workplace, during VCT procedures and even in areas of confinement. The aim is to avoid stigma and discrimination that is directed to people who test positive.

3. Rights of PLWHAs

PLWHAs are human beings like any other and all the provided rights apply to them too so the State is under an obligation to maintain those rights. PLWHAs are bound to suffer stigma and discrimination due to their status. Everyone has a right to active, free and meaningful participation in public life. The government is urged to support PLWHAs in development and implementation of HIV&AIDS related programmes. Participation of PLWHAs in aspects of HIV&AIDS policy design and implementation is crucial to combating the pandemic.

Realization of human rights and freedoms for all PLWHAs is essential to reduce vulnerability to HIV&AIDS.

4. Matrimonial/Family issues

Issues that have been identified to fuel HIV&AIDS in this relationship include; divorce and separation, marital rape, abuse of reproductive rights and infidelity in marriage thus having multiple partners.

5. HIV&AIDS and Criminal Law

The critical issue of consideration in criminal law has been to balance the rights of PLWHAs and the punishment to be accorded those who recklessly, deliberately and knowingly pass on HIV&AIDS infection and put others at risk.

Some proponents against resorting to criminal sanctions have argued that it amounts to criminalization of the Virus and would be dangerous for PLWHAs.

The difficulties the law would be faced with in criminal law are to establish firstly whether there was consent at the actual time of transmission or whether there was disclosure or not. The law would have to deliberate on how to deal with the issues of commercial sex workers who despite knowing their status continue with their trade.

Consensus has been reached after various stakeholder consultations that PLWHAs who recklessly and knowingly transmit the virus must be punished under criminal law.

It is appreciated that the current Kenyan criminal law has no specific provision regarding HIV infection. However, deterrent punishment is proposed.

The proposed HIV&AIDS prevention and control Bill 2006 (Amended) proposes a jail term of 7 (seven) years or fine of Kshs 500,000 or both. Concerns have been voiced by organizations of PLWHAs, that the punishment is excessive. However, the office of the Attorney General has been requested to reconsider the relevant section in line with other existing penal laws and accord a fairer punishment.

In accordance with the International Guidelines on HIV&AIDS 2001, States are called upon to ensure that their criminal laws and penal institutions are consistent with international human rights obligations and not misused in the context of HIV&AIDS or targeted against vulnerable groups.

6. HIV and the Rights of the Child

There is no doubt that children are quite vulnerable in the wake of HIV&AIDS. All children are entitled to their rights without discrimination. Orphaned children are rendered more vulnerable. Breakdown in social structures makes children susceptible to HIV infections, including disinheritance by parents.

Orphaned children who have HIV&AIDS have double jeopardy. They need protection and access to health services. Due to high level of stigma and discrimination, they are likely to be denied admission in schools thus their right to education. This makes them feel rejected and isolated to the extent that some may lose their lives.

Transmission of HIV from Mother to Child (MTCT) presents difficult situations on how to balance the right of the mother and those of the unborn child. However, it is acknowledged that 30% - 40% of babies born to HIV positive mothers will be positive, a suggestion that high percentage would be negative.

High number of child-headed homes experienced is an indication that a strong framework is needed to protect the rights of these children. All other relevant human rights are applicable. Children should be protected in terms of right to privacy including confidentiality. This is necessary to avoid high levels of stigma and discrimination.

For purposes of testing for HIV on children consent must be obtained from parents or guardians. In respect of mature teenagers who understand the procedures, they may give own consent. In all dealings with children, principle of best interest of the child is paramount together with non-discrimination principle. A child is defined as anybody below 18 years old.

7. HIV&AIDS and Biomedical Research

In the wake of HIV&AIDS, it is necessary to regulate research involving human subjects. Fundamental rights of every individual have to be protected.

Issues emerging from the above are how to keep to the legal ethical standards. Of great concern is how to ensure that research subjects benefit from such research. UN guidelines on HIV and human rights stipulates that everyone has the right to enjoy benefits of scientific progress and its applications including equal access to treatment. The UNGASS Declaration of commitment on HIV&AIDS states that the right to enjoy the benefits of scientific progress required that HIV&AIDS prevention, treatment, and care and support should be based on sound analysis and evidence.

Governments are to ensure that prevention approaches are based on complete factual and unbiased information about HIV prevention.

Unethical biomedical research involving human subjects is a violation of human rights of PLWHAs. However, diagnostic and therapeutic research can be allowed under regulated circumstances.

The general public including PLWHAs have a right to receive appropriate information about research and results that are effective.

The *Declaration of Helsinki*, drawing the world Medical Association 1964 and revised in 1975 provides that:-

“Biomedical research involving human subjects must conform to generally accepted scientific principles and should be based on adequately performed laboratory and animal experimentation and on thorough knowledge of scientific tradition”.

Therefore PLWHAs must consent to be used as subjects of biomedical experiments related to HIV&AIDS. Above all, principles of privacy and confidentiality must be observed and respected.

8. Non-Discrimination and Equal Access to Treatment

It is against principles of human rights to discriminate against PLWHAs. It is the duty of governments to avail information, commodities and services such as condoms.

No one should discriminate against any other individual on the basis of age, marital status, occupation, sexual orientation or expressions, gender identity or expression or disability.

HIV&AIDS disproportionately affects those people least able to claim their human rights thus the poorest, least educated and the marginalized in society. Discrimination and stigma fuel the pandemic at all stages from prevention and treatment to the care and support of PLWHAs or those affected such as orphans, widows and the elderly care givers.

Governments should ensure equal access to all HIV related treatment, including anti-retroviral medicines, and removal of all barriers that hinder access to health services such as costs, transportation and user fees to encourage the poor to access services.

1. Introduction

The interconnection between gender and HIV&AIDS cannot be understood without understanding the key concepts of gender and sexuality. It is important to define what is meant by the term “gender”, and how it differs from the closely related term “sex”. “Sex” refers to the biological and physiological characteristics that define men and women. “Gender” refers to socially constructed roles, behaviours, activities, and attributes that a given society considers appropriate for men and women.

Gender is defined as the set of characteristics, roles and behaviour patterns that distinguish women from men socially and culturally. Gender is learned and can therefore be unlearned. Unlike gender, sex is biologically determined, universal and cannot be changed. The concept of gender refers not only to the roles and characteristics of women and men but also to the power relations between them. In gender and development terms, women’s roles are classified as reproductive, productive and community management roles.

2. Gender, Sexuality and Vulnerability to HIV Infection

In sub-Saharan Africa, HIV is primarily, a sexually transmitted disease, therefore centrally involves sexual relationships. Gender renders women most vulnerable. Examples of how gender and sexuality render females vulnerable to HIV transmission include the norm of virginity for unmarried girls that increase young girl’s risk because the virginity norm inhibits young women from seeking information about sex.

Sexual behaviour is greatly influenced by a person’s understanding of sexuality, broadly understood as the social construction of a biological drive. One’s sexuality is defined by whom one has sex with, in what ways and why, under which circumstances, and with what outcomes. In addition, a person’s sexuality is in turn defined by gender, age, economic status, ethnicity etc. Therefore, gender and sexuality are at the heart of any understanding of the dynamics of HIV transmissions.

Gender norms, for example, often dictate that women and girls should be ignorant and passive about sex, which greatly constrains their ability to negotiate safer sex or access appropriate services. Similarly, gender norms cast women as being primarily responsible for reproductive and productive activities within the home, in sharp contrast to men who are cast as primary economic actors and producers outside the home. Such gender stereotypes account for women having much less access than men to key productive resources such as education, land, credit, income and employment which significantly reduces the leverage they have in negotiating protection with their partners and greatly affects their ability to cope with the impact of infection. For men and boys, gender norms create social pressure to take risks, be self-reliant, and to prove their manhood by having sex with multiple partners. Such norms expose men and boys to the risk of infection and create barriers to their use of HIV&AIDS prevention, care or support services. Youth, especially girls, are

particularly vulnerable in the epidemic. Furthermore, research indicates that even gender norms, which supposedly protect youth, such as those that expect unmarried girls to remain virgins, can put them at risk by restricting their access to full information about sexuality and reproductive health services.

3. The Impact of Gender on the HIV&AIDS Pandemic

Epidemiological and bio medical research has long established a link between an individual's sex and his or her risk of HIV infection. It is well known, for example, that physiological factors account for more efficient transmission of infection from an infected man to a woman than from an infected woman to a man. More recently, however, research has also identified the role that gender plays in determining individual risks and vulnerability in the HIV&AIDS epidemic. Socio-cultural norms about masculinity and femininity, and the unequal power relations between men and women that arise from these norms, conspire with biological and physiological factors to compound individual's risk of infection resulting in epidemics of significant size and proportion in different parts of the world.

Whereas sex defines the biological distinction between women and men, gender is a social construct that differentiates the power, roles, responsibilities, and obligations of women from that of men and society. Gender determines to a great extent how we think, how we feel and what we believe we can and cannot do as women and men. Gender roles, norms and expectations vary over the life cycle of women and men, and vary within cultures.

In the HIV&AIDS epidemic, both a person's sex and gender determine the extent to which he or she would be vulnerable to infection or his or her ability to access available treatments. Additionally, gender inequality influences the extent to which an individual would cope with the burden of infection and illness, caring for a family member, or surviving the death of family members both economically and socially.

Gender is a culture specific construct. As a result, there are significant differences in what women and men can do in one culture as opposed to another. But what is fairly consistent across cultures is that there is always a distinct difference between women and men's roles, access to productive resources, and decision-making authority. Typically, men are expected to be responsible for the productive activities outside the home while women are expected to be responsible for the reproductive and productive activities within the home. In addition, in almost every country in the world, women have less access to and control of productive resources than men, creating an unequal balance of power that favours men. Gender gaps between women and men in literacy, school enrolment, labour force participation, land ownership, and access to credit testify to this imbalance in power.

The imbalance in power created by a differential access to productive resources translates into unequal balance of power in sexual interactions whereby men have greater control of their sexuality. The balance of sexual power in any sexual interaction determines the outcomes of the interaction. In the worst cases, this power imbalance plays itself out in terms of violence against women. An understanding of individual sexual behaviour or sexual risk thus necessitates an understanding of gender and sexuality as constructed by a complex interplay of socio cultural and economic forces that determine the distribution of power.

4. The Gender Dimensions of HIV&AIDS and Human Rights

The wide-spread abuse of human rights and fundamental freedoms associated with HIV&AIDS has emerged globally in the wake of the pandemic. Of particular concern is the strong link between violation of human rights of women and girls and the HIV&AIDS pandemic, which has not only been one of the root causes of women and girls' infection, but also one reason why women are particularly severely affected by the pandemic. Women and girls' relative lack of autonomy over themselves and

their sexual lives together with social-economic inequalities, violate a range of human rights including rights to life, privacy, freedom and security of the person and health.

Gender-specific examples of the limitation or denial of human rights include:

- **Stigmatization and discrimination** whereby women tend to be blamed as vectors of the epidemic (to partners and children), labelled as 'promiscuous' and morally unworthy and even abandoned by their families, in addition to being marginalised, publicly censured, abused and denied access to services such as testing, counselling, treatment and care, education, accommodation, employment and in their enjoyment of other rights.
- Limited access by women and girls to relevant **information and education** about HIV&AIDS, gender roles, sexuality and reproductive health including safe sex because of social pressure and cultural norms. Significant gender gaps in school enrolment and retention as well as withdrawal of girls from school to look after sick relatives or to earn money to support their family, further aggravates the lack of access to information and the resources and skills needed to apply that information to avoid HIV infection, and to reduce the impact if infected and affected.
- The **right to health and to life** is compromised by under-investment in research and product development of affordable female-controlled methods of protection and prevention (such as female condoms, microbicides and vaccines) coupled with the general lack of access to treatments for HIV&AIDS and opportunistic infections, or dietary and food supplement inputs to strengthen the immune system for the majority of people in developing countries. Such a situation impacts seriously upon women who outnumber men among those infected in some of the poorest countries and in situations of rape. In addition, women suffer from anaemia or other conditions stemming from repeated pregnancies and childbirth, their immune system is rapidly depleted. Lack of political commitment is also denying women the treatment to prevent mother-to-child transmission of HIV.
- Perpetuation of **poverty** which is a high risk factor for HIV infection and its impact depletes families of all resources and income to maintain their health and well-being after infection, thus endangering the survival of future generations. The intersection of poverty with gender inequality makes women very vulnerable because of unequal access to economic resources, inequality in the sphere of work, problems faced by the girl-child, burden of care, inability to negotiate safe sex because of their economic dependence on men, having to resort to sex work in order to survive and spousal separation in migration. The breakdown of social services such as health-care, education and social welfare, have not only increased the burden of poverty in the developing world, but have also increased the burden on women. This global economic order has increased the vulnerability of developing countries to HIV&AIDS both in terms of infection and impact.
- Widespread malnutrition and starvation in countries most affected by the HIV&AIDS pandemic because **household and national food security** are threatened by the decimation of the agricultural workforce, a substantial number of whom are women. Weakness and exhaustion caused by HIV infection can lead to the inability to perform agricultural tasks resulting in reduced crop yields and a shift away from nutritious but labour-intensive crops. Women who have limited or no land rights and the prospective loss of access to land when husbands die, face particular constraints as farmers, processors and marketers of food. Their attention is also diverted away from important farm tasks when they have to care for dying relatives. Due to their poverty, illiteracy and cultural constraints on using 'masculine' protective clothing, women are at increased risk from contamination by organophosphate pesticides and this has implications for their survival when infected with HIV.

- The lack of **good governance** in the form of effective policies and laws that address gender inequality so as to bring about more democratic and stable social relations and enhancing the possibilities of social change to address HIV&AIDS. Good governance also includes political will and commitment that manifest in strong public voices on the epidemic, an effective government based on the rule of law, freedom from corruption, commitment to respecting, protecting and fulfilling human rights and human security, and the participation of a strong and active civil society, particularly the Greater Involvement of People Living with and affected by HIV&AIDS (GIPA) at all levels of policy formulation, programme implementation, monitoring and evaluation. An absence of good governance increases social and political insecurity, which increases the vulnerability of the population to HIV&AIDS.
- Increasing role of women, including young girls and elderly women as **caregivers**, draining them of their energies and isolating them from their usual social activities because they have to cope with the demands of caring for infected people who have been pushed into home-based care due to the failure of the State health care systems. This usually results in loss of productivity and livelihood by families, made worse when meagre resources have to be diverted into providing treatment and care. If the caregiver is herself infected with HIV, her health might deteriorate quickly under the strain of care giving. In many cases, young girls are withdrawn from school to care for sick family members or younger siblings, if they are orphans. In the absence of good information and suitable forms of protection while caring, many elderly women and care providers may themselves be exposed to the risk of HIV infection.
- The threat of **violence**, physical violence, and abandonment are some of the consequences faced by women who have to negotiate the use of a condom, discuss fidelity with their partners, leave relationships that they perceive to be risky or disclose their HIV status. During armed conflict and political instability, women and girls may face systematic rape and other gender-specific war crimes. Young women and girls face special risks because of the erroneous but widespread belief that sex with a virgin can cleanse a man of infection. AIDS orphans who are often forced to fend for themselves, are also easy prey for sexual abuse and violence. The trafficking of women and girls into prostitution and sexual slavery is another deeply entrenched form of violence against young women fuelled by widespread poverty, international tourism and the forces of globalization. Recent research shows that young men too express their fear of the potential for violence within themselves, the threat of violence from other men and of the violence inflicted on them.
- **War and other armed conflicts** which often increase local and regional insecurity, worsen poverty, encourage violence against women and frequently lead to the breakdown of social services, infrastructure and a lack of food, shelter, medicines and health care professionals. These factors also increase the vulnerability of entire populations and threaten national security and stability.

However the most effective methods of HIV prevention are partner dependent, abstinence, faithfulness and condom use. The extent to which sexual partners are free to negotiate safer sex and to protect themselves and their partners is greatly influenced by the gendered aspects of sexual behaviour. The State has to safeguard women's rights and stop violence against women. Women have to be protected against factors that increase their risk to HIV infection.

1. HIV&AIDS Related Stigma and Discrimination

Since HIV&AIDS were discovered two decades ago, a lot has been done to address it. Globally, many nations including Kenya have put great efforts and resources in order to curb the pandemic. However, stigma and discrimination, both against the infected and the affected is a great barrier to achieving this goal. Stigma is said to be one of the biggest barriers to accessing both HIV preventive and treatment services.

Stigma

HIV&AIDS related stigma is referred to as imposition of a special discrediting and unwanted mark on a person or persons in such a way that they are looked at as fundamentally and shamefully different because they are either living with or are associated with HIV&AIDS. It significantly discredits and devalues an individual in the eyes of others. Stigma is about perceptions and attitudes.

Self-stigma (Internal stigma)

This begins with a HIV positive individual looking at themselves as unfortunate and their concerns and fears about what other people are going to think about them. Self stigma often manifests itself as loss of hope, shame, self blame, guilt, and feelings of worthlessness and inferiority and in severe cases, suicide or suicidal tendencies.

Secondary stigma

This occurs when HIV&AIDS related stigma is extended from an HIV&AIDS positive person to include their families, children, and friends and even care givers.

Discrimination

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

Stigma and 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. 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.

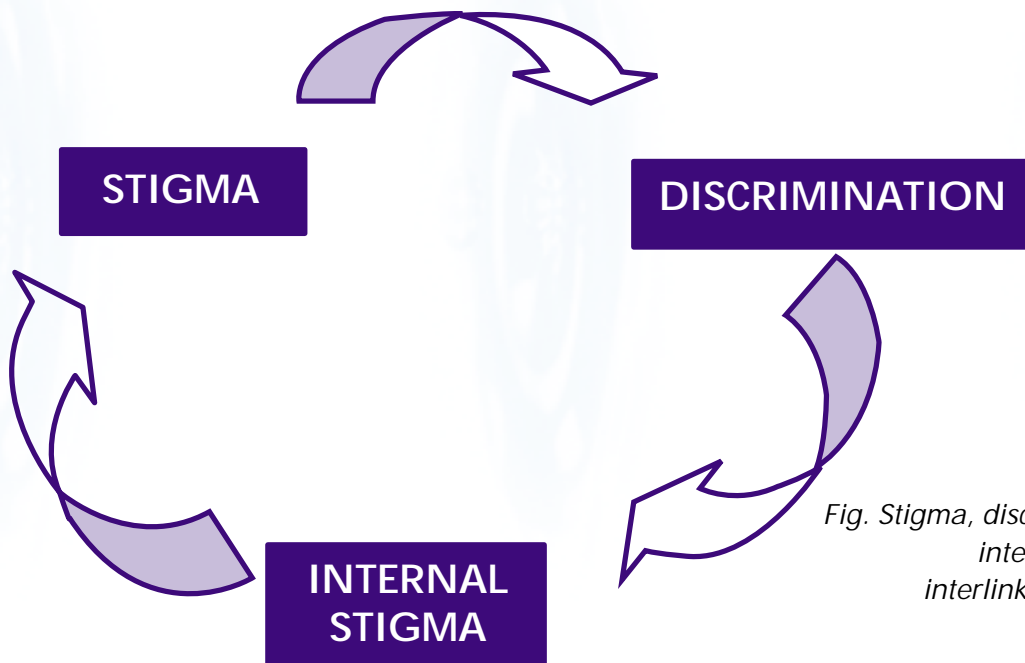


Fig. Stigma, discrimination and internal stigma are interlinked as shown in the figure.

2. Causes of HIV&AIDS related stigma and discrimination

The causes of HIV&AIDS related stigma and discrimination are:-

- HIV&AIDS is a life-threatening disease.
- People are scared of contracting HIV.
- Myths about HIV&AIDS leads people to have an irrational fear that HIV can be transmitted by normal ordinary non-sexual interactions (e.g. hand shaking, touching, sitting next to) people living with HIV.
- AIDS is associated with behaviors (such as sex between men and injecting drug-use, commercial sex work) that are already stigmatized in many societies.
- People living with HIV&AIDS are often thought of and blamed as being responsible for becoming infected.
- Religious or moral beliefs 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 (men having sex with men), Low women's status, Injecting drug users, Commercial sex work, Immigrants , and Minorities.
- 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.
- Prevention of Mother to Child Transmission of HIV. Pregnant women with HIV suffer multiple layers of stigma. Breast feeding becomes an issue whereby HIV positive women may want to breast feed because not breast feeding in some cultures is taken as a sign that one is HIV positive.

3. The Implications for People Living With HIV&AIDS in Kenya

Stigma and discrimination impacts beyond individuals infected with HIV, to affect all those associated with it. It can also impact on society more generally, by extending the epidemic

and undermining whatever behaviour and treatment interventions already in place. In Kenya, the burden of AIDS is significant. Stigma is perceived as a major limiting factor in primary and secondary HIV&AIDS prevention and care. It interferes with voluntary testing and counselling and with accessing care and treatments, thereby increasing suffering and shortening lives.

Stigma and discrimination play significant roles in the development and maintenance of the HIV epidemic. It is well known and documented that PLWHAs experience stigma and discrimination on an ongoing basis. This impact goes beyond individuals infected with HIV to reach broadly into society, both disrupting the functioning of communities and complicating prevention treatment of HIV.

Stigma drives HIV out of public sight, so reducing pressure for behaviour change. Stigma leads to fear of knowing one's status, thus delaying testing and accessing treatment. At an individual level, stigma undermines one's identity and capacity to cope with the disease. Fear of discrimination limits possibility of disclosure even to potential important sources of support such as family and friends. Finally stigma impacts on behaviour changes as it limits possibility of using certain safer sexual practices. Behaviour such as use of condoms could be seen as a marker of HIV, leading to rejection and stigma. All interventions need to address stigma as part of the focus. However, addressing stigma and discrimination should not be underestimated. Although in Kenya as per the criminal statutes, discrimination based on race, gender, disability and sexuality is illegal, the abuses still persist.

Anger and fear contribute to the development of discrimination in both HIV Positive and negative groups. Morality has become a key factor in development of stigma and discrimination in AIDS. A judgmental discourse has distinguished sharply between those 'innocents' who contract HIV via organ or blood transfusions, the children of women with HIV, those whose partners are unfaithful, and those who are considered guilty and almost 'deserve it'.

Religious groups may intentionally or inadvertently contribute to discrimination by making explicit or implicit judgment against those who are infected with HIV. Attempts to label the epidemic as God's punishment to sinners, especially commercial sex workers and drug users exacerbate the problem of stigma and discrimination.

Blaming others is psychologically reassuring as it divides the society into 'us' and 'them'. The attachment of gender discrimination to HIV stigma has led women being blamed for spreading the epidemic. Thus women are contradictory expected to provide sexual services to men generally, be chaste and pure, and take on the responsibility of preventing pregnancy and other sexual transmitted diseases. Another difficulty that has been observed is lack of knowledge of how to behave to someone with HIV.

4. Stigma and Discrimination and Human Rights

At the international level, stigma and discrimination has led some countries not to enact legislation to protect people infected or affected by HIV&AIDS. Lack of such legislation may lead to PLWHAs or the affected being barred from entering those countries or deportation

of infected foreigners. This limits international travel and migration. In addition, lack of the said legislation may give room to compulsory screening of such groups' thus perpetuating stigmatization of the said groups. There are also countries that have laws that insist on compulsory testing of HIV cases and restriction of person's right to anonymity and confidentiality as well as the right to movement of those infected. Though justified on grounds that HIV forms 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. In some societies, laws, rules and policies can increase 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, and failing to recognize growing epidemics in belief that HIV&AIDS 'can never happen to us' are some of the most common forms of denial. These denials fuel AIDS stigma by making those individuals who are infected appear abnormal and exceptional. If human rights are respected, stigma and discrimination will be curbed.

1. What is the GIPA principle?

GIPA means Greater Involvement of People Living with or Affected by HIV&AIDS and is a principle, formally cemented in the *Paris AIDS Summit Declaration* of 1994. At this summit, leaders of 42 countries acknowledged the central role of people living with HIV&AIDS in the design and implementation of policies and programs towards a successful response to the global HIV&AIDS crisis.

The Declaration, signed by all nations attending the meeting, stated in Article 1 that:

“The success of our national, regional, and global programmes to confront HIV effectively requires the greater involvement of people living with HIV&AIDS... through an initiative to strengthen the capacity and coordination of networks of people living with HIV&AIDS ... by ensuring their full involvement in our common response to HIV&AIDS at all – national, regional, and global – levels, this initiative will, in particular, stimulate the creation of supportive political, legal and social environments”.

The Declaration committed governments to empowering HIV positive people both through facilitating their increased participation in all matters related to HIV&AIDS care, treatment, and support, and through strengthening existing networks of people living with HIV&AIDS.

The Paris Declaration also expressed “determination to mobilize all of society; the public and private sectors, community-based organizations and people living with HIV&AIDS; in a spirit of true partnership”, as well as to fully involve “people living with HIV&AIDS in the formulation and implementation of public policies and ensure equal protection under the law for persons living with HIV&AIDS”.

At the 2001 United Nations General Assembly Special Session on Aids (UNGASS), all member UN nations signed the United Nations Declaration of Commitment on HIV&AIDS, reaffirming commitment to GIPA and acknowledging it as a priority concern in response to the AIDS pandemic. The GIPA principle was further upheld in the Guiding Principles of the World Health Organization’s ‘3 by 5’ Treatment Initiative. These guiding principles state that, “The Initiative clearly places the needs and involvement of people living with HIV&AIDS in the centre of all of its programming” (WHO, 2003).

2. History behind the GIPA Principle

In June 1983 in Denver, Colorado, United States of America, a movement of people living with HIV&AIDS emerged at the Second National Forum on AIDS. The ‘Denver Principles’ adopted at the forum called for those living with

HIV to be supported when they opposed AIDS-related stigma and discrimination. The Principles also stated that people living with HIV should “be involved at every level of decision-making; for example serve on the boards of directors of provider organizations, and participate in all AIDS related meetings with as much credibility as other participants, to share their own experiences and knowledge”. This was the beginning of the movement that later led to the creation of the GIPA principle. As coalitions formed and gathered momentum, the number of national and global groups promoting the increased involvement of HIV positive people in all HIV&AIDS-related activities also grew.

By 1988, the publication *AIDS Treatment News* listed more than 20 coalitions of people living with HIV across the Canada, United States, and the United Kingdom. Globally, an international network of people living with HIV was initially formed in 1986, and later became the Global Network of People Living with HIV&AIDS. In July 1992, the International Community of Women Living with HIV&AIDS was formed by a group of HIV-positive women from 30 different countries who were attending the 8th International Conference on AIDS in Amsterdam. The Community drew on the growing movement of HIV-positive women in Africa, which led to a new kind of activism extending beyond the immediate concerns of creating self-help and support groups. In 1994, the Paris AIDS Summit Declaration put the GIPA principle on the map, but unfortunately, no mechanism was established to monitor the progress of GIPA-related activities worldwide. In 1997, during the XIIIth International Conference of people living with HIV&AIDS in Thailand, UNAIDS hosted a meeting on the GIPA initiative which recommended action to provide HIV-positive people with appropriate skills. This became the seed for *development* of the GIPA principle.

In 1999, UNAIDS published the first guideline on GIPA and expanded its meaning to include all people directly affected by HIV&AIDS. A publication, *From Principle to Practice: Greater Involvement of People Living With or Affected by HIV&AIDS*, describes the rationale for involving HIV-positive people in the response, and addresses many challenges to the principle. It also put forward the importance of creating safe and enabling environments for HIV&AIDS infected and affected people to get involved. This guide provided the conceptual foundation for the GIPA principle upon which future activities and policies could be based.

3. Pyramid of Involvement by PLWHAs

This pyramid¹ models the increasing levels of involvement advocated by GIPA, with the highest level representing complete application of the GIPA principle. But ideally GIPA is applied at all Levels of organization.

¹ Adapted from *Principles to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS*, UNAIDS, 1999.

DECISION MAKERS: PLWHAs participate in decision-making or policy-making bodies, and their inputs are valued equally with all the other members of these bodies.

EXPERTS: PLWHAs are recognized as important sources of information, knowledge and skills who participate on the same level as professionals in design, adaptation and evaluation of interventions.

IMPLEMENTATIONS: PLWHAs carry out real but instrumental roles in interventions, e.g. as carers, peer educators or outreach workers. However, PLWHAs do not design the intervention or have little say in how it is run.

SPEAKERS: PLWHAs are used as spokespersons in campaigns to change behaviours, or are brought into conferences or meetings to “share their views” but otherwise do not participate. (This is often perceived as “token” participation, where the organizers are conscious of the need to be seen as involving PLWHAs, but do not give them any real power or responsibility.)

CONTRIBUTORS: Activities involve PLWHAs only marginally, generally when the PLWHAs is already well-known.

For example, using an HIV-positive pop star on a poster, or having relatives of someone who has recently died of AIDS speak about that person at public occasions.

TARGET AUDIENCES: Activities are aimed at or conducted for PLWHAs, or address them en masse rather than as individuals.

However, PLWHAs should be recognised as more than (a) anonymous images on leaflets, posters, or in information, education and communication (IEC) campaigns, (b) people who only receive services, or (c) as “patients” at this level. They can provide important feedback which in turn can influence or inform the sources of the information.

4. Implementing the GIPA Principle Worldwide

Although the GIPA principle itself is a giant, progressive step for those infected and affected by HIV&AIDS, the active involvement of people living with HIV in decision-making is still far from universal. Furthermore, the involvement of HIV-positive women, youth and children has lagged far behind that of men in most parts of the world. Others are unable to be open about their status because they fear they will face discrimination and stigma.

5. GIPA in Policy-Shaping

The movement of people living with HIV has become stronger and more influential. For example, in Ukraine, the All-Ukrainian Network of Persons Living with HIV&AIDS has helped shape the National AIDS Prevention Programme, and is increasingly involved in providing HIV-related care services (UNDP, 2003).

In Cambodia, the Cambodian People Living with HIV&AIDS Network has been actively involved in policy development. As a member of the Country Coordinating Mechanism, it helped formulate Cambodia's successful funding proposal to the Global Fund to Fight AIDS, Tuberculosis and Malaria. Similarly, partnership forums have been established in many countries, bringing together people living with HIV and other government and non-governmental partners in shaping AIDS responses.

Elsewhere, the Asia-Pacific Network for People Living with HIV&AIDS has united people from over 20 Asian countries under the United Nations Development Program's (UNDP) 'Leadership for Results' programme. This regional network has fostered developing national organizations of people living with HIV.

In Kenya various organizations of PLWHAs have been established and have made tremendous efforts in encouraging positive living. PLWHAs are represented in the country coordinating mechanism for Global fund and at the board of National AIDS Control Council.

6. GIPA in National HIV&AIDS Advocacy

In other cases, people living with HIV have long been involved in national decision-making. Increasingly, HIV-positive people are actively participating in local decision-making processes, and in providing services to others with HIV. Often, they are at the front line of care and support. For instance, in Cambodia, through the 'Friend Help Friend' units at district health centre, volunteers living with HIV provide AIDS information and support, and help people adhere to their treatment regimens.

The link between providing services and national advocacy has most prominently come into play around the issue of extending access to treatment; one of the main priorities of AIDS activism.

7. GIPA in the Workplace

Presence of people openly living with HIV in workplace shows it is possible to go on living and working normally, a critical first step in successfully dealing with work-related discrimination. The United Nations Volunteers Programme has backed GIPA in Southern Africa by placing people living with HIV in mining companies, parastatal organizations, and United Nations agencies, among others. Programme participants carry out advocacy and education programmes, and actively help to develop AIDS workplace action plans. Similarly, in the Caribbean, since 2000 about 50 HIV-positive members of the United Nations Volunteers Programme have worked to counter AIDS-related discrimination in seven countries in the region.

Rarely do HIV-positive people get paid for caring for and supporting others living with the virus. One exception is Botswana, where a member of the country's Network of People Living with HIV&AIDS works as a community liaison officer with the infectious diseases clinic in the capital, Gabarone. Her personal experiences encountered in the process of living with HIV have been particularly important in helping patients (especially those who have come from distant villages) talk about the difficulties they have with adhering to their drug regimen, or the pressures that relatives exert on HIV-positive mothers to breastfeed their newborn children (UNAIDS, 2003).

Corporate, trade union and government support for AIDS workplace programmes exists in many places. However, the informal work sector still poses a significant challenge. India is a case in point. Some 92% of India's people work in the informal economy. The International Labour Organization (ILO), along with employers' and workers' organizations, has supported the Network of Positive People of Delhi's work in the informal sector. The Network's members provide training, job assistance, and care and support to both HIV-positive workers and the families of those who have died of AIDS.

8. GIPA and HIV&AIDS Support Services

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

Financing for the greater and meaningful involvement of PLWHAs is crucial. People living with HIV need access to antiretroviral drugs and other essential care, and they need to receive a salary or other paid compensation for their time and contributions. Otherwise, their capacity to participate in the AIDS response is seriously hindered. One example of an innovative effort to plug the gap is in Uganda. A Treatment Fund for HIV&AIDS Advocates in Uganda currently provides six advocates with antiretroviral treatment, and is funded by Rotary International, and its Belgian and Ugandan branches (Uganda AIDS Commission and UNAIDS, 2003). The Fund is co-managed by the Persons Living with HIV&AIDS Forum, which brings together all of Uganda's relevant networks and associations.

HIV-positive African women taking on activist roles have faced enormous challenges. They are frustrated over the pressures they encounter to disclose their status as part of prevention campaigns, while their own financial, medical and emotional needs are ignored. The commitment and volunteerism of people living with HIV has been exploited by NGOs and government programmes that use this cheap or free labour in place of health-care services (Manchester, 2003).

A study of 17 NGOs providing HIV&AIDS services in four countries (Burkina Faso, Ecuador, India and Zambia) revealed that failure to account for the needs of HIV-positive people reduced the effectiveness of the services provided. Involving people living with HIV in outreach education, before they receive the necessary training and ongoing support, can have a negative impact on service quality, and can also harm the individuals themselves (Horizons Program, 2002). Participation of people living with HIV at the international level can be hindered by difficulties obtaining travel insurance to cover any HIV-related illnesses or travel restrictions that many countries impose on people living with HIV.

9. Challenges for the GIPA Principle

Challenges faced by PLWHAs are reflected in the difficulties in implementing the GIPA principle in projects, policies, and services dealing with those living or affected by HIV&AIDS. Lack of finances, bureaucracy in accessing funds, delay in disbursements, and lack of skills in proposal writing all help to further marginalize PLWHAs. PLWHAs are not empowered with the necessary knowledge and skills, especially for dealing with the issue of tokenism. PLWHAs feel that there is lack of commitment and transparency by some partners in establishing partnerships with them. They feel that there is unfair competition and commercialization in HIV&AIDS programming, and no genuine commitment to fighting HIV&AIDS.

There is still discrimination and stigma in the work place, churches, schools and at all levels (national to grassroots). Care and support programmes need scaling up; particularly access to treatment, management, and ARV provision (JAPR 2004 Report).

The identified challenges to full realization of the GIPA principle are: late diagnosis, socio-economic differential, stigma and discrimination, improving counselling, keeping HIV-positive people alive, outgrowing tokenism, building confidence and capacity, sustainability, and government attitudes.

A brief outline of each is given below:

a) Late Diagnosis

Most people who have HIV do not know that they are infected. Most positive people are diagnosed late in their infection when they already have an AIDS-related illness, and this clearly reduces their ability to make an impact. As costs for antiretroviral therapy fall, and access is extended massively, we must ensure that those who are 'living' positively are encouraged to continue to do so.

b) Socio-Economic Differential

As noted earlier, many positive people come from very different backgrounds as to those involved in program management or policy development. Many are much younger. In environments where age is respected, this makes it difficult for many positive people. Even if people are able and willing to be involved, they may not have the confidence. HIV diagnosis is renowned for shattering people's self-esteem. We can work to overcome these challenges, although many may never be comfortable relating with those in positions of power.

c) Stigma and Discrimination

Stigma and discrimination are perhaps the greatest catalysts for the spread of HIV. People with HIV are stigmatized as different because they are assumed to have been involved in 'immoral' behaviour such as pre- or extra-marital sex or injecting drug use. People stigmatize those with HIV because they are ignorant of the modes of HIV transmission and are afraid of contracting HIV from casual contact. People isolate persons with HIV, ostracize them, harass them, ridicule them, and in some instances kill them. People don't want to associate with those who are HIV-positive because they are afraid of the shame and blame.

Positive people with HIV are frequently treated in morally disdainful and judgmental ways. Breaches of confidentiality frequently precede discriminatory acts. Often positive people are denied treatment or treatment is delayed, they pay more for health services than untested or HIV-negative people and health workers patronize them. In homes, some positive people are

not allowed to associate freely with family members and are forced to eat and sleep separately. Many people have lost their employment because of their HIV status- this is a waste of the country's human resources. Many people's skills are lost simply because they are diagnosed as positive and then subsequently lose their work opportunities.

Many positive people's universal human rights are violated. A person known to be an injecting drug user, a sex worker or a man who has sex with men are usually further stigmatized. This leads to a vicious cycle. Most people diagnosed as positive experience self-imposed stigma; many decide not to disclose their HIV status to anybody because they are terrified of how people will treat them. Invariably, there is very little to be gained by being open about one's status but a great deal to be lost, so most people choose to keep quiet and carry the burden of their secrecy in silence and isolation.

The strongest tools to fight stigma and discrimination are the voices of positive people. They should be encouraged to start with limited disclosure; however, if they experience discrimination at any stage, further disclosure and involvement may be hindered.

In Kenya organizations like KANCO, MMAAK and many others are working to eliminate stigma and discrimination in society and in the workplace of people living with HIV&AIDS. More specifically, KANCO is working to alleviate the burden of HIV&AIDS on women, especially those who have been stripped of their property and/or inheritance after losing a spouse to AIDS.

d) Improving Counselling

Much discrimination originates from testing without due process; inadequate or no pre- or post-test counselling, lack of informed consent; and violation of confidentiality. For optimal public health outcomes, testing must be completely voluntary and accompanied by quality pre and post counselling and information. The recent APN+ documentation of AIDS-related discrimination indicates that approximately half of the people tested for HIV in several Asian countries were tested without being fully aware of what HIV was or the consequences of an HIV-positive diagnosis. They were tested without appropriate (or any) counselling. These people subsequently were most likely to experience greater levels of discrimination compared with people who were informed about HIV before their diagnosis and who willingly chose to go for an HIV test.

In the first instance, we must examine the context of HIV testing and the conditions under which people test for HIV. Positive people need tools to move beyond the news of their diagnosis - the support of counselling and referrals to any social networks of support available in the community. Quality pre- and post-test counselling can prevent somebody who tests HIV-positive from dropping out of the system and failing to get access to essential information regarding their health management.

Many people need a range of counselling following an HIV-positive diagnosis. This includes couples counselling those considering having children; counselling on legal matters such as making a will; counselling for those considering starting antiretroviral therapy; and counselling for families and partners. For many of these tasks, positive people are best placed to provide empathic responses and guidance. A massive effort to provide training guidelines and training of trainers is urgently needed. In addition, many issues are rapidly changing, and trained counsellors must be connected into a network that provides them with updated information.

With increased access to antiretroviral medication, an even greater effort to scale up voluntary counselling and testing is required; otherwise, there is considerable risk that counselling standards will slip further. Positive people are uniquely qualified to take on these counselling tasks.

e) Keeping Positive People Alive

All positive people need access to treatment and care. But GIPA has often failed because many positive people who have gained skills and self-esteem and started to make an impact have fallen sick and died, and a wealth of expertise has been lost.

Those who make a real impact on the epidemic should have high priority for provision of treatment. Today it is possible to keep positive people alive on triple combination antiretroviral therapy for less than US \$1 per day (excluding cost of CD4/viral load testing and diagnostics). This is within the means of the global economy, provided the will to do so is created. There is a need to lobby and persuade governments that it is in the greater economic interests of the nation to keep people who are in the most productive period of their lives alive and healthy. We must also solicit support from people in the developed world who owe their lives to free health services.

f) Outgrowing Tokenism

Developing relationships with organizations on an equal basis can be a very productive way of developing capacity, and there are instances of this starting to happen, such as the work being done by the International Federation of the Red Cross / Red Crescent.

Unfortunately, in many countries, involvement has translated into finding a positive person, attaching them to an organization and bringing them out to speak at events such as World AIDS Day. In some cases positive people are persuaded to participate in this tokenism by the offer of a small stipend, and then suffer abuse and discrimination as a consequence, often with no support or assistance from the organizations that involved them in the first place. There is a consensus that many positive people have been exploited by organizations and sometimes used as avenues for them to obtain a greater funding. Many organizations tend to create strong 'victim – saviour' dependent relationships instead of equal partnerships.

Where this kind of relationship is apparent, positive people are now becoming more empowered and are voicing their opinions that they are not prepared to be used as tokens and that they want to take ownership of their own affairs. In order for this to happen, they have to be provided with appropriate skills.

g) Building Confidence and Capacity

It is essential that positive people be provided with adequate skills and opportunities to participate fully in the response to HIV&AIDS. Many HIV-positive people are articulate and intelligent but, coming from diverse backgrounds, they often lack the necessary skills required to operate within the HIV&AIDS sector. Because people are uneducated does not necessarily mean that they are incapable of being trained usually it is a reflection of lack of opportunities in their country. Women are usually less fortunate than men in receiving a decent education yet many women are willing to speak out about HIV.

Skills training are necessary to increase people's capacity to manage their lives effectively while living positively. Positive people need skills to build networks, carry out their own research,

design and implement their own programs, and sit down with government and take part in the design of policies that will protect their rights and improve the quality of their lives.

Positive People need guidance on how to develop their organisation when they are working with people from diverse socio-economic and educational backgrounds and with diverse interests and needs. They need skills on how to communicate effectively and deal with conflict.

h) Sustainability

If GIPA is to be taken seriously, funding organisations must address the issue of core funding of positive people's organizations as opposed to just funding projects with tangible outcomes. Positive people need funding in order to operate and have enough staff to identify and respond to their needs.

i) Government Attitudes

Though GIPA is critical to ethical and effective national responses to the epidemic, governments have done little to make this principle a reality.

In how many countries are positive people involved in the National AIDS Planning? In most cases, the reality of GIPA is not being 'lived'. Many governments only pay lip service.

At the community level people lack adequate health care and provision of antiretroviral medication. Positive people need to be active on all local, provincial and national AIDS policy-making boards and committees. The Global Fund is a great opportunity for governments to allow GIPA to work, via the involvement of positive people in the Country Coordinating Mechanisms.

1. What is a Human Rights Based Approach?

A human rights-based approach is a conceptual framework for the process of human development that is normatively based on international human rights standards and operationally directed to promoting and protecting human rights.

In the rights-based approach, (RBA) every human being is recognized both as a person and as a rights holder. An RBA strives to secure the freedom, well being and dignity of all people everywhere, within the framework of essential standards and principles, duties and obligations. As earlier discussed under human rights obligations, the Government has three levels of obligations; to respect, protect and fulfil every right.

It is good to remember that rights are inherent, indivisible, interdependent and interrelated. The RBA focuses on those who are most vulnerable, excluded or discriminated against in the community. A programme guided by a human rights based approach takes a holistic view of its environment considering the family, the community, civil society, local and national authorities.

An RBA changes the situation of the beneficiary or beneficiary group from passive aid recipient to rights-holders, empowered to hold responsible actors accountable to human rights standards. It translates people's needs into rights and recognizes the human person as the active subject and claim-holder.

As opposed to needs-based or poverty-reduction approaches which are often top-down and technical, suggesting that beneficiaries of social and economic policies are passive targets without their own objectives or interests, the systematic application of human rights principles during all phases of program policy development and implementation can be empowering, transformative and locally generated.

2. RBA Approach in programming

The right based approach is used as:-

- Advocacy tool
- Guides design and implementation of programs
- Advocacy for an enabling environment to promote rights of PLWHA and affected

Examples

- Right to health-Available to all people.
- Right to equality and non-discrimination
 - Cornerstone of the UDHR 1948 is that all human beings are born free and equal in right and dignity.

- o Discrimination is prohibited on grounds of race, colour, sex, language, sexual orientation.
- Rights to privacy- No one to be subjected to arbitrary or unlawful interference with his/her privacy.
- Right to information-Everyone has a right to freedom of expression that includes the freedom to seek and receive and impart information and ideas of all kinds.
- Right to participation-Everyone has the right to active free and meaningful participation.
- The right to enjoy the benefits of scientific progress- Everyone has the right to enjoy the benefits of scientific progress and its application.
- Freedom from torture- No one to be subjected to cruel in human and degrading treatment.
- Freedom of association- Freedom of association including the right to form and join trade unions.
- Right to work- Right to work and free choice of employment.
- Right to education-Everyone has right to education directed to full development of the human personality and sense of it's dignity.
- Right to a adequate standard of living.
- Right to development - Everyone has the right to participate in contributing and enjoy economic, social cultural and political development in which all human rights and fundamental freedoms can be fully realised.

3. The Ingredients of an RBA

There are five in number and include:

- Express linkage to rights such as right to education, right to food, right to health among others.
- Participation.
- Empowerment.
- Twin Principle of Equality and non-discrimination.
- Accountability.

Remember: There exists the duty bearer and the claim holders in the rights based approach to programming. The duty bearers also include non-state actors.

The Rights based approach to programming assists civil societies to influence key policy makers to ensure reforms are undertaken.

In each situation of programming, we have to ask the questions below:-

- What is the content of the right?
- Who are the human rights claim holders?
- Who are the corresponding duty-bearers?
- Are claim-holders and duty bearers able to claim their responsibilities?
- If not how can we help them to do so?

4. RBA Application in practice

a) Expressly apply the Human Rights framework

This defines all development terms into international human rights commitment of the State- as legally enforceable entitlements on the national level.

How?

Explicitly take human rights obligations into account at every stage of the process.

- Address full spectrum of indivisible independent and interrelated rights.
- Ensure every sector of national planning reflects the human rights framework such as education, health, justice administration and political participation.

b) Empowerment:

- Ensure policies and programmes are based on empowerment not charity
- This means ensuring that people have the capacities, power and access needed to improve their own communities and influence their own lives.
- Ensure that rights holders and duty bearers share a common understanding of human rights goals and duties to respect, protect and fulfil human rights.
- This means systematic educating and raising awareness of public representatives, civil service providers and other duty bearers.

c) Participation:

- Ensure participation is active free and meaningful.
- This includes communities, civil societies, minorities' women and children.
- Mere formal consultation is not sufficient.
- Ensure that national and local development process and institutions are accessible and that informational is transparent and timely.

d) Non- discrimination and participation of vulnerable groups

- Address as a priority discrimination and protect groups that are most vulnerable.
- Ensure official data is disaggregated by gender, religion, language, sex and any other category of human rights concern.
- Ensure gender proofing is part of the wider human rights proofing of all programming.
- This assesses the implication for women and men of any planned action including policies legislation and programmes at any level.
- Pay alternations to formalization of poverty.

e) Accountability:

Apply human rights impact assessment to all plans, proposals, policies, budgets and programmes to determine progress in human rights terms.

- Identify both positive obligations of duty holders (protect, promote and provide and negative obligations to abstain from violations of the full range of relevant actors including local authorities and private companies.
- Identify claim holders and their entitlements) and corresponding duty holders (their obligations).

- Develop effective laws, policies, institutions, administrative procedures and mechanisms of redress that ensure delivery of entitlements respond to denial and violations and ensure accountability.

5. Challenges in implementation of RBA process

The challenges below have been identified:-

- Un- coordinated interventions from donors.
- Ignorance of human right values by implementers.
- Participation not seen as a human right and inadequately applied in programmes.
- Weak capacity to undertake RBA programming by implementers.
- Lack of clarity on meaning of RBA.
- Distorted public perception of human rights.
- Low public awareness of human rights and low expectation of change.
- View held that human rights need lots of money and cannot be afforded.
- Poverty not viewed as a human rights issue.

6. What difference can RBA programming make?

In a successful human rights based approach the following progress will be made.

- Human right will be integrated in all development plans.
- Standards of human rights will be applied to the most vulnerable.
- Human rights will gain legitimacy.
- Greater involvement and empowerment of vulnerable groups is guaranteed.
- Standards will be established.
- Greater impact on sustainability.
- Greater accountability on all part of the duty bearers.

In order to promote the legal framework to HIV&AIDS related human rights, it is important that the current HIV&AIDS Prevention and Control Bill (2006) pending in parliament be enacted into law.

In GIPA programming, the missing link is the understanding of and the commitment of meaningful participation of people infected and affected by HIV&AIDS. PLWHAs, ought to be included in meaningful participation in decision making processes.

The RBA will place PLWHAs and the most vulnerable at the centre of programming.

This will achieve:

- Acceptance by most PLWHAs.
- Protection and promotion of the rights of PLWHAs.
- Increase access to treatment for HIV&AIDS.
- Respect of human rights of PLWHAs.
- Activities in programmes will not discriminate or marginalize PLWHAs.
- Promote linkages of HIV and other development and governance issues.
- Will address HIV&AIDS related legal issues like testing for employment, for marriage, for insurance, issues of access to treatment, privacy and confidentiality including children rights and the criminalization of deliberate infection.

7. RBA in HIV&AIDS programming

The RBA will offer a framework that will address the underlying determinants of HIV infection care and impact. It will situate the prevention and care continuum within the centre of the responsibility of the state to protect, respect and fulfil human rights. If States observe their human rights obligations, they will achieve their HIV&AIDS related goals.

As indicated, PLWHAs and those affected face stigma and discrimination in all spheres of life. Women and children are categorized to be the most vulnerable mainly due to political, economic, social, and cultural aspects.

The current Kenya National HIV&AIDS Strategic Plan 2005/6 2009/10 has a section on effective protection of human rights aimed at safeguarding human right of the infected and affected. It stresses on the right to information, right not to be discriminated and right to treatment among others.

1. PLWHAs and Advocacy

This section of the information pack gives PLWHAs tips on how to go about advocacy work at the community level and key HIV related advocacy issues.

What is Advocacy?

There are many definitions of advocacy but we shall give only four definitions:

- The act of publicly speaking in favour or support of a cause;
- The ability to successfully influence decision-makers to act on something of mutual interest to all stakeholders to effect meaningful change or;
- A set of actions undertaken by a group of individuals or organisations acting in concert in order to gain consensus or support for introducing or changing specific laws, policies, programmes or strategies or beliefs or attitudes and practices or;
- Speaking up, drawing a community's attention to important issues and directing decision- makers towards a solution.

An advocacy campaign is usually a set of well targeted actions in support of a cause or issue. Reasons for advocacy usually are:

- Building public support and sympathy for that cause or issue
- Influencing others to support it
- Trying to influence or change legislation or policies that affect it.

Often there are two distinct strategies for conducting advocacy work. One is confrontational where direct actions such as demonstrations, work boycott, among others are used to embarrass the government or the concerned policy making body. The other strategy blends lobbying with media campaigns and is more often than not driven by the need to seek legitimacy among policy makers than to embarrass them.

2. Why Advocate in HIV&AIDS?

It should be crystal clear why PLWHAs should advocate. The purpose of advocacy should be geared towards promoting or reinforcing change in policy that touches on HIV&AIDS at the community level.

Rather than providing support directly to clients or users of services, advocacy aims at winning support from others, i.e. creating a supportive environment.

3. How to Design an Advocacy Strategy

Step One: Problem Identification

Communities in Kenya are burdened by a myriad of problems. There are important HIV&AIDS issues around which policies are needed. These include stigma and

discrimination, human rights violations, harmful socio-cultural practices such as wife inheritance, polygamy, female genital mutilation, and traditional male circumcision ceremonies, early marriages, and girl child discrimination. Other issues include use and disposal of condoms, treatment, care and support for PLWHAs and OVCs.

PLWHAs role in advocacy should be to sensitize all persons operating in the community to identify themselves with the HIV&AIDS challenges at individual, family or community levels in order to create a conducive environment for responding to the pandemic.

While identifying the challenges of the pandemic in the community there is need to pay attention to the following questions:

- Is HIV&AIDS a problem in my community?
- Since when did we realise it as a problem?
- Whose problem is it specifically?
- What has been the trend in the last so many months/years?
- If we do nothing, what is the trend likely to be in the future?
- What is the trend likely to be if we took aggressive action?
- Have we done enough?
- What is it that needs to be done?
- Who is going to do it and what are the specific roles of each one of us?
- What support have we got and from whom?
- What extra support do we need and from where?
- Who is mainly affected by age, gender, educational level, class/social status and how?
- How does HIV&AIDS affect us collectively?
- What are the key issues/areas?
- Which of these issues/problems do we need to advocate for?

Convince the public and policy makers by buying their support towards the cause that the identified issues need to be taken seriously and that social and individual responses are required to stop the pandemic.

To prioritize effectively, the issues at hand and select one or two that can be addressed. Hold an open process involving as many groups as possible likely to be involved in the campaign. This results in increased commitment to the choice by all stakeholders. It is important to note that a campaign with too many issues proves very difficult to coordinate. Nonetheless, it does not mean abandoning other issues of concern all together. Background work can continue on issues, which may be the focus of a campaign at a latter time.

Step Two: Establish Advocacy Strategy

After identifying the issues that need to be addressed come up with a mission statement, goal, objectives, tasks, a constituency and a target group.

Mission Statement

Advocacy must have a mission. The mission statement identifies and declares the ultimate goal or goals of the advocacy campaign and answers the question *what is the purpose of this campaign?* It also clarifies to those involved what the campaign hopes to achieve. A

mission statement should not be written in a hurry and should involve discussion prior to being written. The following approach may be followed to generate a mission statement.

- Identify the goal of the campaign.
- Divide the team into small teams and ask each of them to draft a mission statement.
- Reassemble the group and ask each team to read or display its draft.
- With the help of everybody identify the common ideas and language and synthesize them into a single draft.
- Circulate the draft to other stakeholders for their comments, suggestions and endorsement.
- Bring the draft back to the campaign coordinating body for final approval.

Through this process all stakeholders would not only understand the mission statement that emerges but more important their commitment to it would be ensured.

Establishing Goals, Objectives and Tasks

The mission statement establishes the main aim or ultimate goal but for it to be realised there is bound to be some immediate or short-term goals, which are stages in the attainment of the ultimate goal/main goal. To enhance the campaigns chances of success it is important to define these goals at the beginning of the campaign.

Setting Goals

As PLWHAs and other stakeholders ask yourselves what changes you would like to see in the community. From the mission statement, come up with an advocacy goal. That is, what you hope to achieve over the next planned years. The more concise the goals, the easier it will be for the campaigners to measure the areas of success and failure as well as getting a pointer on where and how to proceed. Relying on the mission statement to come up with a goal, development of indicators for measuring success or victory which must correspond, ultimately, to the main aim as set out in the mission statement.

There is always a tendency of campaigners to over estimate their capacity to influence things and to overlook such critical factors as time, the availability of human resources, material resources, infrastructure, political situation and level of awareness prevalent in the community.

For example, a reduction by 20% of silent wife inheritance practices among the Kikuyu of Nyeri district in the next five years.

The goals set should be realistic and attainable. While setting the goal ask yourselves the following questions:

- Who will participate in this campaign in helping us attain these goals?
- Who are our constituents and allies in this campaign and what role are they going to play?
- What are the resources financial and material that we as PLWHAs can mobilise to meet these goals?
- Are our goals achievable with the resources we have at our disposal?
- Who are our opponents and what resources, goodwill and time do they have?
- What are the likely problems or obstacles that we might face on the way and are they solvable? If yes, how?

Formulating Objectives

Objectives comprise specific activities to be undertaken in a given time to meet the set goals. The objectives should be SMART: Specific, Measurable, Achievable, Realistic and Time-bound. It is advisable to focus on objectives that can be realistically achieved. Succeeding first with simpler objectives gives the enthusiasm, experience and credibility to conquer more ambitious objectives.

Tasks

For each objective, there should be a corresponding task or tasks. These tasks further specify and quantify the objectives. They are indicators for success or failure of the campaign. The identified tasks would also enable the campaigners to draw up an action plan within which to carry out the campaign.

Example,

For your campaign to be successful, it requires much more than a mission statement supported by set goals, objectives and tasks. You must have a well defined and supportive constituency.

Building a Supportive Constituency

Successful advocacy is of necessity if it is built upon its ability to enlist people to think the way its initiators think and support the cause being advocated for. The more people won to advocate a cause the higher the chances of its success. But caution need to be exercised, while recruiting the constituency avoid achieving the numbers alone. There should be well worked blend of quality and quantity. You may start with a small group that understands and is committed to the task and expand gradually with well-targeted recruits.

It is important to note that successful campaigns usually result from collaborative efforts that bring together the resources, time, energy and talents of many different people and organizations. It is therefore important to strategise and bring together community members such as the local MP, civic leaders, NGOs, CBOs, youth organizations, religious institutions, schools and colleges.

Once you have established a core group of campaigners, embark on the process of recruitment of a support constituency. The following questions may guide you in recruitment:

- Who are seeing things our way?
- Who are the already converted?

If the above categories of people are readily identified, establish or re-establish links with them and explain to them elaborately the goal, strategy, tactics and potential obstacles associated with the campaign.

Other questions to ask are:

- Are there other potential partners on this issue? For example, religious groups, women groups, youth groups, teachers associations and so on.
- Are there other groups whose support might be enlisted only on specific aspects of the campaign, even if they don't lend their support on other issues?
- Are there groups in specialized areas (for example, Human Rights Organizations, Medical Practitioners, Trade Unions, among others) who might support you on this particular issue?

Once you identify these potential support areas strategize on how to reach them. After building a core constituency, put in place an expansion process. This is done through networking and coalition building. Networking is simply initiating, maintaining contact and having joint activities with individuals and organizations, which share your vision and goals. (There is an information pack on this process that you are recommended to look at)².

How to expand your base of support for advocacy programme;

- Make a list of groups and individuals who are working on similar issues.
- Make a list of other groups who may not be working on the similar issues but whom you think it is important to influence. These might include:
 - o Parliamentarians
 - o Celebrities and public figures who can add credibility to your efforts and publicise them
 - o Community leaders
 - o Wealthy individuals who can contribute funds to your campaign
 - o Religious leaders

With the list ready your next challenge is to reach those that you have listed down. Here are some of the ways to reach the listed groups.

- Include the listed groups on your mailing list so that they receive your materials.
- Invite representatives from these groups to participate in your events and activities.
- Share out the names of contact persons
- Show keen interest in all their activities.
- Keep track of what they are doing so that they can participate in their activities where your help is possible.

Other ways that may be useful in expanding your advocacy support base include using local events like football matches, wedding ceremonies, chiefs barazas among others to distribute information, posting information about campaign in public places and informing people about the ways they can help, sending educational materials to the media and inviting media people to events organised by the campaign.

Step Three: Identify and Target the Audiences

With clearly defined mission statement, goal and objectives, potential supporters and detractors decide on the message and how to frame the issue. To guide you in this process you must decide on:

- The target audience.
- Spokes person.
- Vehicles for disseminating information.

² *Networking Guide for NGOs, CBOs and Religious Institutions*

Targeting Audiences and Goals

There are two types of audiences that you should always put into consideration. The *Targets* and the *Influential*. The primary audience (targets) includes decision-makers with the authority to directly affect the outcome of an objective while the secondary audience (influential) is the individual or groups that can influence decision-makers (primary audience).

Since resources devoted to an advocacy process are limited, target the people who have the greatest capacity to respond and bring about the changes you are seeking for. This is called an **audience-centred approach**. You must decide what goal you are achieving by reaching a particular audience.

Different audiences require different strategies. For example, if the target audience is policymakers, then direct lobbying may bear more fruits than other strategy. To reach the general public, care should be taken not to lump all members of the general public together however, use of educational materials; publications and/or the media might be more appropriate. It is also important to note that within each target group there are important sub groups, which you cannot afford to ignore. For example, if women are picked as a target group, there are sub groups as teenage girls, single mothers, widows, and businesswomen. The kind of audience one seeks to address will determine the packaging of the message. The more advocates narrow down their audience, the more effective the message will be in reaching the audience.

The following are the major target audiences that you may need to target in your advocacy work.

- The Government
- Multi-lateral and bi-lateral development partners
- The private sector and industrialists
- The NGOs
- People Living with HIV&AIDS
- Religious institutions
- The community in general

Packaging the Message

The issue selected for advocacy is probably well understood by PLWHAs or other people involved in organizing the campaign. It is therefore important to brief the general public and /or policy makers on the issue and goals of the campaign.

Think of a message equivalent of the headline of a newspaper article – it's designed to grab the reader.

An advocacy campaign relies on clearly understood, short and catchy messages. Refine the message to identify the core of the issue and find ways to express it so that people will get the idea and remember it. At the same time the message cannot be so superficial that it loses any meaning. Instead the message should include the reason for the campaign, the issue or problem

AIDS kills is such a message; a reader can say **Yes, I know, but so what!**

being addressed by the campaign, reasons why the problem exists, reference to earlier efforts to deal with the issue, the solutions being offered by the campaign, 2 –3 recommendations, mention of endorsement by known figures, a direct appeal for people to be involved.

When designing a campaign message the following can be important:

- Identity your specific target audiences and package your message to address that constituency. The language you use should be appealing to your target. For example, language for teenagers is definitely different from that used to address parents.
- Personal experiences and stories appeal to people better than dry facts. Collect examples or personal stories that illustrate the message or issue.
- Quotable quotes from well-known individuals and experts associated with campaign issues should also be used provided permission is obtained for their use.
- Facts and back up information is important in substantiating the message.
- Stress the positive values and de-emphasize the negative
- Use values that are morally and culturally acceptable to your target audience.
- For every good thing you advocate, be sure to remind people of your opponent's opposition to it.
- Your message should be simple and clear. Use every word and images and don't veer away from the issue you are addressing. Repeat this message in all your materials. The more it is repeated the more likely it is to be heard or read.
- Start with your most important point. Background information can be covered elsewhere.

Spokespersons

Not everyone involved in the advocacy campaign should speak publicly for the effort. One-person or a few must be designated as spokespersons. The people, who are chosen, as spokesperson must be articulate, be able to communicate the message as candid as possible.

People who are well known, people with public credibility for example, lawyers, clergy, human rights activists, civic leaders or legislators and or people who are energetic and enthusiastic about the cause of the campaign and are capable of reaching others through their personality or status make the best spokespersons.

For effective lobbying, there are a number of communication channels available. These include telephone conversation, a letter to the policymakers, or a personal meeting. You could also hold periodic briefings for policymakers and other stakeholders. Briefing enables policymakers to learn about the issues, get latest data on the issue and ask questions about aspects they don't understand.

Step Four: Maintaining the Momentum

In short campaigns (several days to several weeks), the momentum will exist. People will remain enthusiastic and commitment will remain high. However, in longer campaigns, momentum may become a problem especially where advocacy is new to people, as their expectations for quick achievements of goals are likely to be high. The campaign should build in events and activities, which will maintain people's commitment. These could be through newsletters, bringing in celebrities and known experts to generate attention.

Step Five: Recovering from Set Backs

There is likely to be opposition to the campaign or the issue at hand requiring an action to defuse the opposition. In such an event get allies within the organizations likely to oppose the campaign and use them to moderate the opposition.

There will also be periods in campaign when things don't go right, when plans are upset by unexpected events. Set backs of this nature are likely to turn up as short-term crises. Anticipated set backs make it easier to eventually get back on course. It may be a crises but approaching it in a problem-solving mode makes a response easier and appear more routine. A crisis in some cases may lead to burn out among constituents and other unforeseen obstacles. With this kind of scenario as campaign leaders re-look at the strategy to see if it needs to be revised or complemented.

For example, the withdrawal of supporting organization from the campaign, refusal of authorities to provide a permit for an event, policy makers speaking against the campaign issue.

Due to stigma and discrimination associated with HIV&AIDS, inadequate experience and skills in advocacy, set backs may arise occasionally. Usually counter this kind of discouragement by holding open discussions, which permit an airing of the frustrations and confusions, and contribute to a problem-solving atmosphere. Recovery from set backs can add new momentum to a campaign, give new life to advocates at the same time brining new ideas to the process.

Step Six: Celebrating Success

Achievement of the goal(s) of the campaign is a definite success and calls for celebration by all concerned. Celebration is a form of self-congratulation; a recognition that the efforts of each person involved made a difference and is being acknowledged by others.

It is also appropriate to celebrate incremental successes. This includes congratulating others who have helped organise event, prepared latest posters/newsletters, appeared on a radio/ TV talk show will help maintain morale and group coherence. Also, an occasional celebration is a way to recognize that the campaign is a process that is spread out over time. Finally, celebration is a period of fun as campaign itself is serious; those involved can take time to enjoy their efforts and company.

3. HIV Related Advocacy Issues

a) Advocating against denial, stigma and discrimination

Given the close links between HIV&AIDS related stigma, discrimination and human rights violations, multiple interventions are needed. Action must be taken to:

- Prevent stigma and to challenge discrimination when it occurs,
- Monitor and redress human rights violations.

HIV&AIDS-related stigma and discrimination will only be reduced if it is challenged simultaneously on several fronts:

- Inside communities, where media-based efforts can be directed at public opinion to improve the environment of people living with HIV&AIDS;

- In settings such as workplaces, hospitals and clinics, places of worship and education establishments, where equitable policies and educational programmes can counter stigma, discrimination and human rights violations;
- In the courts, where people can invoke legal rights and duties in order to promote and protect the human rights of people living with HIV&AIDS.

b) People living with, or affected by, HIV&AIDS

- Some of the most powerful efforts to curb HIV&AIDS-related stigma and discrimination are driven by the involvement of people living with, or affected by HIV&AIDS.
- Organisations and campaigns have been formed that mobilize action against the epidemic and that pressure leaders to tackle the epidemic with resolve. Examples abound—from programmes for leadership training, to media and advocacy activities in newspapers and TV programmes, organized by organisations working in HIV&AIDS.

The community-centred approach for example, can prompt leaders such as chiefs, councillors and MPs to lead by example and take an HIV test, successfully mobilizing community members into following their lead. It would be important for leaders to decree against widow inheritances and other practices that discriminate against women and girls, leaving them more vulnerable to HIV infection.

c) Workplace

While some companies still prefer to shift the HIV&AIDS burden elsewhere; by demanding pre-employment HIV screening, reducing or removing medical benefits for HIV-positive workers or even firing them; an increasing number of businesses are now implementing workplace prevention and care programmes.

d) Putting the law against stigma and discrimination

The law can be a powerful tool against stigma and discrimination. For example:

- The Philippines' [HIV&AIDS Control and Prevention Act](#) remains an example of how legislation with strong provisions for protecting people living with HIV&AIDS can serve as a useful instrument for combating HIV-related discrimination.
- Such legislative and supportive policy environments can help empower communities to tackle stigma, discrimination and human rights violations more effectively.
- Venezuela's [Acción Ciudadana Contra el Sida](#) (Citizens' Action against AIDS), has, since the late 1980s, been fighting human rights violations against persons living with HIV&AIDS. It provides:
 - o Free legal advice.
 - o Acts in cases and handles legal appeals regarding discrimination in employment, medical practice, and social services.
 - o Enabled extension of the scope of a treatment-and-care programme and it was instrumental in obtaining antiretroviral and other treatment.

e) HIV and gender

It is important for organisations always to bear in mind the way in which gender roles have a part to play in the AIDS crisis:

- The sexual subordination of women makes it much more difficult for them to avoid infection.

- Biologically young women are more prone to infection and their low social status and cultural expectations of sexuality further compound their vulnerability.
- Men are part of the solution to the HIV pandemic, and men need to understand how their actions contribute to the spread of HIV&AIDS.
- Men need to play an active role in promoting their own health as well as protecting their partners from the HIV infection, and advocacy can reinforce this process.
- Advocacy initiatives that target young boys are increasingly being seen as valuable in promoting more gender-equitable relationships between men and women.
- Another important dimension of gender and HIV&AIDS is that of gender-based violence and discrimination against women and girls. This makes them vulnerable and unable to negotiate safer sex. Sexual violence and coercive sex, (which often carries a high risk of infection) must also be addressed.

Studies confirm that women who disclose their HIV positive status often face further violence and discrimination. Advocacy initiatives should focus on eliminating all forms of violence against women and on campaigning to change laws and make them appropriate.

Advocacy for gender-sensitive programming will help identify the differential needs of men and women, boys and girls.

Advocacy aims at empowering women and giving them more negotiating skills as an important tool for combating HIV&AIDS as well as for the promotion of women's rights.

Specifically, advocacy aim at improving women's access to education and to economic resources, such as training, legal reform and credit schemes, can contribute to women's overall decision-making power within households and in sexual relationships.

f) Involving people with HIV&AIDS

Involving people with HIV&AIDS in policy design, planning and the implementation of AIDS-related work is itself an important aspect of advocacy. This will:

- Increase the relevance of advocacy in reducing stigma and discrimination.
- Help the needs of people with HIV or AIDS to be recognized.
- Assist in the process of destigmatising HIV&AIDS.
- Enable a greater understanding of the impact of HIV&AIDS.
- Present a human face to AIDS.

People living with HIV&AIDS have a key role to play in education and prevention. Discrimination against such people is widespread, and involving them is a vital element in changing attitudes.

g) HIV testing

Organisations should advocate availability and accessibility of good-quality, voluntary and confidential HIV testing and counselling and discourage mandatory testing.

h) Microbicides and Vaccines

Eradication of HIV&AIDS is likely to be hastened by the development of effective vaccines against HIV and efficient microbicides able to better protect against STIs and HIV transmission. NGOs should advocate for their governments to support the necessary research and development.

i) Parent-to-child transmission of HIV

Parent-to-child transmission of HIV is the most significant source of HIV infection in children below the age of 10 years. Since 1998, UNAIDS has recommended that pregnant women who are HIV-positive should be offered a short antiretroviral course which has been shown to reduce transmission by at least 50 per cent when used properly. CSOs should therefore advocate for the government to integrate such prevention interventions into existing reproductive health services.

j) Promoting condoms

Promotion of male and female condom for dual protection against STIs, HIV&AIDS and unwanted pregnancy. The condom is one of the available options of preventing the spread of the pandemic. While both male and female condoms are good at preventing HIV and STI transmissions, there are limits to their wide use. These include:

- Cost and availability.
- Belief that it should only be used to prevent pregnancy.
- Failure by service providers to promote the condom as an effective method of contraception.
- Reliance on non-barrier methods of contraception.
- Condom use by married partners is often not socially acceptable.
- Religious opposition to its use – generally, or among the unmarried.
- Condom campaigns can have spectacular results. Thailand's 100% condom campaign has averted 2 million infections, saving some \$US 6 billion.

k) The female condom

The female condom is the first contraceptive barrier controlled by women that also protects against STIs, including HIV. It therefore expands the choices that both men and women have to protect themselves from HIV infection. The female condom is particularly important to women whose partners refuse to use the male condom. However, the condom may initially meet opposition from both users (because it is unfamiliar) expensive and not readily available. Advocacy can play an important role both in making the female condom more widely available (through convincing providers that it is cost-effective), and in increasing its acceptability.

Most of the challenges facing the use of male and female condoms could be addressed through:

- Peer education among women and men.
- The promotion of high-quality condoms and water based lubricants, and ensuring their continuing availability.
- Safer sex campaigns and skills training, including the use of condoms and promotion of lower-risk sexual practices as alternatives to penetrative sex.
- Strengthening organisations of self-identified gay men, enabling them to promote HIV prevention and care programmes.
- Promoting culturally appropriate mass media campaigns.
- Education among health and clinic staff to overcome ignorance and prejudices about CSW, MSM.

Conclusion

The wide-spread abuse of human rights and fundamental freedoms associated with HIV&AIDS has emerged globally in the wake of the pandemic. Hence human rights approach as reflected in this information pack emphasizes the claims or entitlements that all people including people living with HIV&AIDS and the affected have to a full and satisfying life, in which each person is able to develop to her or his full human potential. Importantly, the document has shown that human rights set standards for human well being and development, and constitute important means for their achievements.

The gender approach to HIV&AIDS and human rights as contained in this document should ensure that the experience of women and men infected and affected by HIV&AIDS is reflected in the interpretation and application of human rights in all spheres of life. The greater participation of PLWHAs in human rights advocacy would help mitigate stigma and discrimination as it changes the way PLWHAs are viewed, offering an image that shows they have the capacity, ability and knowledge.

An environment in which human rights are respected ensures that vulnerability to HIV&AIDS is reduced, those infected and affected by HIV&AIDS live a life of dignity without discrimination and the personal and societal impact of HIV infection is alleviated. Respect of human rights also require that these rights are protected and fulfilled at all levels in the family, community, workplace and State, thus affirming democratic principles of accountability and participation.

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