Gender, HIV and Human Rights: A Training Manual

UNIFEM is the Women's Fund at the United Nations. It provides financial and technical assistance to innovative programmes and strategies that promote women's human rights, political participation and economic security. UNIFEM works with and in partnership with UN organisations, governments and non-governmental organisations (NGOs) and networks to promote gender equality. It links women's issues and concerns to national, regional, and global agendas by fostering collaboration and providing technical expertise on gender mainstreaming and women's empowerment strategies.

The views expressed in this publication are those of the authors, and do not necessarily represent the views of UNIFEM, the United Nations or any of its affiliated organisations.

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ISBN: 0-9679502-28

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Gender, HIV and Human Rights

A Training Manual

Foreword

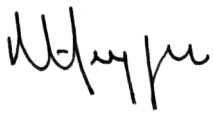
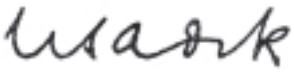
Would the world have a serious AIDS epidemic today if gender inequalities were less pronounced? If more women had greater control of matters related to their reproductive and sexual health? If they enjoyed greater access to economic opportunities and resources so that they would not need to resort to exploitative occupations? If more men were willing to assume responsibility for preventing HIV transmission and for caring for family members who are HIV-positive?

As the 21st century begins, over 33 million adults are living with HIV, the virus that causes AIDS. Once largely a disease of men in distinct populations, HIV is currently infecting women at faster rates than men in key regions, such as Sub-Saharan Africa. The gap between the male and female ratio of people infected by HIV is narrowing in many countries in the world. Current empirical evidence shows that macro economic and political factors exacerbating gender inequalities lie at the core of the epidemic and directly influence the epidemic's rapid spread. Experience has shown that community-based AIDS projects that enhance the economic and decision-making power of women – in partnership with men – work well both to prevent transmission of the virus and to enrich their capacities to care for people who are afflicted by it. So do macro economic and political policies that promotes the status of women in their communities and in the world of work.

HIV/AIDS requires a gender-specific response. This manual has been prepared in response to this need. It aims to help trainers enhance their understanding about the gender dimensions of HIV/AIDS, so that they can then effectively influence a critical mass of change makers in their "spheres of influence" to undertake appropriate responses to the challenges being posed by the epidemic.

This manual shows that neither AIDS nor gender disparities are unbeatable. The manual draws on more than a decade's experience from the field, building on the lessons learned and analysing and synthesising them within the conceptual framework of gender and human rights.

We hope that people who will use the manual find it valuable in their work.

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INTRODUCTION TO THE MANUAL

This manual is the product of an interactive and rewarding process. About 200 reports on indicative research in various parts of the world were analysed and the information synthesised together in a manner that could help the reader understand the gender dimensions of HIV/AIDS. The reports scrutinised were not necessarily gender responsive but often offered insights that enhanced understanding about the ways in which the epidemic had been affecting and continue to affect the lives and livelihoods of men, women and children across the globe.

This manual is divided into four sections:

(a) **Section I – Challenges of the HIV/AIDS Epidemic: The Gender & Human Rights Context**: This section highlights the basic facts on HIV/AIDS and the growing global, national, and regional challenges of the HIV/AIDS epidemic within a gender framework.

(b) **Section II – Gender Concerns in HIV and Development**: This section outlines a one-day training module on "Gender Concerns in HIV/AIDS and Development." The section describes the structure, agenda and methodology of the sessions, training aids and notes for the facilitator.

(c) **Section III – Gender and HIV/AIDS: A Human Rights Approach**: This section outlines a two-day training module on "Gender and HIV/AIDS: A Human Rights Approach." The module describes the structure, agenda and methodology of the sessions, training aids and notes for the facilitator.

(d) **Section IV – Learnings from the Workshops**: This section presents the insights gained during the use of these modules in various parts of the world. The insights are reflected from the perspective of the facilitator as well as from the perspective of the participants.

The manual offers a set of learning tools presented in a linear learning mode. However, the tools can be used individually and non-sequentially depending on the learning objective a trainer hopes to achieve and on time available.

The tools have been prepared drawing on both qualitative and quantitative information, generated through epidemiological analysis as well as indicative research experiences in various parts of the world. An effort has been made to ensure that the learning experience is culturally neutral, by a presentation of universally applicable facts and discussions.

Because HIV/AIDS is an unfolding epidemic, users would need to update the manual regularly, drawing on information provided through sources such as UNAIDS, UN publications, and the internet.

SECTION I

CHALLENGES OF THE HIV/AIDS EPIDEMIC: THE GENDER AND HUMAN RIGHTS CONTEXT

HIV: BASIC FACTS ABOUT THE DISEASE

i. HIV - Human Immune Deficiency Virus

- HIV is a retrovirus.[1]
- HIV attacks the immune system, which helps defend the body against infections. Over a period of time, the virus overwhelms the immune system. The body is then not able to successfully defend itself from opportunistic infections[2].
- The virus targets a cell known as the T4 lymphocyte.
- It can be isolated from blood, semen, and secretions that include cervical and vaginal, breast milk, saliva, tears and urine. But a certain viral load[3] is necessary for the infection to be successfully transmitted.

ii. AIDS – Acquired Immune Deficiency Syndrome

- It is a life threatening condition and is characterised by the destruction of certain cells mainly the T4 lymphocytes. This leads to opportunistic infections, which are severe and ultimately fatal.
- The length of time from when a person is infected with HIV to the development of AIDS varies from person to person. People can remain healthy for any time from a few years to more than ten years before developing any AIDS related symptoms.
- If a blood test shows that a person has HIV it does not necessarily mean that he/she has AIDS.

iii. Modes of Transmission

- Sexual Intercourse
- Pregnancy-related vertical transmission
- Blood transfusion
- Sharing of infected needles used to inject drugs intravenously.

iv. HIV Cannot be Transmitted by:

- Casual everyday contact e.g. shaking hands, hugging, kissing, coughing, sneezing
- Donating blood
- Using common swimming pools or public toilet seats

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[1] A virus containing genetic RNA material rather than DNA. For the virus to replicate itself within an infected cell its RNA must be converted to DNA. It does this by using an enzyme known as reverse transcriptase.

[2] Over the course of a lifetime, starting from infancy, we are all subjected to infections that are held in check by our own immune systems. When HIV suppresses a person's immune system, these infections can manifest themselves, e.g. tuberculosis while others may never cause disease unless the immune system is weakened, e.g. CMV retinitis. These infections move a patient from HIV status to AIDS, and are referred to as opportunistic infections.

[3] Viral load is the amount of HIV per milliliter of blood.

- Sharing bed linen, eating utensils, food
- Animals, mosquitoes, and other insects

v. Origin and History

- In the late 70's doctors began to recognise a new pattern of illnesses.
- In 1981 – AIDS was recognised as a syndrome (a group of symptoms emerging from a common cause) of illnesses.
- In 1983 – HIV was identified.
- In 1984 – HIV was isolated in France and the United States.[4]
- In 1985 – HIV semen antibody test for the diagnosis of HIV became available.

vi. Diagnosis

- HIV antibodies can be detected through the HIV antibody test about 3-6 months after infection.
- The period during which the antibodies are not yet detected is called the window period. Transmission of infection can take place during this period.
- Screening is done by a test know as the ELISA test – Enzyme Linked Immuno Sorbent Test Assay. If it is positive it is followed by a confirmatory test which is either Western Blot or Fluorescent Antibody Technique.
- Incubation period of AIDS is the time between infection and the onset of symptoms. It varies from person to person.

vii. Treatment of HIV

Since HIV is a retrovirus, medications are mainly anti-retroviral. Treatment is a three-drug combination therapy. The drugs are:

a) NRTIs: Nucleoside Reverse Transcriptase Inhibitors[5]

b) NNRTIs: Non-Nucleoside Reverse Transcriptase Inhibitors[6]

Reverse Transcriptase is an enzyme that changes the HIV in a way that enables it to become part of the nucleus of a target cell thereby allowing it to make copies of itself. NRTIs and NNRTIs inhibit (slow down) the action of this enzyme. If this enzyme does not do its job properly HIV cannot take over and start making new copies of itself.

[4] France – Luc Montaguier et al, 1983. US – Robert Gallo, et al, 1984.
[5] NRTI's : Retrovir (AZT/Zidovudine), Videx (ddi/Didanosine), Zerit (d4T/Stavudine), Hivid (ddC/Aziciabine), Epivir (3TC/Lamivudine)
[6] NNRTI's: Delavirdine (Rescriptor), Nevirapine (Viramune)

c) PI: Protease Inhibitors[7]

These slow down the enzyme protease, which works on the HIV virus after it comes out of the nucleus of the cell. Protease acts like a pair of chemical scissors by cutting up the long chains of HIV proteins into smaller pieces so that it can make active new copies of itself. Protease Inhibitors gum up (block) the protease scissors.

d) Prophylactic Medications

These help prevent opportunistic infections when the immune system becomes weak e.g. Foscarnet and Ganciclavin to treat Cytomegalovirus Eye infections, Fluconozole to treat yeast and other fungal infections, TMP/SMX or Pentamidine to treat Pneumocystis Carinii Pneumonia.

[7] Protease Inhibitors: Indinavir (Crixivan), Nelfinavir (Viracept), Ritonavir (Norvir), Saquinavir (Invirase/Fortovase)

GLOBAL SUMMARY OF THE HIV/AIDS EPIDEMIC[8]

People newly infected with HIV in 2000	**Total** Adults Men *Women* Children <15 years	**5.3 million** 4.7 million 2.5 million *2.2 million* 600,000
Number of people living with HIV/AIDS	**Total** Adults Men *Women* Children <15 years	**36.1 million** 34.7 million 18.3 million *16.4 million* 1.2 million
AIDS deaths in 2000	**Total** Adults Men *Women* Children < 15 years	**million** 2.5 million 1.2 million *1.3 million* 500,000
Total number of AIDS deaths since the Beginning of the epidemic	**Total** Adults Men *Women* Children <15 years	**21.8 million** 17.5 million 8.5 million *9 million* 4.3 million

[8] AIDS Epidemic Update: December 2000.

REGIONAL OVERVIEW OF THE EPIDEMIC

Region	Epidemic started	Adults & children living with HIV/AIDS	Adults & children newly infected with HIV	Adult prevalence rate[9]	Percent of HIV-positive adults who are women	Main mode(s) of transmission[10] for adults living with HIV/AIDS
Sub-Saharan Africa	Late '70s - Early '80s	25.3 million	3.8 million	8.8%	55%	Hetero
North Africa & Middle East	Late '80s	400 000	80 000	0.2%	40%	IDU, Hetero
South & South-East Asia	Late '80s	5.8 million	780 000	0.59%	35%	Hetero, IDU
East Asia & Pacific	Late '80s	640 000	130 000	0.07%	13%	IDU, Hetero, MSM
Latin America	Late '70s - Early '80s	1.4 million	150 000	0.5%	25%	MSM, IDU, Hetero
Caribbean	Late '70s - Early '80s	390 000	60 000	2.3%	35%	Hetero, MSM
Eastern Europe & Central Asia	Early '90s	700 000	250 000	0.35%	25%	IDU, MSM
Western Europe	Late '70s - Early '80s	540 000	30 000	0.24%	25%	MSM, IDU
North America	Late '70s - Early '80s	920 000	45 000	0.6%	20%	MSM, IDU, Hetero
Australia & New Zealand	Late '70s - Early '80s	15 000	500	0.13%	10%	MSM, IDU
TOTAL		**36.1 million**	**5.3 million**	**1.1%**	**47%**	

[9] The proportion of adults (15 to 49 years of age) living with HIV/AIDS in 2000, using 2000 population numbers.

[10] MSM (sexual transmission among men who have sex with men), IDU (transmission through injecting drug use), Hetero (heterosexual transmission).

HIV: A RAPIDLY EXPANDING EPIDEMIC[11]

- In 1999, there were nearly 33.6 million people living with HIV. By the end of 2000, this figure rose to approximately 36.1 million.
- The percentage of women infected by HIV in 1997 was 41%, in 2000 this figure had risen to 47%.
- Since 1994 in almost every country of Asia there has been a 100 percent increase in the prevalence rate.
- In the last three years the prevalence rate in 27 countries has doubled. In Botswana and Zimbabwe the prevalence rate among adults is 25 percent.
- HIV infections in the former Soviet Union have doubled in just two years.
- The Caribbean is the region hardest hit by HIV/AIDS in the world outside sub-Saharan Africa.
- HIV is considered to be among the top ten killers in the world.
- In 1998, there were 2.6 million deaths from HIV/AIDS, as many as from malaria.
- Thirty percent of the AIDS deaths have resulted from tuberculosis (TB).
- Around half of all the people who acquire HIV become infected before they turn 25 and typically die of the life threatening illnesses called AIDS before their 35th birthday.
- In 1998, Africa witnessed 5,500 funerals per day due to HIV/AIDS related deaths.
- At the end of 1999, there were 11.2 million AIDS orphans around the world.

[11] AIDS Epidemic Update: December 1999; AIDS Epidemic Update: December 2000; and the Speech to the House Committee on International Relations on 16 September 1998 by Peter Piot M.D., Ph.D. Executive Director Joint United Nations Program on HIV/AIDS.

HARD WON VICTORIES[12]

There is sound evidence that HIV infection rates are stabilising or decreasing in places where focused and sustained prevention programs have resulted in significantly safer behaviour. This is not just the case in the developed countries in Europe and the Americas. It is true around the world. Widespread access to highly effective antiretroviral therapy has significantly prolonged life and improved the quality of life for people living with HIV in the western world and has resulted in a dramatic decline in AIDS deaths in these countries.

- In Uganda delayed first sexual intercourse, increased condom use, and fewer sexual partners have been responsible for a 40 percent drop in HIV prevalence among pregnant women.

- In Thailand there is comprehensive evidence that prevention campaigns work. Annual representative surveys in young men showed both substantial reductions in risk behaviour and decreases in HIV infection levels. Between 1991 and 1995, visits to sex workers reported by these men were cut by almost a half; and those who reported using a condom on the last visit increased from nearly 60 percent in 1991 to slightly under 95 percent in 1995. HIV prevalence among this group has gone down as a result from 8 percent in 1992 to less than 3 percent in 1997.

- In Senegal, prevention efforts appear to have reduced rates of sexually transmitted diseases and stabilised HIV rates at low levels of less than 2 percent among sexually active adults.

- In northern Tanzania the first sign of an HIV turnaround has also been seen among young people. In areas with active prevention programs, prevalence in young women fell by 60 percent over a period of six years.

- New research findings from Thailand demonstrate that even a short course of AZT for HIV-infected pregnant women could reduce by half the risk of HIV transmission to their new-born.

- It has been confirmed that the usefulness of tuberculosis prophylaxis will now allow more effective action against this important co-epidemic.

- Brazil and other South American countries have started widening access to treatment, including access to antiretroviral therapy.

- Significant progress in expanding global capacity to monitor the epidemic has also been made. There are now country-specific estimates and data for almost every country in the world.

[12] Speech to the House Committee on International Relations on 16 September 1998 by Peter Piot M.D., Ph.D. Executive Director Joint United Nations Program on HIV/AIDS.

UNDERSTANDING GENDER

Gender

The word "gender" differentiates the sociologically attributed aspects of an individual's identity from the physiological characteristics of men and women. Gender has to do with how we think, how we feel and what we believe we can and cannot do because of socially defined concepts of masculinity and femininity. Gender relates to the position of women and men in relation to each other. These relationships are based on power.

Difference Between Sex and Gender

The word gender is used to describe socially determined characteristics; sex describes those, which are biologically determined. Sex is something one is born with, whereas gender is imbibed through a process of socialisation. Sex does not change and is constant, whereas gender and consequent gender roles change and vary within and between cultures.

Implications for HIV/AIDS[13]

- Where sex is biological, gender is socially defined. Gender is what it means to be male or female in a certain society as opposed to the set of chromosomes one is born with. Gender shapes the opportunities one is offered in life, the roles one may play, and the kinds of relationships one may have – social norms that strongly influence the spread of HIV.
- For women, risk-taking and vulnerability to infection are increased by norms that make it inappropriate for women to be knowledgeable about sexuality or to suggest condom use; the common link between substance abuse and the exchange of sex for drugs or money; and by resorting to sex work by migrant and refugee women and others with family disruption.
- For men, risk and vulnerability are heightened by norms that make it hard for men to acknowledge gaps in their knowledge about sexuality; by the link between socialising and alcohol use; by the frequency of drug abuse, including by injection; and predominantly male occupations (e.g. truck-driving, seafaring, and military) that entail mobility and family disruption.
- In cultures where HIV is seen as a sign of sexual promiscuity, gender norms shape the way men and women infected with HIV are perceived, in that HIV-positive women face greater stigmatisation and rejection than men. Gender norms also influence the way in which family members experience and cope with HIV and with AIDS deaths. For example, the burden of care often falls on females, while orphaned girls are more likely to be withdrawn from school than their brothers.
- Hence, responses to the epidemic must build on an understanding of gender-related expectations and needs, and may need to challenge adverse norms.

[13] UNAIDS, Gender and HIV/AIDS: Technical Update, September 1998.

HIV: A GENDER ISSUE

HIV is a gender issue because:

i) Although HIV/AIDS affects both men and women, women are more vulnerable because of biological, epidemiological and social reasons.

- 41 percent of 33.4 million adults living with HIV/AIDS are women.
- 55 percent the 16,000 new infections occurring daily are women.
- 43 percent of pregnant women tested positive in Francistown, Botswana.
- Following a trend observed in some countries the male to female ratio among HIV infected persons has begun to equalise. In fact in some of the worst affected countries, women outnumber men.

"I have AIDS…Today it is me, tomorrow it's someone else. If I am not kind, if I do not sympathise and get involved with my neighbours, what will happen to me when my turn comes?"[14]

ii) The epidemic is fuelled by situations where macro policies have led to an increase in gender disparities.

- In Sub-Saharan Africa, policies leading to internal and external conflicts have resulted in mass population displacements. This has created unequal sex ratios among refugees, internally displaced and those remaining in the areas of conflict exacerbating gender disparities. As a result six women for every five men in conflict situations are HIV positive.
- UNDP estimates over 85 percent of the cases of paediatric infection in Africa have resulted from perinatal transmission. The infant mortality rate in this region is expected to increase by up to 30 percent.
- In the Asia-Pacific region, the exclusion of women from the emerging market economies led to an increase in existing gender disparities. Out of the 2.7 million estimated new HIV cases in the world in 1996, 1 million were in South and Southeast Asia.
- In Latin America and the Caribbean, policies promoting high urbanisation have pushed women into a low productivity informal sector, where they have to cluster for survival. In Sao Paolo, HIV/AIDS was the leading cause of death amongst women in the age group of 20-34 years.

"To be alone and dying, yet to care for one's own HIV infected child is tragedy, the dimension of which few of us can truly comprehend."

"Like every other epidemic, AIDS develops in the cracks and crevices of society's inequalities…."

[14] All the quotes in italics are voices of women living with HIV/AIDS.

iii) The rapidity of the spread of HIV/AIDS among women can be slowed only if concrete changes are brought about in the sexual behaviour of men.

- A study of female youth in South Africa showed that 71 percent of the girls had experienced sex against their will.
- A behaviour survey financed by USAID in Tamil Nadu in India shows that 82 percent of the male STD patients had sexual intercourse with multiple partners within the last 12 months and only 12 percent had used a condom.

" The women tell us they see their husbands with the wives of men who have died of AIDS. And they ask what can we do? If we say no, they'll say: pack and go. If we do, where do we go to?"

iv) The feminisation of poverty is a key characteristic of the socio-economic impact of HIV/AIDS

The burden of care of the infected and sick invariably falls on women in the family. In households where women are responsible for subsistence farming this leads to:

- Reduction of productive time on farms.
- Threat to the food security of the family.
- Withdrawal of the girl child from school to bridge the demand for additional unpaid labour in the household.
- Increase in households headed by women, at times by girl children with little access to productive resources, often driving them into sex work for survival.

"The children are lonely and sad without any family…I do not know how to comfort them. I tell them they cannot even rely on me, as I fear I am infected. I know I am asking them to grow up before their time, but I see no other alternative, if they are to survive."

"It is as if we are beginning a new life. Our past is so sad. We are not understood by society…we are not protected against anything. Widows are without families, without houses, without money. We become crazy. We aggravate people with our problems. We are the living dead."

v) Existing legal and policy frameworks need to be reviewed with a gender sensitive lens to ensure positive and sustainable changes.

The laws that need to be reviewed include:

- The laws relating to the prevention and suppression of commercial sex work.
- The laws relating to homosexuality. (Homosexuality is an act categorised under sodomy, which is punishable by law.)
- The laws both federal and personal that reduce women's access to productive assets like laws on inheritance, marriage, divorce, and cultural sexual practices.
- Policies regulating sex education in schools.
- Rules relating to ethical and professional orientation of service providers.

"*Sometimes sex work is a form of self-defence: We are going to sell what they want to take by force or by chance."*

"Through my and others personal experience I have learnt that many women suffer in silence…Now HIV has changed many aspects of our lives and humanity is facing a plague which requires that we reassess and reform some of our cultural and traditional values."

Gender inequality is a key variable in the incidence of HIV/AIDS. As gender disparities increase, the epidemic is affecting more and more women who bear the negative consequences of the gender imbalances. And as the epidemic is maturing, it is drawing in women who have had only one sex partner. A decade ago women seemed to be on the periphery of the epidemic. Today they are at the centre of concern.

HIV/AIDS: MEN MAKE A DIFFERENCE[15]

All over the world, women find themselves at special risk of HIV infection because of their lack of power to determine where, when and how sex takes place. What is less recognised, however, is that the cultural beliefs and expectations that make this the case also heighten men's own vulnerability. HIV infections and AIDS deaths in men outnumber those in women on every continent except sub-Saharan Africa. Young men are more at risk than older ones: about one in four people with HIV are young men under the age of 25.

There are sound reasons why men should be more fully involved in the fight against AIDS. All over the world, men tend to have more sex partners than women, including more extramarital partners, thereby increasing their own and their primary partners' risk of contracting HIV, a risk compounded by the secrecy, stigma and shame surrounding HIV. This stigma may keep men and women from acknowledging that they have become infected.

Men need to be encouraged to adopt positive behaviours, and, for example to play a much greater part in caring for their partners and families. Numerous studies world-wide show that men generally participate less than women in caring for their children. This has a direct bearing on the AIDS epidemic, which has now left over 11 million children orphaned and in need of adult help to grow up clothed, housed and educated.

[15] Excerpts have been taken from a press release (6 March 2000) from UNAIDS about the UNAIDS Campaign 2000 to target men.

HIV: A HUMAN RIGHTS ISSUE

The WHO Constitution has defined health as "a state of complete physical, mental and social well being, not merely the absence of disease and infirmity." This state of human well being has been guaranteed as a human right through a number of international human rights treaties. Although health was first articulated as a human right in the Universal Declaration of Human Rights, a more detailed articulation of this right was set forth in Article 12 of the Covenant on Economic, Social and Cultural Rights and the Convention on the Elimination of All Forms of Discrimination Against Women reaffirmed these rights further.

The rapid spread of the HIV/AIDS epidemic has led to an infringement of the human rights of men, women and children affected by the epidemic in various ways. According to the World Development Report of 1993, half of the world's burden of disease is attributable to communicable diseases, to maternal and perinatal causes and to nutritional disorders. However women, particularly women in low-income nations, bear a large proportion of this disease burden. The overall morbidity and mortality for women from sexually transmitted diseases excluding HIV/AIDS is over 4.5 times that of men. The onset of the HIV/AIDS epidemic has exacerbated this situation in no small way. It has opened up a whole new area of human rights violations as the epidemic depicts a congruence of two most insidious forms of human oppression – gender and sexuality.

In response to this state of affairs the Second International Consultation on HIV/AIDS and Human Rights concluded that: the protection of human rights is essential to safeguard human dignity in the context of HIV/AIDS and to ensure an effective rights based response to the epidemic. This conclusion was based on the recognition that when human rights are protected, less people become infected and those living with HIV/AIDS and their families can better cope with the disease.

Prevention and care for women are often undermined by pervasive misconceptions about HIV transmission and epidemiology. There is a tendency to stigmatise women as "vectors of disease," irrespective of the source of infection. As a consequence, women who are or are perceived to be HIV-positive face violence and discrimination in public and in private life. Sex workers often face violence and discrimination in public and in private life. Sex workers often face mandatory testing with no support for prevention activities to encourage or require their clients to wear condoms and with no access to health-care service. Many HIV/AIDS programs targeting women are focused on pregnant women but these programmes often emphasise coercive measures directed towards the risk of transmitting HIV to the foetus, such as mandatory pre- and post-natal testing followed by coerced abortion or sterilisation.

The protection of the sexual and reproductive rights of women and girls is, therefore, critical. This includes the rights of women to have control over and to decide freely and responsibly on matters related to their sexuality. States should thus ensure women's rights are upheld in matters relating to property, employment, divorce, access to economic resources so that women can leave abusive relationships which threaten them with HIV infection. This will

also enable them to cope with the burden of caring for people living with HIV/AIDS in their households. An engendered human rights approach to the epidemic is therefore imperative.

SECTION II

GENDER CONCERNS IN HIV AND DEVELOPMENT

INTRODUCTION

i. THE MODULE – AN OVERVIEW

This module is entitled "Gender Concerns in HIV and Development". It is used in a one-day workshop meant to assist planners and practitioners in seeing HIV as a critical gender issue. At the end of the workshop, it is anticipated that the participants will be able to perceive gender as a critical variable in any aspect of the epidemic.

The Training does not impart skills – it enhances perception. The tool used for this is that of gender analysis. Gender analysis is presented to the participants in three areas:

- A gender analysis of the epidemiological data
- A gender analysis of the causes of the epidemic at the macro and the micro levels
- A gender analysis of the consequences of the epidemic

The ultimate goal is to ensure that gender is mainstreamed into all aspects of the response to the epidemic

ii. OBJECTIVES OF THE MODULE

The main objectives of the training module are:

- **To enhance understanding about gender concerns in HIV development.**
- **To identify strategies that can address the challenges of HIV/AIDS from a gender perspective.**

iii. WHO SHOULD PARTICIPATE

The selection of participants is crucial to a successful training program. They should be drawn from wide ranging fields so that the information disseminated during the training is spread to a wider base. The participants could be representatives of:

- Research and training institutions
- Policy makers and planners from national machineries on women and from the sectoral ministries
- Non-governmental organisations
- Mainstream media
- Multilateral and bilateral donors

a) Criteria for Selection

- Worked on gender and not necessarily on HIV.[16]
- An understanding of participatory approaches in development.

[16] It was found that people who had worked on HIV found that the training was pitched too low.

- Decision-makers in their areas of work.
- Commitment and interest in working on HIV/AIDS.
- Willingness to work towards the realisation of the objectives of the workshop within their own spheres of influence for at least the following year.

A participant list of 25 persons is ideal. However, successful workshops have had as many as 35 participants.

iv. FACILITATION

The facilitator should have:

- A good understanding of HIV/AIDS and be up to date with the epidemic over the last few years.
- He/she should have a sound grounding in gender.
- Good listening skills.
- An understanding of group dynamics between himself/herself and the group.
- Ability to guide and synthesise the group's thinking.
- Be able to inspire and empower the group to move beyond the ideas he/she introduces to their own concerns and issues.

The facilitator helps create an enabling response by:

- Encouraging all the participants to take part in the discussion and helping the group to keep focus.
- Encouraging participants to explore different beliefs, values and positions, with a willingness to change.
- Encouraging mutual trust and respect for conflicting opinions and facilitating arriving at a consensus by the group.
- Summarising the sessions for closure and guiding the group to the next issue.

The facilitator should guard against:

- Acting as more of a "timekeeper" than as a mover of the event. To avoid this different participants could be asked to volunteer to keep time for the different modules.
- Allowing the group exchange to stray from the subject and failing to bring the focus back to the central theme.
- Lecturing rather than promoting an interactive exchange among the participants.
- Allowing an individual to dominate the dialogue in the workshop.
- Giving inadequate time to enable the participants to get to know each other.
- Being overly dependent on the resource guide or other materials, thus being unable to be spontaneous.

v. MATERIALS NEEDED

- Flip charts
- Flip chart markers

- Overhead projector
- Transparencies
- Demographic Silhouettes.

vi. BACKGROUND READING

The following are a few of the materials, which may be informative as background reading material.[17]

Ankarah, M., Schwartz, M., Miller, J. Women's Experiences with HIV/AIDS: An International Perspective. Columbia University Press, 1996.

Foreman, Martin, ed. AIDS and Men: Taking Risks or Taking Responsibility? England, PANOS Institute and Zed Books, 1999.

Nath, Madhu Bala. "She Can Cope", National AIDS Control Organisation, Government of India, March 1997.

Piot, Peter. "Intensifying the Global Response to the HIV/AIDS Epidemic" (16 September, 1998), Statement to the United States House of Representatives International Relations Committee.

Rao, Gupta, & Weiss, E. Women and AIDS: Developing a New Strategy. Washington D.C. International Centre for Research on Women, 1993.

Topouzis, Daphne. "Socio-Economic Impact of HIV/AIDS on Rural Households in Uganda", UNDP HIV & Development Programme.

UNAIDS. "Gender and HIV/AIDS: UNAIDS Technical Update", September 1998.

UNAIDS. "UNAIDS Epidemic Update", December 1999.

UNAIDS. "Report from a Consultation on the Socio-Economic Impact of HIV/AIDS on Households", 22 – 24 September 1995.

Visaria, Leela. "Men as Supportive Partners: Evidence from India", Population Council, June 1998.

World Bank. "Intensifying Action against HIV/AIDS in Africa: Responding to a Development Crisis", 1999.

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

AGENDA

9:00am – 9:10am	Welcome and Introduction
9:10am – 9:30am	Keynote Address
9:30am – 10:00am	**Session 1** Introduction and Expectation Setting
10:00am – 11:15am	**Session 2** Gender Concerns in HIV/AIDS and Development
11:15am – 11:30am	Tea Break
11:30am – 12:00pm	**Session 3** Implications of Gender Relations
12:00pm – 1:30pm	**Session 4** Demographic Silhouettes
1:30pm – 2:30pm	Lunch Break
2:30pm – 3:30pm	**Session 5** Bringing HIV into the Room
3:30pm – 3:45pm	Tea Break
3:45pm – 4:30pm	**Session 6** Planning for the Future
4:30pm – 5:00pm	**Session 7** Evaluation and Closing

SESSION 1

Introduction and Expectation Setting

i. Objective

To create a supportive learning environment and generate positive group dynamics during the process of the workshop.

ii. Time

30 minutes

iii. Materials/Equipment

1. Flip Chart/markers
2. Overhead projector
3. Transparency 1 – Objectives of the Workshop

iv. Methodology

1. Lecture by keynote speaker
2. Introduction in pairs

v. Steps

1. The facilitator welcomes the participants and introduces himself/herself to the group.
2. The facilitator invites the keynote speaker to deliver his/her address before the session is formally opened. It is recommended that the keynote speaker be senior enough to ensure the sustainability and effective follow up of the outcomes, recommendations, and future directions that are drawn up as the workshop is concluded. A senior decision-maker from the national government is therefore a good choice.
3. The facilitator invites the participants to introduce each other to the group through a participatory exercise. The participants are paired off, each introducing the other focussing on name, organisation, and two expectations for the workshop from each.
4. The facilitator writes the expectations on a flip chart.
5. Using Transparency 1, which highlights the objectives of the workshop. The facilitator clarifies which expectations can be met by the workshop. It is useful to provide reasons as to why certain expectations of a participant are outside of the scope of the workshop.

Note for the Facilitator Session 1

It is important to understand the value of aligning the expectations of the participants and the objectives of the training, in order to avoid any frustration that may arise if they anticipate a particular outcome that may not be appropriate to address in the workshop.

Transparency 1

OBJECTIVES OF THE WORKSHOP

- To enhance understanding about the gender concerns in HIV/AIDS and development.

- To identify strategies that can address the challenges of HIV/AIDS from a gender perspective.

SESSION 2

Gender Concerns in HIV/AIDS and Development

i. Objective

- To enable the participants to understand the gender dimensions of the epidemic globally and nationally.
- To move the common perception of the epidemic from being just a health issue to a greater understanding of its multisectoral nature.

i. Time

1 hour 15 minutes

ii. Materials/Equipment

1. UNAIDS country specific epidemiological sheets
2. Overhead projector
3. Transparency 2 – Gender and HIV – Critical Concerns and Insights

iii. Methodology

A dissonance-generating questionnaire to promote strategic questioning is filled out, to promote a self-evaluation of each participants knowledge about the epidemic. It also aids self-examination of each participant 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.

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 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 and familiarity with the status of the epidemic in the country in which the workshop is being conducted, are prerequisite for the successful outcome of this exercise.

Questionnaire Tips and Answers

i) 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 1 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.**

ii) 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.**

iii) Consequences – a Gender Analysis

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

iv) 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."

QUESTIONNAIRE
(Correct answers in bold)

Prevalence – a gender analysis

1. Today approximately _____ of the 33.4 million adults living with HIV/AIDS are women and the proportion is growing.

   - 21%
   - **46%**
   - 11%

   (Source: UNAIDS global data December 1999)

2. Of the new 16,000 infections occurring everyday, the percentage of women infected is

   - 80%
   - **50%**
   - 30%

   (Source: UNAIDS global data December 1997)

3. Following a trend observed in some countries, the male to female ratio among HIV infected persons has begun to equalise globally. In Russia the infected men now outnumber the infected women by _____ instead of an earlier figure of 6: 1.

   - 3:1
   - **2:1**
   - 1:1

   In Brazil the male to female ratio stood at 16:1 in 1986. Figures for 1997 indicate the ratio as _____.

   - 5:1
   - **3:1**
   - 1:1

   (Source: UNAIDS fact sheet December 1996)

4. In Thailand, where a combination of HIV prevention methods have successfully lowered infection rates in men, the prevalence in women attending ante natal clinics has continued to rise steadily from 0% in 1989 to _____ in 1995.

   - 0.2%
   - 23%
   - **2.3%**

(Source: UNAIDS Fact Sheet December 1996)

5. In Francistown, Botswana _____ of the pregnant women tested positive in a major urban surveillance site.

   - 2.3%
   - **43%**
   - 10%

   (Source: UNAIDS Fact Sheet December 1997)

6. Recent data from Mexico indicates that nine percent of all reported AIDS cases have been among housewives, and _____ among sex workers.

   - **0.8%**
   - 28%
   - 80%

   (Source: The Documentation of an Epidemic – Columbia University – Akeroyd Anne)

7. In men the highest prevalence of HIV infection is in the 25 – 35 year age group whereas in women prevalence peaks in the age group of _____.

   - **15 – 25 years**
   - 35 – 45 years

   (Source: UNDP Issue Paper No. 10.)

8. In Zimbabwe, among 537 adolescents identified as HIV positive, girls outnumber boys by _____.

   - 10:1
   - 5:1
   - **3:1**

(Source: Women AIDS Research Program – Department of Community Medicine - University of Zimbabwe)

Causes – a gender analysis

1. Heterosexual intercourse accounts for more than _____ of global adult infections.

   - 17%
   - 37%
   - **70%**

   (Source: UNAIDS Fact Sheet, December 1996)

2. Increase in STD cases indicates an increase in unsafe sex. WHO estimated that in 1995, there were 333 million cases of STD's of which 65 million were in Sub Saharan Africa and 150 million were in South and South East Asia. The presence of STD's increases the risk of HIV transmission _____ .

   - two fold
   - **five fold**
   - ten fold

   (Source: Health and Population Occasional Paper – ODA)

3. While HIV prevalence in male STD clinic attendees was stable between 1993 – 1994 rates have increased more than _____ fold among female STD attendees over the same period.

   - two
   - **five**
   - ten

   (Source: UNAIDS Fact Sheet December 1996)

4. In some villages in Uganda, focus group discussions revealed that _____ out of 22 men present had used a condom.

   - 18
   - 8
   - **2**

   Among all the women in these villages, _____ had seen a condom.

   - 50%
   - 15%
   - **0%**

   (Source: UNDP's Study Paper No. 2 The Socio-Economic Impact of AIDS on Rural Families in Uganda)

5. A behaviour surveillance survey financed by USAID in Tamil Nadu in India shows that 82% of the male STD patients had had sexual intercourse with multiple partners within the last 12 months and only _____ had used a condom

- 52%
- 22%
- **12%**

(Source: Health and Population Occasional Paper ODA)

6. Research shows that many men who have sex with men also have sex with women. Studies in India revealed that _____ of the male clients of male sex workers reportedly were married.

- **90%**
- 60%
- 20%

(Source: Review of "Best Practice" for Intervention in Sexual Health – Gordon and Sleightholme)

7. A survey on spousal communication in some developing countries found 35 percent of the women in the Philippines, never talked to their husbands about sexual matters. In Iran the figure was _____.

- 23%
- **53%**
- 73%

(Source: UNDP Issues Paper No. 3)

8. It has been reported that sexual activity in Uganda begins between the ages of 10 – 15 years and that the average age of first sexual intercourse for boys and girls in Uganda is about 15 years. An only girl's sample however revealed that the sexual intercourse occurred _____ than 15 years.

- **earlier**
- later.

(Source: UNICEF SYFA ibid)
Community based research has shown similar findings in Asia, Pacific and Latin America and the Caribbean.

9. A recent study by SAKSHI, an NGO in India, has indicated that _____ of the 13 – 15 year olds attending school had been victims of sexual abuse.

- 16%
- **60%**
- 75%

(Source: She Can Cope – Nath)

10. A study of female youth in South Africa showed that _____ of the girls had experienced sex against their will.

- 17%
- **71%**
- 50%

(Source: Taking Stock - Whelan and Rao Gupta ICRW.)

11. Researcher Anne Chao's data from Rwanda shows that the younger the age of first pregnancy or first sexual intercourse the _____ the incidence of HIV infection.

- lower
- **higher**

(Source: UNDP Issues Paper No. 8.)

Consequences - a gender analysis

1. In a study among women living with HIV/AIDS _____ had experienced violence.

   - 6%
   - 66%
   - **96%**

   (Source: Partner Violence in joint HIV Substance Abuse – Krauss, Goldamt and Bula)

2. Projections for Zambia and Zimbabwe indicate that because of AIDS, child mortality rates may increase _____ by the year 2010.

   - five fold
   - **three fold**

   (Source: UNAIDS Fact Sheet December 1996)

3. _____ of all parentless children in Uganda are between the ages of 10 – 19 years. This has increased their vulnerability to sexual abuse.

   - 29%
   - 40%
   - **69%**

   (Source: UNDP Study Paper No. 2 The Socio-economic Impact of AIDS on Rural Families in Uganda)

4. In the state of Sao Paulo AIDS became the leading cause of death in the 20-34 year old women in1992. In rural Uganda AIDS caused _____ out of 10 deaths for women between 20-44 years of age.

   - 3
   - 5
   - **7**

   (Source: UNDP Study Paper No. 2, The Socio-economic Impact of AIDS on Rural Families in Uganda)

5. If a woman living in an agricultural community where women are responsible for subsistence farming, becomes infected and falls ill the cultivation of subsistence crops in her household will _____.

   - **decrease**
   - increase

   (Source: Social Impact of HIV/AIDS in Developing Countries – Danziger)

6. To fill gaps in food production in instances where outside workers cannot be hired due to depletion of the economic resources of the household, given the evidence available from the field of education _____ are pulled out of school.

- **girls**
- boys

(Source: Orphans of the HIV/AIDS Pandemic – Levine, Michaels and Back)

7. Since traditional gender norms support the primary role of women in child welfare, the burden of caring for the present 10 million AIDS orphans is likely to be borne by

- men
- **women**.

(Source: Orphans of the HIV/AIDS Pandemic – Levine, Michaels, and Back)

Do you agree or disagree with the following?

1. In many cultures, female ignorance of sexual matters is a sign of purity.[18]

2. Men don't like to admit their lack of knowledge and therefore do not seek out accurate information regarding HIV/AIDS prevention.

3. Women gain self-worth and social identity with the birth of children, so it is understandable that women have difficulty with the idea of non-penetrative sex and the use of barrier methods such as condoms.

4. Multiple sexual partnerships are acceptable for men in many societies.

5. Sex between men is socially stigmatising and often illegal which makes it difficult to access information on safe sex practices.[19]

6. Modesty and virginity as a value is central to the image of womanhood.

7. There is no positive language for sexuality. For example, Mexican women asked to name the parts of their bodies could find no word for the vagina except "la parte" or the part.

8. Behaviour change strategies need to address socio-cultural norms, in order to be effective in preventing the spread of the epidemic.[20]

[18] Conversely knowledge of sexual matters and reproductive physiology a sign of easy virtue.
[19] The same applies to commercial sex work.
[20] For example, having sex with a virgin can cure STDs, or for effective and safe truck driving, it is necessary to let the heat out of your body byhaving sex every 400 kilometers.

Transparency No 2

GENDER AND HIV – CRITICAL CONCERNS AND INSIGHTS

- Although HIV/AIDS is a disease affecting both men and women, recent trends show an increase in the number women becoming infected at a very young age.

- Regional factors, age and gender implications are key variables in the incidence of HIV/AIDS.

- The promotion of behaviour change is important for the prevention of the spread of the epidemic as well as in minimising its impact.

    - Change in behaviour has to focus not only on individual behaviour, but also on collective behaviours, norms, and values of the society.

    - Men have a key role to play in interventions designed to benefit women.

- The feminisation of poverty is a key characteristic of the socio-economic impact of HIV/AIDS.

- Legal and policy frameworks need to be made more enabling to ensure positive and sustainable changes.

Speaking points for the facilitator Session 2

"Myths and Rituals – Increasing Women's Susceptibility" – by Madhu Bala Nath

AIDS was first detected as a distinct clinical syndrome in the summer of 1981, when physicians in California and New York noted clustering of unusual infections and cancers in their patients. Almost all these patients were young gay men, a group not previously known to have such 'opportunistic' infections. In August, a mere two months after the first cases were reported in men, the same syndrome was identified in a woman. It was soon apparent that women were also vulnerable and within a year or two there was data to suggest that women were as likely to become infected with the virus as men. The initial misunderstanding that AIDS was a disease of men could be attributed perhaps to a historical accident. Yet myths around the virus prevailed. In 1985, a cover story in "Discover," a popular U.S. science magazine dismissed the idea of a major epidemic in women. The explanation given was that because the rugged vagina was designed for the "wear and tear of intercourse and birthing," it was unlikely that women would ever be infected in large numbers through heterosexual intercourse. Nevertheless, even as such projections were being written, HIV was affecting millions of women. By 1991, AIDS was a leading killer of young women in most large US cities.[21] Today approximately 41 percent of the 30.6 million adults living with HIV/AIDS are women and the proportion is growing. Of the new 16,000 infections occurring everyday, the percentage of women infected is 50 percent. Following a trend observed in other countries, male to female ratios among HIV infected persons have begun to equalise. In Brazil the ratio stood at 16:1 in 1986 but the figures for 1997 indicate the ratio as 3:1.[22] The first myth that women were not vulnerable or susceptible to the epidemic had been broken.

Why are women more vulnerable?

Women are biologically more vulnerable:

- As a receptive partner women have a larger mucosal surface exposed during sexual intercourse.
- Semen has a far higher concentration of HIV than vaginal fluid.
- Women thus run a bigger risk of acquiring HIV, more so if the intercourse takes place at an age when the mucosal surface is still tender or when it is damaged due to rituals and practices like infibulation, early marriage etc.

Women are epidemiologically more vulnerable than men:

- They tend to marry or have sex with older men who may have had more sexual partners and hence be more likely to be infected.
- Women frequently require blood transfusions during childbirth and abortions, as prevalence of anaemia amongst pregnant women in developing countries is usually very

[21] Lurie, Hitzen and Lowe 1995
[22] Source – UNAIDS fact sheet - December 1996 and 1997.

high. In India, an evaluation by the Indian Council of Medical Research reported the prevalence of anaemia amongst pregnant women as high as 87.6 percent.

The inside – outside dichotomy which has socially confined women to the inside has in fact a definite bearing on women's sexuality. This relates to her powerlessness to deal with the outside.

- Can a woman be sexually assertive?
- Can she suggest safe sex to her spouse or partner without fear of violence as the suggestion itself carries with it an indication of infidelity.
- Is she sexually safe from even her so-called protectors? A recent study by SAKSHI an NGO in India has shown that 60 percent of the 13-15 year olds in schools had been victims of sexual abuse, 40 percent within families and 25 percent were victims of serious abuse e.g. rape.
- The inside outside dichotomy has also led to the issues of lack of access and control over productive resources. The issues of survival are only increasing and are in fact transforming people from creators to survivors. HIV has been able to grow and survive in such situations where commercial sex remains at times the only viable option for survival.
- The epidemic is thus, now drawing in women who have had only one sexual partner. 97 percent of the female respondents in a STD study in Zimbabwe cited their husbands as the source of their infection.

Inspite of these realities, why then were the voices of women with HIV/AIDS absent from scientific and popular commentary a full decade into the pandemic? If a search is conducted using the term, 'AIDS,' over 100,000 references are instantaneously available. In restricting the search by adding the term, 'Women and AIDS,' one finds a little over 2000 references. But if the search is restricted to, "Women, Poverty and AIDS," the computer informs you that there are no references meeting this specification.[23]

One explanation for this silence is that a majority of women had been robbed of their voice long before HIV appeared to further complicate their lives. "In settings of entrenched elitism they have been poor. In settings of entrenched racism they have been women of colour. In settings of entrenched sexism they have been women."

The social construction of sexuality with its inherent myths and values around morality, fertility and sexuality has been used to project social values and norms that have been different for men and different for women. Thus multiple sexual partnerships are accepted and condoned for men in many societies whereas, modesty and virginity as a value is central to the image of womanhood. Cultures in many parts of the world consider female ignorance of sexual matters a sign of purity and conversely, knowledge of sexual matters and reproductive physiology, a sign of easy virtue. Added to this is the absence of a positive language for sexuality. The existing language around sexuality is perhaps the most difficult

[23] Farmer, Connors and Simmons 1996.

means of articulating the same. A conspiracy of silence therefore continues to surround HIV/AIDS.

How have these cultural blocks affected women?

- Women have found it difficult to overcome these barriers of silence and have not been able to open up communication with clinicians and counsellors – the two critical pillars to assist a woman to overcome the impact of the epidemic.
- Because women have been constrained in talking about sexuality, there is little known about the disease in women. The men have comprised the majority of subjects in studies that form a foundation for our current treatment of HIV infection with anti retroviral therapy as well as our best knowledge about prophylaxis and treatment of opportunistic infections. Cotton and co-workers reviewed data regarding accrual of patients to multicenter trials and found that only 6.7 percent of the participants were women. As a result, timely diagnosis for women has been compromised by inappropriate case definitions of the symptoms of AIDS.[24]

The existence and persistence of this social construction of sexuality has led to the evolution of a number of rituals that have made women more vulnerable to the epidemic. The rituals take various forms in various countries The underlying message that all these rituals portray is that women's sexuality represents the interface between two most potent and insidious forms of oppression that prevail in society – gender and sexuality. The reluctance to address these issues has limited the effectiveness of programs designed to improve women's health, develop life skills and prevent HIV and other sexually transmitted diseases.

How do these rituals affect women?

The Girl Child

In South Asia, some cultures celebrate the girl's coming of age. Menarche is viewed as a symbol of the girl's fecundity and the family begins to think of arranging the girl's marriage. Among the rituals performed is a ceremonial bath and the distribution of sweets in the neighbourhood. However linking menstruation to child bearing and delinking it from sexuality is a mechanism by which the latent sexuality of a woman is curbed. Marriage soon after menarche is one method by which parents channel the potent sexuality of young women into a socially acceptable state – the state of nurturing motherhood rather than a seductress. There is thus an enormous gap between women's lived experience and what women want sexual relations to be. Women in large parts of South Asia have sex, performing it as a duty, to ensure a socially secure position or in order to become pregnant. Soon the young girl child gets pregnant[25]and the ritual of 'Vallaikappu' is performed. The hands of the pregnant

[24] For example cervical dysplasia and tuberculosis are two diseases that often herald HIV infection in women. Poor women are much more susceptible to infection with human papilloma virus (HPV)and Mycobacterium tuberculosis . However, because, tuberculosis and HPV were not "AIDS defining illnesses" according to the criteria established by the Centre for Disease Control, women presenting with these problems were overlooked.

[25] In Mauritiana, 15 percent of girls have given birth by the age of 15, in Bangladesh 21 percent have at least one child by the age of 15 – Source United Nations 1991

woman are decked with bangles, ostensibly to deter any further conjugal relationships during that pregnancy and the completion of this ritual signals a temporary separation between the husband and the wife until the delivery and in fact until a few months after. It is during these periods of forced separation that men seek sexual gratification outside of marriage, behaviour that is more often than not condoned by society.[26] The girl child now a young mother returns to her husband's house once again to perform sex as a duty, little aware of her husband's infidelity and her own vulnerability to the epidemic.

The Young Mother

In West Africa, a system of societal beliefs has been developed over time to manage the process of procreation. In the scale of social values, childbearing is elevated to a value, which confers a high social status. On the other hand a stigma is attached to a childless woman. In parts of West Africa, the ultimate punishment is reserved for barren women. They are denied normal funeral rights and are buried secretly at night outside the village. Thus if a woman did have sex with a condom to protect herself from HIV/AIDS how would she be able to prove that she is fertile? In some cultures in Nigeria women perform painful rituals to ensure fertility. In Nigeria, "gishiri" or salt cut is practised traditionally. This involves an incision on the interior of the vaginal wall, which is believed to cure infertility.

The loss of life of a woman in childbirth is expressed as the falling of a soldier in the line of duty. This ethic of nobility and duty has been internalised by women in a manner so that pain and discomfort emanating from their sexual and reproductive roles are accepted as the very essence of womanhood. The psychological preparation of young girls for childbirth instead of being factual information on safe motherhood aims to increase the threshold of the tolerance to pain. A common example is the advice given to young mothers to endure a level of effort equal to that which would be required to produce water by pressing hard enough on a stone. Because of this stoicism, vital life threatening signals are not often communicated until too late. For instance, severe haemorrhage is viewed by women to be a good sign because the body is seen to be eliminating bad blood.[27] The consequence is a poor state of reproductive health with lesions and cuts in the woman's reproductive tract. This coupled with a societal induced inability to practice safe sex, has increased women's susceptibility to the epidemic.

The Widow

In a UNDP study paper entitled, "The Socio-economic Impact of HIV and AIDS on Rural Families in Uganda", author Daphne Topouzis, brings out the stark realities of such situations through the real life story of Miriam. Miriam, a widow from Gulu, lost her husband to AIDS and is herself sick with the virus. Her brother–in–law tried from the very beginning (as per custom) to inherit her but she categorically refused, so as not to infect him and his wife. He harassed her for almost a year and when she still held firm he cut off all financial support to her and her four children. Now he is trying to claim the land that his brother left. A widow's dilemma is whether to be inherited or be abandoned. Wife inheritance thus

[26] Whispers from Within by Solomon and Pachauri
[27] A Tora Mousso kela La –A Call Beyond Duty – Alpha Boubacar Diallo.

greatly facilitates the spread of HIV and has the potential of infecting several families very rapidly. When widows are inherited by their late husband's brother, they risk infecting them as well as their co-wives. If any of the wives subsequently give birth to children, they may also be infected with HIV. In some cases widows whose husbands have died of causes unrelated to the epidemic may become infected with HIV if the brother in law is already infected.

The rituals cited above are only indicative and not exhaustive. They are indicative of the way in which women are susceptible to the virus at every stage of their lifecycle – as young girls, as mothers, as wives and as widows. The list of such myths and practices that have enshrouded human sexuality is long. In many cultures, the genitals are surrounded by mystery because they are the 'instruments' used to put curses on others. Among the Kikuyu, for example, the worst curse that can be bestowed on a man is usually is that when a woman, the age of his mother, lifts her skirt and turns around. [28]

- In India and Indo China it is believed that having sex with a virgin can cure sexually transmitted diseases in men.
- Western Kenya abounds with stories among teenage peers that failure to indulge in sex results in backaches.
- The truckers in South Asia have been socialised to believe that it is important to have sex every 400 miles, to release the heat generated in the body as a result of driving long distances sitting in hot cabins.
- In Papua New Guinea, a widely held belief is that a prophylaxis for STDs is to cut the penis and drain off the possibly infected blood after an intercourse.
- In Mexico, it is generally acceptable for men to have sex with men provided they take the active insertive role in anal intercourse as this is regarded as macho or super masculine.
- In many parts of Africa, women insert external agents into their vagina, including scouring powders and stones, to dry their vaginal passages in the belief that increased friction is sexually more satisfying to the males and this will prevent them from "wandering out."

Myths are also rooted in the nature of denial that is associated with HIV/AIDS. Because HIV/AIDS is so frightening, there is a temptation to deny the existence of the disease. After all wouldn't it be nice if the disease were not there. In large parts of the world even today, there is a tendency to attribute HIV/AIDS to witchcraft, or to believe that a cure for the virus is available in traditional and alternative medicine. This precondition of the human mind has been keeping people from owning responsibility about their sexual decisions.

Women living with HIV today are challenging this state of affairs. Their voices ring out loud and clear. There is a firmness and conviction in the statements being made. Says Lydia, who for eight months weathered bouts of diarrhoea, fought herpes zoster, lived with a horrible persistent cough, vomited most of what she ate and bore drenching night sweats and

[28] Source – Understanding the Challenge – Raphael Tuju.

ulcers: “The Kenyans should stop cheating themselves about this disease. Let us stop pretending about the problem. The problem is real. I am a living example. There are thousands suffering out there. The disease is spreading like wildfire every day and night. So why all this pretence? Many people are engaging in promiscuous behaviour as if there is no AIDS. AIDS is here with us. The sooner we face the reality as individuals and as a society the better for us all.”

In Uganda, Agnes living with HIV is successfully resisting wife inheritance. “Poverty is not an excuse for wife inheritance.” She thinks that women can resist being inherited but that self-assertiveness largely depends on how they are raised and on the type of relationship they had with their husbands.

Patricia is working towards setting up a group in her village, Tororo, that would encourage girls to develop life skills so that myths around sexuality can be exploded and to create income generating opportunities that would keep them away from “bad company” as she puts it.

In Asia, Mala is living positively, with her second husband who is also HIV positive and they are both working with a support group for people living with AIDS. They both feel wanted and valued. The work they do is important.

The task for development workers is to transform this fragmented energy into a holistic force - a force that moves from questioning deeply rooted myths and practices to building a body of information that is grounded in reality, and that which is based on lived experience. It may seem like utopia but women are beginning to dream this utopia. And as we advance into the next century women are beginning to discover ways of living positively with HIV/AIDS. This perhaps is a major step forward in reducing women’s susceptibility to the mutating virus.

SESSION 3

Implications of Gender Relations

i. Objective

- To enable participants to explore their own values towards gender, sex and sexuality.
- To enable the participants to evaluate with a gender perspective their understanding of the basic facts of HIV/AIDS.

ii. Time

30 minutes

iii. Materials/Equipment

Handouts: Three sets of two or three controversial statements printed in bold. (See end of Session 3).

iv. Methodology

Consensus building through group discussion and participatory brainstorming.

v. Steps

1. The facilitator divides the participants into three groups by having them count off in threes.
2. The facilitator distributes to each group one set of the controversial statements. Each group is asked to reach consensus on whether they agree or disagree with the statements giving reasons for the positions that they take.
3. The statements are:

   Group One

   - Homosexuality is abnormal.
   - HIV positive women can give birth to an HIV negative baby.

   Group Two

   - Women with HIV should not breast feed their babies.
   - There is a less than one- percent chance of transmission of HIV per intercourse through unprotected penetrative sex.
   - Mosquitoes can transmit HIV if they bite within five minutes of biting an HIV positive person.

Group Three

- Sex education encourages early sexual activity.
- Caring for people with HIV/AIDS is risky.
- We can control HIV if we test the whole population of a country and isolate those who are HIV positive.

4. The facilitator requests the group to identify a group leader to guide the discussion and make a presentation in plenary.
5. Each group reports back to the plenary. After each presentation the facilitator asks for comments from the other two groups. The facilitator fills in the gaps in knowledge and understanding drawn from the "Notes to the Facilitator".

Notes to the Facilitator Session 3

- As the participants discuss issues in their respective groups, the facilitator spends time with each group making sure that the discussion within the group keeps to the point.
- The facilitator should feel free to reassign the statements depending on the strengths of the groups.
- This exercise provides an opportunity to strengthen consensus-building skills, which are critical for change agents. The facilitator encourages the groups to make their presentation at plenary only if a consensus is reached. If reaching consensus within the group proves to be difficult, the facilitator should intervene and provide information to the group from the speaker's notes that could accelerate the process of consensus building within the group.
- If a consensus is still not reached the group's presentation is deferred till a later time giving the facilitator the opportunity to provide input over lunch to enable the building of a group consensus.

Speaking points for the facilitator Session 3

The answers to the questions are as follows

Homosexuality is abnormal. – False

Homosexuals are attracted to people of the same sex and derive sexual pleasure from them. Both men and women can have such an attraction. At different times in a person's life they may find they are attracted to different kinds of people. In most people's lives they will experience some level of attraction to others of the same sex. It is common and should be considered normal. Human sexual response doesn't neatly fit into a set of prescribed terms. Each person falls somewhere along a spectrum of sexual attraction. It is estimated that only ten percent of the population is solely attracted to people of the opposite sex. It is estimated that another ten percent is solely attracted to people of the same sex. The remaining eighty percent fall between the two and choose to live predominantly a heterosexual lifestyle.

Sex education encourages early sexual activity. – False

Studies undertaken in Latin America support the notion that teenagers are highly sexually active with most young people beginning sexual activity in their teenage years. Rates of partner change are also higher during the teens and early twenties. Young people are also especially vulnerable to HIV and other STD's: in many countries, 60 percent of all new infections occur among 15-24 year olds. Multicultural, multi-country studies show that teenagers who receive sex education are more likely to postpone initiation of sexual activity, and when they do no initiate sex, they are better able to negotiate protected sexual intercourse than those who do not receive sexual education.

Other studies suggest the importance of community involvement in sex education and that the experience of talking about sexuality with trusted others is in itself an important process. Experience in Zimbabwe suggests the need to focus not only on girls but also on boys, parents and teachers. In this instance a program, which began with girls, at their request, was broadened to include boys (in single sex and then mixed groups) and subsequently was extended to involve parents and teachers.

Where information, skills training and services are made available to young people, they are often more likely to make use of it than older people. Young people may not be most willing to adopt safer behaviours at the beginning of their sexual 'careers'. Peer education, which includes young people talking to other young people, has been shown to be an effective strategy.

Women with HIV should not breast feed their babies. – True

The breast milk in HIV positive mothers transmits the virus to the baby. Hence in the developed countries HIV positive mothers are counselled not to breast-feed their babies. But in developing countries breast feeding is continuing to be promoted, supported and protected, depending on the mothers access to clean water and/or supplies of artificial milk. In

addition, the cultural context would need to be kept in mind that in some societies mothers who do not breast feed will be stigmatised and discriminated against. In May 1998, WHO/UNICEF/UNAIDS announced new guidelines that support alternatives to breast feeding for mothers who test positive. The guidelines stress that access to sufficient quantities of nutritionally adequate breast milk substitutes must be ensured, and they endorse the need to implement measures to prevent breast feeding from being undermined for HIV negative women e.g. compliance with the International Code of Marketing breast milk substitutes.

There is a less than one- percent chance of transmission of HIV per intercourse through unprotected penetrative sex. – True

The rate of transmission of HIV through unprotected sex is less than one percent. HIV cannot penetrate intact skin or mucous membrane and enter the blood stream. It needs a break in the mucous membrane, e.g. an ulcer, through which it can enter the blood stream. It is therefore imperative to promote strategies that improve the reproductive health of most females as a preventive measure for HIV/AIDS.

Mosquitoes can transmit HIV if they bite within 5 minutes of biting an HIV positive person. – False

HIV virus lives within human white cells. It cannot live outside its host. Thus as soon as the white cells die, HIV is inactivated. Mosquitoes suck blood for food and do not inject blood. There is no way they can inject HIV back into another person. Any tiny amount of blood left on the outside of the mosquitoes stinger would be unable to transmit the virus as it dries very quickly. One reassuring statistical proof that mosquitoes do not spread HIV is that demographics of HIV infection and malarial infection are not the same. Because the majority of infections have been through sex, it is largely those people within the most sexually active age range who are infected with and die of AIDS. Most AIDS deaths occur between the age of 25 and 45. Malaria on the other hand, affects people of all age groups. Especially vulnerable are the very young and the very old. Thus, if mosquitoes could also transmit HIV, its prevalence would be as common among the very old and the very young as it is among young adults.

HIV positive women can give birth to an HIV negative baby. – True

The virus can pass from an HIV positive woman to her child during antepartum, intrapartum or postpartum. Still there is seventy- percent chance for an HIV positive woman to give birth to HIV negative baby. She can reduce the chance of transmitting the virus to less than five percent by taking antiretroviral drugs, and by not breast feeding her baby.

Caring for people with HIV/AIDS is risky. – False

Caring for people with HIV/AIDS cannot transmit the virus. HIV is spread through unprotected sex with an infected person, infected blood and blood products and from an infected mother to her baby, before, during, or soon after birth.

HIV cannot spread by casual contact such as touching, holding or shaking hands, body contact in crowded public places, working or playing together, sharing food, vessels and clothes, eating food cooked by an infected person, kissing, mosquito and other insect bites, swimming pools, and toilets.

Caring for people living with HIV/AIDS moreover is risk free if certain precautions are taken by the caregivers, e.g. avoiding contact with body fluids of PLWHAs in case there are cuts and lesions on the care givers hands.

We can control HIV if we test the whole population of a country and isolate those who are HIV positives. – False

Any testing must be done with the consent of the person to be tested. Unlike other diseases like TB and malaria, the HIV / AIDS epidemic involves complex social, cultural, ethical, and political issues. Also, since anything linked to sex, such as prostitution, STD, and now HIV, is considered a taboo subject by society an HIV positive person would be discriminated against and stigmatised. This is turn would encourage people with high-risk behaviour to avoid testing and to go into hiding and thereby hampering any measures taken to control the spread of the infection. Hence, voluntary, consented testing should be encouraged, and testing should not be made compulsory. In addition, there is a “window” of up to six months after being infected before the antibodies can be detected in the blood.

It may be noted also, that it may not be financially feasible to repeatedly test every single person, since costs of testing and counselling are high, and it may be more practical to use such limited resources for preventive and treatment strategies.

GROUP I

1. **Homosexuality is abnormal.**

2. **HIV positive women can give birth to HIV negative babies.**

GROUP II

1. **Women with HIV should not breast feed their babies.**

2. **There is a less than one-percent chance of transmission of HIV per intercourse by unprotected penetrative sex.**

3. **Mosquitoes can transmit HIV if they bite within five minutes of biting an HIV positive person.**

GROUP III

1. Sex education encourages early sexual activity.

2. Caring for people with HIV/AIDS is risky.

3. We can control HIV if we test the whole population of a country and isolate those who are HIV positive.

SESSION 4

Demographic Silhouettes

i. Objective

To create awareness of the social and economic causes and consequences of the epidemic at the level of the family and by extension at the community level.

ii. Time

1 hour and 30 Minutes

iii. Materials/Equipment

1. Silhouette cut-outs representing persons of different ages and sexes. They should have a yellow dot on the top and some should have a blue dot on the back.
2. Overhead Projector
3. Transparency 3 -- Gender disparities and HIV/AIDS.

iv. Methodology

Demographic Silhouettes[29] -- Group work to develop a story of a family selected from the silhouettes provided.

v. Steps

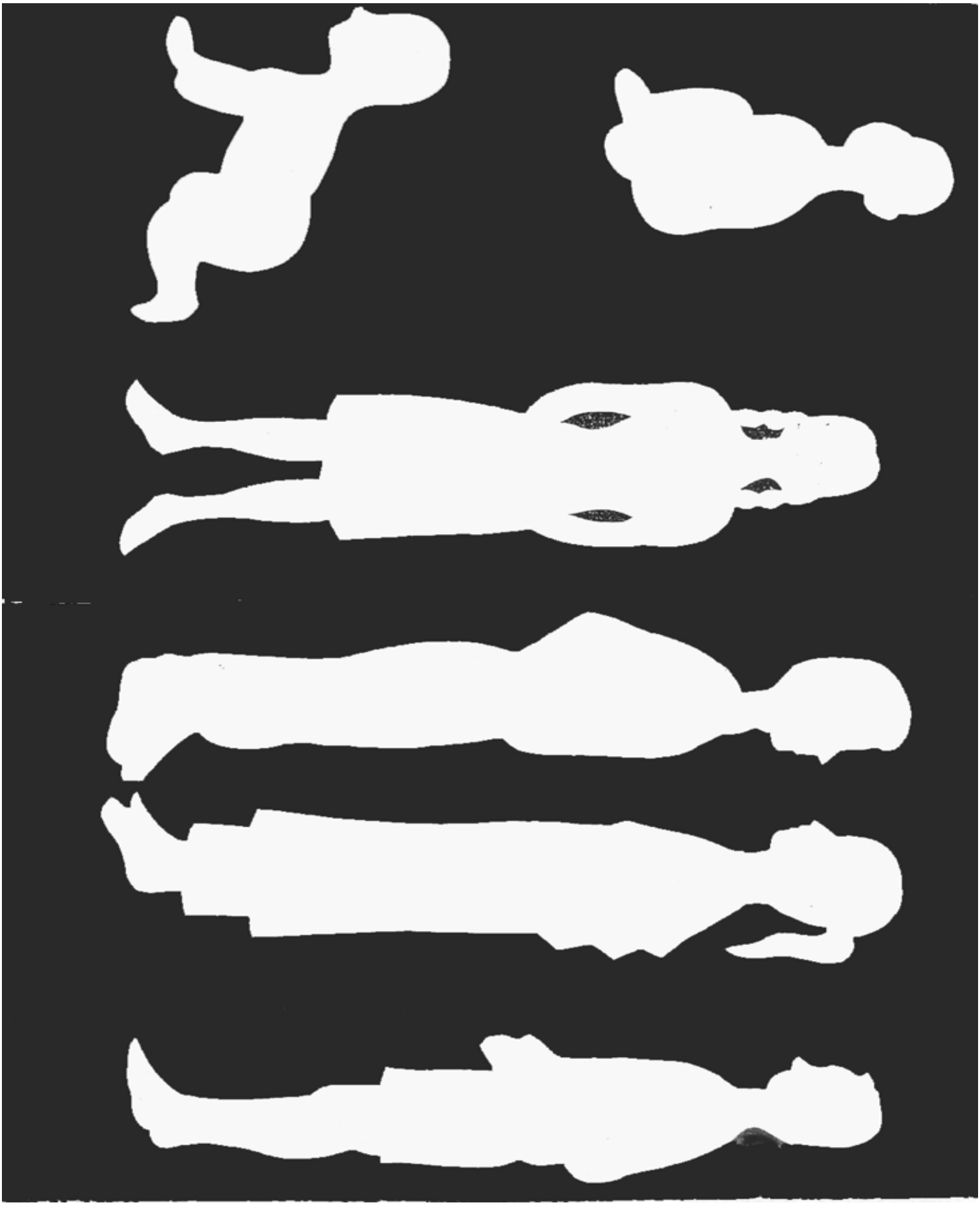
1. The facilitator places piles of silhouettes of men, women, children, old men, and old women on a table with the yellow dot facing up.
2. The facilitator forms three groups and each group is asked to select silhouettes that represent members of an imaginary family of their choice.
3. When all have comprised their imaginary families, the facilitator asks them to develop a story of their family, indicating the roles the members play in terms of meeting the economic, social, health and other needs of the family. This should result in a lively sharing of ideas about how members contribute to a family's quality of life.
4. After the stories are shared, the groups are asked by the facilitator to flip over the cards to expose the other side where some of the cards are marked with a blue dot.
5. The facilitator then tells the group that these members have HIV/AIDS.
6. He/she then asks the participants to develop the story further by reflecting on and discussing how this new information will affect the family roles established, and the well being of the family as a whole.

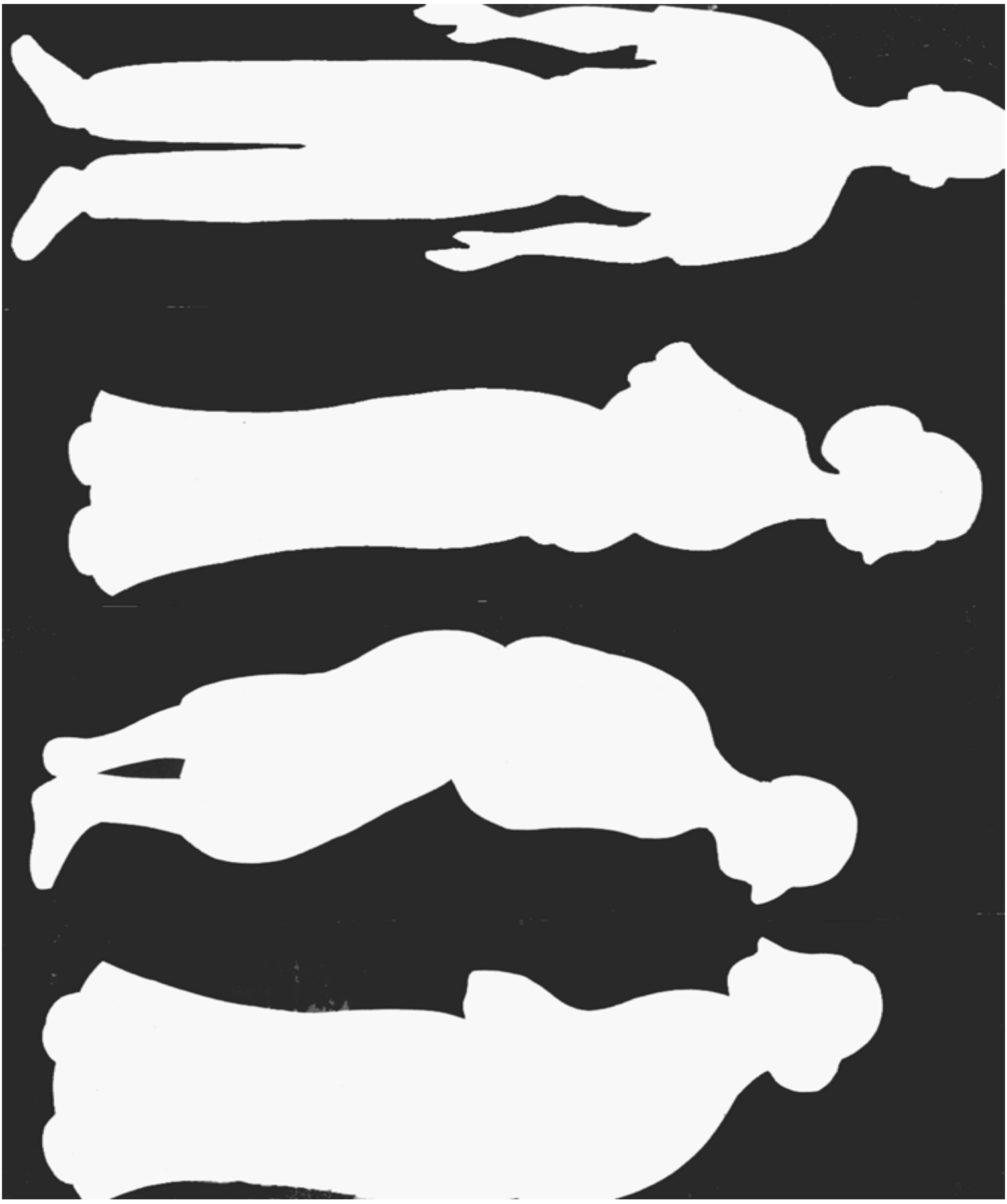
[29] Lyra Srinivasan, ACDIL Goa, India, has developed this learning tool.

7. The Facilitator asks what issues emerge from the stories, e.g. burden on women, denial, impact on the economy and at the end of the discussion the facilitator presents a transparency of the diagram showing the relationship between gender disparities and HIV/AIDS.
8. Time permitting, comments on how an impact at the household level can be transformed into an impact at the national and macro economic level is orchestrated.

Note to the Facilitator Session 4

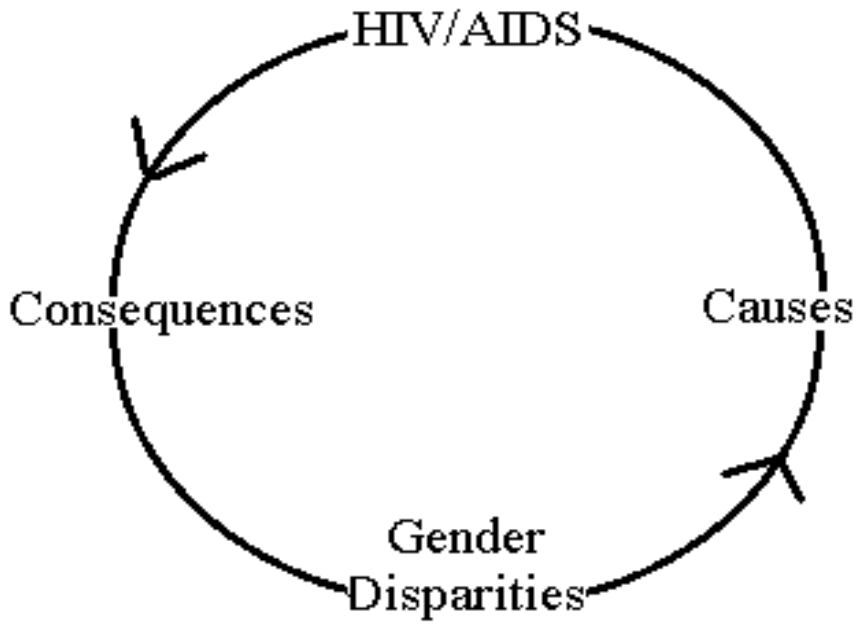
A certain amount of research exists on the impact of HIV on households. This research is available both qualitatively and quantitatively and has been synthesised. It is recommended that the facilitator read carefully the speaking points that are attached along with the article entitled "Living Positively in Changing Demographies". If all of this information on the impact on the household is internalised by the facilitator the discussion at the end of the presentations will be more realistic and credible.





Transparency 3

GENDER DISPARITIES AND HIV/AIDS



Speaking Points for the facilitator Session 4

Impact of HIV/AIDS on Development

i. Infrastructure

- In Cote d'Ivoire, Zambia, and Zimbabwe, HIV infected patients occupy 50-80 percent of all beds in urban hospitals.
  (Source: *Intensifying Action against HIV/IADS in Africa* – The World Bank, August 1999)
- The Ugandan Railway Corporation has been experiencing an annual turnover rate of fifteen percent. About ten percent of its 5600 employees died due to AIDS in recent years.
  (Source: Aids & Society: International Research and Policy Bulletin, Vol. 6, No.2, January 1995.)

ii. Mortality

- Projections for Zambia and Zimbabwe indicate that because of AIDS, child mortality rates may increase nearly 3-fold by the year 2010.
  (Source: UNAIDS Fact Sheet – December 1996)
- According to WHO projections, in Sub Saharan Africa, over the next few years, infant mortality is expected to increase by up to 30 percent as a result of the perinatal transmission of the HIV virus.
  (Source: James Chin – Current and Future Dimensions of the HIV/AIDS Pandemic in women and children 1990)
- By 2005, infant mortality in South Africa will be 60 percent higher than it would have been without AIDS.
  (Source: Intensifying Action against HIV/AIDS in Africa – World Bank 1999.)
- Without HIV/AIDS the average life expectancy in Africa in the year 2000 would have been 62 years. Instead it is expected to fall to 47 years. (Botswana life expectancy was 65.2 years in 1996 but it fell to 52.3 in 1997.)
  (Source: Human Development Report 1997)
- HIV/AIDS is now the leading cause of death in Africa.
  (Source: Human Development Report 1999)

iii. Agriculture

- In some districts of Uganda it is becoming increasingly difficult to implement the agriculture extension service as the agriculture staff are frequently attending funerals. Qualified technocrats are among those dying who are not easy to replace. Agriculture in Uganda accounts for over 60 percent of the GDP and provides 98 percent of export earnings and over 40 percent of government revenue. As of 1996, 10 percent of the total population and 20 percent of sexually active men and women are infected by the virus.
  (Source: *The Socio-Economic Impact of AIDS on Rural Families in Uganda*, Daphne Topouzis)
- According to studies undertaken by FAO, HIV is having a serious effect on rural livelihoods and farming systems in Uganda, Tanzania and Zambia. In Uganda a once prosperous community in the hard hit Rakai district witnesses the absence of young people between the ages 18-35. Homes and farms are in disrepair and there is a clear shift from labour intensive coffee and banana production to starchy staples such as cassava and sweet potato. Half of the plantations are reverting to bush. At the Nakambala sugar estate in Zambia, between April 1992 and March

1993, 75 percent of the deaths were from HIV/AIDS and 73.2 percent of those who died were between 31-50 years old.

- In Kagera, Tanzania agriculture production was reported to have fallen from the previous levels by 3 –20 percent due to HIV/AIDS related deaths
  (Source: *The Implications of HIV/AIDS for Rural Development Policy and Programming*, Topouzis and Hemrich)

iv. Education

- As early as 1991 Population and Housing census showed that in some districts of Uganda, parentless children form 23-33 percent of the population. About 70 percent of these children are 10-19 years old. A USAID study in one such district (Gulu) has reported that in 1990, 71 percent of the boys and 86 percent of the girls dropped out of school between grades 1-7.
  (Source: *The Socio economic Impact of AIDS on Rural Families in Uganda* – Daphne Topouzis)
- Due to HIV/AIDS, on average four teachers per week were lost per school in Zambia, in 1995, due to teacher illness and funeral attendance. The combined morbidity and mortality rate represents a 25 percent increase in public expenditure to maintain recruitment and staffing at current levels in the education sector.
  (Source: SAFAIDS News December 1996 – referring to Researchers Mukuka and Kalikiti 1995)
- By 2010, 15,000 teachers in Tanzania will have died from HIV/AIDS. The cost of training new teachers for replacement has been estimated to be $37.8 million.
  (Source: Intensifying Action against AIDS in Africa – 1999 World Bank)

v. Health

- With HIV on the increase in Cote d'Ivoire, the public health system cannot cope with demand, and people are suffering from non-HIV related illnesses have been driven towards private medicine and traditional healers.
- HIV-related care is taking up an increasing proportion of public health resources. At the university hospital in Treichville, Abidjan, HIV cases take up on an average 25 percent of the hospital days of different departments. The cost of trying to cope with HIV takes up 25 percent of the hospital's operating budget. It takes up 11 percent of the total operating costs of the country's entire public health budget.
  (Source – AIDS Analysis Africa – Research studies sponsored by the European Commission and published at the Abidjan AIDS in Africa Conference in December 1997)

vi. Industry

- A study in Kenya estimated that HIV/AIDS could increase labour costs for some businesses by 23 percent by the year 2005. An assessment of several private sector firms in Botswana and Kenya demonstrated that the most significant factors in increased labour costs were HIV/AIDS related absenteeism and burial expenses. The expenses are expected to double by 2005 if the epidemic continues to spread at its current rate.
  (Source: *Intensifying Action against AIDS in Africa* – World Bank Report August 1997)

Note 1

The UNDP Human Poverty Index (its components are longevity, deprivation in knowledge and deprivation in living standards) as well as the Human Development Index (its components are life expectancy, literacy and per capita) are very sensitive to the impact of AIDS. UNDP supported studies indicate that some countries have on an average lost many years of Human Development progress, a critical contribution to this loss being the impact of HIV/AIDS.

Country	Loss by No. of Years
Zambia	10
Tanzania	8
Rwanda	7
Central African Republic	6
Burundi, Kenya, Malawi, Uganda and Zimbabwe	3-5

Note 2

The approach of promoting community based responses is of special relevance to Asia and the Pacific where economists are arguing that although AIDS is a costly disease on a per case basis, they find no evidence that it is also costly at the level of the national economy in Asian and Pacific countries. This is perhaps due to the labour surplus situation of the continent. Their analysis of the impact of the Black Death on wages in Eastern Europe during the fourteenth century and that of the influenza epidemic of 1918-19 on agriculture output per capita in India further support this finding. Based on these results economists such as Bloom and Mahal have stated through UNDP sponsored research that interventions for HIV and development in Asia would need to be reoriented to focus more on individuals, families and households, on the economic roots of the epidemic in Asia and on the economic evaluation of alternative policies and programs that promote good governance.

Note 3 – A Denial of Choices

Although women are productively engaged in both the formal and informal sectors of the economy, there are gender-related differentials in women and men's access to productive resources such as land, property, credit, employment, training and education.

The various factors discussed previously also need to be viewed within the social construction of women's sexuality where the survival of the society requires that women spend most of their lives pregnant or in rearing children. It is therefore considered appropriate "to curb" women's sexuality so that she is regarded as a nurturing mother.[30] The consequences of this approach has been an enormous gap between women's lived experience

[30] This is not the same for men who as opposed to being passive procreators have to acquire power and status on the outside and so promiscuity needs to be accepted and at worse be condoned.

and what women want sexual relationships to be. Women therefore have sex not necessarily as an expression of love and pleasure, but for the following reasons:

- In order to become pregnant
- As a duty
- As a profession
- To secure survival
- To secure a social position.

The experience for a woman is therefore often harsh and violent. This is one aspect of the feminisation of poverty that needs to be addressed. The Human Development Report of 1997 states, “Human poverty is more than income poverty. It is a denial of choices and opportunities for living a tolerable life.”

Speaking points continued

"Living Positively in Changing Demographies" – by Madhu Bala Nath

A CHANGING DEMOGRAPHY

According to the latest population report prepared by the population division of the UN department of Economic and Social Affairs[31], children born in 29 sub Saharan African nations face a life expectancy of just 47 years because of the toll. This life expectancy figure represents a sixteen-year drop. In the absence of HIV/AIDS the life expectancy in these countries would have been 63 years.

The US Census Bureau has recorded similar trends. In a recent study on the impact of HIV/AIDS on demography, conducted by the US Census Bureau in 23 countries,[32] it has been stated that countries may experience the most severe demographic effects of HIV/AIDS, years after the epidemic has peaked. Life expectancy is expected to drop to 40 years or less in nine Sub Sahara African countries by 2010. The same study states that AIDS will reduce population growth rates to less than half of their expected levels by 2010 and they may remain low or negative for many years. In three countries, Botswana, Guyana and Zimbabwe, fertility rates may drop sufficiently to result in a negative population growth by the year 2010.

A corollary to shorter life expectancies is the increase in the number of orphaned children. In a report entitled, "Children on the Brink," the US Census Bureau has predicted that by the year 2010, the numbers of children who would have lost their mothers or both parents due to HIV/AIDS will swell to 22.9 million. As a result, in sub Saharan Africa, there will be 12 times as many children under 15 as adults over 64. The twenty first century therefore will witness a population profile at least in some parts of the world that will have a greater percentage of children under fifteen, facing unique challenges and performing roles that children have seldom performed in the earlier centuries.

With this as the demographic backdrop, the images of the epidemic in Africa are of families, which have a cognitive unfamiliarity:

- Families headed by children
- The ailing old surrounded by children little aware of how to tend the old and the sick
- Communities on the brink of survival trying to cope with the demand of productive labour
- Sick women tending sick children

22 million people are living with AIDS in this region.[33]

The impact in Asia is projected to be worse than in sub Saharan Africa. Though HIV was a late comer to Asia and the Pacific; its spread has been swift. Since 1994, almost every

[31] Source - Briefing packet – the 1998 revision of the world population estimates and projections
[32] Source - Children on the brink – Strategies to support Children Isolated by HIV/AIDS – USAID - 1998
[33] UNAIDS fact sheet June 1998

country in the region has seen HIV prevalence rates increase by more than 100 percent. Today 6.4 million people in Asia are believed to be living with HIV, a region that houses 60 percent of the world's sexually active population.[34]

In Latin America 1.4 million people are living with HIV. The distinguishing factors of the pattern of development in this region are a high external debt, an equally high debt service ratio, a low food production capacity and a very high urbanisation level. This has resulted in problems of development that increase poverty and give it a feminine face. For poverty that is urban is rootless, and is characterised by the growth of a low productivity informal sector (where women cluster for subsistence) and rapid demographic changes reflecting the disintegration of families and communities. A special feature of the epidemic in this region is the high numbers of young people (especially street children forced out of the security of a stable household as a result of the fast urbanisation) who are at risk. A survey in Rio de Janeiro revealed that 60 percent of the adolescent boys aged 15-19 engaged in sexual intercourse.[35] Rates as high as this have not been seen in samples of male teenagers in other parts of the world.

In recent decades North Africa and the Western Asian region have witnessed major political, social, economic and demographic upheavals, which have led to the exacerbation of existing, fairly large gender disparities. The persisting Gulf war and other armed conflicts like the Iran-Iraq war, the oil conflict between Iraq and Kuwait, civil wars in Algeria, Somalia have created situations of mass displacement of populations. UNAIDS estimates that the region has 210,000 HIV positive people, 20 percent of who are women. [36]

In Eastern Europe, though the absolute numbers are lower, many countries have experienced doubling or tripling of the infections since 1994.[37]

MEN, WOMEN AND THE EPIDEMIC

As the epidemic advances in geometric progressions, its impact on the lives of men and women is becoming more and more visible. Today approximately, 43 percent of the 33.4 million adults living with HIV/AIDS are women and the proportion is growing[38]. Of the new 16000 infections occurring everyday, the percentage of women infected is 50 percent. Following a trend observed in other countries, the male to female ratio among HIV infected persons have begun to equalise. In Brazil the ratio stood at 16:1 in 1986 but the figures for 1997, indicate the ratio as 3:1.[39]. Women's susceptibility to the virus has gradually been increasing.

Women are biologically more vulnerable because as a receptive partner women have a larger mucosal surface exposed during sexual intercourse. Moreover semen has a far higher

[34] Source - Intensifying the Global Response to the Epidemic – Statement by Dr. Peter Piot to the United States House of representatives, International Relations Committee.
[35] Source - AIDS – Images of the epidemic – WHO 1994
[36] Source - UNAIDS Fact sheet – June 1998
[37] Source - Intensifying the Global Response to the Epidemic – Statement by Dr. Peter Piot to the United States House of representatives, International Relations Committee.
[38] Source - UNAIDS Fact Sheet – June 1998
[39] Source – UNAIDS fact sheet - December 1996 and 1997.

concentration of HIV than vaginal fluid. Women thus run a bigger risk of acquiring HIV, more so if the intercourse takes place at an age when the mucosal surface is still tender or when it is damaged due to rituals and practices such as infibulation, early marriages etc.[40]

Women are epidemiologically more vulnerable than men are because, they tend to marry or have sex with older men who may have had more sexual partners and hence be more likely to be infected. Women frequently require blood transfusions during childbirth and abortions, as prevalence of anaemia amongst pregnant women in developing countries is usually very high. In India, an evaluation by the Indian Council of Medical Research reported the prevalence of anaemia amongst pregnant women as high as 87.6 percent.[41]

The inside – outside dichotomy, which has socially confined women to the inside, has in fact a definite bearing on women's sexuality. This relates to her powerlessness to deal with the outside. Can a woman be sexually assertive? Can she suggest safe sex to her spouse or partner without fear of violence as the suggestion itself carries with it an indication of infidelity. The epidemic is as a result, now drawing in women who have had only one sexual partner. 97 percent of the female respondents in a STD study in Zimbabwe cited their husbands as the source of their infection.[42] Is the woman sexually safe from even her so-called protectors? A recent study by SAKSHI an NGO in India has shown that 60 percent of the 13-15 year olds in schools had been victims of sexual abuse, 40 percent within families and 25 percent were victims of serious abuse e.g. rape.[43] The inside outside dichotomy has also led to the issues of lack of access and control over productive resources. The issues of survival are only increasing and are in fact transforming people from creators to survivors. HIV has been able to grow and survive in such situations where commercial sex remains at times remains the only viable option for survival.

A CULTURE OF SILENCE

Despite these realities, why then were the voices of women with HIV/AIDS absent from scientific and popular commentary a full decade into the epidemic? If a computer search is conducted using the term, 'AIDS,' over 100,000 references are instantaneously available. In restricting the search by adding the term, 'Women and AIDS,' one finds a little over 2000 references. But if the search is restricted to, "Women, Poverty and AIDS," the computer informs you that there are no references meeting this specification.[44] One explanation for this silence is that a majority of women had been robbed of their voices long before HIV appeared to further complicate their lives.

This is because the social construction of sexuality with its inherent myths and values around morality, fertility and sexuality has been used to project social values and norms that have been different for men and different for women. Cultures in many parts of the world consider female ignorance of sexual matters a sign of purity and conversely, knowledge of sexual

[40] Source - Young Women, Silence, Susceptibility and The HIV Epidemic – Elizabeth Reid – UNDP Issues Paper.
[41] Source - She Can Cope – Madhu Bala Nath
[42] Source - Psychosocial Aspects and gender Issues in Zimbabwe – Pitts and Bowman
[43] Source - Sexual Behavior Among Adolescents in India – Kapur and Purewal
[44] Source - Women, Poverty and AIDS - Farmer, Connors and Simmons 1996.

matters and reproductive physiology a sign of easy virtue. Added to this is the absence of a positive language for sexuality. The existing language around sexuality is perhaps the most difficult means of articulating the same. A conspiracy of silence therefore continues to surround HIV/AIDS.

Women have found it difficult to overcome these barriers of silence and have not been able to open up communication with clinicians and counsellors. Because women have been constrained in talking about sexuality, there is little known about the disease in women. Up to now men have formed a vast majority of subjects in studies that form a foundation for our current treatment of HIV infection with anti retroviral therapy as well as our best knowledge about prophylaxis and treatment of opportunistic infections. Cotton and co-workers reviewed data regarding accrual of patients to multicenter trials and found that only 6.7 percent of the participants were women.[45]

LIVING POSITIVELY

Women living with HIV today are challenging this state of affairs. Their voices ring out loud and clear. There is a firmness and conviction in the statements being made. Says Lydia, who for eight months weathered bouts of diarrhoea, fought herpes zoster, lived with a horrible persistent cough, vomited most of what she ate and bore drenching night sweats and ulcers, "The Kenyans should stop cheating themselves about this disease. Let us stop pretending about the problem. The problem is real. I am a living example. There are thousands suffering out there. The disease is spreading like wildfire every day and night. So why all this pretence? Many people are engaging in promiscuous behaviour as if there is no AIDS. AIDS is here with us. The sooner we face the reality as individuals and as a society the better for us all."

In Uganda, Agnes living with HIV is successfully resisting wife inheritance. "Poverty is not an excuse for wife inheritance." She thinks that women can resist being inherited but that self-assertiveness largely depends on how they are raised and on the type of relationship they had with their husbands.

Patricia in Tororo village in Uganda, is working towards setting up a group in her village that would encourage girls to develop life skills so that myths around sexuality can be exploded and create income generating opportunities that would keep them away from bad company as she put it.

HIV AND YOUTH – A FORCE FOR CHANGE

These kinds of efforts at preventing the spread of the epidemic have inevitably led to the questioning of existing social norms by young people. A small group of young people; not yet a critical mass are raising questions like – "Why don't parents talk to us about sexuality?" "Why is promiscuity condoned by societies in the case of men and why is virginity so important for girls?" These questions are being raised because young people are realising that their access to information about their sexual health is constrained by the existence of social frameworks. Young women risk their sexual health because they must appear to be ignorant and so cannot openly seek information. Young men risk their sexual health because

[45] Source - Women, Poverty and AIDS - Farmer Connors and Simmons 1996

they must feign knowledge about sexuality even if their social environment does not offer opportunities to access appropriate and accurate information on sexual matters.

In Kenya a recent study revealed that young women felt that they did not have control over their sexuality – instead girls learnt that sex was something that happened to them. It was not something that they could initiate or actively participate in. [46] In Nicaragua, teenaged boys face social pressures from older men (including fathers, older brothers and uncles) to have sex as early as possible and in the recent past it was not uncommon for fathers to arrange for their son's initiation with a sex worker.[47] So while for girls public disclosure of sexual activity leads to dishonour, bragging about sex is common for boys.

Female genital mutilation and male circumcision when practised as part of group initiation ceremonies or in ways involving the sharing of razors, knives and other cutting instruments can increase the risk of HIV transmission from one young person to another.

A broad variety of prevention programs have now been undertaken with the aim of reducing risks of HIV transmission among young people.

There have been programs designed to help adults improve their skills and increase effective communication about sex with young people. In Mexico following a training program involving videos and group discussions parents reported feeling better equipped to talk with their children about sex [48]. In Kenya, an intensive training course for church leaders led to the initiation of a prevention program for young people by the Methodist Church.

There seems to be a belief that giving information about sex to young people will make them more active sexually and perhaps more promiscuous. As a result sex education in schools promotes at best only certain risk reduction measures e.g. abstinence. In response to these challenges, youth programs in many countries have turned to focus on personal capacity building such as assessing personal risk, decision-making and negotiation skills. In addition a full range of "options for prevention" are given to young people. An interesting mix has been derived in Kenya and Nigeria where "Fidelity", "Abstinence" and "Condoms" are pictured as three life boats in the sea of HIV/AIDS – the message being that people may shift from one to another according to their circumstances, as long as they are safely in one boat.

Some peer education programs aimed at young people out of school have helped to bring about significant reductions in HIV-related risk behaviour. In the Rakai district of Uganda, where high rates of HIV infection have been reported among young people, researchers found that sexually active young people involved in peer education programs were five times

[46] Source - Adolescents, Sexuality, Gender and the Epidemic – Kim Rivers and Peter Aggelton (Balmer et al 1997)
[47] Source - Adolescents, Sexuality, Gender and the Epidemic – Kim Rivers and Peter Aggelton (Zelaya et al 1997)
[48] Source - Adolescents, Sexuality, Gender and the Epidemic – Kim Rivers and Peter Aggelton (G.C Vanden et al 1997)

more likely to report using condoms than those who had not been involved in peer education.[49]

In Mumbai, India, practitioners designing HIV-prevention programmes targeting girls found that it was crucial to first gain the support of parent and others in the wider community. A program of HIV/AIDS awareness for the wider community was launched prior to the initiation of the work targeting girls. Program designers also learned those young women and girls had heavy domestic workloads including responsibility for the care of younger siblings. It was important therefore to provide crèche facilities to ensure that young women would be free to attend the program. Rather than concentrating solely on HIV/AIDS, the program designers included a range of topics on reproductive and sexual health as well as discussion of gender issues. Methods included storytelling, role-playing and games. The average age of girls involved in the program was 14 years. The program proved very popular with young women and participation increased as sessions went on. After seven sessions, the young women requested additional sessions. A follow-up survey found that 62 percent of the girls who took part in the sessions reported that they had subsequently discussed HIV/AIDS with others.[50]

Today there is also increasing information about initiatives that have failed. Programs that do not involve young people in the design and implementation fail to respond to the diversity of their needs. For many young people the costs, timing and location of health services are barriers to their effective utilisation. Furthermore, these services require that young people be accompanied by their parents or spouses (in case of married girl children) and the judgmental attitude of many health professionals discourage them from seeking advice on sexual health and related issues. Programs that have not been successful are those that have failed to provide opportunities to think and talk about gender and sexuality.

For example, 50 percent of Sri Lankan male university students interviewed, reported that their first sexual experience had been with another man (Silva, 1997). In addition, there are well documented studies of behavioural bisexuality among men in countries like the Philippines (Tan 1996), India (Khan 1996), Brazil (Parker 1996), and Morocco (Bourshaba et al 1998).[51] Yet there are few programs that take these realities into account and address the needs of homosexual and bisexual adolescents. This has implications for the increasing transmission of the virus in young women.

Investing in the future, investing in the children and in the youth is therefore a critical imperative. The youth of tomorrow, it is envisaged will be bearing new burdens as a result of the epidemic. HIV/AIDS is already placing new demands on family resources and is reducing the time adults can spend on income generating activities. The demand on children's labour for domestic chores and income generation to meet treatment and funeral costs will prove to be quite heavy.

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[49] Source - Adolescents, Sexuality, Gender and the Epidemic – Kim Rivers and Peter Aggelton (Kelly et al 1995)

[50] Source - Adolescents, Sexuality, Gender and the Epidemic – Kim Rivers and Peter Aggelton

[51] Source - Adolescents, Sexuality, Gender and the Epidemic – Kim Rivers and Peter Aggelton (Tan 1996, Khan 1996, Parker 1996, Bourshaba et al 1998)

As mentioned earlier, the U.S. Census Bureau has just concluded a study in 23 countries of the world. According to the findings of this study the total number of children who will lose one or both of their parents from all causes of death in these countries will be 41.7 million, 22.9 million out of which will be largely due to HIV/AIDS. With children who have lost parents eventually comprising up to a third of the population under age 15 in some countries, the epidemic will create a lost generation – a sea of youth who are disadvantaged and lacking both hope and opportunity. In the words of J. Brian Alwood, Administrator, U.S. Agency for International Development (USAID), "This report provides a compelling demographic portrait of an immense problem. However, more important than the numbers contained in this study is the human story they tell. Forty million children losing one or both of their parents are 40 million children more likely to be forced into child labour; 40 million children who may never have an opportunity to attend school; and 40 million children more at risk of HIV. This study should serve as a call to action for developed and developing nations alike. We cannot risk losing an entire generation of children to despair, ill health and hopelessness."

A stark picture of this hopelessness and desperation was recently highlighted by the New York Times - "As the sun sets on this city (Lusaka) casting shadows over the modern Government sponsored high rises, entire families settle in for the night on the sidewalks. Scattered amongst them are the ragged street children, many of who make money as sex workers and look for any means to get high. Workers at the Fountain of Hope a new non profit organisation, that works with the street children, say that the children have even found a way of getting a powerful high from fermented human faeces, a substance known as jekem," The New York Times – September 1998.

CONFRONTING THE CHALLENGES – WHAT DO THE WOMEN SAY?

If the numbers of AIDS orphans are juxtaposed with the rising numbers of women living with HIV/AIDS, the crippling burden of care on women's lives and livelihoods becomes a glaring reality.

Edith and Khuzini Banda lived with their aunt for about a year after their mother died in 1994. But then the aunt said her home was too crowded. She sent the girls then 13 and 14 years old to live alone in their own house. The girls make do by renting out half the two-roomed house for $15 a month and begging from their neighbours when food runs out.[52] The message from this state of affairs is clear, we will keep witnessing shifts in the status of women and assaults on their dignity and rights unless we take cognisance of their multiple roles in society. Women have been bearing the triple burden of production, reproduction and management of the household resources. The HIV epidemic has created a situation, which has exacerbated this burden. Women today are carrying the quadruple burden of sheltering and caring for orphans.

The burden of care is being borne by women in other ways as well: -

- By women living with HIV who via self help groups or informal support groups share their strength, experience and vision with others affected by the virus.

[52] Source - New York Times – 18 September 1998

- By women in their families and social settings who as mothers, wives, sisters, grandmothers, daughters and friends are carrying the emotional and practical responsibility for tending themselves and their loved ones affected by HIV.

The escalating costs of caring are increasing the demands on women's unpaid labour within the family. The economic costs of care in actual terms by way of medicines and treatment are also very high. In Kerala, in India, it has been estimated that the monthly costs incurred by the family on the treatment of opportunistic infections for an HIV infected child is thrice the monthly income of the family. In Haiti, for 24 year old Marie Ange Viaud living with HIV and the costs of the ten medications prescribed for her were well in excess of $10,000 per year.[53] The cost of administering Protocol 076 to pregnant mothers to prevent mother to child transmission amount to $800 per woman.[54]

How then will households cope? Community based research has shown that the socio-economic impact of the epidemic on families has different repercussions depending on whether it is the man or the woman who dies. The epidemic is now at a stage of maturity in some countries of Africa where deaths as a result of AIDS are escalating particularly among men. A significant finding of a study on the socio-economic impact of HIV on rural families in Uganda by Daphne Topousis is that there are far more women who have lost their husbands to AIDS than men who have lost their wives. In Tororo, Helen Onyango of TASO reported that only 5 of her 62 clients were widowers. The rest were young widows aged 15-35 years of age.[55] The epidemic is therefore contributing directly to an increase in female headed households.

Studies undertaken by FAO in Uganda and West Africa show that the most immediate problem for many AIDS affected female headed households is not medical treatment and drugs but food and malnutrition.[56]

Jane, 23, has two children, four and two years old and lives in Bumanda village in Tororo. Her husband, a farmer died of AIDS. Both her children have been sick for a long time and she believes that they are also infected. Jane has not been able to work in the shamba (family fields) for at least three months due to her husband's illness and the fact that family has lost three other members in the last month. Her husband has been dead just a month and she is already experiencing food shortages. She prepares only one meal a day. The family diet consists of cassava and millet bread, occasionally with smoked fish. She says she has no money to buy salt and cooking oil."[57]

For many widow headed households the main constraint following the death of a spouse is not just labour shortage but cash income. According to Gabriel Rugalema, the most

[53] Source – Women Poverty and AIDS edited by Farmer, Connors and Simmons.
[54] Source - Women's Vulnerability and AIDS – Adriana Gomez and Deborah Meacham
[55] Source - Socio Economic Impact of HIV/AIDS on Rural Families in Uganda – Topouzis and Hemrich (1994)
[56] The Implications of HIV/AIDS for Rural Development Policy and Programs – Topouzis and Hemrich
[57] Socio Economic Impact of HIV/AIDS on Rural Families in Uganda – Topouzis and Hemrich (1994)

immediate need recorded by widows in Tanzania was credit to establish small projects that could be combined with farm and domestic work.[58]

Women today are experiencing a sudden change in their roles in agriculture production. They are finding themselves lacking in the requisite skills and experience to respond effectively to the new challenges that confront them in their new roles. A direct consequence is a sudden decline in productivity. This is in fact the female face that poverty is acquiring in countries affected with HIV/AIDS. This feminisation of poverty is a feminisation that is different from similar earlier trends. This poverty is often new for some households, it is a poverty that could often become intergenerational; it is a poverty that is deep.

GENDER AND AIDS IN NATIONAL DEVELOPMENT PLANNING

There is thus 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.

The World Bank finding that each adult death depresses per capita food consumption in poorest households by 15 percent,[59] implies that in responding to the epidemic, national governments will need to use adult death and household dependency ratios as a targeting criteria for poverty alleviation programs. 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.[60]

Women are once again proving to be resilient. In the state of Tamil Nadu in India, Sarita lives with the HIV virus.[61] Her words linger in the air, "Counselling helped me through the initial shock and ensuing depression. Soon I knew that I had won. The frustration gradually wore off. I am now filled with hope and strength to live my life to the fullest even with HIV/AIDS. Nothing will keep me down. As a first step I have divorced my husband. The next thing I have done is to take up a job. Financial independence has made my life meaningful even if it is destined to be short."[62]

In rural Haiti, poor women affected by the virus are telling the story of a woman living with HIV, through a video presentation, using this as a means to educate the community. Proud of their success in being able to break the myths around the epidemic, the women have been

[58] UNDP Study Paper 2 – HIV and Development Program
[59] Source - The Implications of HIV/AIDS for Rural Development Policy and Programming – Topouzis and Hemrich 1997
[60] Source – She can Cope by Madhu Bala Nath
[61] Source - Whispers from within by Dr. Suniti Solomon and Rashmi Rajan Pachauri
[62] Source - Whispers from Within – Dr. Suniti Solomon and Rashmi Pachauri Rajan

speaking of their experiences at a number of meetings. In one of these meetings a Haiti physician commented, "What kind of success is this if we are failing to prevent HIV transmission in the region what is the significance of your project?" The 'malerez' or poor women did not hesitate and answered, "Doctor, when all around you liars are the only cocks crowing, telling the truth is victory."[63]

Today, every minute, eleven more people are being infected about six of them under the age of 25.[64] More than half of these are women. Ninety five percent of these women are living in the developing world[65], a number of them in poverty. These women have been surviving the onslaughts of life and destiny. The challenge for us as development workers is to respect their inherent strength and resilience and to enrol them as partners to leverage new resources to address the emerging challenges like the challenge of the mutating virus. We need to reengineer development or rather "maldevelopment" with the richness of their perspectives. The ways in which we as policy makers and implementers respond to the epidemic now, will influence the ways in which women will participate and contribute to development in the twenty first century. This is because national development will be conditional on human survival and the survival of those who reproduce and nurture the human race. This, in fact, needs to be the primary focus of our attention today.

[63] Source – Women AIDS and Poverty edited by Farmer, Connors and Simmons.
[64] Source – AIDS 5 years since ICPD – Emerging issues and Challenges for Women, Young People and Infants – UNAIDS Discussion Document
[65] Source - UNAIDS AIDS epidemic Update – December 1998

SESSION 5

Bringing HIV into the Room

i. Objective

To enable participants to relate in an emotional and personal manner to the causes and consequences of HIV/AIDS within the contextual reality of their own country.

ii. Time

1 hour

iii. Methodology

1. Testimony of a woman living with HIV/AIDS
2. Case study and analysis

iv. Steps

1. Before the person living with HIV/AIDS comes into the room to give her testimony the facilitator shares with the group the ethics relating to the confidentiality of the identity of the person living with HIV/AIDS.
2. The facilitator informs the participants that no media attention should be diverted to the person or her story.
3. The facilitator explains to the participants that this exercise is a way to give a face to all of the facts and figures discussed earlier in the day.
4. The facilitator should encourage a question and answer session at the end of the testimony only if the person giving the testimony is ready to enter into such a session. Great skill should be used in ensuring that the feelings of the person are not hurt as questions are raised.
5. After the testimony is over the facilitator distributes the case study, "HIV, Sexuality and Violence against Women", and gives the participants five to ten minutes to read it. The case study is then related to the actual testimony. It becomes clear to everyone that there is no difference in the lives of women living with HIV in all the different countries. Essentially the problems faced by women are the same, whichever part of the world they may be living in.
6. This sets the stage for the process of planning for the future.

Notes to the Facilitator Session 5

- It is important to stress the confidentiality of the identity of the woman who comes to speak to the group.
- It is also useful for the facilitator to put himself/herself in the "shoes" of the speaker. This allows the facilitator to have a heightened sensitivity when leading the discussion that follows the speakers testimony.

Case study – A testimony of a woman living with HIV/AIDS

HIV SEXUALITY AND VIOLENCE AGAINST WOMEN

"At the heart of this epidemic either there can be violence and fragmentation or there can be stillness. In the hearts of those yet personally untouched it is the same. It is the same in the hearts of those affected." Elizabeth Reid, UNDP

It is this violence, this fragmentation, this stillness that the life story of an ordinary woman's testimony.

A woman's testimony

This is Mala, (name changed) an ordinary woman from Asia, coping with a strange mutating virus- the virus causing AIDS. What is Mala saying? She is telling in the story of her life, which changed over the last 6 years.

"My first husband was a Christian, a leader and an official in our local church. He was a good man and a good husband. He was often away from the house for weeks at a time, attending to church assignments in other parts of country. I never suspected that he was engaging in extramarital sex. The last year that we were married, my husband began to get sick a lot-coughs, colds, asthma. I did not give it much thought at first, thinking that it was just fatigue caused by his constant travel and work. The doctor advised him took have a blood test. My husband told me not to worry. He did not tell me the result of the test, but I could see from the sad look on his face and the medicines that he was taking that he was hiding something form me. When I asked him about the doctors diagnosis he replied- "Suppose I have HIV/AIDS what would you do?" I told him that I loved him and would stay with him whatever happens.

Then he said, 'If you want to know what is wrong with me, go and have a blood test.' I did just that and found out that I was HIV positive. I assured him that I would stay with him and together we would fight the disease. My reaction made my husband even more sad, guilty for what he had done to both of us.

Soon after my husband got very sick, and after that was completely bed ridden. He died three months later. I took care of him night and day. He had other brothers and sisters but they were busy with their own work. I never complained, I only felt sorry for him. I cleaned him; I washed his soiled bedding. It was tiring and I hardly got any rest. There were times when he would call me but I was too exhausted to even walk to his bed, I crawled.

My husband felt so alone, having been always on the move, it was not easy for him to be confined to the bed. I stayed with him throughout those difficult times. I slept with him at night. We did everything the doctor told us to do and more. We spent everything we had so he would get well. We remembered that the government slogan on the disease had said that if you get AIDS you would die.

When he was in hospital and very sick, the doctor asked me, ‘Are you ready to take your husband home?’ I asked my husband, ‘Are you ready to go home, ready to meet God?’ He answered, ‘I am ready.” He lived for seven more days after leaving hospital.

He was happy and talkative during his last night. He seemed well he looked much stronger. I thought he would really get well. I told him to try to sleep early. He said he wanted to talk. We talked until 2 a.m. He asked me how I would live, where I would spend my life after he was gone. He refused to let me out of his sight even just to go to the bathroom or get a glass of water. We each had our own blanket but that night he asked me if we could share the same blanket. We did, he asked me to hold him until he died and not to leave him. When I woke up that morning, I realised that I had done exactly what he wanted me to do. He died in my arms.

The people who came for the funeral, included some that merely came because they wanted to see how a person who died of AIDS looked. They showed no respect for my feelings. I was an object of curiosity. In my presence they would say, ‘she will die soon too,’ I did not know much about AIDS then, and I believed them. After my husband’s funeral, I spent the time just waiting to die.

We had two children. My mother-in-law took them away from me, fearing that they might get the disease. She said, “ I am old and in case I contract AIDS from you and die, that is not much of a waste. But it will be tragic if the children get it from you and die.” (My children were HIV negative). When some of her friends would drop in for a visit she would introduce me by saying, ‘ She is my son’s widow. She has AIDS.’

After that I decided to move out of the house and live alone. I thought I was going crazy. I whiled away the time listening to the music that my husband loved, playing the tapes over and over again. I socialised very little.

One day I met a pastor of the church and through him a group of people who understood what HIV/AIDS is all about. I realised there were people who cared for me and could give me good advice. They made me realise that I had been living like a demented person, I had neglected my appearance, my health, and myself. I took their advice seriously. I exercised, ate the right food, and gave myself enough rest. More important I did spiritual and mental exercise. I realised that there was nobody who would provide me care. I had to be responsible for myself.

I volunteered to work with the HIV/AIDS support group. I now feel valued. The work I do is important. Life has so much meaning for me now. I believe that every person who has HIV/AIDS loves his or her life. No one gets HIV on purpose.” Mala has now remarried and lives with her second husband who is also HIV positive.

Speaking Points for the facilitator Session 5

What would be the elements of an enabling legal and policy environment that would make behaviour change sustainable so that it would become possible for men and women to live and cope with HIV/AIDS?

To respond to the challenges being posed by the epidemic, men and women have begun to organise themselves, albeit in isolated endeavours and in some geographic pockets. Communities of gay men have organised themselves and led successful campaigns on the use of condoms for safer sex. Communities of women have responded to the impact of the virus on their lives by developing ad hoc mechanisms that have become more formalised over time such as TASO, SWAA in Africa. These groups have been able to work effectively in the area of providing care and support as well as in enhancing awareness about the causes and consequences of the epidemic. There are other organisations of the civil society working towards prevention strategies through activities like condom distribution, IEC, counselling, community based research etc.

Enabling Environment and laws

Do these organisations have an environment that is enabling?
Today a number of legal laws and instruments exist that need to be re-examined with a gender sensitive lens to contribute towards the creation of an enabling environment. Only then can work be undertaken in a sustainable manner so as to lead to a change in behaviour. These include:

- **Policies that foster the participation of the organisations of the civil society to work in partnership with the government.**
- **The laws relating to the prevention and suppression of commercial sex work.[66]**
- **The laws relating to homosexuality.[67]**
- **The laws both federal and personal that reduce women's access to productive assets like laws on inheritance, marriage, divorce, and cultural sexual practices.[68]**
- **Policies regulating sex education in schools.[69]**
- **Rules relating to the ethical and professional orientation of service providers.[70]**

[66] Leads to forced mandatory testing which is an impingement of human rights and drives the epidemic underground.
[67] Hinder preventive work by civil society organisations or by the government amongst communities who need assistance e.g. prisoners.
[68] Because of such laws women find it difficult to break abusive relationships. In Uganda, a wife's adultery even if it is a single act, is sufficient without other grounds for a husband to obtain a divorce. A husband's adultery however does not entitle a wife to a divorce. She must prove in addition that he has been guilty of incest, bigamy, rape, sodomy, bestiality, cruelty or desertion for two years or more.
[69] In some countries sex education is not allowed in schools as it is feared that this may encourage sexual activity amongst adolescents at early ages. Example India – the Delhi Administration has not permitted sex education in the schools as a matter of policy.
[70] To do pre and post test counseling and to keep confidentiality of a patient's seropositive status. Also to probe and identify symptoms of STDs and HIV/AIDS in women who are often shy and reluctant to speak about the same.

Enabling Environment and Affirmative Action

Furthermore recognising the increasing vulnerability of women to the epidemic and the increasing burdens and responsibilities placed on the women to provide for their HIV/AIDS affected families, affirmative action in the form of the following may be useful. The need for the following has been expressed by groups of women living with HIV/AIDS in some countries:

- **More shelter for women in distress and more centres for child care for women who have had to leave home because of abusive relationships.**
- **More schemes to provide group housing for women living with HIV/AIDS.**
- **Support to hospices being run by NGOs to assist women living in nuclear families without any support for care and nursing of the sick.**
- **Support to programs that ensure that women remain visible as workers in the labour market. The work participation rate of women will need to be increased through the provision of resources and skills to enable her to bear the economic shock of the situation.**

SESSION 6

Planning for the Future

ii. Objective

To promote participatory planning to develop strategies to address the challenges being confronted by people living with HIV/AIDS.

i. Time

45 minutes

ii. Materials/Equipment

Flip chart/markers

iii. Methodology

The technique known as headlining.

iv. Steps

1. Based on the information generated throughout the day through data and personal testimony, the facilitator now asks the participants to generate a wish list to improve the lives of people living with HIV.
2. The technique involves generation of a list of concerns through a participatory process whereby each participant is requested to headline what he/she considers to be critical need of a PLWHA. The participants are allowed to speak for just a minute headlining his/her input into a single sentence.
3. The facilitator has to ensure that the inputs are focussed on the "needs" of the PLWHAs and not on broader discussion of issues affecting their lives. The facilitator explains the "rules of the game" whereby each participant is requested to begin his/her headline with, "I wish…" (e.g. "I wish Mala could have had better access to medical facilities", "I wish there were laws to penalise persons that knowingly infect others", etc.)
4. The wishes thus generated are listed on a flip chart by the facilitator.
5. The facilitator requests the participants to think over solutions to the needs listed in the wish list.
6. The facilitator begins the second stage of headlining during which he/she focuses the discussion on solutions asking the participants to present their ideas beginning their headline with the words, "Let's consider…". (e.g. "Let's consider forming groups for people living with HIV/AIDS," "Let's consider organising awareness building initiatives that help households to understand basic facts about HIV/AIDS," "Let's consider working on production and dissemination of guidelines on negotiation of safe sex." etc.)

7. The facilitator then groups all the strategies arising from the brainstorming under three emerging areas of focus:
    - Information gathering and dissemination
    - Capacity building
    - Advocacy in Human Rights
8. The facilitator then asks the participants to sign up for a core group that they consider meets their interests and priorities. The three core groups will work on the following concerns:
    - Empowerment through information
    - Empowerment through human rights
    - Empowerment through capacity building
9. The workshop ends with the formation of these groups and the appointment of a co-ordinator for each group. This co-ordinator is then responsible for calling a meeting of the group to develop a work-plan synthesising the issues highlighted during the “lets consider...” headlining session and moving the process forward.

SESSION 7

Evaluation and Closing

i. Objective

To improve the process and content of the workshop.

ii. Time

30 minutes

iii. Materials/Equipment

Pen and paper

iv. Methodology

Reflection and writing

v. Steps

1. The facilitator asks all the participants to relax and reflect on the process of the workshop.
2. The facilitator asks each participant to put on paper his or her honest feelings. One method is to ask them to think that they are driving home and are looking into their rear view mirror and reflecting on the day's activities. They should then write about what they see in the mirror as they drive away.
3. The participants need not put their names on the response sheet.
4. The facilitator closes the training session by saluting the women and men living with HIV/AIDS as well as with a plea for a sincere effort to address the challenges with whatever little contribution each person can make.
5. The facilitator ends on a note of enlisting commitment of participants either by lighting a candle from a common candle as they depart or picking up a red ribbon from a box in support of PLWHAs.

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.

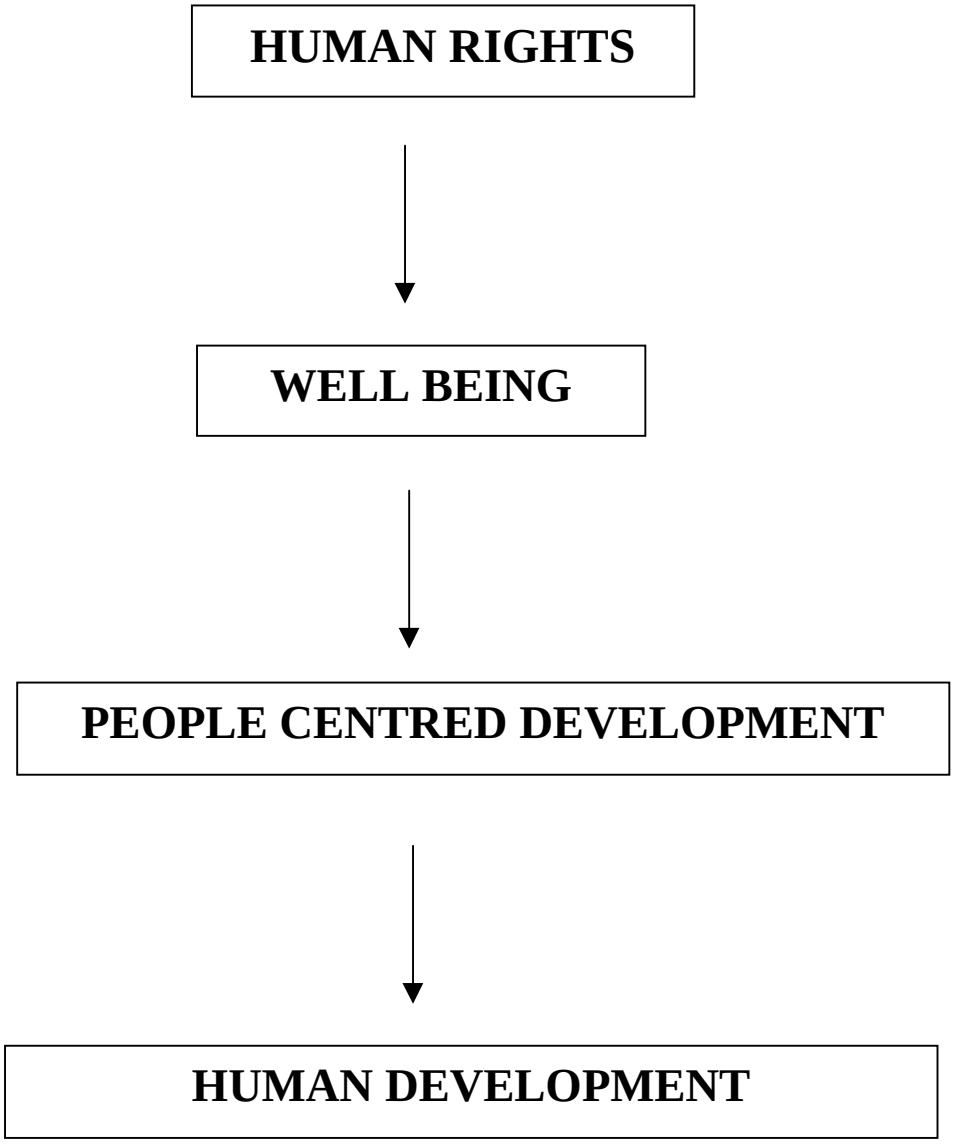
5. The facilitator initiates a discussion linking up the feelings to the fact that such feelings are essential to achieve a sense of well being and security. He/she brings out the link between a state of well being, the upholding of human rights and a people's oriented human development approach using 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.

SECTION IV

LEARNINGS FROM THE WORKSHOPS

LESSONS LEARNT

The two modules discussed in this manual have been field tested over a period of a year. The module entitled "Gender Concerns in HIV and Development" was field tested by the Gender and Development program of the UNDP under its capacity building program and was subsequently used in orientation workshops for UNIFEM and its partners in eight countries namely; India, Vietnam, Senegal, Zimbabwe, Kenya, Nigeria, Mexico, and The Bahamas. The second module entitled "Gender and HIV: A Human Rights Approach", was critiqued by a group of trainers and then field tested in a workshop held in Senegal in which representatives from seven countries were present namely: India, Vietnam, Senegal, Zimbabwe, Kenya, Nigeria, Mexico, and The Bahamas. These experiences have generated a richness of lessons. These lessons are presented below from the perspective of the facilitator and from that of the participants.

I. LESSONS FROM THE PERSPECTIVE OF THE FACILITATOR

a) Location of the workshop

In both the workshops it has been found that it is useful to locate the exercise away from the workplace of the proposed participants. This enables a more complete attendance, which is useful given the method used to envisage the learning process. It was found that when the workshops were held in close proximity to the workplace of the participants, they tended to tie up this commitment along with their obligations, official and personal. As a result attendance in the workshops started to reduce in the post lunch sessions.

It is therefore recommended that either the workshops be organised in locations away from the workplace of the participants or the timings for the agenda be modified so that the workshops commence early and incorporate as many sessions as possible before lunch.

b) Participant Selection

The choice of participants in these workshops is critical to ensure the achievement of the objectives of the workshop. The workshops are meant to develop a new perception towards the epidemic that incorporates the gender dimensions of development. It offers new information for two kinds of participants: **those who have worked on gender but not on HIV, and those who have worked on HIV but not on gender.**

In some countries, a few of the participants had already done extensive work on both gender and HIV, and hence they gained little from their participation in the workshop. For them, as one expressed it, the workshop was "pitched too low".

It is therefore recommended that the participant selection be done carefully so that a synergetic dynamic prevails during the process of the workshop.

c) Module I: Session 3

Both the modules have exercises that promote consensus building through discussion in-groups (refer to pages 43-50). In some workshops it was found that when a group did not reach a consensus the presentation by that group was deferred. However it was found very difficult to place this presentation at some other point in the workshop mainly for two reasons:

- It disrupted the process of the workshop if it was included prior to or after any other exercise.
- It led to a certain amount of frustration by the majority of the members of the group who did agree on the issue but were unable to express their thoughts at plenary due to the difference in opinion of, at times, just one member of the group.

It is therefore recommended that the skill of consensus building be nurtured through this exercise using a certain amount of discretion.

d) Module I: Session 4

The exercise entitled "Demographic Silhouettes" (page 51), is found to be a lively tool that enhances participation in a very effective manner. However, the entire exercise is time consuming and may get a bit tedious in countries with mature epidemics where this information relating to the impact on households may not offer new insights. It was found during the workshops that it was possible to modulate this exercise so that the two stages outlined in this tool could be collapsed into one.

It is therefore recommended that the facilitator assess the knowledge base of the participants, relating to the impact of the epidemic on households, prior to conducting this exercise.

e) Ethical Considerations

In keeping with the principles of partnership and participation, the involvement of people living with HIV/AIDS (PLWHAs) in the workshops has proven to be extremely rewarding. However, ethically it is important that the PLWHAs be briefed thoroughly about the purpose of the workshop.

It is therefore recommended that the organisers of the workshop meet with the PLWHAs prior to the workshop to explain to them the workshop objectives. It is also recommended that an honorarium be provided to the people who come and give their testimonies. They are then respected as a resource person who enriches the knowledge base of the participants through a sharing of their personal testimonies.

f) Time

As seen from the agenda of the two workshops the time slotted for each session leaves little flexibility. The schedule is therefore rather tight and one feedback

that was received from the participants, stated that the workshop should have been spread out over a longer time frame. Whereas this concern is acknowledged and appreciated it is useful to keep in mind that effective participation of key decision-makers is possible only for short periods of time given their overburdened official schedules. The cost implications of an additional day are also worth considering.

It is recommended that the agenda for the workshops be modified in keeping with the time available for the participants. The time frame that is suggested in this manual is optimally cost effective.

g) Co-facilitation

One facilitator can conduct the workshop. One facilitator tends to keep expenses to a minimum. However, it has been found to be useful (particularly for the two day workshop) to involve a 'national' or 'local' resource person as a co-facilitator. This is a step towards building local capacities in this area. It is therefore, recommended that wherever possible, the workshops encourage the co-facilitation using local resource persons.

h) Evaluation

The nine workshops held before the end of 1999 adopted a method of evaluation that was open and did not follow a specific format. This was done because the workshops aimed at fostering an emotional, cognitive, and reflective experience for the participants which it was felt would be difficult to capture on rigid scales or measurement ranging from unsatisfactory to excellent or from one to five. Participants were asked to record and reflect their feelings in a non-restrictive manner. However, there was one view expressed that a formatted evaluation would have been useful. In some workshops, the evaluation forms are distributed at the beginning of the workshop so that they can record their judgements about the various aspects of each session as the workshop moves on from one session to another. Specific time allocations need to be provided by the facilitator to make this kind of a structured evaluation truly effective.

It is therefore recommended that the facilitator discusses this issue with the participants at the outset of the workshop and respond to the requirement of the group accordingly.

A sample form for evaluation is attached.

i) Strategic Use of the Modules

It was found that these modules are most effective if used as part of a larger process rather than as a one-time endeavour (as the "striking of the match"). After the first workshop three core groups were formed (empowerment through information, empowerment through human rights, and empowerment through capacity building), and the following, illustrate the impact of the workshops.

The work undertaken by the group on Empowerment through information

Currently, we have received community based research reports on the gender dimensions of HIV/AIDS undertaken by groups in various countries such as Mexico, India, Zimbabwe, and Senegal. The following are some of the interesting findings that have been drawn from a few of the reports.

The findings of the community based research reports are path breaking and offer excellent opportunities for advocacy with national governments. For example in Mexico, the research team developed instruments that were used to identify and measure levels of depression, low self-esteem, violence and the impact that these have on women's ability to negotiate safe sex. The report examined the issue of providing access to treatment through policy formulation from a gender perspective. Even though Mexican health policy provides free access to anti-retroviral drugs for PLWHAs, women are still disadvantaged as they are largely in the informal sector whereas access to AZT is possible only through the formal sector.

Another path breaker is the information generated by IWID in India, that knowledge about the protective aspects of condom use became available to women only after they had become infected. This information should help development agencies to re-examine the target of their IEC. The issue of better supplies of affordable medicines for opportunistic infections and the need for more attention to be paid to single women who are bearing the brunt of the epidemic, are also interesting from the policy and programmatic point of view.

In Senegal, the effort was to examine the impact of myths and practices existing in the Senegalese society on the HIV/AIDS epidemic. The findings of the study break stereotyped perceptions, e.g. as far as sexuality and knowledge of one's body is concerned there is not too much difference between the literate and the illiterates. Also, the knowledge of sex workers about their bodies was much lower than that of housewives. The need for promoting a process of unlearning has also been brought out quite categorically. Unlearning of existing sexual myths is critical before new learning on HIV/AIDS can be brought in. For example, the commonly held view in Senegal that "circumcised women cannot be satisfied by just one man", or "that a woman who says no to her husband for sex will never have good children for the mother's behaviour during the sex act is decisive for the future of the child."

The research in Zimbabwe focuses on the socio-economic impact of AIDS on the household and suggests valuable directions for policy modifications and directions for planning for NGO's and the national government. This research has focussed on the area of the adjustments that households and communities make regarding their resource allocation for production and consumption activities in the face of HIV/AIDS and the overall welfare outcome as a result of these adjustments. Very little substantive evidence on this was available in Zimbabwe as the literature search revealed and therefore this kind of exploration helps fill the gap.

For example, one finding showed that the home based care givers require organised educational programmes with a special emphasis on signs and symptoms of HIV/AIDS, shared confidentiality, prognosis of diseases, prevention of cross infection and counselling. Another finding that could contribute to the policy dialogue relates to the need to focus IEC initiatives on "how to cope" rather than "how to prevent", given the maturity of the epidemic in Zimbabwe. The study found that support for PLWHAs even within the family is rather "ambivalent" and not solid and unconditional.

The following are some of the valuable observations from the report: the shift in gender roles as industries that were formerly male dominated (e.g. women are now taking over carpentry as men are getting sick and dying); the fact that women are seen to be more courageous and up front than men as far as disclosing their HIV positive status is concerned – the men prefer to die in silence; and the urge to work harder among PLWHAs so as to leave their children some inheritance. These findings can provide some directions to NGO's in Zimbabwe as to how to respond to the capacity building needs to PLWHAs in the country.

All the findings will be discussed with government decision-makers as well as with the representatives of the civil society through advocacy workshops. The considerable potential for influencing national policy has emerged from the research in all the countries.

The work undertaken by the group on Empowerment through Human Rights

Recently we have received feedback on work being done by journalists that participated in the module on "Gender, HIV, and Human Rights". The participants took the lessons that they learned at the workshop and incorporated HIV and gender dimensions into their writing. The following interviews and articles illustrate the type of work that has been carried out since the workshop.

Lydia Cacho Speaks

"After working for three years on gender and HIV/AIDS, I was burnt out and tired of the work. The workshop gave me new information that was presented in a very humane manner. I was re-charged after participating and it stirred my desires to work on the issues."

The following profile of Lydia Cacho gives us an insight into the potential impact of the Gender, HIV/AIDS, and Human Rights workshop. Ms. Cacho participated in the workshop organised under the joint initiative entitled "Gender Focussed Responses to Address the Challenges of HIV/AIDS." She attended the workshop as a representative from the Mexican news service, CIMAC. CIMAC is a multimedia new agency that is comprised of 800 female journalists from various countries in Latin America and Caribbean. After attending the workshop in Senegal in October 1999, Ms. Cacho returned to Mexico and has been able to catalyse the following:

- Orchestrated a training on gender focussed journalism using some of the learning tools that were used at the workshop in Senegal. (Ms. Cacho used the role-playing tool at the training because of the impact that it had on her when she was in Senegal. Ms. Cacho had been assigned to be group leader and she decided to have a man play the role of the woman and a woman play the role of a man. Following the session, Ms. Cacho spoke with the man that played the role of the woman and asked him, "How did it feel to be a woman?" With tears in his eyes the man said, "I wish that I could apologise to my mother for the abuse that she suffered.")
- Became a recipient of the National Journalistic Prize for 1999 in Mexico, *Rosario Castellanos*, for her article she wrote for "La Crisis".
- Wrote ten articles on the gender and human rights implications of HIV/AIDS in Africa. The articles have been cross-referenced by over fifteen mainstream dailies via the CIMAC on-line news wire.
- A Mexican weekly political journal entitled "La Crisis", published one of her articles on the epidemic. This was extremely important due to the fact that all Mexican politicians read the journal.
- Wrote an article, "Enfrentarlo o Morir" for *Novedades*, a leading Mexican daily newspaper, on the impact of the epidemic in Africa.
- In Mexico, many people, including the General Secretary of the Governor, the Director of the Social Security Hospital, and the Mayor of Cancun have called Ms. Cacho to congratulate her on her work.
- The most popular radio station in Puebla, Mexico has read all of the articles that Ms. Cacho has written on the epidemic.

Karen Wallace Speaks

Ms. Wallace is a journalist from the Bahamas who has been writing on the lives of those living with HIV/AIDS. The following is an excerpt from an article that she wrote after the workshop on "Alma", a 50-year old mother of four and grandmother of nine. She has been living with HIV for the past four years and is battling to overcome the stigma that has been placed on her.

"*My time with Alma has left me to believe that at present, people living with the HIV/AIDS virus have nothing to look forward to other than death. They are terminated from work, ostracised by persons in the community, feared because of ignorance of the disease and discriminated against because of the stigma placed on them. Although Alma has experienced the many negatives associated with this deadly disease, somehow she struggles to remain positive everyday. This is not the same for all persons living with HIV/AIDS.*

For me, the visit with Alma has truly placed a face on HIV/AIDS and has changed my outlook on people living with the disease. Because of Alma, I have enhanced my commitment to make the public more aware and sensitive through all avenues of the media of the human side of people living with the virus.

The day spent with Alma was a life-moving experience and with her permission excerpts of our discussions will be used in public presentations and planned workshops. Alma can be used as an example to educate the corporate community that people living with HIV/AIDS are still employable if given the chance to be productive citizens.

The time spent with Alma was video-taped and audio-recorded. The interviews are being packaged for news broadcasts and half-hour television and radio programs. The information has been transcribed and will be incorporated with statistics and other data received for national dissemination."

Pamela Philipose Speaks
An innovative way to combine anecdotal evidence with empirical data and linking the macro and micro issues was provided by a workshop participant from India. Pamela Philipose of the *Indian Express* has devised the "AIDS Blackboard" as a means to move discussion on gender, HIV/AIDS, and human rights in India. A few of her articles are appended.

The Demography of a Disease

The Indian Express, 21 October 1999

> **While sub-Saharan Africa accounts for two-thirds of people living with HIV/AIDS, one country – Senegal – has been relatively successful in its battle against the disease.**

Both geography and history have made Senegal something of an enigma. Bound by the Sahara desert on the one side and the South Atlantic Ocean on the other, this tiny republic was colonised by the French for 200 years and is yet overwhelmingly Islamic in belief.

Since it is perched on the brow of Africa's Northwest coast – the closest Africa comes to the North American mainland – Senegal has been the site of one of humanity's darkest moments. Visit the island of Goree, which lies three kilometres from Senegal's capital, the harbour city of Dakar, and you will be taken to the Maison des Esclaves, or the Slave House. It is a monstrous vestige of the slave trade that saw some 15 to 20 million Africans captured and sold over three centuries – from 1536 to 1848. An estimated six million died in the process.

Today the slave trade is thankfully just an ugly memory but modernity has brought with it fresh threats. One of the biggest social and medical challenges facing Senegal today is dealing with the HIV/AIDS pandemic, which has cut a swathe across the African continent. Approximately two thirds of the people living with AIDS world-wide live in sub-Saharan Africa.

The disease has wrought immense havoc in countries like Uganda, where whole villages have been wiped off the map, where a quarter of the children have at least one parent stricken by AIDS. Here fields lie untended because of the lack of able adult labour and old women are left to nurture the numerous children orphaned by the disease.

And in not just sub-Saharan Africa, Eunice Mafuabikwa, a senior activist/writer from Harare, Zimbabwe, revealed that it is very rare in her country to come across a family that has not experienced a death caused by AIDS.

What disturbs her the most about the situation is that despite Zimbabwe being poised to become the country with the largest number if AIDS cases in the African continent, there has been little or no change in social behaviour. "The general attitude seems to be that 'everyone has to die some day anyway.' Men continue to pride themselves on their promiscuity. There is even a local saying that just as a bull is known by its scars, so is a man by the sexually transmitted diseases he has experienced!"

It is heartening therefore to learn of Senegal's conspicuous success in grappling with the spectre of the dread disease, as a workshop hosted by UNIFEM in Dakar earlier this month revealed. The workshop was part of UNIFEM's two-year pilot project on gender focused interventions in HIV/AIDS involving six countries – Zimbabwe, Senegal, Mexico, Bahamas, India and Vietnam.

Senegal's attempts to address the problem become crucially important – not just for the African continent but for the rest of the world, which is still largely clueless about the social impact of the disease.

According to Dr. Ibrahima Ndoye, co-ordinator of Senegal's national programme on HIV/AIDS, who had addressed the workshop, the country which had a prevalence rate of one percent in '91-'92 now has to contend with a prevalence rate of 10 to 20 percent among high risk groups. "But this is a low figure considering the fact that in many countries of the region the figure is more than 50 percent," says Ndoye.

Data collection was perceived as a crucial input in managing HIV/AIDS. "We have stepped up the monitoring of the disease through scientific, medical and epidemiological surveys – today Senegal, along with Thailand and Uganda, has an extremely good data bank, which helps to provide some focus to the programme," says Ndoye.

Along with the data bank, care has also been taken to clean up blood banks. While many sub-Saharan nations just don't have the health infrastructure to guarantee safe blood, in Senegal strict screening for HIV has been made mandatory.

Interestingly, spiritual leaders have been encouraged to get involved in the nation's AIDS control programme. As Ndoye puts it, "We are 95 percent Muslim and 5 percent Catholic, and we have involved our religious leaders in our campaign. They have helped especially in fighting the stigma traditionally associated with the disease."

But while the men of God promote the values of abstinence and fidelity, Ndoye himself takes no chances. "They preach abstinence. We preach condom use," he remarks dryly.

The national HIV/AIDS programme consciously tries to reach the youth. According to Ndoye, it is crucial that over the next 10 years, young people from the ages of 10 to 25 in all developing nations must be sensitised to the problem.

Senegal has also discovered that no HIV/AIDS control programme can be successful without involving and empowering women. Being a polygamous society, women often find themselves sexually powerless.

Aster Zaoude, Regional Programme Advisor, UNIFEM, Senegal, pointed out that the husband plays an inordinately powerful role in social relations here. "We find that the biggest problem seems to be that while most women know about the dangers of the epidemic, they don't know how to negotiate safe sex," says Zaoude.

This is where recent experiments with the female condom have added a new dimension in the struggle against AIDS in Senegal. Dr. Penda Ndiaye of the Social Hygiene Institute, Dakar, conducted a study on female condom use by local women including sex workers. They were found to be well accepted, indeed even in great demand. According to the study, the female condom seemed to help women gain some control over their sexuality in a society that had always considered them as passive partners in the sexual act.

Experts are now increasingly coming around to the view that the most significant risk factor for HIV/AIDS is not sexual activity or drug use as much as socio-economic helplessness. Since the infection is preventable, people who are literate and have access to information usually take the necessary precautions. Women, given their lack of both economic and sexual independence, are thus more vulnerable to the disease.

Madhu Bala Nath, HIV and Gender Adviser to UNIFEM, and the woman who anchored the Dakar workshop, believes that given the fact that an increasing number of women are affected by HIV/AIDS – approximately 43 percent of adults living with HIV/AIDS are women – the gender dimension of the battle against the disease cannot be emphasised enough.

Says Nath, "On the one hand the campaign against AIDS has not sufficiently focused on women, on the other, the women's movement has just not adequately addressed issues of sexuality or perceived HIV/AIDS as a women's issue."

The AIDS Blackboard

- According to UNAIDS, out of 33.4 million living with AIDS world-wide, 22.5 million live in Sub-Saharan Africa – about half of them women.
- Life expectancy in some severely affected countries in Africa has been reduced by 10 years because of the disease.
- In Uganda, a quarter of the children live in families in which at least one parent has AIDS.
- Situations of social strife have only increased the rapidity of the spread of the disease. In Rwanda, before the war, only two percent of the population was HIV/AIDS affected. The figure now is thirty percent.
- Of the $2 billion allocated to HIV/AIDS world-wide, an overwhelming ninety- percent goes into research and testing.

Irrational complacency, Irrational fears

The Indian Express, 22 October 1999

> ***The HIV/AIDS epidemic in India is largely hidden because society is not prepared to confront the disease***.

"No HIV/AIDS please, we're Indian. We also love our wives." Somewhere, Indian society seems to have internalised the received wisdom that while Africans are promiscuous, Indians are not. Therefore, while AIDS may be a problem for them lot, we really have nothing to worry about.

International data, however, belies such easy complacency. According to the evidence at hand, South and Southeast Asia is the epicentre of the HIV epidemic, the majority of new infections are said to be occurring in this region. In fact, the impact of the disease on Asia could be worse than it was in sub-Saharan Africa because it seems to be spreading at a faster pace. Since 1994, almost every country in the region has seen HIV prevalence rates more than double.

Today, some 6.4 million are believed to be affected by the disease in a region where 60 percent of the population is sexually active. India is estimated to be particularly vulnerable with some 3 to 5 million HIV infections. Officially, by the end of July 1998, the country had 78,904 HIV infections and 6,386 AIDS cases, but the actual figures could be much higher.

Says Madhu Bala Nath, advisor on HIV and gender to UNIFEM, "We are looking at a country where there is a high prevalence of the disease in at least four regions – the Northeast, Tamil Nadu, Maharashtra and Andhra Pradesh. We are looking at a country where a large percentage of the population is in the sexually active category."

Nath is also critical of the view that India should concentrate on fighting malaria and tuberculosis instead of AIDS. "These distinctions are breaking down. Last year, 30 per cent of the TB cases world-wide were AIDS-related,' she says.

Nath finds African societies more pragmatic about the issue. "While we assume that our cultural and social factors will prevent AIDS from acquiring pandemic proportions Africa, I find it far more realistic about such matters."

It is a realism that India can certainly learn from. The ugly and brutish brush with AIDS deaths through the late eighties and nineties have forced countries like Uganda and Tanzania to install systems that could, in the long run, check the rampant spread of the disease. The first signs of an HIV turnaround are surfacing. The prevalence rates among pregnant women in Uganda and those among young people in Tanzania have fallen by 40 and 60 per cent.

Changing social attitudes and government policy towards HIV/AIDS, in a culture where widespread stigma is attached to the disease, is certainly a difficult enterprise. But somewhere along the way, the realisation seems to have dawned in many of these African

nations that without a human rights-based approach to the disease, it would be impossible to challenge its reign.

The Uganda Network on Law, Ethics and HIV/AIDS initiated a legal review process to safeguard the human rights of people living with the condition and recommended that ethical norms govern biomedical research and drug and vaccine trials in the country. It argued that the testing, counselling and treatment of the AIDS-affected must be done with sensitivity and professionalism.

Similarly, the Zimbabwean Intersectoral Committee on AIDS and Employment came up with a national code on AIDS and security, as well as training and employment benefits for the affected.

India, in sharp contrast, has remained supremely indifferent to such issues. As Anand Grover of the Lawyers Collective observed in a recent article, "The number of cases of mandatory testing, isolation of people living with HIV/AIDS, breaches of confidentiality, discrimination and harassment is increasing rapidly throughout the country." He argued that there is an urgent need for law reform, for new laws and for the training of lawyers, legal activist and paralegals on key issues. As he put it, "Thus far the Indian government has failed to develop a sensitive and supportive legal environment to deal with the epidemic."

Every person stricken with HIV/AIDS is literally driven underground by the stigma and discrimination that comes his or her way. In her recent study on 'HIV/AIDS discrimination, stigmatisation and denial,' Shalini Bharat of the Tata Institute of Social Sciences, Mumbai, relates instance after instance of patients being subjected to the treatment that the leprosy-afflicted had experienced in Biblical times.

Bharat cites the case where the dead body of a man who died of AIDS was not allowed to be brought into his village near Bangalore. Within a few days the local community had hounded the man's widow out of the village, accusing her of being an 'AIDS carrier."

It's not just rural India that displays such cruel and uninformed behaviour. According to Bharat, prejudice and stigma are manifest at every level of society. In hospitals, patients are routinely refused treatment and access to common facilities like toilets. Even in death, they are not spared. The bodies of IDS patients are routinely covered with a plastic sheet.

The situation in the workplace is not much better. Summary dismissal and the withdrawal of health and insurance facilities are the norm. Within the family, relationships break down, desertion and separation follow. As Bharat notes, the fear of social opprobrium, guilt, and desperation often keep infected members from accessing help and support. She writes: "HIV/AIDS related discrimination and stigmatisation and denial is pervasive and extensive, affecting people's will to fight and survive AIDS." This, in turn, renders the disease a hidden one and adds to the silent spread of HIV/AIDS in the country.

Much of the popular response to the disease is an irrational fear based on inadequate knowledge and culture of silence about sexuality. Indeed, this fear and silence would first have to be addressed if HIV/AIDS in India is to be defeated.

As Nath say, "Our focus thus far has been on prevention rather than care. If you make care your entry point, you get people sensitised to the disease. Care is, in any case, essential when it comes to managing a disease such as this, which is so closely linked to human behaviour."

The AIDS Blackboard

- Of the 33.4 million living with HIV/AIDS world-wide, 6.4 million live in Asia. Since 1994, almost every country in the region has seen HIV prevalence rates more than double.
- A survey in Tamil Nadu shows that 82 percent of men afflicted with STDs had had sexual intercourse with multiple partners within the last 12 months and only 12 percent had used a condom.
- Another study in India revealed that 90 percent of male clients of male sex workers were married.
- Mahrashtra, Tamil Nadu, and Manipur account for almost 77 percent of total HIV infections in the country.
- Some 75 percent of infections were contracted sexually, while blood and blood products accounted for seven percent and needle-sharing another seven percent.
- The spread of the disease from urban to rural areas is growing thanks to high population mobility. The urban-rural ratio was 4:1. Over the last five years, the rural proportion has registered an increase in North India.

The work undertaken by the group on Empowerment through Capacity Building
A resource guide for NGO's on how to empower women to negotiate safe sex has been prepared drawing on the first hand experiences of women in the field. This resource guide has been endorsed by women's groups in the participating countries and will then be shared with a number of NGO's. The case study below can be found in the resource guide.

The SHIP project in Sonagachi

The SHIP project was an experimental public health intervention, focusing on the transmission of STD/HIV among communities in Calcutta. The project was launched by WHO in 1992 in close collaboration with the Indian Institute of Hygiene and Public Health. It set up a STD clinic for sex workers in Sonagachi, to promote disease control and condom distribution, in line with the then-popular approach of targeting HIV prevention to particular groups who were particularly at risk. However, during the course of the project, the focus broadened considerably beyond disease control, to address the structural issues of gender, class and sexuality. As mentioned above, Sonagachi is a community where constant negotiations are going on, and it was perhaps this aspect of life that inspired work to control HIV through addressing sexuality and gender power relations.

The focus on using `insiders' to work with their peers to motivate them reflects the ideology on which the project is based. At the start of the SHIP project, members of the sex workers' community were invited to act as peer educators, clinic assistants, and clinic attendants in the project's STD clinics. Since that start, SHIP has aimed to build sex workers' capacity to question the cultural stereotypes of their society, and build awareness of power and who possesses it. It seeks to do this in a way, which is democratic and challenging, yet non-confrontational.

Negotiating with the self
The respect and recognition that was provided by the project to these peer educators transformed their lives (personal communication, Calcutta 1999). From the very beginning, the project made it very clear to the sex workers that in no way would a 'rehabilitation' approach be adopted. The project had not been established to 'save' 'fallen women'. The peer educators acquired a uniform of green coats, and staff identity cards, which gave them social recognition. A series of training activities were organised, with the aim of promoting self-reliance and confidence, and respect for them in the community. Comments from peer educators are on record in a project report. One reported: 'The project has enabled me to face society with confidence' (report by the Durbar Mahila Samanwaya Committee, 1998), and another said 'This apron has changed my life, my identity. Now I can tell others that I am a social worker, a health worker' (ibid.).

Once the sex workers saw the results of the discussions and the survey statistics, they could see their vulnerability to structural problems, and those who had previously seen themselves as 'sinners' and `loose women' changed their perspectives. In focus group discussions, peer educators said, "For us, this trade is also an employment. Why wouldn't the government recognise it? Who says we are loose women?"

This awakening is a very significant transformation that the project has achieved. The sex workers of Calcutta have begun to challenge the age-old notions of sin and blame, and are trying to reconstruct their identity. This perhaps, is the first stage of negotiations towards safer sexual practices – a negotiation with the self.

Negotiating with peers

Although the SHIP project had started well, the empowerment of 65 peer educators was not adequate to protect the 5,000 sex workers who lived in Sonagachi alone from this abuse of their rights. How could the project keep a focus on promoting safer-sex practices with this wider issue of political rights going unaddressed? From negotiations with the self, they moved to a new level: negotiations with their peers.

The peer educators began their work, going from house to house in the red light areas, equipped with information on STDs/HIV prevention, AIDS and how to access medical care, and material which suggested ways of questioning power structures that promoted violence. House-to-house work took three hours each morning. Each day, every group of peer educators (4 in each group) contacted between 40 and 50 sex workers, and 10 to 15 brothel owners. They encouraged the sex workers to attend the clinic for regular health check ups; they used flip charts and leaflets for effective dissemination of information on STDs/HIV; they carried condoms with them to distribute to the sex workers.

As these activities got underway, awareness grew in the community about the project. While the project had begun as a targeted intervention to prevent the spread of HIV/AIDS, using a strategy of promoting behavioural change, it had become clear to all involved that the main obstacles facing the successful implementation of the project were not just behavioural. They were to do with the way sexuality is seen in society, the lack of a social acceptance of sex work, the legal ambiguities relating to sex work. All these were now being increasingly recognised by the community as elements to be confronted and battled against and overcome. Sex work was an occupation, and not a moral condition. And because sex work was an occupation, the occupational hazards of STDs/HIV, violence and sexual exploitation had to be acknowledged as such, and overcome.

Building alliances with the clients

In 1993, early in the life of the project, a survey was conducted by the peer educators with babus (long-term, regular clients) (All India Institute of Hygiene and Public Health, 1997). The survey revealed that only 51.5 percent of the clients had heard of HIV/AIDS, but even this group lacked awareness regarding the use of condoms. Only 1.5 percent regularly used condoms, and 72.7 percent had never used a condom (ibid.). After the survey, a meeting was organised, to begin to build alliances between sex workers and their regular clients in the interest of promoting safer sexual practice. About 300 clients attended. The discussions that began at this meeting led to the opening of evening clinics for the clients, where they could receive free treatment, counselling and access to condoms. Socio-cultural programmes were organised to introduce safer sex and HIV/AIDS messages targeting the clients. Today, the clients have come together in a support group called the ‘Sathi Sangha (‘Group of Friends’). This group supports the sex workers in motivating new clients to use the condoms, and supports the sex workers’ efforts to eliminate sexual violence in the area.

The Sonagachi movement has also successfully intervened in stopping child trafficking in West Bengal. The self-regulatory Boards set up in 1999 are the mechanism that enforces this. A number of children trafficked have been returned to their homes, and in this way the organisation is reducing vice and violence in the larger society.

By 1996, research from SHIP showed indicators that were different (All India Institute of Hygiene and Public Health 1997; DMSC 1998). The knowledge of STDs in Sonagachi improved from 69 percent in 1992 to 97.4 percent in 1996; the knowledge of HIV/AIDS rose from 30.7 percent in 1992 to 96.2 percent in 1996. Condom usage shot from 2.7 percent in 1992 to 81.7 percent in 1996. HIV/AIDS prevalence levels plateaued at five percent, when other red light areas the country were recording a rate of 55 percent. In fact, the Telegraph, a leading daily newspaper, hailed Sonagachi as the `biggest brothel in Asia' which had a negative growth rate of HIV/AIDS (Telegraph, 18 September 1995).

II. LESSONS FROM THE PERSPECTIVE OF THE PARTICIPANTS

The responses and evaluations from the participants at the end of the training highlighted the various achievements and failures of the workshops. The responses of the participants have been grouped below in relation to the workshop objective.

Objective I: Working on enhancing the understanding about gender concerns in HIV development.

- "Before attending this workshop, I was of the opinion that HIV/AIDS was only a health issue and if there was any social impact it was gender independent. Why talk about women only when more men were suffering? My impressions have been modified." (Dakar, Senegal)
- "The meeting put HIV/AIDS gender concerns in perspective. The tool used to analyse gender issues in HIV/AIDS is excellent. It can be used at policy level, mid-managerial level and community level." (Nairobi, Kenya)
- "The workshop clearly brought out the impact of the epidemic on men and women, hence the need for gender based institutions to be more productive." (Nairobi, Kenya)
- "What I mainly learnt from the workshop was the necessity and urgency to focus on the gender perspective of AIDS." (New Delhi, India)
- "I see a platform being built to see the problem of women and HIV in an integrated system perspective and not only as a health issue." (New Delhi, India)
- "The issue of gender in HIV/AIDS has become clearer to me – it is like a cycle. It expresses the fact that women are still on the receiving end in this issue – the statistics are alarming. It creates a desire in me to do more research and ensure the dissemination of the results of those already done." (Lagos, Nigeria)
- "Many eye-opening and alarming data has touched me to the core. I feel more responsive in all the programmes of community mobilisation and gender sensitisation camps." (New Delhi, India)

Objective II: To understand the complex dimensions of the challenges being posed by HIV/AIDS within a framework of human rights with a gender lens.

- "I was sensitised to the gender and human rights issue of persons living with HIV/AIDS particularly as it relates to women." (Nassau, Bahamas)
- "Was able to gain greater insight and understanding about gender, HIV/AIDS, and human rights from the global perspective." (Dakar, Senegal)
- "This is the first workshop I have attended that has left me with motivation and limitless energy to do my part in sensitising persons in the Bahamas about gender, HIV/AIDS, and human rights." (Dakar, Senegal)
- "The gender aspects are now clearer in my mind. I am now armed to know what to say, who to say it to, how to say it, and why." (Dakar, Senegal)

Objective III: To identify strategies that can address the challenges of HIV/AIDS from a gender and human rights perspective.

- "The workshop has served as a moment of coming face to face with the realities of HIV/AIDS. As a researcher I can see that I have a critical part to play in helping such victims, the society at large and women in particular." (Lagos, Nigeria)
- "There is a need to intervene through aggressive campaigns, building capacity of all citizens to avoid and prevent the disease." (Lagos, Nigeria)
- "I want the Broadcasting Corporation of Bahamas to play an integral role in helping to make a change in the perception of people living with HIV/AIDS." (Nassau, Bahamas)
- "I am leaving here further energised and committed to continue to educated, network, share, and grow." (Dakar, Senegal)
- "Many eye-opening and alarming data has touched me to the core. I feel more responsive and committed to include the issue of women and HIV in all the programmes of community mobilisation and gender realisation camps." (New Delhi, India)
- "I leave inspired to do more articles, better informed on gender and HIV/AIDS." (Dakar, Senegal)

The following were some suggestions to improve the workshop:

- "Good workshop but I felt it was pitched too low." (New Delhi, India)
- "Unhappy that there were less men/government people participating in the workshop." (New Delhi, India)
- "I only missed the participation of more males." (Harare, Zimbabwe)
- "More time needed for the workshop. Need to include PLWHAs as participants." (Dakar, Senegal)
- "Would have liked more reading/reference material." (Dakar, Senegal)
- "How are we going to get men more actively involved in these human issues? It is still very difficult and was not touched deeply in the workshop." (Dakar, Senegal)

EVALUATION FORM

1. What happened in the workshop?

2. Key issues included in this workshop were:
   - A gender analysis of the prevalence, causes, and consequences of HIV/AIDS.
   - A review of the gender based construction of sexuality.
   - An analysis of the impact of HIV/AIDS on the household.
   - A discussion on the gender based impact of the epidemic on national economies.
   - An insight into the life of people living with HIV/AIDS.

   Indicate those which were of most interest to you and explain how they are relevant to your work.

   What other issues would you have liked to discuss at this workshop?

3. Did the workshop contribute towards the building of any skills?

4. How do you think you will use the outcomes of the workshop?

5. In what aspects of the follow-up activities would you like to participate in?

6. How has your understanding of the epidemic changed after participating in this workshop?

7. If a similar training format were used again, what would you suggest to do differently?

8. What aspect of the workshop did you most appreciate? Why?

9. Additional comments.

SECTION V

APPENDIX

Prevalence – a gender analysis

1. Today approximately _____ of the 33.4 million adults living with HIV/AIDS are women and the proportion is growing.

   - 21%
   - 46%
   - 11%

   (Source: UNAIDS Global Data, December 1999)

2. Of the new infections occurring everyday, the percentage of women infected is _____.

   - 80%
   - 50%
   - 30%

   (Source: UNAIDS Global Data, December 1997)

3. Following a trend observed in some countries, the male to female ratio among HIV infected persons has begun to equalise globally. In Russia the infected men now outnumber the infected women by _____ instead of an earlier figure of 6:1.

   - 4:1
   - 2:1

   In Brazil the male to female ratio stood at 16:1 in 1986. Figures for 1997 indicate the ratio as _____.

   - 10:1
   - 3:1

   (Source: UNAIDS Fact Sheet December 1996)

4. In Thailand where a combination of HIV prevention methods have successfully lowered infection rates in men, the prevalence in women attending antenatal clinics has continued to rise steadily from 0% in 1989 to _____ in 1995.

   - 0.2%
   - 23%
   - 2.3%

   (Source: UNAIDS Fact Sheet December 1996)

5. In Francistown, Botswana _____ of the pregnant women tested positive in a major urban surveillance site.

   - 2.3%
   - 43%
   - 10%

   (Source: UNAIDS Fact Sheet December 1997)

6. Recent data from Mexico indicates that 0.8 percent of all reported AIDS cases have been among sex workers, and _____ among housewives.

   - 9%
   - 19%
   - 90%

   (Source: The Documentation of an Epidemic – Columbia University – Anne Akeroyd)

7. In men the highest prevalence of HIV infection is in the 25-35 year age group whereas in women prevalence peaks in the age group of _____.

   - 15-25 years
   - 35-45 years

   (Source: UNDP Issue Paper No. 10)

8. In Zimbabwe, among 537 adolescents identified as HIV positive, girls outnumber boys by _____.

   - 3.1
   - 2:1

   (Source: Women AIDS Research Program – Department of Community Medicine – University of Zimbabwe)

Causes – a gender analysis

1. Heterosexual intercourse accounts for more than _____ of global adult infections.

   - 17%
   - 37%
   - 70%

   (Source: UNAIDS Fact Sheet, December 1996)

2. Increase in STD cases indicate an increase in unsafe sex. WHO estimated that in 1995, there were 333m cases of STD's of which 65 million were in Sub Saharan Africa and 150 million were in South and South east Asia. The presence of STD's increases the risk of HIV transmission _____ .

   - two fold
   - five fold
   - ten fold

   (Source: Health and Population Occasional Paper – ODA)

3. While HIV prevalence in male STD clinic attendees was stable between 1993 – 1994 rates have increased more than _____ fold among female STD attendees over the same period.

   - two
   - five
   - ten

   (Source: UNAIDS Fact Sheet December 1996)

4. In some villages in Uganda, focus group discussions revealed that _____ out of 22 men present had used a condom.

   - 18
   - 8
   - 2

   Among all the women in these villages, _____ had seen a condom.

   - 50%
   - 15%
   - 0%

   (Source: UNDP's Study Paper No. 2 The Socio-economic Impact of AIDS on Rural Families in Uganda)

5. A behaviour surveillance survey financed by USAID in Tamil Nadu in India shows that 82% of the male STD patients had had sexual intercourse with multiple partners within the last 12 months and only _____ had used a condom

- 52%
- 22%
- 12%

(Source: Health and Population Occasional Paper ODA)

6. Research shows that many men who have sex with men also have sex with women. Studies in India revealed that _____ of the male clients of male sex workers reportedly were married.

- 90%
- 60%
- 20%

(Source: Review of "Best Practice" for Intervention in Sexual Health – Gordon and Sleightholme)

7. A survey on spousal communication in some developing countries found 35 percent of the women in the Philippines never talked to their husbands about sexual matters. In Iran the figure was _____.

- 23%
- 53%
- 73%

(Source: UNDP Issues Paper No. 3)

8. It has been reported that sexual activity in Uganda begins between the ages of 10 – 15 years and that the average age of first sexual intercourse for boys and girls in Uganda is about 15 years. An only girl's sample however revealed that the sexual intercourse occurred _____ than 15 years.

- earlier
- later.

(Source: UNICEF SYFA ibid)
Community based research has shown similar findings in Asia, Pacific and Latin America and the Caribbean.

9. A recent study by SAKSHI, an NGO in India, has indicated that _____ of the 13 – 15 year olds attending school had been victims of sexual abuse.

- 16%
- 60%
- 75%

(Source: She Can Cope – Nath)

10. A study of female youth in South Africa showed that _____ of the girls had experienced sex against their will.

- 17%
- 71%
- 50%

(Source: Taking Stock - Whelan and Rao Gupta ICRW.)

11. Researcher Anne Chao's data from Rwanda shows that the younger the age of first pregnancy or first sexual intercourse the _____ the incidence of HIV infection.

- lower
- higher

(Source: UNDP Issues Paper No. 8.)

Consequences – a gender analysis

1. In a study among women living with HIV/AIDS _____ had experienced violence.

   - 6%
   - 66%
   - 96%

   (Source: Partner Violence in joint HIV Substance Abuse – Krauss, Goldamt and Bula)

2. Projections for Zambia and Zimbabwe indicate that because of AIDS, child mortality rates may increase _____ by the year 2010.

   - five fold
   - three fold

   (Source: UNAIDS Fact Sheet December 1996)

3. _____ of all parentless children in Uganda are between the ages of 10 – 19 years. This has increased their vulnerability to sexual abuse.

   - 29%
   - 40%
   - 69%

   (Source: UNDP Study Paper No. 2 The Socio-economic Impact of AIDS on Rural Families in Uganda)

4. In the state of Sao Paulo AIDS became the leading cause of death in the 20-34 year old women in1992. In rural Uganda AIDS caused _____ out of 10 deaths for women between 20-44 years of age.

   - 3
   - 5
   - 7

   (Source: UNDP Study Paper No. 2, The Socio-economic Impact of AIDS on Rural Families in Uganda)

5. If a woman living in an agricultural community where women are responsible for subsistence farming, becomes infected and falls ill the cultivation of subsistence crops in her household will _____.

   - decrease
   - increase

   (Source: Social Impact of HIV/AIDS in Developing Countries – Danziger)

6. To fill gaps in food production in instances where outside workers cannot be hired due to depletion of the economic resources of the household, given the evidence available from the filed of education _____ are pulled out of school.

- girls
- boys

(Source: Orphans of the HIV/AIDS Pandemic – Levine, Michaels and Back)

8. Since traditional gender norms support the primary role of women in child welfare, the burden of caring for the present 10 million AIDS orphans is likely to be borne by _____.

- men
- women.

(Source: Orphans of the HIV/AIDS Pandemic – Levine, Michaels, and Back)

Do you agree or disagree with the following?

1. In many cultures, female ignorance of sexual matters is a sign of purity.[100]

2. Men don't like to admit their lack of knowledge and therefore do not seek out accurate information regarding HIV/AIDS prevention.

3. Women gain self-worth and social identity with the birth of children, so it is understandable that women have difficulty with the idea of non-penetrative sex and the use of barrier methods such as condoms.

4. Multiple sexual partnerships are acceptable for men in many societies.

5. It is unfortunate that sex between men is socially stigmatising and in many cases illegal and so contributes to the inability of those men to gain information and services to reduce their personal vulnerability.[101]

6. Modesty and virginity as a value is central to the image of womanhood.

7. There is no positive language for sexuality. For example, Mexican women asked to name the parts of their bodies could find no word for the vagina except "la parte" or the part.

8. Behaviour change strategies need to address socio-cultural norms, in order to be effective in preventing the spread of the epidemic.[102]

[100] Conversely knowledge of sexual matters and reproductive physiology a sign of easy virtue.
[101] The same applies to commercial sex work.
[102] For example, STDs can be cured by having sex with a virgin, or for effective and safe truck driving, it is necessary to let the heat out of your body by having sex every 400 kilometers.

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.

   c) 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

   d) 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)

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)

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)

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)

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)

Websites:

1. The Participation Learning Centre
   http://www.pwci.org (forthcoming, can be viewed currently at
   http://members.xoom.com/afzalhossain/
   This site contains a set of sample SARAR materials as applied by the Peopleworks Collaborative Inc. in a variety of sectoral field programmes.

2. IDS Participation Group Page
   http://www.ids.ac.uk/ids/particip/index.html#pghome
   The Participation Group is a group of people at the Institute of Development Studies in Sussex, UK, working in support of participatory approaches to development.

3. Strategies for Hope Series
   www.stratshope.org
   Site about the Publications and Media series, Strategies for Hope. Explores approaches of different agencies to the HIV/AIDS epidemic in developing countries.

4. UNICEF
   http://www.unicef.org
   Has several sub-sites regarding HIV/AIDS, especially with regard to children.

5. UNAIDS
   http://www.unaids.org/
   The Joint UN Programme on HIV/AIDS: A major resource site of the joint UN Programme. The site has a large electronic bibliography with many articles on site. Includes sub-sites on HIV/AIDS Education.

6. UNDP, HIV & Development Programme: Bureau for Development Policy, UNDP
   http://www.undp.org/hiv

7. HIV/AIDS Workplace Toolkit
   http://www.shrm.org/diversity/aidsguide/
   In an effort to provide employers with accurate, helpful and up-to-date information, the Society for Human Resource management and the National AIDS Fund have created this website to assist human resource professionals with handling workplace issues involving HIV/AIDS. While oriented towards the USA, concepts derived from the site could be applied to other settings.

8. The World Bank
   http://www.worldbank.org
   Many publications are available through the web page, plus general information on HIV/AIDS and the Bank. Search their publication categories on HIV/AIDS.

9. International Council of AIDS Service Organisation (ICASO)
   http://www.icaso.org

Publications, details of International AIDS Conferences and the work of partner NGOs.

10. EU HIV/AIDS Programme in Developing Countries
http://www.europe.eu..int/comm/development/aids/
Publications & funding information and details of ongoing programmes of the European Union.

11. Centre for Disease Control & Prevention – Division of HIV/AIDS
http://www.cdc.gov/hiv/dhap.htm
Information on basic science, surveillance, vaccine research, prevention research, treatment & funding.

12. Harvard AIDS Institute
http://www.hsph.harvard.edu/hai/home.html
The website gives details of proceeding of online chat search, online viewing of photographs spotlighting the individual journeys of participants of some women only protease inhibitor clinical trials, details of campaigns to mobilise policy support in Africa and Latin America and some interesting care Institutions.

13. International Centre for Research on Women – ICRW
http://www.icrw.org/
Details of Publications, Fellows Programme, Development Links etc.

14. HIV Positive.Com
http://www.hivpositive.com
Details on who's behind us? Find a doctor? Awards & Recognition – Voices of PLWHAs.