SECTION III

GENDER AND HIV/AIDS: A HUMAN RIGHTS APPROACH

INTRODUCTION

i. THE MODULE – AN OVERVIEW

This module is designed as a two-day workshop tailored to the needs of representatives of non-governmental organisations, government ministries, and training organisations. It is tailored for those working on influencing policy and decision making, rather than for grass root level workers. The workshop will be of special significance for media personnel to enhance their analytical and reporting skills by providing empirical evidence to strengthen anecdotal writing.

ii. OBJECTIVES

- **To understand the complex dimensions of the challenges being posed by HIV/AIDS within a gender responsive human rights framework.**
- **To develop suitable responses to these challenges adopting a human rights approach with a gender lens.**

iii. PARTICIPANTS

The workshop could be global, national or regional. The people who participate in the training could include:

- Representatives of key training institutions from various countries.
- Media representatives from mainstream dailies of the countries represented.
- Representatives of non-governmental organisations and government ministries who are decision-makers and can influence policy.

iv. BACKGROUND READING MATERIAL[71]

The following reading material provides helpful background information.

Ainsworth, Martha & Amie Batsonand, & Sandra Rosenhouse. Accelerating an AIDS Vaccine for Developing Countries: Issues and Options for the World Bank (July 1999), prepared by the AIDS Vaccine Task Force of the World Bank.

Jayasuriya, D.C. World-wide Restrictions Placed upon People with HIV/AIDS (1992), Medical Virology Vol.2, 191 – 194

[71] For information on attaining copies of the materials please contact the Gender and HIV/AIDS Adviser at UNIFEM, 304 E. 45th Street, 15th floor, New York, NY 10017.

Gomez Adriana & Deborah Meacham. Women's Vulnerability and HIV/AIDS – A Human Rights Perspective (1998). LACWHN (Latin American & Caribbean Women's Health Network).

UNAIDS. "Guide to the United Nations Human Rights Machinery", (1997), UNAIDS.

UNDP. "HIV, Ethics, Law, and Human Rights", (December 1997), UNDP

United Nations Population Division – Dept. of Economics & Social Affairs. "World Abortion Policies", (1999), United Nations (DESA).

"Women in Law and Development in Africa (WILDAF): A Snapshot of the Current Status of Women's Health in Africa", Information Packet for the 43rd Session of the Committee on the Status of Women.

AGENDA

Day 1

9:30 – 10:00am	Welcome and Introduction
10:00 – 11:00am	**Session 1** Gender and HIV/AIDS – The Status of the Epidemic
11:00 – 11:45am	**Session 2** He has HIV/ She has HIV – An Analysis Within the Human Rights Framework
11:45 – 12:00pm	Tea Break
12:00 – 1:00pm	**Session 3** The Right to Good Health – Exploring the Normative
1:00 – 2:00pm	Lunch
2:00 – 3:00pm	**Session 4** Viewing the Reality
3:00 – 3:15pm	Tea Break
3:15 – 5:00pm	**Session 5** Viewing the Reality continued

Day 2

9:30 – 10:00am	Recapitulation
10:00 – 11:30am	**Session 1** The Critical Imperatives Facing Men and Women – Ethical Debates
11:30 – 11:45am	Tea Break
11:45 – 1:00pm	**Session 2** Critical Imperatives continued
1:00 – 2:00pm	Lunch

2:00 – 3:30pm	**Session 3** The Impact on National Development Planning – Building the Rationale for the Human Rights Approach to the Epidemic
3:30 – 3:45pm	Tea Break
3:45 – 4:30pm	**Session 4** Future Directions
4:30 – 5:00pm	**Session 5** Evaluation and Closing

SESSION 1

Introduction and Expectation Setting

i. Objective

To create an environment conducive to learning and to generate positive group dynamics during the process of the workshop.

ii. Time

30 minutes

iii. Materials/Equipment

1. Personal data forms
2. Polaroid camera
3. Overhead projector
4. Transparency 1 – Objectives of the Workshop
5. Flip chart

iv. Methodology

1. Short lecture
2. Participants introduce themselves through filling out biographical forms.

v. Steps

1. The facilitator distributes the personal data forms to each of the participants when he/she arrives the evening before the workshop or as he/she enters the training room before the workshop opening. A polaroid picture of each participant is taken to paste on the form or if no polaroid is available each participant is asked to bring a photo of themselves such as a visa photo with them.
2. The completed personal data forms are pinned up on a bulletin board or wall the next morning at the venue of the training session, or in the tea break.
3. The facilitator opens the workshop by introducing herself/himself to the participants and welcoming them.
4. A senior national policy maker who has been invited as the guest of honour is then asked to inaugurate the session. The official should be encouraged to limit his/her words to a maximum of 10 minutes. Such an official will help obtain the necessary political commitment from the national government to help implement recommendations of the workshop and ensure sustainability of the programme.
5. The participants introduce themselves, giving their name, country, institution and one expectation for the workshop. The facilitator records these on a flip chart.

6. The Facilitator points out any expectations that are outside the scope of the workshop and aligns the rest with the objectives of the workshop, which are shown on Transparency 1.

Notes for the Facilitator Session 1

- In the event that the participants arrive to attend the workshop a day early, the evening before can be used for filling in personal data forms. It is also a good way for participants to meet and get to know each other informally.
- It is important to understand the value of aligning the expectations of the participants and the objectives of the training. This is done to avoid the frustration that may arise if an expectation is not met.

Transparency 1

OBJECTIVES OF THE WORKSHOP

- To understand the complex dimensions of the challenges being posed by HIV/AIDS within a gender-responsive human rights framework.

- To develop suitable responses to these challenges adopting a human rights approach with a gender lens.

Personal Data Form

Photo goes here

Name _____

Country _____

Title/type of work _____

Organisation _____

If you could give only one piece of advice to a teenager close to you (male or female) on how to prevent HIV/AIDS, what would you tell him/her?

_____
_____
_____
_____
_____

What is your experience in working on issues related to gender, HIV/AIDS, and/or human rights?

_____
_____
_____
_____
_____

How many years have you worked on:

Gender _____ **HIV/AIDS** _____ **Human Rights** _____

SESSION 2

Gender and HIV/AIDS – The Status of the Epidemic

i. Objective

To enhance the understanding of the gender related socio-economic causes and consequences of the epidemic.

ii. Time

1 hour

iii. Methodology

Dissonance generating questionnaire (questionnaires are found on pages 28-35) used to promote strategic questioning. It leads to self-evaluation regarding one's knowledge and feelings raised in response to the data presented. It also provides an opportunity an examination of the participant's values and perceptions relating to the gender construction of sexuality.

iv. Steps

1. The facilitator distributes the questionnaire and asks the participants to go through the questionnaire and select their answers (10 minutes).
2. The facilitator goes through the questionnaire, question by question reading out the correct answers at plenary.
3. The facilitator uses this process to generate discussion on the gender dimensions of the epidemic. A number of related questions are asked by the facilitator (refer to "Questionnaire Tips and Answers".)
4. The facilitator uses the questionnaire to bring out the comparisons in the data at the global, national, and regional levels (refer to "Questionnaire Tips and Answers".) Information could be provided to the participants by quoting from and referring to the UNAIDS country fact sheets available on the internet at www.unaids.org.
5. The facilitator asks the participants to explore and share their feelings at the end of the exercise. The participants might voice a range of feelings such as anger, indignation, despondency, inadequacy, hurt, determination to go forward, and motivation. The facilitator records each emotion on a flip chart as it is expressed.
6. The facilitator goes through the second part of the questionnaire that contains nine statements that bring out the gender construction of sexuality. The statements are taken up one at a time at plenary and the participants are asked whether they agree or disagree with the statement (refer to "Questionnaire Tips and Answers".)
7. The facilitator sums up the data at the end of the discussion by putting up Transparency 2 (page 36, Section II).

Notes for the Facilitator Session 2

- The facilitator reassures the participants that this exercise is not an exam or any effort to assess the knowledge of the participants.
- The facilitator keeps the focus of the discussion on "feelings" and not on the analysis of the data from the questionnaire. This helps link the cognitive to the emotional and sets the stage for the generation of the motivation and emotional commitment necessary to enhance learning.
- Synthesising the wide discussion the questionnaire and the agree/disagree statements generate into four main points is useful. The main points are in bold in the "Questionnaire Tips and Answers" box.
- Internalisation of the speaker's notes provided at the end of Session 2, Section II (pages 37-42) and familiarity with the status of the epidemic in the country in which the workshop is being conducted, is a prerequisite for the successful outcome of this exercise.

Questionnaire Tips and Answers

v) Prevalence – a Gender Analysis

The facilitator should bring out the gender dimensions of the epidemic by posing relevant questions while reading out the answers to the questionnaire. Furthermore, the facilitator should compare data at the regional, national, and global levels. For example:

- After answering question one the facilitator poses the following question: "What is the percentage of women affected with HIV/AIDS in your country?"
- After answering question five the facilitator poses the following question: "What is the percentage of pregnant women testing positive in your country?"
- After answering questions one through four the facilitator poses the following question: "Why do you think more and more women are becoming infected?"
- After answering question six the following question could be asked, "Why do you think that more housewives than sex workers are being recorded with new infections as the epidemic is maturing?"
- **It is important to note that questions one through four and question seven confirm that more women are becoming infected and at lower age groups.**

vi) Causes – a Gender Analysis

- After questions four through ten the facilitator poses the following question, "Is the situation similar in your country?"
- **Note that questions four through eight verify that behaviour change is an important element in preventing and minimising the spread of the epidemic.**
- **Questions eight through ten show how age is a key variable in the incidence of HIV.**

vii) Consequences – a Gender Analysis

- **Note that questions five through seven address the socio-economic impact of HIV/AIDS and the feminisation of poverty.**

viii) Agree/Disagree

- These statements bring out the gender construction of sexuality.
- The statements are taken up by the facilitator at plenary. Sharing examples specific to the country in which the workshop is being conducted enriches the discussion.
- After statement seven the facilitator poses the following questions, "What is the word used for vagina in your country? Is it socially acceptable?"
- After statement eight the facilitator poses the following question, "Give an example of a socio-cultural norm that is an impediment to preventing the spread of the epidemic?"
- Examples to draw on are contained in the attached paper, "Myths and Rituals."

SESSION 3

He has HIV/She has HIV – An Analysis within the Human Rights Framework

i. Objective

To highlight the gender based discrimination affecting people living with HIV/AIDS.

ii. Time

45 minutes

iii. Materials/Equipment

1. The paper entitled "He has HIV and She has HIV", which presents real life situations of men and women living with HIV/AIDS.
2. Transparency 2 – Human Rights Abuses

iv. Methodology

Role-play and group work

v. Steps

1. The facilitator divides the participants into three or four groups and distributes the paper entitled: "He has HIV/ She has HIV." The participants are asked to read the paper and enact a role-play depicting the scenario presented. They should be encouraged to use the given scenarios as a guide, and use their own experiences/imaginations in developing the role-plays. They are given 15 minutes to plan their performance.
2. The facilitator invites each group to perform their role-play at plenary, allocating five minutes to each group. The role-playing brings out the discrimination and the stigma faced by the women quite starkly.
3. The facilitator sums up areas of gender based discrimination in the lives of people living with HIV/AIDS linking up the role-play to the information in Transparency 2.
4. When all the role-plays have been enacted, the facilitator asks the actors what feelings emerged during the acting of the role-plays.

Note for the Facilitator Session 3

The role-play helps personalise the issues relating to the gender based discrimination faced by the people living with HIV/AIDS. It reinforces the learning generated through the dissonance-generating questionnaire. It sets the stage for moving into the next session which delves into the normative framework relating to the "Right to Good Health."

He has HIV/She has HIV

	He has HIV	**She has HIV**
The Doctor breaks the news	You have tested positive for HIV. This is a terminal illness. Be careful about your health.	You have tested positive for HIV. This is a terminal illness. Make sure that you do not conceive as it will transmit to your child and you will be the one to blame for the misery which the child will suffer. If you are pregnant, it is imperative that you abort the child as early as possible.
Notifying their respective spouses	You should not fall sick. I will be by your side. Your service is my honour.	You woman with a large vagina. You must be sleeping with someone else. You're a curse to my life. You need not stay here at all. Find a place for yourself.
The family learns of their HIV positive status	You have brought us shame. It is better that we keep the family's honour by dissociating ourselves from you. Please leave the house. Take your wife and children with you.	We did not know that we were sheltering a whore in this household. Leave the children here and before the sun rises tomorrow we do not want to see you here. Even your shadow is doomed for us. She leaves alone.
The community learns about their HIV positive status	It is unfortunate that this has happened to him. After all men will be men. They do go around sometimes but such misfortune does not strike everybody. It is his destiny. In any case a bull is not a bull without scars.	The kind of activities she has indulged in, she has got away lightly by just being thrown out. In our times she would have been branded so as to be a lesson for other girls to keep away from base activities.
The employer learns about their employees' HIV positive status	None of those interviewed had revealed their husbands' sero-status to their employers.	Prior to receiving their HIV status, none of the women had held jobs. Upon learning of their status and being kicked out of their homes the women have looked for work with little success. There is a deep fear of rejection.
The individuals begin getting opportunistic infections	His wife has provided the medical staff with extra money and favours in order for her husband to be seen by	The woman is made to wait by the clerical staff, the nurses, and the doctor.

	the doctor. The doctor refuses knowledge of patients' HIV status.	
The need for medical treatment arises	The family uses all of their savings and his wife seeks additional work to pay for the medications. She eats less and cuts down the nutrition of her children in order to be able to provide medicines for her husband. **OR** If they are living in an agricultural subsistence economy in rural India the burden of care for the husband leaves very little time for the wife to work in the fields. She grows tuber instead of wheat or rice which is less labour intensive and the produce is inadequate to nourish either her or the children.	The need for medicine remains unfulfilled. The issue of survival looms large – food and shelter are more critical than medical care. **OR** If she lives in an agricultural subsistence economy, her marginal land is lying fallow and she is waiting for a show of sympathy by the members of the community to save herself and her children from death.
The inevitable happens – death	The woman is left alone hearing the inevitable from all quarters – "she will also die soon". The burden of childcare and their survival lingers on… There is a very bleak chance that she will ever remarry – perhaps another man with HIV. The question that arises is will she want to go through it all again.	The children wail. More orphans join the children of the street.

Women will continue to live with the burden of the epidemic and die of the burden of the epidemic unless enabling environments are created and stereotypes related to gender and sexuality are broken down with accurate and appropriate information to people. (Adapted from discussions with poverty stricken women in India some of them living with HIV/AIDS.)

Transparency 2

HUMAN RIGHTS ABUSES – HE HAS HIV / SHE HAS HIV

HUMAN RIGHTS	MANIFESTATIONS OF ABUSE
Right to information	*No information provided on:* ➢ *Abortion* ➢ *Mother to Child Transmission*
Right to dignity	*Abusive language*
Right to equality	*Attitude of community*
Right to employment	*Loss of paid work on disclosure of disease*
Right to property	*No access to housing if thrown out by the husband*
Right to marriage and family life	*Isolated by the family*

SESSION 4

Right to Good Health – Exploring the Normative

i. Objective

To create an understanding of the need to adopt a rights-based approach to development.

ii. Time

1 hour

iii. Materials/Equipment

1. Two sets of colour coded cards.
2. Pens
3. Flip Chart/markers
4. Overhead projector
5. Transparencies:
    - 3 – Developmental flow chart
    - 4 – Backlogs of development
    - 5 – Development Facts
    - 6 – Human Rights Instruments
    - 7 – Rights
    - 8 – Frameworks established by International Instruments

iv. Methodology

Group work

v. Steps

1. The facilitator hands out two sets of colour coded cards to the participants and asks them to write on a specified card one incident from their lives where they successfully raised issues that upheld their fundamental rights. On the other card they are requested to write down the feelings they experienced as they struggled for their fundamental rights.
2. The facilitator divides the participants into four groups and asks them to identify a group leader to guide the group discussion.
3. The facilitator asks the group to discuss the different incidents and to choose one to present to plenary. Each group makes a presentation at plenary.
4. The facilitator writes down on a flip chart all the feelings expressed by the presenters as they relate the incident. These range from elatedness, righteousness, happiness, victory, empowerment, confidence, etc.

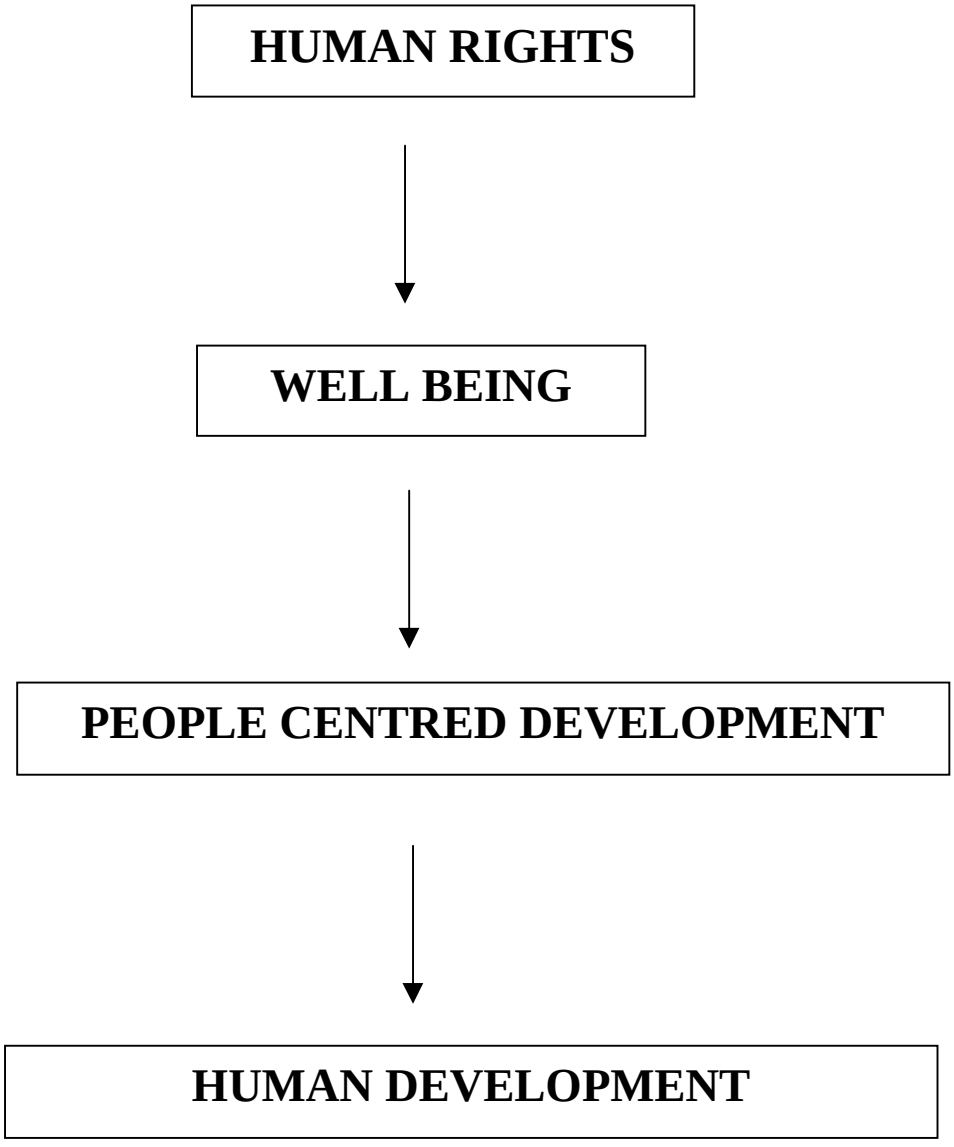
5. The facilitator initiates a discussion linking up the feelings to the fact that such feelings are essential to achieve a sense of well being and security. He/she brings out the link between a state of well being, the upholding of human rights and a people's oriented human development approach using Transparency 3.
6. The facilitator explains the pitfalls of not following a people's centred development approach by drawing attention of the participants to the backlogs of development, which are a consequence of deprivation and inequality using Transparencies 4 & 5.
7. The facilitator brings the attention of the participants to the urgent need of supporting human development by recognising the human rights of individuals as entitlements as had been guaranteed by various international human rights instruments using Transparencies 6,7, & 8.

Notes to the facilitator Session 4

- While talking about the peoples' centred approach to development refer to some examples from the Human Development Report of 1990. This report indicates that countries with high per capita income but low human development have been ranked lower on the HDI as opposed to countries with low per capita but high human development (e.g. Sri Lanka vs. Saudi Arabia, according to the UNDP Human Development Report, 1990, Sri Lanka has been recorded with a family per capita income of $400 but with high indicators of human development, a 77 percent adult literacy rate and a life expectancy of 78 years. Saudi Arabia on the other hand has been recorded as a country having a high per capita income of $6250 but low human development indicators with an adult literacy rate at 51 percent and life expectancy at 54 years.) The posers that therefore arise are:
    - Development – for whom?
    - Development – how?
- For discussion read the attached notes titled "Exploring the Normative"
- Transparencies three through eight attached.

Transparency 3

DEVELOPMENT FLOW CHART



Transparency 4

BACKLOGS OF DEVELOPMENT

- **Over a billion people are deprived of basic consumption needs.**

- **Of the 4.4 billion people in developing countries, nearly three-fifths lack basic sanitation.**

- **Almost one-third have no access to modern health services.**

- **One-fifth of children do not attend school beyond fifth grade.**

- **The diet of about one-fifth of the world's population is deficient in calories and protein.**

- **Micronutrient deficiencies are even more widespread. World-wide two billion people are anaemic, including 55 million in industrial countries.**

Source: HDR - 1998

Transparency 5

DEVELOPMENT FACTS

THE RICHEST FIFTH:

- **Consume 45 percent of all meat and fish. The poorest fifth 5 percent.**

- **Consume 58 percent of total energy. The poorest fifth less than 4 percent.**

- **Have 74 percent of all telephone lines. The poorest fifth 1.5 percent.**

- **Consume 84 percent of all paper. The poorest fifth 1.1 percent.**

- **Own 87 percent of the world's vehicle fleet. The poorest fifth less than 1 percent.**

Source: HDR - 1998

Transparency 6

HUMAN RIGHTS INSTRUMENTS

Human rights have been reinforced by international instruments including:

- The International Covenant on Civil and Political Rights
- The Convention on the Rights of the Child
- The Convention on the Elimination of All Forms of Discrimination against Women (CEDAW)
- The African Charter of Human and Peoples' Rights
- The European Convention on Human Rights

Transparency 7

RIGHTS

- **The right to dignity**
- **The right to work**
- **The right to education**
- **The right to social security and services**
- **The right to equality – equal protection before the law**
- **The right to marriage and family life**
- **The right to health**

Transparency 8

THE FRAMEWORK ESTABLISHED BY THESE INTERNATIONAL INSTRUMENTS HAVE GUIDED:

- Law making at the country level
- Evolution of objectives and agreed conclusions in international conferences e.g. the Cairo Program of Action: the Beijing Platform for Action; resolutions of the Commission on the Status of Women, etc.
- Development of international guidelines that emerge from bilateral/multilateral consultations at the regional and global levels.

Speaking points for the facilitator Session 4

Exploring the Normative

The International Conference on Primary Health Care which ended on 12 September 1978 in Alma–Ata, Kazakhistan, concluded with the famous declaration that health is a fundamental human right and that the attainment of the highest possible level of health for all is a most important world-wide social goal. This realisation requires the action of many other social and economic sectors in addition to the health sector. It affirms the urgency of bringing health care as close as possible to where people live and work and at affordable cost, providing promotive, preventive, curative, and rehabilitative services.

Now, over twenty years after the Alma Ata Declaration where do we stand? The poorest twenty percent of the world's population have been left out of mainstream development. The 1998 UNDP report states that over a billion people are deprived of basic consumption needs. Of the 4.4 billion people living in developing countries: nearly three-fifth lack basic sanitation, almost one-third have no access to clean water, a quarter do not have adequate housing, a fifth have no access to modern health services, a fifth of children do not attend school to grade five, and about a fifth do not have enough dietary energy and protein. World-wide, two billion people are anaemic, including 55 million in industrial countries.
The richest fifth:

- Consume forty five percent of all meat and fish, the poorest fifth five percent.
- Consume fifty eight percent of total energy, the poorest fifth less than four percent.
- Have seventy four percent of all telephone lines, the poorest fifth one and a half percent.
- Consume eighty four percent of all paper, the poorest fifth one and one tenth percent.
- Own eight seven percent of the world's vehicle fleet, the poorest fifth less than one percent.

Despite of these imperatives discrepancies still remain. Why do these discrepancies remain? They remain because the development paradigm has not been properly understood. The paradigm focussed on economic growth and not on a people-centred development pattern. The approach used was supply oriented and not people focussed or demand and need oriented. We seldom stopped and asked ourselves some very basic yet key questions:

- Development – Why?
- Development – For whom?
- Development – How?

A people-centred approach needs to incorporate a human rights approach, wherein the indicators of development are viewed as entitlements. This approach has an inbuilt mode of accountability – accountability of the decision-makers and of those wielding power and influence to those whose lives are to be influenced and affected.

Conceptually and in principle the need for this kind of governance was recognised five decades ago when the United Nations drafted and approved the Universal Declaration of

Human Rights in 1948. This declaration has been recognised as the Magna Carta of human rights all over the world. The basic tenets of this declaration are:

- The right to liberty security and freedom of movement
- The right to dignity
- The right to work
- The right to education
- The right to social security and services
- The right to equality – equal protection before the law
- The right to marriage and family life.
- The right to health

These rights have been further reinforced by subsequent international instruments, including:

- The International Covenant on Civil and Political Rights
- The Convention on the Rights of the Child
- The Convention on the Elimination of All Forms of Discrimination against Women
- The African Charter of Human and People's Rights
- The European Convention on Human Rights

It needs to be mentioned here that these human rights codes by themselves cannot provide adequate protection of individual rights but equally it would be wrong to dismiss them as entirely ineffective. The framework established by these international instruments have guided:

- Law making at the country level
- Evolution of objectives and agreed conclusions in international conferences (e.g. The Cairo Program of Action of the International Conference on Population and Development, The Beijing Platform for Action of the Fourth World Conference on Women, Resolutions of the Commission on the Status of Women, etc.)
- Development of international guidelines that emerge out of bilateral/multilateral consultations at the regional and global levels.

It is these international recommendations, resolutions and conclusions that provide guidelines for states to reorient and design their policies and programs ensuring a respect for the human rights of individuals. If well implemented these programs and policies create the enabling environment that promotes a people-centred development pattern. They support the creation of a sense of well being that is essential to enable development and progress of societies and nations with a human face.

SESSION 5

Viewing the Reality

i. Objective

To integrate the normative framework of human rights, gender and HIV/AIDS into the reality of the lives of people living with HIV/AIDS.

ii. Time

2 hours and 30 minutes

iii. Materials/Equipment

Newspaper cuttings of articles relating to the present reality of the lives of people living with HIV/AIDS.

iv. Methodology

Group work

v. Steps

1. The facilitator divides the participants into four groups and provides each group with a different newspaper article from recent coverage of the lives of people living with HIV/AIDS.
2. The facilitator asks each group to identify a group leader to facilitate the discussion within the group and make a presentation at plenary.
3. The group is asked to read the article, and analyse the content within the framework of the rights guaranteed to an individual under international conventions and national constitutions keeping the UN language policy in view.
4. The facilitator promotes a participatory brainstorming as each group makes its presentation to the plenary.
5. Time permitting the facilitator requests the presenter from each group to write a short article rewording the article discussed in the context of the issues raised during the brainstorming. This piece is given to the participants for their records.

Notes to the Facilitator Session 5

- The last step of writing the article is undertaken only if there is time remaining at the end of discussion.
- This exercise contributes towards strengthening analytical skills, linking the micro and the macro in reporting and using empirical evidence to enhance anecdotal data thereby helping media personnel create powerful advocacy material through their work.
- Five media reports are appended. The facilitator should choose four for distribution.
- The facilitator should get acquainted with the UN language policy (document attached) so that the use of the appropriate terminology is transmitted by the facilitator to the participants.

UNDP HIV-RELATED LANGUAGE POLICY[72]

Language and the images it evokes shape and influence behaviour and attitudes. The words chosen locate the speaker with respect to others, distancing or including them, setting up relations of authority or of partnership, and affect the listeners in particular ways, empowering or disempowering, estranging, and so on. The use of language is an ethical and a programmatic issue.

UNDP has adopted the following principles to guide its HIV-related language.

- **Language should be inclusive and not create and reinforce a Them/Us mentality or approach**. For example, a term like "intervention" places the speaker outside of the group of people for or with whom he or she is working. Words like "control" set up a particular type of distancing relationship between the speaker and the listeners. Care should be taken with the use of the pronouns "they" "you", "them", etc.

- **It is better if the vocabulary used is drawn from the vocabulary of peace and human development rather than from the vocabulary of war**. For example, synonyms could be found for words like "campaign", "control", "surveillance", etc.

- **Descriptive terms used should be those preferred or chosen by persons described**. For example "sex workers" is often the term preferred by those concerned rather than "prostitutes"; "people living with AIDS" are preferred by infected persons rather than "victims".

- **Language should be value neutral, gender sensitive and should be empowering rather than disempowering**. Terms such as "promiscuous", "drug abuse" and all derogatory terms alienate rather than create the trust and respect required. Terms such as "victim" or "sufferer" suggest powerlessness; "haemophilic" or "AIDS patient" identify a human being by their medical condition alone. "Injecting drug users" is used rather than "drug addicts". Terms such as "living with HIV" recognise that an infected person may continue to live well and productively for many years.

- **Terms used need to be strictly accurate**. For example, "AIDS" describes the conditions and illnesses associated with significant progression of infections. Otherwise, the terms used include "HIV infection", "HIV epidemic", "HIV-related illnesses or conditions", etc. "Situation of risk" is used rather than "risk behaviour" or "risk groups", since the same act may be safe in one situation and unsafe in another. The safety of the situation has to be continually assessed.

- **The terms used need to be adequate to inform accurately**. For example, the modes of HIV transmission and the options for protective behaviour change need to be explicitly stated so as to be clearly understood within all cultural contexts.

[72] Taken from UNDP HIV and Development Programme Issues Papers.

The appropriate use of language respects the dignity and rights of all concerned, avoids contributing to the stigmatisation and rejection of the affected and assists in creating the social changes required to overcome the epidemic.

THE REALITY, NEWSPAPER ARTICLE I

Bengal AIDS Victim Dies a Lonely, Undignified Death, by Gautam Chaudhuri
Hindustan Times, 12 May 1999

Dhiren Sarkar died unsung, unwept, unattended and without any treatment, simply because he had AIDS. A resident of Chakkabirajpur village in Katwa block of Burdwan district, Dhiren Sarkar worked for a long time in Dubai and subsequently in Mumbai. It was only about two months ago that he had come back to settle in his native village with his wife and children.

Fifty-three-year-old Sarkar was said to be suffering from persistent fever and chronic weight loss which first made doctors suspect that he was HIV positive. His travails began from that period as word spread that he was afflicted with AIDS.

First he was ostracised by his family and the villagers. His wife walked out with their two children. His neighbours shunned him, as did the other villagers. He was left alone in his house, even unable to walk after some time.

Matters came to a head last week when some villagers locked him from outside and decided to set fire to the house. It was only because a kind-hearted neighbour decided to inform the Katwa police of the plot being hatched that the tragedy was averted.

Last Monday, a team from the Katwa police station rescued Sarkar and took him to the local hospital. But this brought forth a fresh set of problems for him.

He was left in an abandoned room in the hospital and attended only cursorily by doctors on the plea that the local hospital did not have facilities available to treat an HIV-positive patient. In an attempt to get rid of him, he was sent to the Burdwan district hospital. Here, too, there was a problem because no driver was willing to take him to the hospital because he had AIDS.

At the Burdwan hospital Sarkar was not accepted. His blood sample was collected and sent for the ELISA test to Calcutta. He was diagnosed as HIV-positive and in the last stage. Doctors were unsympathetic and other patients wanted to stay away from him. That was virtually the end of the road for him.

Sarkar died last weekend all-alone in a dark little corner in the hospital. Dr. Nirmal Maji, assistant secretary of the Indian Medical Association said he would bring the case to the attention of the State AIDS Cell to ensure that similar tragedies were avoided in future.

THE REALITY NEWSPAPER ARTICLE II

Drifter gets 4 to 12 Years in HIV Case: Episode Sparked Debate over Spreading of Virus,
by Richard Perez-Pena
New York Times, 1999

Nushawn J. Williams, a young drifter who ignited a national debate on whether spreading the AIDS virus could be a criminal act, was sentenced yesterday to 4 to 12 years in prison after several of his alleged victims refused to cooperate with prosecutors.

When it first came to light in October 1997, Mr. William's case seemed to crystallise many of society's worst fears about the AIDS epidemic, bringing to light a subculture of aimless young people who traded sex partners as casually as they would clothes. Authorities in Chautauqua County, in the far western corner of New York State, called Mr. William's a sexual predator who some times traded crack cocaine for sex, knowing that he had HIV, the virus that cause AIDS.

They said that in the year he lived in Jamestown, a faded industrial city south of Buffalo, he had sex with at least 48 young women and girls in the area, infecting 13 of them with HIV. The frenzy over his case mounted when health officials who interviewed Mr. William's, a native of Brooklyn who has also lived in the Bronx, told them he had 50 to 75 more sex partners in New York City.

Mr. Williams, 22, became the first person in New York, and one of only a handful around the country, to face criminal charges for giving someone HIV.

Yesterday's sentence was handed down in Chautauqua County Court in Mayville, under a plea agreement with the District attorney's office. Mr. Williams pleaded guilty in February to one count of reckless endangerment for having unprotected sex with a women whom he did not warn of his HIV status-prosecutors did not say whether she was infected-and two counts of second-degree rape, for having sex with a 13 year old schoolgirl.

"These were the only two victims who were willing to testify," said William Coughlin, an assistant district attorney who handled the sentencing. But he said that the case "only encompasses the people the police were aware of," and that the discovery of new victims could yield new charges.

Mr. Williams faces sentencing next week in the Bronx on a charge of reckless endangerment for having unprotected sex with a 15 year old girl. Under an agreement between his lawyers and Bronx and Chautauqua prosecutors, his sentence on that charge will run concurrently with yesterday's Bronx case. " I think it's lucky for everyone that this didn't go to trial. It would have been quite a circus."

Mr. Williams is already serving one to three years for a conviction on selling crack cocaine in the Bronx. Mr. Cember said the new, 4 to 12 year sentence would begin running retroactive to when Mr. Williams first became eligible for parole on the drug case last year. That means he will be eligible for release in 2002.

Calls to Mr. Williams's Chautauqua County lawyer, Richard Slater, were not returned yesterday, but Mr. Slator told The Associated Press: "He's not an evil person. He's been painted as an evil person. He feels badly that he's ill. He expressed to me the concern he may not live out his sentence."

Mr. Williams, who at times was homeless, has been diagnosed as schizophrenic and has been treated for depression. Mr. Cember declined to discuss his client's mental condition,

but both he and prosecutors have noted that it would not necessarily constitute a defence against criminal charges.

Publicity over Mr. William's case helped persuade the Legislature last year to pass a law requiring that everyone with HIV be reported by name to the State Health Department, a move the Democrats had resisted for years. It also prompted some legislators to call for a law providing tougher penalties specifically for knowingly infecting someone with HIV.

Mr. Williams is the only person whose HIV status was publicly disclosed by health officials. A decade-old state law generally shields the identities of people with HIV from public disclosure, but the law provides for exceptions when there is a risk to public health and safety.

It was under that exception that, in the fall of 1997, officials obtained a court order permitting them to go public in Mr. Williams's case, identifying him and urging people who might have had contact with him to get tested for the virus.

The Chautauqua County District Attorney, James Subjack, originally planned to seek indictments for first degree assault, a much more serious charge than the ones that were eventually brought, with a maximum sentence of 12 to 25 years on each count. Legal scholars said no one had ever been charged with assault for transmitting a disease.

First-degree assault requires grievous bodily harm, and no prosecutor had ever tried to prove such a charge when that harm lay in the future. "We concluded that the law just wasn't meant to handle this kind of thing," Mr.Coughlin said.

THE REALITY NEWSPAPER ARTICLE III

Writer Helps Soweto Strip the Shame from AIDS, by Rachel L. Swarns
New York Times, 24 Oct. 1999

Soweto, South Africa: For three years, Lucky Mazibuko obeyed his society's unwritten rules. He kept silent about the virus in his blood. He wept at night, when his mother could not hear him. He hid his suffering form the world and waited quietly for death.

On the dusty, bustling streets here, where at least one of every people carries the virus that causes AIDS, people still call it the white man's disease, the gay man's disease, the foreigner's disease. Even discussing the sickness is shameful, so shameful that an advocate for people with AIDS in another township was killed by her neighbours in December for disclosing that she was HIV positive.

But Mr. Mazibuko finally got tired of hiding. Earlier this year, he called The Sowetan, the biggest daily newspaper in South Africa. He wanted to write a weekly column. He wanted his photograph to run with it. He wanted to show the nation that a black man could live with the human immunodeficiency virus and still hold his head high.

"Just call me lucky," said Mr. Mazibuko, 30 his eyes dancing. "Because I'm the luckiest man in the world."

Three months after the killing of activist, Gugu Dlamini, Mr. Mazibuko became the first black person to be hired by a major newspaper to shatter the culture of shame and silence surrounding HIV and to his astonishment, he has been embraced, not hounded from town. Since the column began in March, he has been courted by television shows, radio programs, magazines and local schools.

He tells the audience that it is safe and sexy to use condoms. He urges people to stay healthy, "No fried food," he chides, "No sugar, margarine, butter, oil or fat." Every Tuesday, for the newspaper's overwhelmingly black readers- a circulation of over 200,000 but the editors estimate that shared copies reach 1.5 million people. He chronicles a dying man's struggle to deal passionately, mischievously and plaintively with deadly illness that has invaded his body and community.

"I saw a man who was dying of AIDS on television," he wrote this month. "His ribs looked like the strings of a guitar. His eyes were huge like an owl's. I could see myself in that man's battered body."

People gasp when they read his words and see his face. He is an ordinary man- not a journalist-who used to drive a jitney for a living. "Isn't that our hometown boy, they whisper as he walks by. Isn't that the man with HIV?."

But newspaper employees, who once feared that he might infect the Sowetan newsroom, now share his meals, wrinkled women squeeze beside him on the jitneys he rides to work and share stories about sick children. Social workers tape his columns to hospice walls, to give dying patients hope. And with each unexpected handshake and each tentative question, Mr. Mazibuko says he feels the winds of change blowing across his shoulders.

The reality is more complicated. Deeply held hostilities fade slowly. And advocates for people with AIDS emphasise that many people here still die alone in hospitals or shacks, abandoned by family and friends.

But as the sickness sweeps through Soweto, and the faces peering from the funeral announcements grow ever younger, it is becoming harder to ignore the crisis. And with his column, the activists say, Mr. Mazibuko is helping to open eyes that were once squeezed shut.

"His column cuts across all the myths: that it's somebody else, somebody overseas, somebody in Zambia," said Glen Mabuza, the project manager of AIDS Counselling and Training, a non-profit group that counsels and supports HIV positive people here.

"This is somebody here, somebody in Soweto," Ms. Mabuza said. "His picture is real. They can see he's a real person. And he's speaking to us, to the black community."

Not everyone loves the new column. Some church leaders have condemned his endorsement of condoms, Mr. Mazibuko said. Some elders have grumbled that he promotes premarital sex. A former girlfriend called to complain that he had embarrassed her and possibly infected her with the disease. (He suggested that she take an HIV test. She never called back.) And his 8-year old son, Nkululeko, was peppered with questions by classmates, who had heard the news.

The boy asked his father: " I know you have it. But what does having AIDS mean?" Mr. Mazibuko explained sadly: " I just told him, it is like flu. The only difference is that it doesn't go away; eventually it kills you."

For now, he is healthy. He is short and stylish, with budding dreadlocks, wire-rimmed glasses and a booming laugh that rumbles through the newsroom. He was born in Soweto and never left. When he finished 12th grade, he started driving a jitney.

His mission is to spread the word through those familiar streets, to the young men hawking tires, the giggling girls in blue school uniforms and the barefoot children who race gleefully through the dust.

He grew up like them, poor, without electricity, without information. And he rages against prominent white advocates for AIDS victims, who, he complains, rarely bring their message to the townships.

"These people, they have all these galas, all these lunches in posh places, but they've never been to Soweto," Mr. Mazibuko said. "They are not reaching my people, the majority of people on the street, the ordinary people like myself, the people who face the brunt of the disease."

His columns are plainspoken and no-nonsense. He urges HIV positive workers to study their legal rights. He attacks drug companies for making medication too costly. He describes poignant letters from parents who have abandoned children with AIDS. And he tells readers they must take responsibility for their sex lives.

"Why are people still engaging in unprotected sex, thus exposing innocent children to HIV infection through pregnancy"? He wrote in a column published in June. "Is it not our own people who have to understand that their behaviour had to change"?

Recheal Plo, who has been HIV positive for three years, was stunned to read his words. "I wanted to know, who was this man? Who was he?" said Ms. Plo, 24. "I read it each and every time it comes out. I knew then that I wasn't the only person with the problem."

But in the newsroom, some employees still viewed Mr. Mazibuko with suspicion. Aggrey Klaaste, the editor of The Sowetan, explained that the column would help the paper fulfil its goal of better informing readers about HIV. The United Nations, which runs a

program to support HIV infected workers, would help pay the salary. And Mr. Mazibuko would counsel staff members about the virus.

Still, some workers worried: could touching him, eating with him, sitting next to him infect you? "I was very uncertain about him being here," said Thembinkosi Nxunalo, 34, the manager of building services. "There are so many myths. I didn't know what to believe." Finally, he decided to ask Mr. Mazibuko. The columnist told him all he knew about HIV and in the end, Mr. Nzumalo decided to take an HIV test and to use condoms regularly. "It was really an eye-opener," Mr.Nxumalo said.

The experience has also been an eye-opener for Mr. Mazibuko, who has been forced to confront his sexual past. Earlier this year, he got a phone call from another old girlfriend, who had seen his photo in the paper. She asked whether he remembered her name.

He confessed he could not. He has had sex with so many women without ever using condoms that he cannot remember them all. "There was a time when I called them all darling because I had forgotten their names," he said.

Then he remembered. They met seven yeas ago. He was driving a jitney and she was a passenger. She was a beautiful woman he said, and they had sex several times. On the phone, she told him she had been infected with the virus then, and that she had probably infected him. She was already losing weight feeling the symptoms.

And suddenly, he found himself face to face with his own mortality. "I couldn't work," he said. " I cried sitting there."

Mr.Mazibuko says he tries not to think about getting sick. There are too many things he wants to do. He wants to write a book. He wants to negotiate a raise. (He earns about $650 a month.) And he wants to spend time with his son, daughter, mother and other relatives.

But it is impossible to ignore the inevitable. His mother says she plans to sell her house when he gets sick, and pay for medication. His boy points at the neighbourhood cemetery and asks whether he will find his father there someday.

"I used to want to be a top businessman, a rich black businessman in this community," Mr. Mazibuko said. " Now I just want to live, you know?"

THE REALITY NEWSPAPER ARTICLE IV

For Subjects in Haiti Study, Free AIDS Care Has a Price, by Nina Bernstein
New York Times, 6 June 1999

The impoverished patients, who step from the dirty sidewalk into the modern AIDS research clinic run by Cornell Medical College in Port-au-Prince, Haiti, are offered a seemingly simple arrangement.

"We would like to test your blood because you live in an area where AIDS may be common," the English version of the clinic's consent form reads. "We will provide you with medicine if you fall sick and cannot afford such care."

But the transaction is not as straightforward as it sounds. Many Haitians who visit the clinic are at once patients and subjects of United States financed medical research, and circumstances that are bad for their health are sometimes best for research results.

The conflict is especially true in Cornell's most tantalising research in Haiti, a study of sex partners, only one of whom is infected with AIDS virus. Researchers, seeking time to developing a vaccine, study the blood of both partners, particularly the uninfected ones who continue to be exposed to the virus through unprotected sex. They are trying to find out whether some people have natural protections against infection with the AIDS virus that could be replicated in a vaccine.

The Haitians are ideal research subjects, largely because they are not receiving the kind of care now standard in the world's developed countries. Condom use is low in Haiti, for cultural and other reasons. Anti-retroviral drugs that are successful at suppressing the virus are unavailable except to the very wealthy, and are not included in Cornell's promise to provide medicine.

Nearly 20 years after Cornell opened the clinic, it provides some of the best AIDS treatment available in the country devastated by the epidemic, fighting the myriad illnesses that result from AIDS. But that is a lower standard of care than patients receive routinely at American institutions, including the hospital affiliated with Cornell in New York City.

If the research were done in the United States, experts agree the physicians would be obligated to prescribe the anti-retroviral and deliver the most effective possible counselling against unprotected sex.

The ethical questions posed by Cornell's work among Haiti's poor are the heart of a global debate about AIDS research that is rolling international health organisations.

THE REALITY NEWSPAPER ARTICLE V

AIDS is everywhere, but Africa Looks Away
New York Times, 1999

Mercy Makhalemele found out she was HIV-positive when she was pregnant with her second child. She was 23, had been married for five years and was faithful to her husband. She cried all the way home from the prenatal clinic, but was too afraid to tell anyone for nearly a year.

When she finally did tell her husband, he beat her to the ground, knocking her against a lighted stove and badly burning her wrist, she said. Then he threw her out of the house, refusing to believe that he had given her the virus. The next day, he went to the shoe store she managed. With everyone watching, he shouted at her to collect all her things, he would have nothing to do with someone with HIV, the virus that causes AIDS.

Her employers dismissed her that afternoon.

"My story," she told a women's group gathered for a luncheon here recently, "is not just my story. If you talk to other women, you will hear ninety percent the same. It will not be 50 different stories. Rejecting us is not going to solve the problem of this disease. It's just going to cause stress. So please, just accept us."

Across sub-Saharan Africa, the AIDS epidemic is everywhere. In several countries, one out of four people is now infected with the virus and will probably die within 10 years. The disease is flooding hospitals, changing the face of work places and orphans. But go to a village and ask if anyone is suffering from AIDS, and the answer will likely be no, there is only malaria or tuberculosis or diarrhoea.

It is hard to find anyone who publicly admits to being HIV-positive. Many go to their graves with their secret, so great is the stigma. Discrimination against people with the virus exists to some degree in most countries around the world. But experts say the problem is particularly severe in Africa, where little has been done to study or attack the stigma.

The shame that people feel and the treatment they suffer at the hands of their communities has far-reaching consequences for efforts to fight the spread of the virus and treat the sick, experts say. For one thing, it keeps people from wanting to find out whether they have AIDS, and it encourages even those who know they are infected to act as everyone else does, and perhaps even spread the disease. For instance, a mother who is trying to hide her HIV status may be unwilling to try infant formula to help prevent transmission to her child if other mothers in her village are breast-feeding.

Fear of discovery can also keep people from seeking services of any sort. In South Africa, facilities earmarked for AIDS patients often stand virtually empty, even though the help they offer is desperately needed.

SESSION 6

Critical Imperatives Facing Men and Women

i. Objective

To create awareness about the legal and ethical issues that affect the lives of people living with HIV/AIDS.

ii. Time

2 hours 45 minutes

iii. Materials/Equipment

1. Questionnaires for each of the five critical imperatives on basic data and statistics.
2. Five sheets of paper with one statement on each of them.
3. Overhead Projector
4. Transparencies
   9 – Mother to child Transmission
   10 – Breast Feeding
   11 – Abortion
   12 – Partner Notification
   13 – Discrimination

iv. Methodology

1. Group Work
2. Dissonance generation
3. Participatory Brainstorming

v. Steps

1. The facilitator divides the participants into five groups and gives each group a statement to discuss, keeping the contextual realities of their geographical locations in mind. The statements are:
   - **Group I:** A pregnant woman who realises that she is HIV positive should begin to take AZT in the 14^{th} week of her pregnancy as this reduces the chances of mother to child transmission by 66 percent. The costs for this treatment amount to $800.
   - **Group II:** Women living with HIV/AIDS should not breast-feed their babies as this carries with it a 15 percent chance of transmission of the virus from the mother to the child.

- **Group III:** Women living with HIV/AIDS should immediately seek abortion the moment they learn that they are pregnant.
- **Group IV:** A doctor should notify the husband of his patient about her serostatus without essentially informing the woman.
- **Group V:** People living with HIV/AIDS should be isolated/quarantined because collective survival is more important than the exercise of the individual's human rights.

2. The facilitator asks each group to choose a group leader to facilitate the discussion and make a presentation at plenary. The presentation can only be made if a consensus is reached in the group. The exercise therefore also builds the capacity of the participants in consensus building.
3. Report back and group discussion takes place in stages:
   - Group I reports back on its response to the critical imperative it was given to consider (Mother to Child Transmission (MTCT).
   - Before opening the discussion to the group, the facilitator hands out a short quiz on the critical imperative topic being considered and asks the participants to fill it out individually and score themselves. (5-10 minutes per quiz)
   - The facilitator provides the answers to the plenary, using these as an entry point for group discussion. The discussion is closed after 15 minutes. The facilitator synthesises the issues raised using the relevant transparency. (e.g. Transparency 9 for MTCT)
   - The process is repeated for each of the remaining critical imperatives: breastfeeding, abortion, partner notification, and discrimination and stigma.

Notes to the facilitator Session 6

- There are five critical imperatives that need to be discussed: mother to child transmission, breast-feeding, abortion, partner notification, and access to resources/discrimination.
- It is very important that the facilitator has read and internalised the facilitator's notes thoroughly so that the use of the questionnaires as an entry point for the group discussion can be done effectively.
- Since many of these issues remain controversial and information from field level research is still inadequate, the facilitator should present the ethical debate in a non-partisan manner. It should be left to the participants to adopt any approach that is appropriate within their contextual realities.
- The notes for each of the critical imperatives in detail are appended.
- The questionnaires for each of the critical imperatives are also appended.

Statement One

A pregnant woman who realises that she is HIV positive should begin to take AZT in the 14th week of her pregnancy as this reduces the chances of mother to child transmission by 66 percent. The cost for this treatment amounts to $800.

QUESTIONNAIRE ON CRITICAL IMPERATIVE I
Mother to Child Transmission

1. Approximately _____ of the one million children under 15 living with HIV around the world acquired the disease from their mothers during pregnancy at birth or from breast-feeding.

   50%
   10%
   90%

   (Source: Prevention Strategies and Dilemmas – Marcel Bianco)

2. In 1994, Protocol 076 proved that mother to child transmission could be effectively prevented by administering AZT to HIV positive women beginning in the 14th week of pregnancy, then intravenously during child birth and finally to the baby in the first six weeks of life. The success in the prevention rate of transmission was recorded as being _____.

   16%
   66%
   6%

   (Source: Women's Vulnerability and AIDS – Adriana Gomez and Deborah Meacham)

3. Although the World Health Organisation (WHO) has claimed that there is _____ valid public health rationale for forced HIV testing many countries still impose this practice on specific groups of people, including prisoners, sex workers, resident aliens, migrant workers, and pregnant women.

   Some
   A strong
   No

   As far back as 1987, WHO declared that HIV testing in order to identify specific individuals should be voluntary, should entail free and informed consent, should be confidential and should be followed with counselling.

   (Source: AIDS in the World – Mann, Tarantola, Netter; v.1, pag.561)

4. As of 1991, _____ countries allowed excessive restrictions on HIV-infected citizens, including forced hospitalisation, isolation, and quarantine for HIV infected people.

   No
   Two
   Seventeen

(Source: AIDS in the World – Mann, Tarantola, Netter; v.1, pg.561)

5. In 1988, in the former Soviet Union, four million pregnant women were the target of a compulsory screening program. Of the women tested, _____ HIV+ women were identified.

   60,000
   6,000
   6

   (Source: AIDS in the World – Mann, Tarantola, Netter; v.1, pg. 561)

6. UNAIDS states that the cost effectiveness of a short course of the anti-retroviral regime (SCARVE) for pregnant women varies according to the HIV prevalence levels.

   a) In Tanzania, SCARVE could cost less than _____ per averted HIV infection (1/2 the cost of providing supplementation to avoid malnourishment in pre-school children.)

      $600
      $6000

   b) In Thailand where prevalence is high, the cost per avoided infection would be _____ (just over twice the cost per year of caring for a child with AIDS.)

      $280
      $2800

      (Source – HIV and Infant feeding: Guidelines for Decision-making, UNICEF, UNAIDS, WHO)

TRANSPARENCY 9

ETHICAL DILEMAS: Mother to Child Transmission

- Who decides? The State? The couple? or more specifically the Woman?

- Will the massive application of protocol 076 ensure that the reproductive rights of women are guaranteed e.g. information and services?

- If not, will the pilot studies in a few developing countries be used only to demonstrate and reinforce to others in wealthier countries that the treatment actually works and AZT must be sold?

Speaking Points for the Facilitator Session 6

CRITICAL IMPERATIVE
Mother to Child Transmission

UNAIDS estimates that approximately 2.7 million children under 15 years of age had died of AIDS by 1998. As many as 1,600 children world-wide are now infected daily with HIV, more than 90 percent of whom acquire the virus from their mothers. Infection rates in pregnant women in many African countries remain high, e.g. 43 percent in Francistown, Botswana. The rates among young mothers are especially alarming: 13 percent of pregnant teenagers aged 15-19 years in South Africa; 28 percent in Botswana. In many cases women are unaware of their positive status. In a Kenyan city for example only one of the 63 randomly chosen women who tested HIV positive knew that she was infected. (Source – Prevention of Perinatal HIV transmission by Maria de Bruyn)

In 1994, Protocol 076 proved that mother to child transmission could be effectively prevented by administering AZT (zidovudine) to HIV positive women beginning in the fourteenth week of pregnancy, then intravenously during child birth and finally to the baby during the first six weeks of life. In the initial study done in the US, the transmission rate declined from 23 percent in untreated women to 8 percent in women who received treatment. (e.g. a 66 percent prevention rate in mother to child transmission)

Issues:

1. **Protocol 076 implies screening all pregnant women with their informed consent.** This is neither simple nor achievable since public health departments in many countries fail to recognise the rights of individuals to make decisions regarding their health. The practice is to let the doctor make these decisions. Prenatal clinic HIV testing of pregnant women is already mandatory in some countries e.g. Chile and Malaysia and other governments are considering this measure.
2. **Massive screening accompanied by pre- and post-test counselling requires a significant investment, not only to cover the cost of the test but also the staff and infrastructure for effective counselling.** Only with such counselling would a woman then be able to make the decision herself, free from any coercion and pressure. In 1997, 13 research projects in Africa surveyed the acceptability of voluntary counselling and testing. The median overall acceptability was 65 percent ranging from 33 percent to 95 percent. Furthermore, an infrastructure of care providing for the HIV infected individual and family has to precede a testing policy.
3. **As the costs of AZT continues to remain very high – about $800 for the administration of this protocol.** There appears to be little point to screening women if they are unable to benefit from treatment because of a lack of financial resources.
4. **More research needs to be undertaken to provide data on whether there are negative effects of this treatment on women.** Considering that single drug treatments for people living with HIV/AIDS are not recommended anywhere in the world, because they produce rapid resistance to AZT, why should this treatment be applied universally in pregnant women? With the advent of triple therapy, (analogues and protease inhibitors

along with AZT) single drug treatment is becoming less common in the industrialised countries.

5. **The issue that arises is who is really being protected in such cases?** The mother child unit or just the new-born?
6. **Some pharmaceutical companies have offered to provide AZT for pilot studies on pregnant women in some developing countries and agreements between governments and the private sector on this have already been signed in a number of countries**. This raises some ethical questions. For example if pilot studies are carried out using donated drugs and does demonstrate reduced transmission, will the countries be able to afford and offer treatment to all pregnant women needing it?

The issue of mother to child transmission has opened up a number of **ethical dilemmas:**

- Who decides: The state? The couple? Or more specifically the woman?
- Will the massive application of protocol 076 ensure that the reproductive rights of women are guaranteed?
- If not, will the pilot studies in a few developing countries be "used" only to demonstrate and reinforce to others in wealthier countries that the treatment actually works and AZT should be sold?

Note:

- *Some findings indicate that pregnant women given multivitamins and the use of more effective anti bacterial agents during labour may further reduce vertical transmission while a combination of elective caesarean section and short term AZT diminishes the risk of infection for the new-born to below one percent. (Source – Picard 1998)*
- *Recently some trials have demonstrated that Viramune® (nevirapine) safely and effectively reduced HIV transmission from mothers to their infants. A simple, inexpensive regimen of one oral dose of Viramune given to an HIV-infected woman in labour and another to her new-born within three days of birth was almost twice as effective in reducing mother-to-infant HIV transmission as a short course of ZDV (zidovudine, AZT, Retrovir®) regimen. (Source – Boehringer Ingelheim September 1999)*

Statement Two

Women living with HIV/AIDS should not breast-feed their babies as this carries with it a 15 percent chance of transmission of the virus from the mother to the child.

QUESTIONNAIRE ON CRITICAL IMPERATIVE II
Breast Feeding

1. In 1992, analysis of six studies including one from Africa indicated that the contribution of breast feeding to perinatal transmission is _____.

   40%
   14%
   4%

   (Source: Review of Current Research on Breast Milk & MTCT of HIV – UK NGO-AIDS Consortium 1998.)

2. In February 1998, a study in Thailand indicated that the risk of perinatal transmission was reduced by _____ if a short-term doze of AZT was given to women in their 34th week of pregnancy and if no breastfeeding was allowed once the child was born.

   5%
   50%
   15%

   (Source: Synopsis of Bangkok Short Course Perinatal ZDV Trial – Mastro T – PROCARE Email list 27 Feburary 1998)

3. The Chief of Obstetrics and Gynaecology at Makere University School in Uganda recently stated that about 30 percent of babies born to infected mothers become infected from breastfeeding. In rural areas _____ of all babies will die from dirty water used in formula.

   50%
   85%
   20%

   (Source: Prevention of Perinatal HIV Transmission, Maria de Bruyn)

4. UNICEF has noted that approximately _____ hours a month could be spent on cleaning and preparations of food in the first three months of child rearing.

   15
   50
   100

   (Source: WHO/UNAIDS/UNICEF Technical Consultation on HIV & Breastfeeding: Report of Meeting – Geneva, April 1998)

5. In Zambia, the average family income is less than $100 a month. The costs of providing the least expensive formula of powdered milk to an infant amount to _____ a month.

   $16
   $36
   $66

   (Source: HIV and Breastfeeding, and Old Controversy, Z. Gelow)

6. The cost of formula for one child in Uganda averages _____ times the rural family's average annual earnings.

   1/2
   1/3
   1 ½

   (Source: Breastfeeding and HIV- Weighing Health Risks- M Specter – New York Times, 19 August 1998)

7. Baby food manufacturers suggested in July 1997 that they were giving mothers free supplies in Thailand as part of a government project for infants of PLWHAS. Twenty five percent of the mothers received free samples while only _____ were positive.

   10%
   2%
   50%

   (Source: Rundall P. – Implications for Commercial Exploitation U.K. NGOs AIDS Consortium 1998)

Transparency 10

ETHICAL DILEMAS: Breast Feeding

- Edward Mbidde, chief of Uganda's Cancer Institute has commented, "What is worse? – To let a baby die of AIDS when you can save it, or to let the baby into the world just to become an orphan in a society that has been overwhelmed by death?"[73]

- Frerichs has posited that it is a question of the mother's rights versus the child's rights – the child's right to life or the mother's right to keep her HIV status confidential i.e. her right to dignity[74]

[73] Spectre M. "Breastfeeding & HIV: Weighing Health Risks" – New York Times, 19 August 1998
[74] Right's of the mother vs. the rights of the child – SEA- AIDS email list, 11 February 1997.

CRITICAL IMPERATIVE
Breast feeding and HIV/AIDS

Given the economic difficulty of applying protocol 076 in poor countries with a high incidence of HIV/AIDS, studies using lower doses of AZT were begun. These studies tested the effectiveness of transmission by initiating treatment in the 34th week of pregnancy and using control groups that were given a placebo. The study on this short-term treatment ended in February 1998 in Thailand with favourable results. The study indicated that the risk of perinatal transmission was reduced by 50 percent. However, to ensure effectiveness of this treatment it is critical that mothers do not breast-feed their babies. The infants are not given the drug under this regimen.

HIV–1 has been found both in the cell free fractions as well as the lymphocytes of breast milk.[75] Transmission through breast milk may increase if the mothers had recently sero converted, have sores or cracks around the nipples and if the child is teething or has some oral pathology. In 1992, analysis of six studies including one in Africa indicated that the contribution of breast feeding to perinatal transmission is 14 percent. In the African studies 4-20 percent of infants were infected after three months of age, presumably through prolonged breast-feeding.[76]

It has been found that infants of HIV negative mothers have been infected after receiving breast milk from an HIV positive wet nurse and from unpasteurised pooled breast milk from untested donors.[77] Overall it has been estimated that breast-feeding by an HIV positive mother increases risks of transmission to the child by about 15 percent.

Issues:

1. The AZT trials in the developing countries have aroused a great deal of debate concerning the ethics of using placebo controls.[78] The justification given is that placebo controlled trials can help evaluate whether shorter regimens, that can be realistically implemented, are better than no treatment at all. However, it is critical that the trial participants truly understand what a placebo is. In Cote d'Ivoire, one woman who participated did not know a year later whether she had received AZT or a placebo. At the International AIDS Conference in 1998, it was reported that some women in a Thai trial had not really understood why the drug was being administered or why it was suddenly stopped.
2. In May 1998, WHO/UNICEF/UNAIDS announced new guidelines that support alternatives to breast feeding for mothers who test positive. They stress that access to sufficient quantities of nutritionally adequate breast milk substitutes must be ensured and endorse the need to implement measures to prevent breast feeding from being

[75] Broadhead – Tropical doctor 1996
[76] Lyall EGH, UK Consortium 1998; Kreiss J in Acta Paediatr 1997
[77] UNICEF/WHO/UNAIDS – A Guide for Health care managers and Supervisors
[78] Lurie P and Wolfe in the New England Journal of Medicine 1997

undermined for HIV negative women (e.g. compliance with the International Code of Marketing breast milk substitutes).

3. Four factors in particular make it difficult for HIV positive women in most developing countries to avoid breast feeding:

    - **A lack of access to clean water for substitute preparation**. In Uganda it has been noted that, "Twenty-seven percent of babies born to infected mothers will become infected from breast feeding. In rural areas eighty five percent of babies will die from dirty water used in formula."[79]
    - **Time involved**: UNICEF has noted that 49-56 hours a month could be spent on cleaning and preparation of feeds in the first three months of infancy
    - **Additional expense**. A year's supply of artificial milk in Vietnam would cost more than the country's GDP.[80] The costs of commercial infant formula are equivalent to 31 percent of the monthly urban minimum wage in Pakistan and 84 percent in Kenya.
    - **Social factors also affect decisions to breastfeed**. Research in Zimbabwe has shown that women do not make the decision on whether or not to breast-feed alone. This decision is influenced by multiple socio cultural factors e.g. paternal attitudes, a belief that suckling is important to reinforce mother child bonding, a belief that a good mother is one who breast feeds etc.

Curtis of BMA Foundation for AIDS has remarked, "The formula manufacturers are itching to get some kind of international public health endorsement for advertising based on the message that formula feeding will save babies from AID...The overall message will come across that breast feeding causes AIDS, so caring mothers should avoid it." In Thailand as part of a government program for infants of women living with HIV, more than 25 percent of the mothers received free samples whereas only 2 percent were registered as HIV positive.[81]

As more measures become available to prevent Mother to Child Transmission we may see an increase in the number of children born to women living with HIV. New issues relating to this scenario are already emerging:

- Edward Mbidde, chief of Uganda's Cancer Institute has commented, "What is worse? – To let a baby die of AIDS when you can save it or to let the baby into the world just to become an orphan in a society that has been overwhelmed with death?"
- Frerichs has posited that it is the question of the mother's rights versus the child's rights – the child's right to life or the mother's right to keep her HIV status confidential (e.g. her right to dignity). [82]

[79] Chief of Obstetrics and Gynaecology in Makere University
[80] Report of the Global HIV/AIDS epidemic – UNAIDS 1997
[81] Rundall P – AIDS Newsletter 1997
[82] Rights of the mother vs. the rights of the child – SEA – AIDS 11 February 1997

Note

It is necessary to shift the emphasis from a focus on the children to a focus on the mothers. Enhancing maternal well being, health and survival will ultimately contribute most to enhancing the health and survival of the children. In this context the expansion and improvement of reproductive health services in general is critical. The less expensive options for reducing perinatal transmission – vitamin supplementation, avoidance of invasive procedures during delivery, modification of breast feeding practices (traditional breast milk alternatives like paps based groundnuts in Zambia, sorghum in Zimbabwe, beans in India, supplies from breast milk banks where donors are screened for HIV – therefore deserve increased emphasis and support.

Statement Three

Women living with HIV/AIDS should seek an abortion upon learning that they are pregnant.

QUESTIONNAIRE ON CRITICAL IMPERATIVE III
Abortion

1. a) Of the 50 million induced abortions world-wide every year, _____ are illegal.

   1/2
   1/3
   2/5

   b) Nearly _____ of all abortions are performed outside the health care system.

   50%
   75%
   25%

   (Source: Unwanted Pregnancy, HIV/AIDS and Unsafe Abortion, by Radhakrishna, Gringle and Greenslade – Women's Health Journal, February 1997)

2. Abortion under any circumstances is illegal in Mauritius, even in cases of rape and incest. In 1992, ___ of maternal deaths were related to complications from illegal abortions.

   14%
   24%
   44%

   (Source: Women in Law & Development (WILDAF) Info Practice for the 43rd Session of the Commission on the Status of Women, March 1999)

3. In developing countries, only _____ of women live in states where abortion is legally available to save a woman's life.

   60%
   10%
   30%

   (Source- Unwanted Pregnancy, HIV/AIDS and Unsafe Abortion-Radhakisha, Gringle and Greenslade)

4. If a woman has advanced HIV, pregnancy carries the risk of hastening her own progression to full blown AIDS. In a study undertaken amongst tribal women in India living with HIV/AIDS,

   a) _____ of the women who had an uneventful legal and safe first trimester abortion, died.

   16%
   60%
   96%

b) _____ died undelivered between 30-34 weeks of gestation.

14%
41%
4%

c) Twenty seven percent of women living with HIV/AIDS but who were not pregnant died during the time frame of the study compared to _____ of pregnant women with HIV/AIDS.

17%
56%
83%

d) The study reported a negative outcome for the pregnancies that resulted in live deliveries with _____ of the infants who died within 6 weeks of birth diagnosed with an AIDS defining illness.

28%
82%
58%

(Source-AIDS in Pregnancy among Indian Tribal Women-Kumar, RD Rizvi and A. Khurana)

Transparency 11

ETHICAL DILEMAS: Abortion

- Should abortion laws be reviewed and made less restrictive especially in the context of the HIV/AIDS epidemic?

- Should the right to terminate pregnancy on the grounds of HIV infection be expressly stated through amendment to the current legislation?

- Should our health care system be more responsive to adolescents who are unrelentingly faced with the triple jeopardy of HIV infection, unwanted pregnancy and unsafe abortion?

- Should the ethical code of conduct of the health care providers be reviewed to ensure more sensitivity to women with HIV seeking abortion?

Speaking Points for the facilitator Session 6

CRITICAL IMPERATIVE
Abortion and HIV/AIDS

UNAIDS has estimated that the new HIV/AIDS infections are disproportionately high among young women between the ages of 15-19 years. This same group has the highest rate world-wide of unwanted pregnancy leading to a potentially significant epidemiological overlap of health risk. An estimated 2 million women in the developing countries have illegal unsafe abortions every year.[83] This is because in developing countries almost one third of the women live in countries where abortion is legally available only to save a woman's life. Even where abortion laws are less restrictive, abortion services are not always available to women especially adolescent women.

The demand for abortion services could increase significantly as more and more women discover their HIV status, and understand the risk of mother to child transmission. Even today some women are seeking termination of pregnancy if they find out that they have HIV. This is because women in countries with mature epidemics are realising that if a woman has advanced HIV, pregnancy carries the risk of hastening her own progression to AIDS.

An IPAS survey at the 1997 Adolescent Reproductive Health Forum has however concluded that 47 percent of professional health providers feel that the majority of the health providers would refuse to provide abortion related care if they knew that an adolescent had HIV/AIDS. Two issues emerge that explain this situation:

1. Values and attitudes of the health care providers re adolescent sexuality. These are based on the socialisation process that has to date revolved around the social construction of sexuality.
2. Misinformation re the mode of spread of the HIV/AIDS virus.

Berer and Ray point out that when HIV positive women seek medical abortion they are frequently turned down by providers. This is particularly devastating for adolescent women leading them to pursue unsafe abortion practices.

Strangely and conversely, there is also anecdotal evidence of HIV positive women given false/ inadequate information about HIV/AIDS to convince them to agree to an abortion especially in developing countries where health care providers observe a high death rate among infants born to HIV positive women.

Note
The task for development workers and activists will remain to lobby for:

- ***The right to accurate information of the pregnant woman****. The guilt that a woman carries of transmitting HIV/AIDS to her child and therefore contemplates abortion would need to be responding to with accurate information to enable guilt*

[83] Blum R – Journal of the American Medical Association

free informed choice regarding the termination of pregnancy. Women need to know that 75 percent of women will not transmit HIV to their infants even without AZT during pregnancy.

- ***The right to autonomy, integrity and safety of the body.*** *Abortion laws would need to be reviewed and made less restrictive especially in the context of the HIV/AIDS epidemic. Should the right to terminate pregnancy on grounds of HIV infection be expressly stated through amendment to the current legislation?*
- ***Access to services by adolescents in keeping with the right to health.*** *The services will need to be reviewed and modified to protect adolescents who are unrelentingly faced with the triple jeopardy of HIV infection, unwanted pregnancy and unsafe abortion.*
- ***An ethical code of conduct of the health care providers*** *especially as they provide their service to women with HIV seeking abortion. The right to life will need to be reinforced and categorically advocated for.*

Statement Four

A doctor should notify the husband or parents about the serostatus of a woman living with HIV/AIDS without informing the women first.

QUESTIONNAIRE ON CRITICAL IMPERATIVE IV
Partner Notification

1. a) In Cote d 'Ivoire, under a UNAIDS pilot project, _____ of women refused to be tested for HIV.

   50%
   20%
   5%

   b) _____ of those tested did not return for the test results.

   50%
   5%
   20%

   c) _____ of those who tested positive did not inform their partners of the result.

   25%
   50%
   5%

   (Source –Relevance of Current Trials to Breastfeeding Policy and Practice – Vande Pierre)

2. _____ of the STD clinics in Delhi have a contact card or referral slip for partner notification.

   0%
   50%
   80%

   (Source- NACO-Study to Map Patterns of Risk Behaviour in the State of Delhi)

3. A 1993–94 survey in South Africa of more than 700 HIV-infected clients who had been in counselling sessions at an AIDS service group found that more than _____ had not told their spouse or regular partner of their positive HIV status.

   6%
   60%
   20%

   (Source- New York Times-December 4, 1998)

Transparency 12

ETHICAL DILEMAS: Partner Notification

- Should the woman/man have the right to know about her/his partner's HIV status, particularly given the data on discordance among couple's?

- Should this confidential information be shared and how should this be undertaken?

- Who should undertake it?

- Will it necessarily violate counsellor client relationship?

- What about the right to confidentiality?

Speaking Points for the facilitator Session 6

CRITICAL IMPERATIVE
Partner notification and HIV/AIDS

The issue of partner notification is an issue of varying dimensions. In 1993, Oleary and Cheney had remarked, " Among all the personal and ethical dilemmas faced by people with HIV, those related to pregnancy and motherhood are most difficult." Why is this so? This is so because, although there have been attempts made by the women's movement to ensure that the recognition of being a "true woman" in a relationship emanates from the concept of being capable of loving and being loved without necessarily having a baby; most societies continue to believe that women must become mothers in order to be "real women." This being the case the issue of partner notification for a woman is especially difficult. The issues that arise for her are:

- Having children is still a central issue even if I am HIV positive. How will this happen if my partner gets to know that I am HIV positive?
- If my partner gets to know that I am HIV positive he will label me as a prostitute.[84] How will I cope with the rejection?

A study entitled, "Women Between Motherhood and AIDS," undertaken by Cristiane S. Cabral from the Public Health Institute in Rio de Janeiro concludes that, "There is clearly a conflict between this disease, which is still fatal, and the desire for motherhood, reflecting the eternal conflict between life and death. According to these women, motherhood is not only a way to build an identity and have a social role but also a way to fulfil one of the most important dreams. Not being able to be a mother is a source of intense psychological suffering and may even gravely affect their health which should be taken into consideration when offering health care and counselling to HIV positive women."

In Cote d'Ivoire, under a UNAIDS pilot project on combination therapy for pregnant women, 20 percent of the women refused to be tested. Fifty percent of those tested did not return and 50 percent of those who tested positive did not inform their partners of the result.[85]

It is no only women who are finding it difficult to inform their partners about to their HIV status. Men are also not informing their partners about their HIV positive status. This latter scenario is one of greater concern as the social construction of sexuality condones men's promiscuity. The case of a woman in the interior of Honduras illustrates this point. Her husband did not tell her that he was HIV positive before they got married even though he was aware that his first wife had died of AIDS. His mother and sister knew as did the neighbour and the pastor of their church. Everyone knew except her. According to Helen Jackson, executive director SAIFAIDS, "Within a family, the husband is more likely to be affected first. It may also take some time before the wife becomes infected." This has been shown clearly by the studies on discordance among couples in both Zimbabwe and Zambia. In

[84] HIV/AIDS is still regarded as a disease of gay men, prostitutes and intravenus drug users.
[85] Van de Perre – Relevance of Current Trials To breast feeding policy and practice. – 12th International AIDS Conference, Geneva 1998)

Zambia up to one third of the couples studied were discordant. Far more commonly the husband positive and the wife negative.[86]

The issues that arise here are:

- Should the woman/man have the right to know about her/his partner's HIV status, particularly given the data on discordance among couples?
- If this confidential information is to be shared how should this be undertaken?
- Who should undertake it?
- Will it necessarily violate counsellor client relationship?
- What about the right to confidentiality?

The questions raised are sensitive and require careful analysis through public information and consequent debate. This is essential to prevent uninformed decision making by our policy makers and planners. The recent ruling of the Bombay High Court in India, questioning the right of a PLWHAS to marry is a case in point. An article on this case is appended.

An information packet prepared by the Women in Law and Development in Africa (WILDAF) for the 43rd session of the Commission on the Status of Women states, "Finally, despite their rhetoric, African states often have non compassionate, non supportive and discriminatory HIV/AIDS related policies and practices. In Zimbabwe for example, the justice department has drafted a law, which proposes a maximum 20-year mandatory jail term for anyone who knowingly infects another with HIV/AIDS, **excluding spouses**. Given that married women are the highest risk group for HIV transmission and husbands are not covered by this draft, the proposal can only be described as a mockery."

Note 1
The critical imperative is that good and effective counselling and accurate information on the epidemic needs to be in place before any laws or judgements on partner notification are outlined and enforced.

Note 2
The issue of "partner notification" is different from the issue of "obligatory notification," which makes HIV/AIDS a notifiable offence. Obligatory notification should be understood as the obligation of informing the relevant health authorities with the aim of determining the number of cases and their variables in order to program prevention activities. With obligatory notification, individual identities are not important. Rather, it is data of epidemiological interest that is important, such as age, place of origin, occupation, mode of transmission. The information given to health authorities must be anonymous and confidential. In addition, to the health authorities the sexual partners should also be notified. Legislation has interpreted the definition of "contacts" of a person with HIV in a number of ways, allowing in some cases the notification of the family members who are in no danger of contagion. This unnecessarily violates the right to privacy of the patient. For epidemiological purposes, only notification of the sexual partner of the seropositive individual is justified that too often counselling the PLWHAS and seeking his approval.

[86] Dr. M. Sichone Head of the Central Board of Health, Zambia October 1997

Parents or guardians of all minors also must be notified, as this is necessary to ensure treatment. In any case all contact notification should be carried out with a spirit of respect of human rights of individuals and within the context of prevention.

Should HIV Victims Marry?

Indian Express News Service, 14 November 1999

Recent statistics put the number of HIV positive cases in India at 3.5 million. Of these, Maharashtra tops the list. The disease is showing a paradigm shift in movement from urban to rural areas, from high risk to general population, through migrant labourers from the cities to the waiting wives in the villages. Also, one in every four HIV positive cases are women, the statistics say.

In the light of these facts, should HIV victims be given an untrammelled right to marry even with full disclosure to their respective spouses? If no, where does one draw the line and how should the restrictions be legislated?

The Bombay High Court bench of Justice M.B. Ghodeswar and Justice S. Radhakrishnan is expected to deliver a crucial judgement on these issues next week when the court reopens, on a petition filed by the Lawyers Collective on behalf of two HIV positive patients, who will be referred to as A and C.

According to the petitioners' plea, given that the Supreme Court had in a case, 'Mr. X vs. Hospital Z,' held that marriage for HIV patients was a suspended right, they wanted a "clarification" from the High Court that "provided there was full disclosure and informed consent," HIV patients could marry.

But the many arguments, in many ways, ended up as "HIV positive men vs. the right of women to public health," where Additional Solicitor General D.Y. Chandrachud and women's rights activist Flavia Agnes opposed the submissions of the petitioners, represented by counsels Anand Grover and C.U. Singh.

Chandrachud argued before the bench that there were very few facts before them for consideration. "The law should not be benefited by people who were liable to misuse it," he said, adding that the socio-economic disabilities of women, where poverty and illiteracy exists, made them as a class, extremely vulnerable to exploitation. "It would not be adequate to just tell the prospective spouse that I am HIV-positive and leave it at that."

Drawing on the limitations of consent, where Section 375 of the IPC lays down that sexual intercourse by a man with his wife does not constitute rape, no "consent" other than that to marriage is contemplated under the section, Chandrachud pointed out. He admitted that though the mere act of solemnisation of a marriage was not an offence under Section 269/270 (spreading of infectious diseases) of the IPC, but one could not ask for a carte blanche non-applicability of that section.

STATEMENT FIVE

People living with HIV/AIDS should be isolated/quarantined because collective survival is more important than the exercise of the individual's human rights.

QUESTIONNAIRE ON CRITICAL IMPERATIVE V
Discrimination

1. Women in Asia and the Pacific Region are considered to have a _____ times greater risk of contracting HIV/AIDS than men due to their greater social and biological vulnerability.

   Two
   Five
   Ten

   (Source: World Bank 1993)

2. After a positive diagnosis, women generally experience AIDS related illnesses _____ than men do.

   Sooner
   Later

   (Source: Women's Vulnerability and AIDS – Gomez and Meacham)

3. The ratio of AIDS cases of men to women dropped from 31:1 to _____ in 1995 in Chile.

   25:5
   15:5
   10:5

   (Source: CONSIDA 1997)

4. In one survey on KAP (Knowledge, Aptitude, Perception) done in Colombia, _____ of those consulted said they were unsure of how to protect themselves from STD's and AIDS.

   91%
   61%
   21%

   (Source: Sexual Conduct in the Adult Population, Profa Milia – Bogota Seguro Social Vol. 3, 1994)

5. In the same survey, the reported use of condoms among women with their partners was _____.

   14%
   4.1%
   41%

   (Source: PROFAMILIA (1994))

6. As shown clearly by studies of discordance among heterosexual couples in both Zimbabwe and Zambia, up to _____ of couples studied were discordant (far more commonly the man positive and the wife negative).

   1/3
   1/5
   1/4

   (Source: Key Problems Facing Women in the Concept of HIV/AIDS in South Africa –Helen Jackson)

7. An IPS Survey at the 1997 Adolescent Reproductive Health forum found that _____ of professionals stated that the majority of health providers would refuse to provide abortions related care if the adolescent had HIV/AIDS.

   17%
   47%
   7%

   (Source: Unwanted Pregnancy: HIV/AIDS and Unsafe Abortion – Radhakrisha, Gringle and Greenslade)

8. A recent survey undertaken by YRG Centre on PLWHAS observed that of the respondents, who had been victims of violence, _____ had experienced that violence at home and 21.4% had experienced it in the community.

   12.3%
   80.1%
   50.5%

   (Source: Challenges Facing People Living with HIV/AIDS – Soloman and Sathiamoorthy)

9. In the same survey when they disclosed their positive serostatus to health care providers, _____ of the respondents claimed to have experienced discrimination from those providers.

   37%
   80%
   5%

   (Source: Challenges Facing People Living with HIV/AIDS – Soloman and Sathiamoorthy)

10. The study on high-risk behaviour conducted by NACO in the state of Kerala, India states that IVD users when spotted by police in Trivandrum are _____.

    Taken to drug addiction centres
    Counselled by the police and restored to their families
    Beaten up

11. A recent finding of a study conducted by the University of California notes that _____ of medical professionals throughout the world have refused care to at least one HIV infected person.

    39%
    12%
    7%

    (Source: Challenges Facing PLWHAS – Solomon and Sathiamoorthy)

12. FGM is a socially sanctioned practice in many parts of Africa. In some countries _____ out of 10 women have had at least some part of their external genitalia removed.

    4
    7
    9

    (Source: WILDAF: Information Packet prepared for the 43rd Session of the Commission on the Status of Women, March 1999)

13. A 1997 study in Zimbabwe found that _____ out of 10 people caring for someone with AIDS was/were willing to admit that they were nursing someone with the disease.

    1
    5
    8

    (Source: New York Times – December 4, 1998)

ACCESS

1. Despite the high degree of government involvement in health care, most African states continue to suffer from circumstances related to insufficient infrastructure. In Ethiopia, there are only _____ health centres (including hospitals) to serve 55 million people.

    2,200
    22,000
    220,000

    (Source: A Snapshot of the Current Status of Women's Health in Africa – WILDAF, March 1999)

2. Women are hardest hit by cutbacks in health services and fee impositions. In West Africa, where SAP's caused rates of inflation to soar to 300 percent in the 1990's and underemployment to soar as high as 80 percent, the per capita income has plummeted from an average of $1000 in 1970 to _____ in 1995.

   $500
   $700
   $300

   (Source: A Snapshot of the Current Status of Women's Health in Africa – WILDAF, March 1999)

3. In countries like Zimbabwe where 86 percent of the women live in rural areas, women must frequently walk _____ or more to a clinic.

   30 minutes
   One hour
   Three hours

   (Source: A Snapshot of the Current Status of Women's Health in Africa – WILDAF, March 1999)

4. In South Africa, there are about _____ people per doctor in the former homelands.

   3,000
   13,000
   30,000

   (Source: A Snapshot of the Current Status of Women's Health in Africa – WILDAF, March 1999)

5. Cost recovery programs in which people are asked to contribute to the cost of condoms they buy and use have in fact discouraged the use of condoms. In Zimbabwe, where cost recovery for condoms was introduced in 1993, the number of condoms distributed at the survey site health centres fell by _____.

   25%
   50%
   75%

   (Source: A Snapshot of the Current Status of Women's Health in Africa – WILDAF, March 1999)

Transparency 13

ETHICAL DILEMAS: Discrimination

- Should we adopt the public health approach of saving health at the cost of elimination of the sick?

- Is collective survival more important than the exercise of individual rights and freedom?

Speaking points for facilitator Session 6

CRITICAL IMPERATIVE
Discrimination and Stigma

HIV/AIDS is a "prismatic problem", because it explores our most severe social and economic vulnerabilities. In fact people living with the virus are seeing social disparities reappearing combined with fears of sexuality, and death: Over the years, we thought we had begun to conquer gender and class discrimination. The epidemic has made these disparities reappear once again.

Discrimination is both a cause and a consequence of the epidemic. Let us examine the following in light of this statement.

1. In 1987 there were HIV-positive sex workers in a Honduran city who were persecuted by the police. We don't know where they are now. In the streets, people yell at the housewives who are getting infected, and at their children.
   (Source: New Forms of Control Over Women's Bodies, by Rocio Tabora)

2. In northern Honduras, a 20-year old factory production supervisor got sick repeatedly, so her boss sent her to have an HIV test. The day that she learned she was HIV positive the company fired her with severance pay. She has a son. She stays shut up in the house and her aunt provides her room and board.
   (Source: New Forms of Control Over Women's Bodies, by Rocio Tabora)

3. A 24-year-old maquiladora worker was fired when the results of her test were known. She was also interrogated about whether she had gone out with anyone else from the company.
   (Source: New Forms of Control Over Women's Bodies, by Rocio Tabora)

4. A 42 -year old woman with five children has been a widow for a year. She says, "I only worked in houses washing clothes. When the people found out that I had HIV, they asked me to stop working for them. They took away the house we were renting and the people asked me to use gloves if I went somewhere else to wash clothes. Everything collapsed. My husband's family took my youngest daughter away from me. They never accepted that he died of AIDS and that my daughter has it too. Sometimes I want to talk about it and open my feelings, but I can't because I'm afraid I'll be rejected. When I used to visit my family, they gave me water from a broken glass. They told my children not to hug or touch me. I can't go to see them anymore. When I had a bout of herpes, they said they were taking me to the hospital to die and that when I died they weren't going to bring me home…"
   (Source: New Forms of Control Over Women's Bodies, by Rocio Tabora)

5. "We know that HIV affects women differently from men, but we still really don't know enough…It is still mostly men who are in the clinical trials. Drugs get licensed by testing on men. There haven't been large-scale trials looking at how

these drugs affect women in particular. All we know is that women are having more kidney and live complications proportionally as compared to men".
(Source: Joan Manchester)

6. We know of cases of minors who after having survived a false seropositivity are not allowed to attend school in an appropriate manner or have been prevented from attending at all.
(Source: Mothers and AIDS in the Dominican Republic, by Bethania Betances)

7. Lori who was five months pregnant learned she was HIV positive. "I wasn't really told anything. It was just "you've got 24 hours to decide whether you want to abort or not." Everybody who I talked to said I should abort…And to this day I don't think I've ever dealt with it. I sort of put it in the past and try not to think about it".

For a long time now we have been saying that HIV-positive men and women have been facing terrible experiences; experiences of sexual abuse, forced abortions, forced sterilisations, inadequate access to contraceptives and abortion, or even a caesarean section. As women from the ICW have remarked, "We have been saying what the issues and needs are, but we haven't been listened to because it is anecdotal evidence".

The history of public health has been marked by assaults on human rights and dignity. Many of the traditional measures to combat epidemics such as obligatory testing and notification, surveillance and quarantine place priority on collective survival and thereby create serious obstacles for the exercise of individual rights. The public health approach focuses on saving the health of the public at the cost of elimination of the sick. The HIV/AIDS epidemic constitutes a challenge for health policies in our era. Its appearance at the end of the 20th century demands consideration of the potential repercussions of public health policies and programs in the context of human rights of individuals.

Note
An important first step is to establish a dialogue between the health and human rights section, to recognise the synergy between them and to follow this up by co-ordinating actions towards a common goal, taking advantage of the diverse skills, strategies and spheres of influence of each of these sectors. For example, health specialists can testify to the benefits of education and the negative effects of discrimination against women. In the same way human rights specialists can promote an active debate and legislation on issues of equality; access, dignity which would enable health specialists to achieve their goals.

SESSION 7

Role of Law and the Role of Media

i. Objective

To enhance understanding about the role of law and the media in highlighting the human rights issues which are at the core of the HIV epidemic.

ii. Time

1 hour and 30 minutes

iii. Materials/Equipment

Newspaper article on HIV/AIDS issue.

iv. Methodology

Participatory brainstorming

vi. Steps

1. The facilitator distributes a recent article on the impact of HIV/AIDS on national development planning to the participants and they are then requested at plenary to comment on the article bringing out its strengths and weaknesses.
2. The facilitator uses the discussion of the article to highlight the role of law as well as the role of the media in promoting advocacy about HIV and human rights, linking the macro and the micro.
3. The facilitator steers the discussion in the direction of agreement by the group to work jointly on:
   a) The need to combine anecdotal to the empirical evidence.
   b) The need to combine the normative to the reality.
   c) The need to combine the cognitive and the emotional experiences.
   d) The need to build up a body of literature recording the abuses of human rights of PLWHAS.

Notes to the Facilitator Session 7

- An example of how the article can be analysed is given below.
  Analyse this article for its writing style – power, language policy of HIV, is it good/bad? How would you improve it?

  A. Strengths

  The impact of the epidemic has been brought out well by:

  - Highlighting how half a century of progress has been turned back, for example through the gains in child survival being reversed.
  - Highlighting Botswana as an example of a country that although not at war is still losing 20 years in life expectancy over just five years.
  - Linking up issue of orphans and HIV to health and immunisation.
  - Bringing out dilemmas relating to funding by donors, whereby funds to challenge existing stereotypes in sexuality are not easily available.
  - Introducing the sensitive issue of mother to child transmission (MTCT) in a non-threatening way.
  - Offering solutions to the problems stated – e.g. peer projects.
  - Not using negative words such as "deadly", "killer disease", etc.

  B. Weaknesses

  - The stereotype examination of the macro impact of HIV could have been taken a step further by bringing out the gender dimension of the discussion.
  - The analysis regarding issues of MTCT and breast-feeding remains incomplete. A line on this factual situation would have made it complete.
  - The article does not bring out the human rights focus.
  - The linkages between the macro and micro issues have not come out clearly.

- The speaking points for the discussion on Impact on Development is appended.
- Notes on the role of law and the role of the media are also appended and should be read to facilitate a discussion.

AIDS Is Blamed for Reversing Health Gains in Poorest Countries, by Barbara Crossette
New York Times, 1 December 1998.

The explosion in the world's poorest countries of AIDS, or of infection with the virus that causes it, is turning back half a century of progress in making life healthier for children, the director of the United Nations Children's Fund says, "The implications are quite extraordinary," said Carol Bellamy, Executive Director of the agency, UNICEF. "In 23 countries, largely in sub-Saharan Africa, we already see HIV-AIDS virtually reversing the gains that have been made in child survival."

"More children are dying and they're dying sooner, even though immunisation programs might be more successful," she said. "The fact is that improvements that were being made are being reversed. Not just stalled. Reversed."

What United Nations experts now feel that the AIDS pandemic, coupled with the increasing vulnerability of millions of families due to the disruption and violence of civil wars, is forcing agencies dealing with children to rethink priorities and to introduce new programs.

"The pandemic is hitting most harshly, at this point, in southern Africa and eastern Africa," Ms. Bellamy said last week before leaving for a news conference in London, in advance of United Nations AIDS Day on Tuesday, where new AIDS figures were made public by the World Health Organisation and the joint program called UNAIDS, in which UNICEF takes part.

"Botswana, for example, is losing 20 years in life expectancy in just about a five-year period," Ms. Bellamy said. "It's not a country in conflict, or a country at war. It's stable."

At the news conference, AIDS experts announced that the number of cases world-wide of people living with the human immunodeficiency virus which causes AIDS, had grown by 10 percent in a year, to 33.4 million.

For UNICEF, the AIDS crisis poses a range of problems. The number of orphans is soaring, Ms. Bellamy said. "It is expected to grow, and these are guestimates, to 40 million by the year 2020."

In eight sub-Saharan countries, more than 25 percent of children under 15 have already lost at least one parent, she said. These children are more likely than others to drop out of school and are less likely to be brought to clinics for vaccination.

Because AIDS strikes hardest at the 10 - 24 age group, UNICEF, which is identified mostly with programs for early childhood, will have to concentrate more on adolescent sex education, she said, something that is not always popular among donors. The fear of transmission of the AIDS virus is also forcing UNICEF to modify, to some extent, its strong preference for breast-feeding.

“We are not reopening the discussion about breast-feeding being the best thing you can do for your child, except, yes, you specifically open it around the subject of mother-to-child transmission.” Ms. Bellamy said. “It’s not something that can be ignored.”

Ms. Bellamy said that because half of the 7,000 new cases daily are among young people, the best hope of stopping the rapid spread of the disease lies in creating intensive education programs and in encouraging peer-group projects.

“This is one ray of hope,” she said. “The future does lie in adolescents’ hands and if there could be more effort, really very concentrated advocacy, information and services, programs focused on adolescents, there is some potential for getting control of this pandemic.”

Speaking points for the facilitator Session 7

Impact on National Development Planning

Illnesses linked to AIDS are already the second leading cause of death due to infectious disease in the developing world, and it is estimated that they may soon be responsible for half of all deaths by the year 2010.[87] This kind of mortality/morbidity has definite repercussions on national development planning. The indicators of a people centred development pattern are already showing signs of nervous vulnerability in some countries, especially those with mature HIV/AIDS epidemics.

Feminisation of poverty and increase in female headed households

- Research on the impact of HIV/AIDS on the household is being undertaken in a number of countries but few studies have examined gender as a variable in measuring the household and community impact of the epidemic.[88]

Food Security

- In communities where women are responsible for subsistence farming, when women become infected, the cultivation of subsistence crops falls resulting in an overall reduction in food availability in the household.[89]

Access to Education

- When opportunistic infections begin to occur, in the absence of access to medicines sickness is prolonged and girls are often pulled out of school before boys to fulfil household duties when help cannot be hired due to the depletion of household economic resources.[90]

Sexual Abuse

- As a result of loss of income from a male income earner when he falls ill, women and children are required to seek other sources of income. Research has shown that adolescent girls may be particularly vulnerable as a result of bartering sex for cash or other resources.[91]

Reproductive Health

- Other evidence suggests that the epidemic is contributing to a downward trend in the age of marriage for young women, as men seek younger wives to protect themselves from infection and families seek the economic protection of marrying off their daughters to

[87] World Bank: Confronting AIDS: Public Priority in a Global Epidemic – Electronic Journal Sept. 26, 1998.

[88] Source: (1) Report from a Consultation on the Socio-Economic Impact of HIV/AIDS on Households, Chiangmai, Thailand, 22-24 September 1995. (2) Taking Stock on Gender and HIV/AIDS, by Whelan and Rao Gupta. (3) Economic Implications of AIDS in Asia, by Bloom and Lyons.

[89] Reference: The Implications of AIDS for the Agricultural Sector in Lao PDR, by Anthony M. Zola.

[90] Reference: Study of the Economic Impact of Fatal Adult Illness from AIDS and Other Causes in sub-Saharan Africa, conducted jointly by the World Bank and the University of Dar e Salaam.)

[91] Reference: The Socio-Economic Impact of HIV and AIDS on Rural Families in Uganda: An Emphasis on Youth, by Daphne Topouzis.

economically stable adult men. This phenomena has far reaching consequences in terms of access to education by young girls, the diminished access to productive resources, the economic dependency on the male partner and poor reproductive health as a result of early intercourse and childbearing.

Abandonment and Destitution

- In instances where the male head of household has died, studies have shown how women face a tragic set of circumstances in terms of loss of social support from family members, ostracisation from the community and lack of legal protection to inherit land and property. Instances have been cited wherein a husband's family may blame a widow for the death of her husband and refuse to accept her or her children into the family support system. Other instances have been cited where family members encourage a husband who is asymptomatically HIV positive to leave his wife who is also infected and find another woman.[92]

A Denial of Choices

All the above factors need to be viewed within the context the fact that although women are productively engaged in both the formal and informal sectors of the economy, there are gender related differentials in women's and men's access to productive resources such as land, property, credit, employment, training and other services.

With regard to treatment of HIV related conditions the man is often first in many aspects and more often the husband dies before the wife. It may also take some time before the wife becomes infected, as shown clearly by studies of discordance among couples in both Zimbabwe and Zambia. In Zambia up to one-third of the couples studied were discordant for more commonly the man is positive and the wife negative. The entire family savings had been spent on the treatment of the husband. He is also more likely to have had remunerated employment and medical aid. It was found that when the wife became sick later on there was no money and no medical aid coverage.[93]

Prevention initiatives are therefore critical. Prevention interventions will need to include

- Efforts that transform the social and economic conditions that prevent some people from protecting themselves from HIV/AIDS. These efforts could include programs on gender, on poverty issues etc., programs that improve access to development resources in keeping with the principle of equity (essentially focusing on gender and poverty issues.)
- Efforts that reduce discrimination and permit people living with HIV/AIDS to adopt responsible behaviours relating to their sexuality. (These programs would need to focus on the principle of inclusion rather than exclusion for example

[92] Reference: Studies of household and community responses to HIV and AIDS in India, Tanzania and Thailand by Aggleton, Bharat, Leshabari and Singhanetra-Renard

[93] Source Helen Jackson SAIFAIDS – Key Problems facing Women in the Context of HIV/AIDS in S. Africa

provisions of counselling and support for people living with HIV/AIDS with a gender perspective.)

Women continue to be regarded as vectors of infection, not as persons entitled to adequate health care resources. "In Brazil as in many other countries, women were treated as if they did not have any sex or sexuality. There was no concern with the impact of the illness or even the impact of its treatment on women's hormonal cycle; no priority was given to counselling or research on innocuous contraceptive methods that also protected against HIV; and no technological investment was made to advise HIV positive women who wished to bear children."

The number of AIDS cases among women in Brazil doubled between 1990-98 and AIDS is now the main cause of death amongst women aged 15-49 in the largest Brazilian city.[94] Gender discrimination was the root cause of this state of affairs.

Discrimination relating to access to resources is manifested in other arenas as well. Despite the overwhelming incidence of HIV/AIDS in developing countries, UNICEF estimates that only 10 percent of the 2 billion dollars spent each year on AIDS prevention reaches these countries. [95]

A human rights focus is therefore key to the success of any strategy to combat HIV/AIDS. This focus assumes an even greater significance in an era when in the world's poorest countries, health and education spending is a minuscule proportion of the gross domestic product compared to debt repayments. The Asian financial crises have led to drastic cuts in social sector spending in countries that have for long invested strongly in health and education. Coupled with the precipitous devaluation of national currencies, this has placed food, medicines and other essentials beyond the reach of large sections of the population. Even in Japan, the economic crisis has spawned a growing category of new poor who are not covered by any form of health insurance. There is now global evidence of the erosion of equity and rights based approaches in health as a result of the economic environment.

And yet there is a potentially important synergy between AIDS mitigation and anti-poverty programs, especially anti-poverty programs that are gender sensitive. Rural development programs aimed at improving women's access to sustainable livelihoods are likely to lessen the impact of the epidemic. For example, access to clean water is likely to have a marked effect on the amount of time women have for other productive activities and for the care of the sick and the orphans. Access to labour saving technologies such as fuel efficient stoves, food grinding machines will similarly increase the amount of time women have to be able to shoulder new burdens.[96]

The World Bank finding that each adult death depresses per capita food consumption in poorest households by 15 percent, implies that in responding to the epidemic, national governments will need to use adult death and household dependency ratios as a targeting

[94] Source – Women Vulnerability and AIDS – Adriane Gomez and Deborah Meacham.
[95] Buchanan and Cernada 1996/97
[96] Source – The Implications of HIV/AIDS for rural development Policy and Programming – Daphne Topouzis.

criteria for poverty alleviation programs.[97] And as we reprioritise our national spending we will need to do it even more critically with a gender lens. Women in Asia living with the virus are today silently expressing a need for support to break abusive relationships, support for their children to be placed in foster homes, support for access to housing, support by way to hospices and finally support to access a stable means of livelihood.[98]

The Role of Law

The notion of the law as an instrument of social and behavioural change has been the subject of a long and controversial jurisprudential debate. There are countless examples of how the law has been ineffectual in changing social behaviour either because it has been ignored or because it has been selectively enforced. The issue of rape and domestic violence are two such examples that are particularly relevant to women. Nevertheless along with this notion there is reason to believe that the creative use of law based on an appreciation of complex social values, may be able to bring about changes so that the abuse of human rights is minimised if not altogether eliminated. The law can therefore play an important role in seeking to change underlying values and patterns of social interaction that create vulnerability to the HIV virus.

The Enabling Law

In many developing countries there exist legal regimes that entrench the economic dependence of women through land ownership and marital property laws which deny women independent ownership of property or through laws which deny women access to certain forms of paid employment. Law reform in this area could have a reasonable impact on women's economic independence which in turn could assist in permitting access to health care and in reducing her reliance on sexual activity as a source of income. Similarly laws can be enacted which require or mandate a minimum level of participation and representation of socially disadvantaged groups e.g. women and people living with HIV/AIDS in the policy making process. Such laws if implemented in their true spirit could help in strengthening processes, which would redress the social imbalances. Furthermore, in some countries where laws uphold certain customs or behaviours that increase the risk of HIV transmission, such as harmful traditional practices and traditional marriage patterns, the abolition of these laws can provoke a questioning of the customs and values that underpins them.

The Protective Law

The law can also have a protective function through which it can be used to uphold the rights and interests of particular classes of people notably those living with or affected by HIV/AIDS. There is now an increasing recognition of the interplay between human rights and the epidemic. At a recent consultation on AIDS and Human Rights held in Manila in July 1997, the APCASO[99]Compact on Human Rights agreed that, "Respect and concern for human rights, at all levels, should be at the core of our collective response to the pandemic." The following conceptual framework was discussed This brought out very clearly the interplay between human rights and HIV/AIDS.

[97] Source – Same as 6
[98] Source – She can Cope by Madhu Bala Nath
[99] Asia and Pacific Council of AIDS Service Organisations

The impact of law in its proscriptive mode on HIV/AIDS policy has often obstructed rather than facilitated effective policy implementation. Such laws include those that have imposed criminal sanctions on the sale of condoms or those that have led workers in needle exchange programs to fear that they may be prosecuted for aiding and abetting an illegal activity. Examples of proscriptive laws include laws for the compulsory reporting of HIV seropositivity, laws, which require HIV testing on certain population groups etc. The coercive nature of these laws have in effect impeded prevention efforts by alienating those people who are at risk of HIV and making it less likely that they will cooperate in prevention efforts

The Role of Media

The role of the media in development is critical to:

- Enhance understanding of crucial partners about the socio-economic causes and consequences of the epidemic, especially focusing on the critical imperatives that need to be discussed, through information that is accurate and objective.
- Promote alliance building amongst activists, government functionaries, researchers, trainers etc. by playing a pivotal role in broadening the debate on these critical imperatives so that more enabling environments for PLWHAS could be created.
- Bring about the shift from anecdotal evidence through reporting to evidence with an empirical validity. This is essential to bring about changes in people's lives as it is then able to influence decision-making.

The human rights approaches propagated by multilateral organisations, national governments, activists, media bodies and legal partners have started succeeding even in a macro environment of depleting monetary resources. For example, in Egypt the FGM Task forces composed of activists, researchers, doctors and feminists, played a pivotal role in broadening the debate on the sensitive and charged issue of female genital mutilation thereby creating a climate for a political ban on the practice. In Brazil the National Council of Women's Rights revitalised in 1995, worked with the National Commission on Population and Development to defeat an anti-abortion provision in Congress in 1996.

Similar alliances between activists and policy makers in South Africa led to the historic Choice of Termination of Pregnancy Act in 1997, the first of its kind in Africa. In Sri Lanka an emerging partnership between NGOs and women legislators calls for legalisation of abortion services.

SESSION 8

Future Directions

i. Objective

To promote participatory planning and develop strategies to help address the situation nationally and globally.

ii. Time

45 minutes

iii. Materials/Equipment

Flip Chart/markers

iv. Methodology

Headlining

vi. Steps

1. The facilitator asks the participants to express in one sentence - how they feel they can help address the situation from their position of strength. E.g. "Being a representative of an institute I can…" or " Being a media body we can…"
2. In keeping with the headlining technique the facilitator asks the participants to start sentences with the phrase "Lets consider" to offer possible strategies that could affect positively on the lives of people living with HIV/AIDS. E.g. "Let's consider reserving a column on gender and HIV issues in a mainstream daily", "Let's consider organising workshops for editors of mainstream dailies on Gender, HIV and human rights", "Let's consider incorporating the discussion on Gender, HIV and human rights into the training modules for policy makers and planners."
3. Once all the participants have contributed, the facilitator divides them into groups (by state or by country) and to translate the ideas outlined through headlining into a concrete plan. This should be a short-term plan over six months and one, which is realistic, practical, and doable. The facilitator asks the participants to fix responsibility and a time limit for the work plan.

Notes to the Facilitator Session 8

- An example of a work plan that should emerge from this session from each group is appended to guide the facilitator.

WORK PLAN FOR ZIMBABWE

ACTIVITY	RESPONSIBLE	TIMEFRAME
Meeting to share Dakar module with training Institutions	Martha	November 1999
Share module with colleagues and community at large through informed articles	Luy Gina	Long term
Share information with GWAPA (former CSW)	Martha	November 1999
Fund raise for 2 day workshop to train and lobby media and partners of the project and members of Gender Forum	All	January/February 2000
Initiate a monthly column on gender and HIV/AIDS.	Gina	Jan 2000
Create mail groups and incorporate HIV/AIDS and Gender into existing health page (weekly)	All Ivy	Jan 2000 Ongoing
Train Ministry and Health officials.	Martha	Dec 1999
Utilise Radio and TV shows.		
Empowerment of Women living with HIV/AIDS.	All	Dec 1999
Circulate guidelines on the acceptable language when reporting on HIV/AIDS.	All	Nov. 1999
Mainstreaming gender into international events – Int'l Women's Day.	Gina/Ivy All	Dec. 1999 March 2000
Lobby for training on HIV/AIDS at Training Institutes.	All	2001

SESSION 9

Evaluation and Closing

i. Objective

To improve the process and content of the workshop

ii. Time

30 Minutes

iii. Materials/Equipment

Pen and blank sheets of paper

iv. Methodology

Reflection and writing

vi. Steps

1. The facilitator asks the participants to relax close their eyes and go into an introspective state and reflect on the process of the workshop.
2. After a minute, he/she asks them to put on paper their honest feelings about the workshop, the information imparted and the methodologies used and the strategies charted out.
3. The participants need not put their names on the sheets of paper.
4. The facilitator then closes the workshop by emphasising the sense of commitment to move beyond facts and figures and give them a human face so that human rights remain the basis of all the work that is done on the epidemic.