

GENDER CONCERNS IN HIV AND DEVELOPMENT



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. <u>FACILITATION</u>

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. <u>BACKGROUND READING</u>

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

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

Foreman, Martin, ed. <u>AIDS and Men: Taking Risks or Taking Responsibility?</u> 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. <u>Women and AIDS: Developing a New Strategy</u>. 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.

20

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 focusing 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.

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 uns 1995, there were 333 million cases of STD's of Saharan Africa and 150 million were in South and STD's increases the risk of HIV transmission	which 65 million were in Sub South East Asia. The presence of
	- two fold	
	- five fold	
	- ten fold	
	(Source: Health and Population Occasional Paper - ODA)	
3.	While HIV prevalence in male STD clinic attendees rates have increased more than fold among same period.	
	- two	
	- five	
	- ten	
	(Source: UNAIDS Fact Sheet December 1996)	
4.	In some villages in Uganda, focus group discussion men present had used a condom.	ns revealed that out of 22
	- 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 Uganda)	Impact of AIDS on Rural Families in

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.
	lowerhigher
	(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 foldthree 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.

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 socioeconomic impact of HIV/AIDS.
- > Legal and policy frameworks need to be made more enabling to ensure positive and sustainable changes.

"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. 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 pregnant²⁵ 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 Silhouettes²⁹ -- 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.

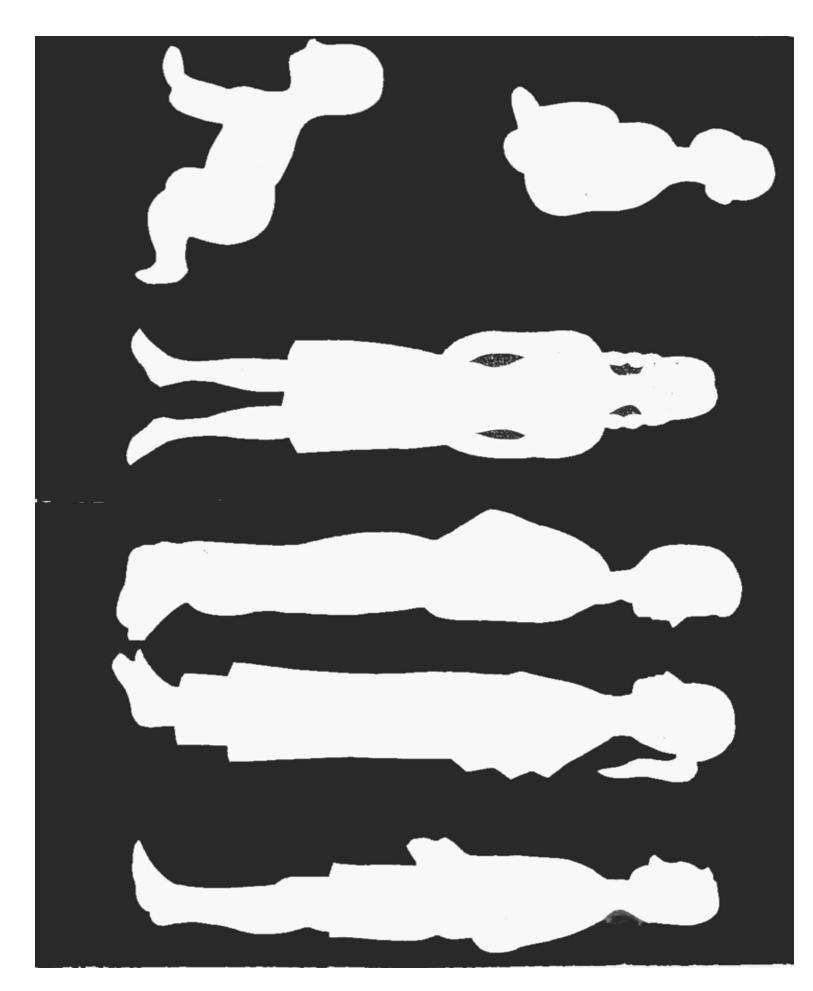
- 2. The facilitator forms three groups and each group is asked to select silhouettes that represent members of an imaginary family of their choice.
- 3. When all have comprised their imaginary families, the facilitator asks them to develop a story of their family, indicating the roles the members play 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.

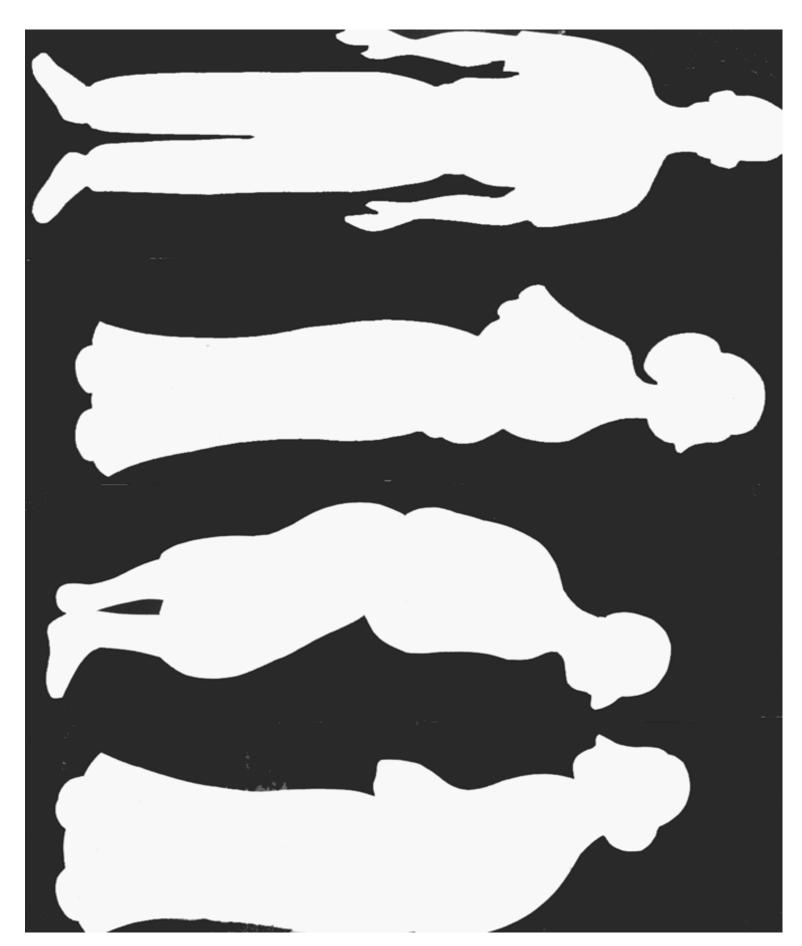
²⁹ Lyra Srinivasan, ACDIL Goa, India, has developed this learning tool.

- 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.

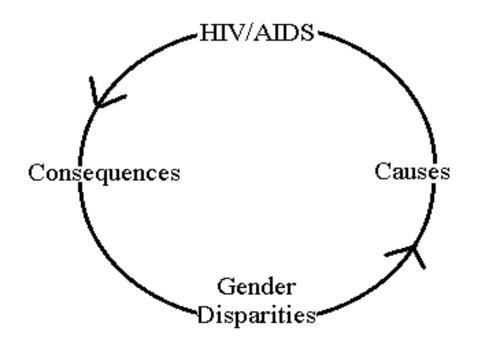
Note to the Facilitator Session 4

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.





GENDER DISPARITIES AND HIV/AIDS



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	3-5
Zimbabwe	

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. 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."

"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 Affairs³¹, 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 growing³⁸. 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. 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. 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

63

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). 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.

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. 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. The cost of administering Protocol 076 to pregnant mothers to prevent mother to child transmission amount to \$800 per woman.

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. 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

⁶¹Source - Whispers from within by Dr. Suniti Solomon and Rashmi Rajan Pachauri

⁶²Source - 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."

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 world⁶⁵, 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.

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.

⁶⁷ Hinder preventive work by civil society organisations or by the government amongst communities who need assistance e.g. prisoners.

⁶⁶ Leads to forced mandatory testing which is an impingement of human rights and drives the epidemic underground.

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.