Gender and HIV/AIDS

A Regional Workshop for Building Knowledge and Capacity among Community based Organisations and Women's Groups in Northern Region

22-26 October 2002
Vishwa Yuvak Kendra
Chanakya Puri, New Delhi

Organised by :

Institute of Social Studies Trust
U.G. Floor, Core 6A
India Habitat Centre
Lodi Road, New Delhi – 110 003

Sponsored by :

UNIFEM
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Proceedings of the Workshop

A capacity-building regional workshop on Gender and HIV/AIDS was organised by the Institute of Social Studies Trust from October 22–26, 2002 at the Vishwa Yuvak Kendra, New Delhi. Sponsored by UNIFEM, the workshop sought to introduce issues concerning HIV/AIDS to organisations working at the grassroots level in northern India to highlight the importance of including gender and HIV/AIDS in their work agenda. It also sought to develop their capacity at the individual and organisational level.

About fifty grassroots level workers from organisations in Chandigarh, Delhi, Haryana, Himachal Pradesh, Jammu and Kashmir, Punjab, Uttar Pradesh and Uttaranchal attended the workshop in which Hindi was the medium of communication.

Resource persons and guest speakers at the workshop included, Ms Chandni Joshi (UNIFEM, South Asia Regional Director); Ms. Suneeta Dhar (UNIFEM, National Programme Officer, HIV/AIDS); Dr David Miller (UNAIDS, Country Advisor); Ms Revathi Narayanan (UNAIDS, Programme Co-ordinator); Mr Subhash Mendhapurkar (Director, Social Upliftment Through Rural Action (SUTRA), Himachal Pradesh); Prof. Shalini Bharat (Tata Institute of Social Sciences, Mumbai); Ms Tripti

Tandon and Ms. Leena (Lawyers Collective, New Delhi); Mr Shantanu Chowdhury (Sahara Foundation, New Delhi); and Dr. Sushma Mehrotra (Consultant, NACO).

The following issues were discussed at the workshop:

- HIV/AIDS: Basic facts and its status in India
- Gender and sexuality
- Discrimination, stigma, legal rights and ethics
- Counselling and care
- National and International policies.

Day 1

Inaugural session

The inaugural day's events commenced with an informal address by **Ms Chandni Joshi, UNIFEM Regional Director South-Asia**. Pleased at the large turnout of women at the workshop, she stated that she was doubly happy to note that there was participation from the male segment too. She opined that men's participation, especially in such large numbers, would take the concerns and messages much further. So far, it was believed that women's participation in health programmes was not an important issue, but this view is undergoing a change, albeit slowly, as it was felt that women's participation was far more important being directly relevant to them.

Ms. Suneeta Dhar expounded the role of **UNIFEM** in Gender and HIV very concisely. UNIFEM was established in 1975 as a result of the women's movement. With its headquarters in the USA it now has regional offices in 13 countries. UNIFEM's main focus is on women-related issues such as political leadership, economic security, women's rights and empowerment, and since 1998, UNIFEM had also included the HIV/AIDS pandemic as it impinged on human rights. Inequality between men and women was steadily rising both inside the household and in the

society. In 1999, UNIFEM had sponsored various community-based studies at Delhi, Pune, Chennai and Guwahati for a clearer understanding of gender dimensions of HIV/AIDS as a social problem. The studies brought out the seriousness of the issue. The importance of working with community-based organisations was felt but the core issue then was how to build upon their capacity to deal with HIV/AIDS. Very often it was observed that voluntary organisations that work for HIV/AIDS do not include gender in their programme and those that work on gender issues do not pay attention to HIV/AIDS!

Ms. Dhar informed participants that various UN organisations had collectively formed a joint team for HIV/AIDS to work with the Indian government, as HIV/AIDS was, and is, perceived as a health problem and not a developmental problem. It was necessary to have women's active support and participation at every level while the men too needed to be involved and educated on these issues. In conclusion she expressed enormous satisfaction at the participation of various organisations and stressed the need to work on dowry, sexual abuse and other gender related violence. She emphasised that when talking about rights, violence, equality, etc, one should understand men's perceptions and garner support and assistance from men in their work.

Ice Breaking

Professor Swapna Mukhopadhyay, Director ISST, requested the participants to introduce themselves formally. The formal introductions were followed by informal introductions of the participants. The ball was set rolling by asking the participants to introduce themselves informally through a simple memory game, so as to register names with faces. The game consisted of the 50 participants sitting in a circle and while one participant spoke out her/his name, the second would have to repeat the first participant's name and then add her/his name to it. Eventually, the last participant had to remember all the names and add his/her name to the memory list! Quite a tough one, really to recall fifty names, but that was the fun element.

However, it also ensured participants got to know each other and hopefully at a later date remember these friends and contacts they made here.

To facilitate interaction between participants, the memory game was followed by another game wherein the men were asked to put their name-tags in a bag and the women participants had to pick a tag from the bag. Each female participant was then requested to pair up with the person whose name-tag they had picked. The objective of this game was to allow male-female interaction as well as increased group participation. The 25 pairs were then given five minutes to exchange information about each other, including hobbies and their favourite heroes/heroines. Each participant then had to introduce her/his partner to the group and recall as much of what their partner had disclosed as possible.

As the session ended, a very informal environment was created.

Gender

The post lunch session was dedicated to the issue of understanding gender and gender-related perceptions of the group. The discussion centred on the following issues:

- How gender is socially constructed
- How gender is different from biological sex
- Social norms and values, which are extremely gender-biased
- Different attitudes of society towards men and women
- Decision-making power of men and women in the family.

To get these issues across to the group in a comprehensive way, certain activities were taken up.

Participants were first divided into four groups — two female groups and two male. Each group was given chart paper and asked to divide it into two columns: male and

female. Under each column they were asked to discuss and write down what they felt was different between men and women; the different activities men and women perform in everyday life; or if there was any difference in behaviour, etc. Twenty minutes was given for this activity. While the charts were being collected, each participant was asked to relate the approximate age when they realised he/she was a boy or a girl. The conclusion drawn from these experiences revealed that at some instance or other, it was the family, friend or the society at large that made each one realise that they were a girl or a boy.

Following this, a person from each group was asked to narrate what they had listed in the charts on the roles of men and women. The differences and variations that the groups had listed were as follows:

For men:

- Gruff and heavy voice
- Provide security to family
- Bread winner
- Decision makers within and outside home
- Independence
- Lack sensitivity
- The successor of the family
- Higher social status
- Violent/aggressive in nature
- Freedom to make political, economic and social decisions.

For women

- Capable of conceiving and breast feeding
- Manage responsibilities at home and care for children
- Lack of health care, education
- Social control is exercised on them
- Show qualities of love, affection, kindness, etc.

- Mentally stronger because in spite of going through all the difficult circumstances, they live longer than men
- Secondary status at home and in society.

A question that cropped up during the discussion was to list areas where women enjoy certain status but men were unable to enjoy the same. Joy of motherhood and dressing up were the most common answers. However, a participant from Ladakh shared a completely different experience. She spoke about their society where women were economically independent and the birth of a female was celebrated and, there was no system of dowry. The discussion also brought up the question as to the kinds of work men could perform but women could not. The conclusion reached was that women could do all kinds of work but society created obstacles for her.

At the end of this discussion it emerged that two kinds of differences exist between men and women — firstly, physical differences that is natural and cannot be changed, secondly, differences brought on by society.

Explicitly as well as reading between lines, it is clear that gender is a balanced concept and cannot be seen as a man versus woman issue. Gender is a social construction and there is nothing natural about it. These disparities which take the form of discrimination against women are manifested in the political, social and economic aspects of life. To reduce these differences, social awareness is necessary and the process of social change is slow. One can change one's attitude, behaviour to bring about change and reduce these differences.

Day 2

Gender and HIV/AIDS

The first session of the day began with a summary of the previous day's session on gender. There were some participants who were unclear on aspects relating to

gender. Professor Swapna Mukhopadhyay divided the participants into six groups and asked them to write down the highlights of the previous day's session and spell out the questions that they wanted an answer to. These were:

- All groups accepted the understanding of natural and social differences among men and women.
- The physical differences give rise to social differences and these get manifested into different roles for men and women. These differences are seen in all aspects of life — social, economic and political.
- To reduce the gap between men and women.

Summarising, the session, Prof. Mukhopadhyay, stated that the workshop had brought together community-level workers generating various viewpoints on gender that required discussion and debate. She added that the main theme of the workshop was HIV/AIDS and its relation to gender. She pointed out that gender was a social construction, and therefore the need to look for social and political answers. On the basis of physical differences, society had brought about these differences evidenced in family life, economic aspects, work life and other aspects of life. These could be discerned even before a child was born, manifest in female feticide, etc. Although the female child was biologically stronger than its male counterpart, the unbalanced sex ratio gives a very different picture showing a decreasing female population. She stated that discrimination had no correlation with respect to whether a society was educated or uneducated. For example, while Kerala and Himachal Pradesh showed better literacy rates, the sex ratio continues to fall drastically in both regions.

In a short presentation on gender and its relation with HIV/AIDS, Prof. Mukhopadayay adroitly bound together gender with HIV. She elaborated that everyone experienced gender discrimination in their daily lives. Gender discrimination is discerned in terms of indicators and these indicators changed with specific context. In pointing out that the community workers would have a better idea of how gender disparities manifest themselves in specific contexts, she added that it

was important to understand HIV/AIDS in relation to gender. In most areas, women might have some power to influence decisions but when it came to sexual relations she had absolutely no autonomy or control over her body. Her powerlessness and vulnerability regarding decision-making around sex and sexual relations were one of the main causes of the spread of HIV. Women were socially and biologically vulnerable to the infection. She cautioned that one had to remember that the issue of gender was not of man versus woman but of one set of values against another set of values.

UNAIDS presentation

Dr. David Miller Country Advisor, UNAIDS, presented an overview of the global scenario of HIV/AIDS with emphasis on India. Introducing his organisation, UNAIDS, he stated that a number of UN agencies were its partners all forming a large network working on HIV/AIDS with UNAIDS at the centre. He stated that various UN agencies had tried to approach areas the government had not reached. He went on to say that the reported number of HIV positive cases was much less than the actual figures in India. Of late, the Indian government too had realised this discrepancy. Of the total HIV infected population in the world, ten percent of them were living in India. In terms of numbers, India had the dubious distinction of scoring a second place with an estimated four million HIV positive population. But this estimate, according to Dr. Miller, was less than the actual figure. The number of infections had increased in the rural population, and that too had not come out in the open. The work on HIV being done in India was very scattered with little or no networking between the agencies.

Dr. Miller pointed out that sex was a taboo subject in India and hence, not openly discussed. In India, men were supposed to take decisions about sex and sexual relations. Women on the other hand were considered ‘decent’ if they maintained their silence regarding sexual matters. He went on to say that the Indian situation was very vulnerable. South Africa, which went through a similar phase ten years ago

is presently faced with 6.1 million HIV positive people. In Africa as a whole, there are an estimated 28 million positive population. In the last one year, India had seen an increase of one million new cases.

Expressing his concern that if India did not take serious action now, he opined that India would face a similar fate as Africa. Presently, about 15,000 new cases of HIV are reported everyday around the world. Of these, 10 percent cases come from India's i.e. 1,500 people are infected everyday in India. Half of those infected were women and the rest were youth. According to the available data, on an average 85 percent were infected through unsafe sexual practices, 3.36 percent through intravenous drug use, 3.27 percent from mother to child infection and 2.14 percent through blood transfusion. In the North-East, 6.7 percent get infected by intravenous drug use and 2.8 percent through mother to child transmission.

Dr. Miller also explained that while HIV/AIDS was once perceived as a disease of poverty this has since been proved wrong and cited the example of Botswana. Botswana, which was liberated 15 years ago, became a prosperous country because of its diamond mines and was ranked amongst the richest countries with good infrastructural facilities like educational institutions, health services, roads, etc. Despite this, 40 percent of its population were affected with HIV/AIDS. The life expectancy dropped from 70 years to 38 years. The country was still in a phase of denial though Botswana had the ability to bear the costs of managing the infection. To slow down the spread of infection through mother to child transmission, a proposal was forwarded that said that anti-retroviral should be provided to all women irrespective of their positive status. Special attention was given to the fact that women should not breast feed their children as the possibility of the child getting the infection from mother's milk increased. Despite this, treatment was inaccessible to many. Also, many men hid or did not divulge their status to their wives or partners for fear of discrimination, and their partners were therefore not tested for HIV. In spite of economic stability and other factors, programmes could not succeed due to the fear, stigma and gender discrimination linked to HIV/AIDS.

Dr. Miller drew attention to the fact that India too is face to face with similar problems. Other than inadequate facilities and financial constraints; fear, stigma, discrimination, lack of decision-making and negotiating power in women were major challenges. Migration too led to vulnerable behaviour, a direct outcome of poverty.

He spoke about his experience of working with HIV positive people and the importance of empathising with their state of mind. HIV positive people wish to live a normal and healthy life and they have a strong desire to live. His experience, he said, showed that positive people were very sensitive and extremely careful of infecting others. Social ostracism is a tremendous setback for them, which aggravates their mental and physical suffering.

Ending his presentation, he requested participants to try and identify HIV positive people in the hospitals and villages within their reach and to establish a connection with them. It was important to provide them with information and counselling so as to gain support and strength to fight against the infection. By doing this, he said, their life would be happier and they would be able to lead their life with respect. He reminded the participants that this infection could affect anyone and was not a result of one's deeds.

Ms. Revathi Narayanan, **UNAIDS Programme Co-ordinator**, imparted information about a new programme: Co-ordinated HIV/AIDS Response Through Capacity Building and Awareness (CHARCA), which six state governments, state AIDS control societies, and six UN agencies have jointly formulated. The main objective of this programme was to create awareness among adolescent girls on sexually transmitted infections and HIV/AIDS and methods to protect themselves. Implemented through small women's groups that discussed various issues related to HIV, the programme was for three years in areas where women were considered more vulnerable to HIV. These regions include: Guntur in Andhra Pradesh, Jaipur in Rajasthan, Kishanganj in Bihar, Bellary in Karnataka, Kanpur in Uttar Pradesh and Aizwal in Mizoram. Mahila Samakhya, a woman's organisation has been given the

status of nodal agency. Prior to the actual implementation, the organisation had made an evaluative study in Bellary district to assess the status of the pandemic. The study highlighted women's vulnerability in the region. Ms Narayanan, concluded by saying that such a programme was a challenge to implement and she hoped that the programme would spread further.

Basic facts on HIV/AIDS

Rajib Nandi and Madhurima Nundy of ISST facilitated the post-lunch session with some basic facts of HIV/AIDS. They covered issues on:

- What HIV and AIDS meant and differences between the two
- The main modes of transmission
- Preventive methods.

The discussion elicited a number of questions. One was that if the virus is to be found in all body fluids then why is it that one gets infected through certain body fluids and not others. For example, although saliva contains the virus, the probability of one getting the infection through saliva is negligible as compared to semen or direct blood flow from one to other? Rajib Nandi explained that the fundamental reason was the amount of virus contained in the body fluid. While blood and semen have a very high concentration of the HIV virus, saliva and tears contain a minuscule amount of the virus. Mr. Mendhapurkar interjected that it would take a bucketful of saliva to get infected. Rajib Nandi further added that the HIV virus was a weak one, and when boiled, gets killed in a few seconds. In contact with oxygen it does not survive longer than 3 minutes. As saliva and tears come in contact with oxygen, the virus dies. Giving the example of intravenous drug users, he pointed out that since people, when using injectable drugs, generally sit in a group and exchange syringes quickly, the virus does not come in contact with oxygen for a long time and therefore, enters the body.

Mother to child transmission was another issue that was discussed. Questions as to whether the positive mother should breast-feed the child or not were raised as the milk does carry the virus to some extent. Mother's milk is good for the child's immune system, but at the same time the positive status of the mother can prove to be dangerous for the child. It was pointed out that today, medicines exist to reduce the transmission rates to a very large extent. This led to another question as to when does one get to know that a new-born baby is HIV positive? Rajib Nandi, explained that the test had to be performed at three different times to confirm the child's positive status — immediately after birth, after 6 months and finally when the child is 18 months old.

Rajib Nandi also spoke about the type of HIV tests that are conducted in India. HIV tests can be direct or indirect. An indirect test locates the HIV antibodies in the blood and a direct test can identify the virus in the blood. Currently, in India, two indirect tests are available: Elisa and Western Blot. However the indirect tests are not foolproof since the human body might take 2-6 months to produce the antibodies. This period is referred as 'window period'. This is the time taken for the T cells (a type of white blood cell which fights viruses) to create antibodies to fight the virus. If a person is diagnosed as HIV negative, he or she is always requested to come in for a second test in six months time. This would be considered the confirmatory test.

Finally, he stated that since this infection was initially detected among sex workers and homosexuals, the pandemic has resulted in a wrong labelling and the subsequent stigma attached to it. It was seen as 'their' problem not 'ours'. Thus, the truck drivers, drug users, migrant workers got labelled. But one has to remember that anyone could get infected. In a recent survey conducted by ISST, it was found that married women in a monogamous relation were equally vulnerable to HIV infection.

Sex, Sexuality and Reproductive Health

Mr Subhash Mendhapurkar, Director SUTRA, started the session with a brief introduction on why sex and sexuality was important in any discussion on HIV/AIDS. He added that sexual behaviour was linked to the spread of HIV infection and nearly 85 percent of the infection was spread through unprotected sex. As this issue was never discussed openly, it had resulted in the faster spread of the infection. He opined that if people were to work on HIV-related issues, they had to understand the sensitive aspect associated with it and be willing to talk about it openly so as to work in the right direction. Mr Mendhapurkar handled this difficult and unspoken issue through small group exercises.

In the first exercise, participants were given three words — vagina, penis and sexuality. Each participant was given three cards and asked to write not more than five points on each word. These cards were then collected and divided into three categories depending on whether the participant's response was negative, positive and neutral and this was then put up on the board. The cards revealed that there were very few positive responses where people used words like, pleasure, joy, etc. Most of the participants gave neutral responses that highlighted the fact that expressions, specifically positive expressions, for anything related to sex, sexuality is extremely limited in our society. This exercise revealed that the issue of sexuality was largely a hidden issue.

For the second exercise, participants were divided into four groups. Each group was given an envelope in which three to four sentences were written. Each group had to create a story from the sentences given. The groups were given 20 minutes to develop a story. Each group then enacted their stories and after each presentation, time was given for discussion. All the stories had a woman as the main character.

Story-1

A girl is born in the family. When the girl was six years old her uncle rapes her. She starts to menstruate at 16 years of age. Her mother tells her that all girls have menstrual periods. At this point the girl tells her mother about being raped by her uncle. On hearing this, her mother tells her not to speak about this to anyone and that she should forget about it. Around this time, she is told about her body in school. She gets married at the age of 20 to a 30-year-old man. After marriage, her husband tells her that he has had relationships with other women. When she is 30, she donates blood for a friend and is told that she is HIV positive. She does not know anything about HIV. Till the age of 40 she looks after herself without any support from the family. Then she comes in contact with a NGO that gives her support, information and treatment. Thereafter she comes in contact with other positive people and lives an ordinary life. She ultimately dies at the age of 60.

Story 2

For the third time a daughter is born to Ramlal. Ramlal's mother is very upset. The whole household is in mourning and even the neighbours come to console. After some time a son is also born in the family. But Ramlal's daughter faces discrimination in every aspect – behaviour, food, clothes, education, etc. The brother is sent to school while the daughter is made to stay at home and do housework. She starts having periods at the age of 12. She is a very carefree and restless girl. She attracts a lot of boys. She has boys constantly following her home. When she turns 16, her parents start talking of her marriage. They fix her marriage to a truck driver who has had other sexual relationships and which she suspects he continues to have. As he keeps falling ill, the doctor asks him to go in for a blood test and he is found to be HIV positive. But she does not know anything about this. The husband is given counselling by a voluntary organisation and is told to use condoms and not to have children. But the wife is keen to have children since she has not conceived any. As she is 35 years of age, she is told that it is not right to have children at this age. The in-laws blame the woman for not having children. The husband's condition deteriorates and she gets to know that even she is HIV positive.

Comments:

Story 1- what happened between ages 40-60 is not clear and moreover one with infection usually does not live that long.
If a 6-year-old gets raped, it is difficult to keep it hidden.
The woman did not know about HIV.

Story 2- If a woman who is married at 20 but does not have children, cannot expect to have children at the age of 40. How did this question arise so late? Our society expects a woman to have children immediately.
The doctor did not give counselling. Husband was a truck driver- a stereotype.

Both stories did not have any mention of children of the woman. There is a lot of pressure on the woman to have children within the first four years of marriage. The woman's life revolves around the husband but none of the stories deal with the woman's life after the death of the husband. In both stories, the infected did not have information about HIV.

Story 3

Lakshmi gives birth to a daughter – Kamala. The family is upset. The constant refrain is, 'how will the lineage continue if you have daughters only'. The mother-in-law is abusive and calls her a witch. Her husband does not speak to her for a week and does not show any affection towards Kamala. But Lakshmi is very fond of Kamala. Kamala plays with other children in the locality. She is very friendly with a boy who is slightly older to her. One day when she is playing with him in his house, he hugs her so tight that it hurts and she starts crying and rushes back home to her mother. Her mother tells her not to play with that boy any more. When she grows up she is admitted to school. After her fifth standard she is sent to middle school. When she is 12, she is told about changes that take place during adolescence in school. She completes her class X when she is 16 years old. Lakshmi wants to educate Kamala further but her husband's parents do not allow it despite pleadings and arguments. Kamala stays at home and is made to do household work. She gets

married at the age of 20. She has three children in the next ten years. She becomes very weak during this time. She gets pain in the lower abdomen and burning sensation in her urinary tract. A social worker begins to visit the area. Kamala is very sad and she tells the worker about her illness. Kamala said that she has heard about an illness with such symptoms and is incurable. The social worker tells her not to worry and that she will get her treated. The social worker takes Kamala to a doctor who tells her that it will get cured and that it is important to take medicines regularly. Kamala also starts working for the organisation. She starts to impart health information to other women. When she turns 60 she also receives an award for all the social work she has done.

Story 4

A daughter is born to Shyam. The family is sad but the mother is happy. But the child could not be immunised. The school was far and she was not sent to school. The years just go by. A social worker comes and informs the daughter about physical changes in the body during adolescence. She starts menstruating at the age of 12 years. When she is 16 a health worker tells her about immunisation against tetanus. At the age of 20 she is married to a middle aged man and gets STIs. At 30 she gets to know about treatment for STIs and gets better only when she is 40-45 years old. But because the STIs were not treated in time she also contracts HIV infection.

Comments

Story 3 – When discussing STIs one has to talk about couple treatment.
The story highlights the difference between STIs and HIV.

Story 4 – The message is unclear.
Even though the husband is middle aged, he is shown to be a sensitive person and they go for couple counselling.
Central point – marriage to a middle-aged man.

Both the stories emphasise on STIs.

All the stories were about the lives of women. The resource person pointed out that the aim was to bring in their sexual relationship. But in all stories there was an attempt to suppress the women's sexuality.

The last session of the day was on some sensitive phrases (Annexure1) which were based on common beliefs. Taking each phrase separately participants had to discuss whether they thought the sentence to be right or wrong. Some of the phrases discussed include the following:

i) Men portray their manliness through physical strength and by the number of sexual relations they have had;
ii) It is not important for men to be soft, they are less sensitive than women;
iii) Women and girls should remain virgins till they marry, etc.

Day 3

Sex, Sexuality and Reproductive Health (continued)

Mr. Mendhapurkar continued with the previous day's session. The participants were divided in to four groups and were asked to write down the highlights of the previous day's sessions.

While beginning the session he said that some people in India believe that discussion on sex and sexuality is not part of Indian culture, however this is not correct. The *Kamasutra* dealt extensively on sex and sexuality. By the 11th–12th century, temple sculptures portrayed the art of love-making in explicit and descriptive forms. The best way of educating people of those times on the issue of sex and

sexuality was through such stone carvings. Even homosexuality was portrayed through these sculptures, something considered abnormal and unnatural in India today. Some temples were even destroyed by people who were unwilling to accept them. Khajuraho and Konarak are two temples that have somehow survived the onslaught.

Mr. Mendhapurkar went on to add that every individual has an independent nature which gets expressed in his/her sexual relations and sexual preferences. People whose desires are fulfilled remain at peace. On the other hand, if these desires are left unfulfilled then this gets reflected in terms of violence or unhappiness.

Participants were again divided into eight groups and four case studies (Annexure3) were given to them. At the end of each case study, some options were given. Each group had to pick out a common answer after discussing with their group members. Groups could also put forward more than one option.

In the first story, a woman who is pregnant for the first time is found to be HIV positive while her husband is not. The participants had to discuss what step the husband should take. The discussion that followed brought out the following points:

- Who has the right to decide for the child?
- Whether divorce can be considered as the solution.
- The woman is just HIV positive, it takes a long time to reach the state of AIDS. It could take from 8 months to 15 years.
- The pressure to have a child is immense after marriage, how does the husband manage the situation.
- The family should be given information about the situation.
- The woman should not give birth to an unhealthy child but then it is not necessary that the child be HIV positive.
- If the husband wants to become a father then the couple should come to a mutual understanding and the husband can go in for second marriage.

- The wife has the right to abort and therefore some groups also this as an option.

In the second story, the couple had been married for five years but did not have children in spite of not using any contraception. The wife has a very strong desire to experience motherhood. She was tested for infertility but was found to be healthy and no gynaecological problem was detected. Later the husband also underwent a medical examination and was found to have a very low sperm count and would not be able to impregnate. The question was what the wife should do in such a situation. The discussion highlighted the following points:

- As the wife wants to experience motherhood, she should get artificial insemination done.
- Both can adopt a child.
- Can the husband accept being a father when someone else's semen is injected?

Mr. Mendhapurkar interjected here that in the *Vedas* it is accepted that if a man is unable to impregnate his wife, then the woman could opt for another man to impregnate her. This was called *beej kshetra nyay*.

In the third story, the woman was unable to bear her husband touching her. Everytime he came close she turned cold and would often vomit in bed. Even after trying continuously for six months the marriage could not be consummated. The discussion revolved around the most appropriate move for the husband to take. The following issues came up during discussions:

- The wife should consult a psychologist.
- Homosexuality is not a disease or abnormality.

Postulating on homosexuality, Mr Mendhapurkar declared that homosexuality is not unnatural behaviour. It has been prevalent in our society for a long time. In certain parts of India, a class of women preferred being with women. These women were

termed ‘yoginis’ and they wore saffron-coloured clothes and necklaces made of shells. Temples dedicated to them abound in Orissa and Madhya Pradesh.

In the fourth story, when the couple got married the wife was 15 years old and the husband is 17. The husband worked for ten years as a farm labourer that involved very heavy work. He also has three children but in the past few years he has become impotent and in spite of treatment the husband’s condition does not improve. The question now was about the various options that were available to the wife. The following points came up during the discussion:

- The wife can keep herself busy by concentrating on other activities.
- She has the right to establish sexual relations with someone else.
- The husband’s willingness to go for treatment at least reflects his willingness to perform better.
- Will society allow the wife to establish sexual relations out of marriage?

Mr. Mendhapurkar explained that all these case studies were real life experiences, but one needs to openly talk about it. None of the stories had a definite answer, as they depend on the context and the situation in existence at that time. What is important is to discuss, debate and understand the situations objectively without prejudices or biases. He concluded the session by stating that if one had to work on HIV/AIDS then one must analyse one’s own attitudes and beliefs. One must have the right kind of understanding and have an open mind about issues of sex and sexuality to start with for only then can one start working on HIV/AIDS. If one sticks to stereotype notions, one will only be promoting patriarchal values and notions.

Stigma and Discrimination

Prof. Shalini Bharat of the **Tata Institute of Social Sciences** chaired the session on stigma and discrimination related to HIV. Having done extensive research on this topic she shared her experience with the participants. She started the discussion by talking of the reaction of HIV positive people when they become aware of their

‘status’. The first reaction is that of denial. Gradually they start accepting the situation and are willing to seek treatment. Thankfully, in a country like India the positive person is not totally cut off from the family for they sometimes get emotional and economic support. But one can perceive a gender bias when it comes to giving support and it comes out in the form of discrimination.

Differentiating between stigma and discrimination, she said stigma is the act of labelling or attributing undesirable qualities that turns into belief. The behavioural outcome of this belief is discrimination.

She clarified that there were four modes of transmission for HIV, but people jump to conclusions and the common belief is that whoever has HIV has it because of ‘unacceptable’ behaviour. Therefore, they deserve what is coming — to be HIV positive. This is the concept or image about AIDS in everyone’s mind, which only makes the belief even stronger. This then gets converted to acts of discrimination and discrimination and stigmatisation get manifested at different levels, in various forms and under varying contexts. She explained the various levels thus:

- Individual level.
- Family level: A HIV positive man might get support from his family but a positive woman does not get the same care and support. If the person is economically dependent then the status decreases in the family.
- At community level / place of work: Groups like sex workers, homosexuals and slum dwellers are discriminated.
- At the level of nation state: Presently Africa has been often in the news due to the increasing number of HIV cases. And the entire continent is getting discriminated on the basis of the beliefs people carry with them.

Discrimination is very prominent at the healthcare delivery level:

- Hospitals do not provide the required treatment.
- Separate beds labelled ‘AIDS’ for AIDS patients.

- The discriminatory attitude of the caregivers like doctors, nurses and the other staff itself reflects the larger social belief.

This discriminatory attitude even reflects in what people say. Phrases like, ‘You must have gone out and done something wrong’ is very commonly used. Words like ‘dirty’, ‘bad’, ‘dreaded disease’, ‘sinful behaviour’ are frequently used. When such phrases are used by a doctor or caregiver, the positive person is totally at a loss to counteract, aggravating their mental trauma. Reactions of people who come in contact with them affects them a lot. While a positive interaction make them feel stronger in mind and spirit, a negative experience brings down their self-esteem further.

During the discussion, a participant raised the question whether this act of discrimination could be a way adopted to protect oneself from getting the infection? Prof. Bharat remarked that it would only be justifying the act of discrimination. Many people, especially doctors or nurses deny treatment to HIV positive people on the grounds that they need to protect themselves though they are duty bound to treat patients. There are ways to protect oneself without discriminating people living with AIDS. She explained that stigma could be broadly categorised into:

- Experienced stigma: Something which the patient experiences; and
- Seeing others being discriminated and getting frightened by what one sees.

Stigma is not tangible, Prof. Bharat said, but the beliefs that have formed in people’s minds regarding HIV/AIDS, manifests into fear. Two central themes that emerge from the phenomena of discrimination and stigmatisation in HIV/AIDS are fear and prejudice. Fear is the prejudice in society towards behaviour considered abhorrent, deviant and unacceptable. Illustrating this, she said fear is also of two types:

- Fear that has a basis
- Fear that has no basis or is exaggerated, like the feeling that one will contract the disease if one shakes hands with a positive person.

Elaborating on this, Prof. Bharat remarked that a number of AIDS programmes talk of controlling infections through scientific ways, like introducing anti-retrovirals, etc. but there is no talk of changing beliefs, prejudices and attitudes in society. The spread of this disease can be directly attributed and linked to stigma, discrimination and the fear generated by lack of information. Discussing this she added:

- HIV infected keep changing doctors because of fear of identification or because of the doctor's attitude. Such cases eventually never get reported and the HIV positive person might spread the infection to their sexual partners inadvertently because there is no one to give them the right information.
- Some people do not report their positive status to their families. Married men can therefore pass on the virus to their wives.
- Homosexuality is considered unnatural. For homosexuals who are HIV positive, the fear of discrimination doubles, first because of their sexual preference and secondly chance of their being infected with HIV. Therefore, they prefer to remain silent.
- For the sex worker also the fear of stigma is immense. First she has to face the stigma of being a sex worker, then that of being HIV positive and finally of that being a woman.

Dr. Bharat reiterated that people living with HIV/AIDS are part of the society. The discrimination they face among their families, place of work, hospitals, etc. are misplaced and unjust. But change is a slow process. She explained the rights of a HIV positive person within a human rights framework, the responsibilities of a positive person and the responsibilities of society and a country towards the positive person.

- Everyone has an equal right to medical care.
- For a sex worker, it is her right to get treatment.
- If the patient wishes, the doctor must maintain confidentiality.
- Every doctor has the right to take necessary information from the patient. The doctor has to respect the patient's right to remain silent if he is not willing to

disclose certain facts. Any patient has the right to information from the doctor regarding tests, medicines.

- Doctors have the right to demand necessary protection when treating a HIV positive person.

Here Dr. Bharat emphasised that all these rights come with added responsibilities. If a positive person wishes to marry, then it is his/her responsibility to notify the partner. But positive people are unaware of their rights and due to lack of information they keep facing discrimination and accept what is happening to them. Rights are not just limited to HIV/AIDS. There are a lot of groups who are unable to voice their rights. One positive thing is that some work is being done through the positive people's network.

Legal rights of positive people

A brief session on legal rights was taken up by **Ms. Tripti Tandon and Ms. Leena**, resource persons from the **Lawyers Collective**.

Informed consent for getting oneself tested and the right to maintain confidentiality are two basic rights of the positive person. If informed consent is not taken, the rights of a positive person is said to have been violated and one can then seek legal redress in court. People therefore should be made aware of the fact that they should always ask their doctor what tests and medicines they have been asked to take and why.

People living with HIV/AIDS are often afraid to go to court to fight for their rights for fear of discrimination if their status becomes public knowledge. In such a case the court also allows a person to file the petition under a pseudonym. Positive people can hence seek justice without fear of social ostracism or discrimination.

A positive person can file a case if he/she is discriminated at the workplace, or at any place where he goes to seek treatment. Someone who is HIV positive, but otherwise fit to continue the job without posing substantial risk to others, cannot be terminated from employment. Such a person who is thrown out of a job because of the positive status can approach the labour or industrial court or can also approach the civil or high court if a government servant.

The discussion also brought out what the rights of a positive person are as against those who are not HIV positive. It was emphasised that partner notification has become a legal right. If a positive person is not willing to disclose his/her status to their sexual partner, then the doctor or the counsellor has the right to notify the partner.

The resource persons then distributed pamphlets, regarding rights of positive people. The session had to be kept short owing to shortage of time.

Day 4

Counselling and Care of People living with HIV/AIDS

Mr. Shantanu Choudhury from **SAHARA** (an NGO that provides residential care and support to people living with HIV/AIDS) was the resource person for the day. SAHARA has been working primarily with drug users for a long time. In the course of their work they had come across many injecting drug users who were also HIV positive. They realised that it had become very important to give support and counselling to positive people. Later they extended their care and support services to positive women and their children. SAHARA has a care home for women and children and a residential care home for terminally ill AIDS cases. Ninety percent of their staff are either ex-drug users or HIV positive.

Mr. Choudhury started with certain controversial statements (Annexure 4) and asked the group to react to it. For example: homosexual behaviour is abnormal, the participants had to say either yes or no and why which was followed by a short discussion. Fourteen such statements were discussed and participants gave their viewpoint for each.

Mr.Choudhury took up the subject of what exactly HIV/AIDS counselling meant and the role of the counsellor. The twin objectives of HIV/AIDS counselling, he said, was to:

- Provide psycho-social support to those already affected
- To bring about change in people's behaviour to prevent the spread of HIV infection.

Counselling as a process can ensure passing of correct information; provide support at times of crisis; encourage change when needed for prevention or control of infection; help clients focus and identify their immediate and long term needs; and also help clients to be well informed and appreciate the technical, social, ethical and legal implications of HIV testing. While doing this the counsellor has to be non-judgemental, a patient and good listener and most importantly should maintain confidentiality. Decisions have to be taken by the client and the counsellor is there only to provide options according to the need and help the client take independent decisions. A counsellor cannot get emotionally involved with the client. Counsellors have to learn to handle the emotional reactions of HIV positive people like anger, despair, fear and denial.

HIV/AIDS counselling is for:

- Persons already identified as having AIDS or being HIV positive
- Those being tested for HIV (pre and post test counselling).

Situation in which counselling is sought by people include:

- People with AIDS or other diseases related to their HIV infection
- People experiencing difficulties with employment, housing, financing, family as a result of HIV infection
- People who want to get tested
- Those who have already been tested like injecting drug users

Other than pre-test and post test counselling, counselling as an on-going process is very important. This is so because infection with HIV is life long and the psychological pressures and anxieties are immense.

Jyotsna Sivaramayya of ISST interjected here and stated that even while counselling, it becomes important to understand who is being counselled and the place of the person in society. For example, a woman might be counselled to ask her partner to use condoms for safer sex. But here the counsellor has to understand the broader gender relations and be sensitive to it knowing that she does not have any say when it comes to sexual relations.

A small break later, the next session began with a discussion on pre-test counselling. The importance of pre-test counselling was that it permitted comprehensive assessment of the individuals risk background, psychological condition, ability to deal with the test result and the needs in the post test period. Counsellors should:

- Start with forming a rapport
- Explain the concept of confidentiality
- Ascertain the reason for client's visit
- Assess the level of information on STIs, HIV/AIDS while gaps should be filled in with appropriate information
- Clarify and correct myths and misconceptions
- Record the personal history of the client
- Assess risk behaviour

- Discuss potential implications and coping ability of a positive or negative test
- Explain testing procedures
- Take informed consent before the test.

With the help of role-play all these issues were brought out and better understood by the participants.

This was followed by a discussion on post-test counselling. Mr Choudhury explained that post-test counselling concerned discussing the test result with the client. Adequate counselling ensures an opportunity to reduce further transmission and if the test result is negative then ways to reduce the risk of getting infected. The goal of post-test counselling is to emphasise social responsibility and provide support for change in risk behaviour. It must instil a willingness to live and deal with an infection that may otherwise lead to a life of fear, isolation, and ostracism. Counsellors should:

- Reveal the test result under absolute confidentiality and give time to the client to absorb and ventilate his/her emotions.
- Check what client understands by the result.

If the test is negative:

- Suggest a re-test after window period if appropriate.
- Reinforce strategies for prevention.
- Stress on avoiding high-risk behaviour.
- Emphasise on the client to negotiate with others in order to maintain the new behaviours.

If the test is positive:

- Acknowledge the shock of diagnosis and offer support and encourage hope.
- Facilitate the client to ventilate her/his feelings.
- Explain difference between HIV and AIDS.

- Identify immediate concerns.
- Discuss who the client would like to disclose the result to.
- Encourage partner notification.
- Identify problems the client may foresee and how to deal with it.
- Provide practical information on how to live with the infection.
- Discuss health-maintaining behaviours such as safer sex, nutritious diet, sleep and exercise.
- Provide information on referral services. This is important because it helps to open up further options to clients and helps to reduce the strain on any one single organisation.

A role-play was conducted and a senior counsellor who was also a participant took up the role of the counsellor.

The last session dealt with the role of NGOs in management of HIV/AIDS. A broad-based comprehensive package of service any AIDS care programme should offer was listed:

- Residential care
- Home-based care
- Community-based care.

Residential care dealt with counselling and other facilities provided by care homes. These fill the gap between the hospital and the home. Here clients and their families are taught how to look after themselves so that in course of time they are able to take care of themselves without having to come to the care home for everything. Giving the example of SAHARA, Mr. Choudhury stated that people who have AIDS are provided with care including palliative care to make their end peaceful. The caregivers are trained and provide care till the very end.

Services recommended are:

- Diagnosis and treatment of opportunistic infections
- Palliative care
- Counselling of client and family
- Laboratory facilities
- Linkages with other hospitals
- Referrals and networking
- Follow ups by home visits or correspondence
- Training programmes in ‘Hands On’ care
- Vocational training and employment opportunities for people living with HIV/AIDS
- Recreational facilities.

For home-based care, clients and their families should be taught basics of care at home. It is important to provide information on provision of cheap and nutritious food, how to deal with soiled clothes and how to dispose of waste. Providing support through counselling to the affected families is a must.

Community-based care is an extension of home based care. Clients and their families have been empowered to provide ongoing support to other infected persons within the community. Myths and misconceptions can easily be dealt with through dialogue.

Mr. Choudhury ended the day’s session with some key concepts:

- A research study revealed that most people face discrimination either in their families or with the medical fraternity.
- Effects on expenditure: Average expenditure on food has increased by 20 percent and average expenditure on education of children has decreased by 75 percent. Therefore treatment, care and support have to be strengthened and more resources need to be provided to NGOs.

- The most affected group is the youth and one needs to reach out to this group on an emergency footing.
- The rural population is still a hidden population, in spite of sentinel surveys. With large scale rural migration, many may carry the virus home.

While concluding his discussion, Mr Choudhury, stated that SAHARA's experience revealed that there was a necessity to have transparent and need-based networking between NGOs and government facilities to strengthen the quality and quantity of services.

Day 5

Dr. Sushma Mehrotra, **Consultant NACO** shared information about the government's efforts and various programmes on HIV/AIDS with the participants. One important thing that she mentioned during her discourse was that each of the NGOs should get in touch with their region state AIDS control societies (SACS) and work towards forming some kind of network. Dr. Mehrotra spent a great deal of time answering queries about various programmes run by the government. A NACO help-line (1097) was also currently functional, which some participants were aware of.

Feedback and Evaluation

The last day also had a feedback and evaluation session where **participants** wrote down their responses to the following:

- Expectations of the participants before coming to the workshop.
- Had the workshop helped in changing their perceptions or helped them to gain new information?
- The shortcomings in the workshop/logistics?
- The kind of follow-up participants expected or wanted.

As the group was very diverse in terms of knowledge levels on HIV/AIDS, type of work and their work profile in their own organisation, the feedback was very varied. The following are the main issues mentioned in the feedback questionnaire.

Expectations from the workshop

Information

Most participants were keen to get more information about the HIV/AIDS epidemic especially about symptoms, its progress as a disease, medicines, etc. There were also some who did not have even the basic information about the HIV virus and the method of its spread. Many were keen to know about the latest research in this field. Participants also wanted information on other issues such as procurement of free/cheap medicines and treatment and other referral services.

The other important area mentioned relates to capacity building when working in the community. How to start a HIV/AIDS programmes in their area where awareness was negligible was mentioned by some. The participants wanted to acquire communication skills to handle HIV/AIDS related issues. Many wanted to know more about care and counselling at the individual, family and societal levels. A number of participants wanted to develop capacity to give care to the infected rather than relying on government hospitals.

Gender issues

The participants were keen to know how and why women were more vulnerable. Some also reported wanting to acquire skills to be able to include gender issues in their work and especially incorporate gender issues with HIVAIDS.

Experience sharing

The participants also looked towards this workshop as a forum for experimental learning to share work experience and work out solutions. One participant stated, ‘In our work we were following government guidelines but we were not able to

implement them in our community work. When we talk in the community about condoms, we have to face a lot of problems, so we wanted someone to guide us in this respect.'

Whether new information/perspective was gained

Information

Most participants said that they gained more information about the extent of spread of the HIV/AIDS epidemic in India and the world over. Many also reported getting new information about mother to child transmission, blood transfusion, sexually transmitted diseases and the current perspectives about breast feeding for positive and negative neonates, etc. Issues of stigma and discrimination, and legal rights were new for a lot of the participants. Information about counselling and care was reported by nearly all the participants.

Change in perception

Listed below are some of the comments of the participants:

'I learnt a lot. It has not only changed my ideas and perceptions about the situation but also about the challenges we are going to face in the field of prevention and care of HIV/AIDS in the country.'

'We had limited knowledge about HIV/AIDS before we came to the workshop and now we got to know the right perspective.'

'Before coming to this workshop we thought only certain kind of people get HIV/AIDS but now we know that anyone can get HIV/AIDS.'

'I reflected on norms, values and practices in society.'

'It is not just a health problem but a societal problem and it affects not just particular groups but the whole society.'

'I got to know about the age group most affected.'

'We should not target specific groups but work with all sections of society.'

'I didn't know that eunuchs were also affected.'

Gender

The importance of including a gender in dealing with HIV/AIDS was mentioned by many. For some the concept of gender was absolutely new.

Sex and sexuality

A very large number of participants mentioned the connection between sex and sexuality, and HIV/AIDS. Various participants reported the necessity to give up inhibitions about using certain vocabulary in discussing sex and sexuality, and the need to talk about it openly in society. Many reported that they had never discussed homosexuality. The need to introduce sex education in schools was opined by many. One of the participants summarized the session succinctly, 'I realised that we cannot talk about HIV/AIDS without talking about sex and sexuality. Till now we had considered sex and sexuality only in terms of reproduction, but we are now aware that it is about mutual trust, respect and a way of expressing our emotions.'

Condoms

Participants also mentioned realising the importance of condoms in preventing the spread of HIV. Some also reported getting to know how to propagate condom use.

Role of Government

A need for the government and other organisations to work together on this issue was also felt by the participants. They also came to know the role of the government and NGOs for the HIV infected.

Stigma and Discrimination

Participants mentioned that they reflected on their own attitude towards the infected and also the realization that stigma and discrimination has no foundation. They also mentioned the need to respect the HIV infected and make them feel a part of society.

Limitations/shortcomings

Time

Shortage of time for some sessions that resulted in some topics being skipped was felt by the participants.

Sessions

Better linkage between sessions especially between gender and HIV/AIDS was needed.

Gender issues were not incorporated in care and counselling. In spite of the workshop being in Hindi, some participants felt that the resource persons used too much English.

Resources

Participants wanted more tools that could be used by grassroots level workers in illiterate communities. They also emphasized the need for more reading material especially in Hindi and also more information on treatment and awareness methods in general.

Some would like to have a review of the resource persons especially to include a medical doctor.

Interaction

The participants also felt that the group should not be of more than 25 participants as this would allow for greater interaction. There was no time for the participants to share their own experiences, nor for ISST to share their own research findings.

Follow-up

The need for *periodic meetings* and *information dissemination* was mentioned by nearly all the participants. A follow-up meeting after six months or a year to

discuss field experiences and to get more information on the most recent developments. A few were also interested to know whether such workshops could be organised at the district level.

Information dissemination

Regular information updates to all NGOs through correspondence was also felt by the participants. They also wanted information about other organisations working in this field.

Impact of the workshop

An evaluation of the way the participants have used the skills they gained in the workshop (could be done through correspondence) was also reported. The participants felt that there should be some space for discussion to see how they could include the workshop experience in their work and for experience sharing between the NGOs.

Other suggestions

- Participants felt that ISST should take up the task of co-ordinating the network and act as a resource base for information and support.
- A fieldtrip to the participant NGOs to evaluate the impact of the training was also recomended.
- A visit to a care centre catering to HIV infected was strongly felt.
- The need to include issues concerning the middle class was also mentioned as was the need to work with adolescents.
- Participants also wanted to know more about services being provided for HIV/AIDS infected.
- Last but not the least participants felt that local NGOs need to form a network.

ISST's Assessment

The workshop should be seen as a first step in a process of capacity building of community based organisations on a gender sensitive approach to HIV/AIDS. In this regard ISST also strongly feels like the participants that this workshop should be followed by another meeting within a year. Even though the workshop focused on issues most relevant to northern India, due to a shortage of time many pertinent issues could not be taken up. ***Therefore there is a necessity to follow up with another meeting with the same participants*** to fill in the gaps and cover the issues that were not covered in the last meeting.

We also feel that in this workshop the focus tended to be more on HIV/AIDS and its link with gender issues could not be followed in depth. We feel that this problem is a reflection of a gap that exists between those working on issues of gender and those working with HIV/AIDS issues. In sessions dealing with HIV/AIDS, gender issues were not incorporated as most have not included a gender perspective in their work. Issues such as sex work and violence against women, and its link with HIV/AIDS requires more discussion. Gender issues also have to be incorporated in HIV/AIDS related care, counseling, stigma and discrimination, and its relevance in a bio-medical context too would need exploration.

The follow-up meeting should focus on the situational and operational problems that the organisations face in the field and provide relevant skills for these problems through experience and information sharing between the participants. This would also help ISST assess to what extent they have incorporated gender and HIV/AIDS in their agenda.

Lack of material in Hindi has been a hindrance to information dissemination and we feel that there is a need to bring out more material in Hindi, based on the experiences in the field of HIV/AIDS and gender. Our experience in the workshop has been that participants also wanted to know about the latest developments in HIV related research. Last but not the least we feel that there is an urgent need to develop IEC material in Hindi that includes gender and human rights perspectives in discussions on HIV/AIDS.

ISST would also like to consider whether this sort of workshop could be carried out in other Hindi speaking states such as Bihar, Jharkhand, Chhattisgarh, Madhya Pradesh and Rajasthan

This workshop has focused on sensitization, awareness generation and capacity building on dealing with HIV/AIDS from a gender perspective in the community. The next stage in our view is to develop empowering strategies that will work towards building gender equitable approach to deal with the epidemic. We also feel that empowering strategies need to involve men in a big way especially as decision making still is rests with men and therefore gender sensitization approaches have to involve them.

Gender and HIV/AIDS

A Regional Workshop for Building Knowledge and Capacity among Community based Organisations and Women's Groups in Northern Region

22 – 26 October 2002

Vishwa Yuvak Kendra
Teen Murti Marg
New Delhi

Organised by	Sponsored by
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