

REPORT

WOMEN'S CONSULTATION
on the
DRAFT LEGISLATION ON HIV/AIDS
17-18 April 2004
Agra

Lawyers Collective HIV/AIDS Unit

BACKGROUND

The Need for a Law on HIV/AIDS

It is now well-accepted that HIV/AIDS is a phenomenon that cannot be looked at solely from the perspective of medical science but requires approaches that are holistic and that consider social, cultural, economic and human rights perspectives.

Protecting human rights – a sound public health strategy

That law can be used as an instrument of social change and that such use of law with a human rights perspective helps in mitigating the spread of HIV/AIDS has been widely experienced and accepted. It has been observed and established that, paradoxically, protecting the rights of those infected by the epidemic and those most vulnerable to it is the best public health strategy in controlling the spread of HIV/AIDS. These rights include among others consent to testing, maintaining confidentiality of status, non-discrimination and access to services including travel, insurance, employment, treatment.

Why do the rights of these individuals need to be protected? Primarily because HIV/AIDS has highlighted such vast inequities, violent abuse and widespread stigma that human rights have been violated in a manner and on a scale rarely witnessed in the public health sphere. However, these rights need to be protected for another, more practical, reason. By protecting the rights of those infected and most vulnerable to HIV/AIDS, an environment will be created whereby stigma, violence and inequity will be lessened thereby bringing the disease into the open and making it easier to control.

The need for statutory law

A consistent and universal legal environment can be created most effectively by a statutory legal regime that guarantees such protection. There are reasons why a specific statute is required to govern the HIV/AIDS scenario in India.

1. The vagaries of common law: The various legal issues that arise in the context of HIV/AIDS, viz. consent, confidentiality etc. are mostly governed by the common law regime. This allows for the personal predilections of individual judges to decide on cases of HIV/AIDS. This lends itself to extreme inconsistency and at times opposition to the existing well thought out policy of the government. Obviously it does not promote a strong, reliable legal system.

2. Addressing discrimination: The violation of rights is rooted in the stigma and fear that the epidemic has caused. These violations are widespread and gross. They detrimentally impact on accessibility to various services and sectors including healthcare, employment and insurance for people infected by or at risk of contracting HIV/AIDS.

Although the Constitution of India guarantees equality, it is available only against the public sector. Therefore, there exists an abject lack of legal control over discriminatory practices carried out in the private sector, be it healthcare, employment, or insurance. This needs to be addressed if the legal regime has to be universally applicable. Most countries that have addressed this area have in place anti-discrimination provisions applicable to the private sector.

3. The insufficiency of policies: Although India does have the National AIDS Prevention & Control Policy; this policy does not have the status of law and is not binding on and enforceable in court. However the common law regime that exists in our country allows individual judges the liberty to decide the law as they see it. The presence of a nationally applicable statute would lend consistency, clarity and predictability in order for courts to effectively pass judgment in HIV/AIDS cases.

Law reform

There are various interventions amongst the marginalised communities that are in place in India which effectively check the spread of HIV/AIDS. Notable amongst these are condom promotion and needle exchange programmes. These safe havens can be set at naught with the existing legislation. Laws impacting such interventions have to be amended to legally protect them. Legislation on HIV/AIDS is also required to guarantee the rights of these marginalised communities so that measures can be taken for them and society at large to resist the spread of the epidemic. This will require simultaneous law reform that removes provisions that prejudice these communities and empowers them to protect themselves and others from HIV/AIDS.

Draft Legislation Process

The process of drafting a legislation on HIV/AIDS began in May 2002, with the inter parliamentary group meeting where Ministers of Parliament including the then Prime Minister and Leader of the Opposition discussed HIV/AIDS and the [] o the epidemic in India. In another meeting of parliamentarians, Anand Grover of the Lawyers Collective emphasised the need for legislation on HIV/AIDS. Then Rajya Sabha member, Kapil Sibal supported this idea and requested the Lawyer's collective to formulate this legislation.

[AWG etc.]

The Unit undertook the task of preparing the draft legislation on two conditions that: thorough research and preparation of background information that consists of reviewing laws in various countries would precede the drafting; and the draft law would not be ad-hoc and the process would include involvement of the community through consultations.

Preparation of background materials

Since then the Unit has carried out extensive research on laws, policies and practices on HIV/AIDS that facilitate HIV intervention programmes in different jurisdictions, particularly common law regimes, to examine their applicability in the Indian context. This research has been presented and discussed at numerous meetings with the group on the draft legislations. The research was then in the form of a book – “*Legislating an Epidemic: HIV/AIDS in India*”. This book embodies fundamental principles of public health and human rights, which form the basis of the draft legislation on HIV/AIDS.

Subsequent to the preparation of the book, the Unit began drafting the law based on the research, provisions of various laws and experiences, both national and international, with the HIV epidemic. Currently in a draft form, the legislation is now slated to go through rigorous consultations with individuals, communities, government and various other stakeholders.

Consultations

HIV/AIDS is a health crisis that has been recognised to impact affected populations not only in terms of their health but economically, socially, culturally and legally as well. This has also been the experience in India, and in response, the Indian government and the country’s civil society have put in place strategies that attempt to address HIV/AIDS holistically and with the promotion of human rights as central to their approach. India now has a large community of persons who work on HIV/AIDS in all its aspects and those who work in spheres that are inevitably impacted by the epidemic. As such, over the last decade many people have gained rich, vital experiences and insights into the epidemic.

Any legislative measure that attempts to address the prevention of HIV infection and mitigation of the impact of the epidemic must, therefore, be informed by these realities, otherwise legislation is bound to fail in addressing the needs of the Indian polity vis-à-vis HIV/AIDS. In a democracy, legislation must necessarily reflect the voice of its people and any attempt to formulate one must, therefore, be consultative to the extent possible. With this in mind, the Lawyers Collective HIV/AIDS Unit proposes to conduct nation-wide consultations on the draft legislation on HIV/AIDS by involving and learning from the representatives of various sectors that are impacted by the epidemic.

The draft legislation is accordingly being shared at various consultative meetings that comprise of individuals, groups and communities who would be affected by this law. The first consultative meeting was with People Living with HIV/AIDS (PLHA), the second one with Sex Workers, Injecting Drug Users (IDUs) and Men who have Sex with Men (MSM) and the third meeting, to which this report pertains, was with Healthcare Workers. Subsequently, a consultation was also held with the ‘world of work’ and meetings with women and children’s groups are also proposed. These will

be followed by regional level consultations to be organised in co-ordination with State AIDS Control Societies in different parts of the country.

INTRODUCTION

The Consultative Meeting on the Draft Legislation with Womens' groups and representatives was held on the 17th and 18th of March, 2004 at the Taj View Hotel in Agra.

Women and HIV

Structure of Consultation and Methodology

The objective of the meeting was twofold: one, to introduce, discuss and analyse the existing legal system and its implications in the HIV context and two, to discuss the proposed law on HIV/AIDS. The consultation was designed to discuss whether and how the new law would benefit the participants and the communities and individuals they represented and the changes required to ensure that the draft law is as inclusive and holistic as possible.

The consultation had representation from the women's movement from all over the country, including groups working on women's rights, violence against women, health, and sexuality. Networks of women living with HIV/AIDS and others working on cross cutting issues of gender and HIV/AIDS also participated in the consultation.

Invitations for participating in the consultation were dispatched a month before the actual meeting along with background materials in the form of a book entitled 'Legislating an Epidemic: HIV/AIDS in India' prepared by the Lawyers Collective HIV/AIDS Unit addressing various legal and ethical issues relating to HIV/AIDS.

At the consultation, the two days were divided according to the main themes and clauses proposed in the draft law. Accordingly, provisions relating to consent, disclosure of information and discrimination were discussed on the first day, while the second day saw presentations and discussions on issues more specific to women such as personal laws, pregnant women, women in the care and custody of the state, and sexual violence followed by presentations and discussions on IEC, risk reduction and implementation.

The consultation was designed to ensure maximum participation and included presentations on various clauses of the draft legislation with special emphasis on areas that were contentious and those that required critical inputs from the group. At the start of each session, participants were given handouts of the presentations. The presentations aimed at providing a broad overview of the law as it stood, point out the issues raised by the HIV epidemic and the provisions of the proposed law. Each session was followed by an open house to address broad issues or doubts relating to the issue while some of the key sessions were further succeeded by group discussions wherein the participants were divided into four groups. Members of the Lawyers

Collective facilitated each group. The division of the groups was pre-determined with the aim that each group would have appropriate regional and issue based representation. Group discussions on the various topics were designed to facilitate a detailed discussion on the provisions of the draft law concepts and theory that informed the drafting and the exact language used in the draft. Representatives of the Lawyers Collective would guide the participants through the various provisions, providing information on Indian and international laws that influenced the drafting, the various concepts and debates surrounding the issues. In the course of the workshop some participants asked why there was no reporting back after the group discussions. LCHAU explained that unlike other workshops where group discussions were designed as working groups which would suggest certain concrete ideas or solve issues, these group discussions were aimed at more thorough discussions on the DL and to ensure that all participants voiced their concerns and experiences. The discussions and questions asked during the groups discussions would be available to all the participants in the report of the workshop.

The following sections will provide a brief description of the presentations, the issues outlined for consideration and then a detailed reporting of the areas of concern expressed by the participants, suggestions and recommendations made by them during open house and group discussions.

SESSIONS

DAY 1

Opening Session

The consultation began with a welcome note from LCHAU. Tripti Tandon from LCHAU took the participants through the agenda, explaining the structure of the consultation with presentations, open house discussions and group discussions designed to ensure maximum discussion and debate. She explained that the draft is based on the Unit's experiences. She also stated that women are impacted by HIV/AIDS the most and their concerns could not be sidelined while drafting any law on HIV/AIDS and hence the workshop. She explained that the draft law was going through a series of consultations, of which, this was one. The critical evaluation by the participants in the meeting would enable LCHAU to get women's perspectives on the draft. It was also clarified that while LCHAU would try to incorporate as many views as possible expressed in the meeting it could not guarantee the inclusion of all views and suggestions in the final draft. The participants were asked if they had any objections to the audio and visual recording of the workshop.

A round of introductions followed the welcome where participants introduced themselves, their affiliations and the nature of their work. They were active in women's issues at different levels such as legal literacy, violence, communication, research, prostitution, rehabilitation, health issues, lesbian, children's rights, positive women's group etc. and only some had dealt with issues related to HIV in their work.

Process & Purpose of the Draft Law

Presenter: Vivek

Overview

The HIV/AIDS Bills and the process of its drafting and consultation is premised in the 'Rights-based approach.' The approach has been best articulated by Justice Michael Kirby of the High Court of Australia as the 'Paradox of HIV' i.e. "Paradoxically enough, the only way in which we will deal effectively with the rapid spread of HIV/AIDS is by respecting and protecting the rights of those already exposed to it and those most at risk." This approach abandons as [] the previous isolationist approaches to the HIV epidemic and recognises the so called integrationist approach as one that correctly embodies and recognises the right of all persons to [a life...] and correctly recognises the important link between HIV and human rights.

Isolationist approaches (which include mandatory testing, breach of confidentiality and often result in discrimination against PLHAs) have been espoused since the beginning of the epidemic within the 'rights of the individual v. rights of the community' paradigm viewing PLHAs and groups and populations most vulnerable

to HIV as a threat to society. This 'debate' that often characterises public health responses to various epidemics has over the past 30 years of the HIV epidemic been proven a 'false debate'.

The Indian legal response to the HIV/AIDS epidemic spans a State Act, bills introduced in Parliament and case law as follows:

- 1986: Goa Public Health (Amendment) Act -- espouses isolation
- 1989: *Lucy D'Souza's* case challenges the Act -- rejected by Bombay High Court. However, the Act is no longer implemented
- 1989: AIDS Prevention Bill - not passed by Parliament
- 1997: Draft National AIDS Prevention & Control Policy -- espouses a rights-based approach (approved by Cabinet in 2002)
- 1997: *MX v ZY* -- Bombay HC upholds right of PWA to employment
- 1998: *Mr.X v Hospital Z* -- Supreme Court suspends the right of PWA to marry (reversed in December 2002)
- 1999: Maharashtra & Karnataka legislators table isolationist HIV Bills
- 2000: NHRC recommends rights-based legal measures
- 2000/1: Bombay & Kerala HC injunct false advertising of 'cures'
- 2001: India signatory to UN Declaration of Commitment on HIV/AIDS
- 2001/2: NGOs interventions with MSM and SW are harassed, raided - workers jailed 2002: Calcutta HC awards damages of Rs. 22 lakhs -- negligence in blood transfusion
- 2002: AP & Goa governments consider mandatory pre-marital testing
- 2002: MCI Regulations fail to reevaluate medical practice
- 2003: GOI announces ARV roll-out
- 2005: TRIPS -- impact on drug prices?

The draft law process commenced in May 2002 with the International Parliamentarians Conference on HIV where the need to frame a law on HIV was voiced. Subsequently, Kapil Sibal, then Rajya Sabha MP convened an advisory working group on the draft legislation, which invited LCHAU to work on the draft law. LCHAU agreed provided that the process would involve research of Indian and International laws and policies and extensive regional and special groups consultations. Consultations have been held since September 2003 with positive people, healthcare workers, the world of work, marginalized populations and with representatives and experts from Gujarat, Madhya Pradesh, Maharashtra, Kerala, Karnataka, West Bengal, Bihar, Jharkhand, Sikkim, []. Future consultations are planned with [].

Issues to Consider

- *Does the draft law/ rights-based approach adequately address women's issues?*

- *The limitations of law in addressing women's concerns and being an instrument of social change.*

Open House Discussions

Participants were then invited to question the process and purpose of the draft law. One participant asked how many countries have passed HIV specific law and why LCHAU chose to pass HIV law instead of making amendments in existing laws.

Another participant noted that Medical Council of India (MCI) guidelines leave the choice with doctors to treat a patient and asked whether this would be affected or changed by the draft law. She also noted that the experience in the field of HIV has been that PLHAs do not get proper treatment. In reply, LCHAU pointed out that the provisions of the DL would cover these issues. If a doctor refuses treatment due to lack of skill then the PLHA cannot be said to have been discriminated against but if s/he possesses the necessary skill and still refuses treatment then that would be considered 'discrimination' under the DL and accordingly, prohibited.

Another participant asked whether there have been dialogues with other groups. LCHAU explained that various stakeholders have been consulted and their inputs have been received.

A participant asked whether the DL is divided into different chapters and whether gender issues have been addressed adequately in it. As this issue was to be raised in the following session, the participant was requested to reserve her question till then.

One participant felt that the consultation process should necessarily include Members of Parliament as they would ultimately debate and pass the bill. She felt it was unlikely that MPs would pass the bill if they were not involved in the process and had no knowledge of the drafting and consultation process. LCHAU said that while some amount of dialogue with MPs had commenced, the process had slowed down in view of the impending elections and would be re-started once the new Parliament was sworn in.

Another participant commented that participants should remain alert about the DL process and that it is necessary to safeguard and advance the law once it is passed. She noted that many similar processes have in the past proved futile and many bills just remain on the discussion table only. She also felt that it was necessary to look beyond possible failures and setbacks and look for safeguards/mechanisms to make courts re-examine current laws and policies and their impact on harmful traditions and practices as in the case of female infanticides.

Women and HIV/Vulnerability of Women

Presenters: Leena Menghaney & Veena Johari

Overview

According to NACO's 2002 estimates, 1 in 3 persons in India testing HIV+ is a woman and infection rates at ante-natal clinics across the country have been as high as 6.5% (Namakkal, Tamil Nadu) and 9.9% (Vijaywada, Andhra Pradesh). HIV for women presents a unique cycle of discrimination and violence that few other groups experience. Thus, while inequality and discrimination in all aspects of life leaves women vulnerable to HIV, the HIV+ status of a woman worsens discrimination and violence faced by her.

While women's rights have been recognized in international conventions, most prominently in CEDAW, under Indian law the Constitution of India and Supreme Court pronouncements form the bedrock of women's rights. Articles 14, 15, 16 and 21 of the CoI recognize the right to equality and life and more specifically the right against discrimination based on inter alia gender. The Supreme Court in various judgments (including Valsamma Paul vs. Cochin University (*AIR 1996 SC 1011*), Vishaka and Others vs. State of Rajasthan (*1997 6 SCC 241*)) has recognized women's rights as human rights and[].

However, despite constitutional recognition, women in India continue to face social, economic and even legal barriers to their achievement of equality. Women remain powerless in accessing education, information, healthcare, employment, equal benefits etc. and continue to be dependent on families and men. Laws continue to discriminate against women. In particular personal laws affecting marriage, inheritance, custody combine with prevailing social and economic conditions to not only disadvantage women but in some cases leave them open to violence, neglect and abandonment. Indian laws for instance do not specifically address domestic violence and allow a man to rape his wife.

Women in the HIV context find themselves further disenfranchised and are often subject to mandatory testing (particularly if they are sex workers or pregnant); if they do test positive for HIV their status is almost immediately revealed to family members and are likely to face increased domestic violence, be refused right of residence, right to marital property and maintenance, and be the last in accessing and receiving treatment. In the context of sex work, many women are refused bail/release on the basis of their HIV+ status

The experience of LCHAU itself is indicative of the manner in which women have been affected by this epidemic. A case study spanning three years (May '98-May '01) and 130 cases show that 67 of the clients were female. Of these 41 were in the 18-30 age bracket, over 55% were widows and 60% were economically dependant and unemployed. Of the 37 widows: 14 back in parents house, 10 in husband's house, 5 with in-laws, 3 staying separately, 1 in house provided by employer, where 4 widows were staying was unknown. Thus, in the HIV scenario we are dealing with a young dependant female population being widowed at an early age. Most of the cases in

court have been civil in nature - for partition of property, maintenance, divorce and separation, custody and guardianship of children.

Women's experiences with the epidemic also differ according to their social, economic and political contexts and it is necessary while looking at legislation to keep these different contexts in mind - Young Girls, Single Women, Working Children, Migrant Women, Women who are Married, Women who are Pregnant, Women in Sex Work, Women Drug Users, Women in Institutional Settings and Women facing Sexual Violence.

Open House Discussions

HIV infections in women: One participant asked if statistics were available on how women get infected and the percentage of married/unmarried women who get infected. LCHAU responded that 87% of the transmission of HIV in India takes place through the sexual route and as the case studies indicate they are mostly young dependent females who are married and in some cases, second wives. Another participant felt that it is one thing to be aware of women's infection conditions, but not to be bogged down with statistics and ratios, which may lead to discrimination simply in the way we view the epidemic and address it.

Another participant shared her experience that till a few years back the proportion of male and female visiting the VCTCs was 4:1 which now stands as 1:4. Out of 50 patients who visit the clinic, 30-40 are HIV positive and are high symptomatic and complex cases. Biologically women are more vulnerable to HIV and the rate of transmission from man to woman is high. In support, another participant gave the example of cases reported at her organisation where out of 600 cases, 400 were women and only 2 women had infected their husbands.

Another participant asked whether the women in the Unit's case study were legally married or not. LCHAU explained that two of the cases related to bigamy and

Property, Maintenance and Marriage: One participant asked if there are any specific provisions in the DL for maintenance and property and regarding harm reduction and sex workers. LCHAU explained that the DL does contain provisions relating to property and maintenance issues. A case was cited where a court receiver was appointed to give the aggrieved woman a share in the property but the procedure took a long time and the woman passed away. Her son then would get the share in the property. Details of a few cases handled by the Delhi office were also shared. In one of the cases, a widow was coerced into sexual activity with her brother-in-law on the threat of disclosing her HIV status in the society. In another case, the woman did not have a place to stay and to procure papers related to property etc. was very difficult.

One participant felt that keeping in mind the vulnerability of women, there should be certain provisions to solve property matters etc. so that women will not suffer. Another participant wanted to know if there were cases where men were thrown out of their houses.

A participant shared a case where a woman was married to a man secretly. It was a love marriage. After marriage, she was transmitted HIV through blood transfusion. Knowing her status, her husband remarried. She has 2 children and her husband wants to get rid of her.

Another participant commented that media, government and religious moralizers propagate the idea that pre-marital testing is necessary to protect the sanctum of marriage.

Lesbians and HIV: A participant complained that nobody speaks about the lesbian groups. There are women who are bisexual and are also at the risk of getting infected.

Categorising women in the HIV context: Expressing her displeasure about dividing women in different groups, one participant stated that there should not be categories like married, unmarried, bisexual, sex workers etc. because that would mean targeting certain groups and instead why not just leave it uniformly under women considering her vulnerability be that for any reason. Another participant however felt that rights arise out of social status (married, unmarried etc) and law reflects social categories hence it is important to consider categories. It was clarified that the presentation contained different categories with a view to cover all the sections of women and the draft does not specify any category or groups with a particular social context. The idea of listing the different contexts which women find themselves in was to ensure that their specific problems and issues were not overlooked and not to create any hierarchy in women's issues.

Addressing women's issues in the DL: Another participant stressed the need of addressing peculiar needs of women and there should be solutions against the wrongs committed against them. She further said that gender specific issues should be incorporated in the DL.

Consent for HIV testing, Treatment and Research

Chair: Akhila Shivdas

Presenter: Vivek

Overview

Consent is based on the fundamental principles of autonomy & bodily integrity i.e. every person has the right to determine what should be done to her/his body. This principle has been recognised in common law, criminal law and the Indian Constitution under Article 21. The basic principle of consent is enunciated in the law

of contract as “when two or more persons agree upon the same thing in the same sense.” Consent must be free i.e. not obtained by coercion, undue influence, fraud, mistake or misrepresentation.

For women the non-recognition of this right [exists] at many levels - marriage, sex, education, work, child-bearing, healthcare, bio-medical research and their inability to actualise this right, even if provided by law/policy (as in international law, CEDAW etc.) *exacerbates their vulnerability to HIV* (CFAR/PWN/UNIFEM study).

Consent under the Draft Law

The draft law first and foremost recognises the right of each person to autonomy and bodily integrity. Consent provisions under the draft law codify principles that already exist under common law and have been applied by courts for some time. HIV testing can be conducted only for the voluntary determination of HIV status or if it is medically indicated and in the interest of the person being tested. Consent must be in writing and must be accompanied by pre and post-test counselling. The draft also makes provision for proxy consent in the case of death, incapacity or emergency. In the case of children it proposes lowering the age of consent for children to 12 years.

The term ‘informed consent’ has different implications for the kind of information to be given depending on the activity being undertaken. Thus, HIV testing must be accompanied by pre and post test counselling, HIV treatment may commence only after an explanation of risks, benefits and alternatives available while HIV research may take place only after the research subject is informed of aims, methods, sources of funding, possible conflicts of interest, institutional affiliations of the researcher, potential benefits & risks, possible discomfort & the right to withdraw consent.

Consent for HIV testing under the draft law is not required when it is ordered by courts, allowed by statute, required for testing blood, organs, semen etc., or for surveillance.]

Issues to Consider

- *Do the provisions address concerns of women esp. in health care, research settings?*
- *Should mandatory testing be allowed in certain situations? Marriage, PPTCT, sexual assault, occupational exposure, under specific laws (ITPA, JJ Act, Prisons Act, vagrancy laws)*
- *Should pre-/post-test counselling be mandatory, even when the person voluntarily forgoes it?*
- *For a diagnostic test, should HIV information or counselling be given?*
- *Do the provisions enable children and young persons to access HIV counselling and testing services?*
- *How should consent for HIV/AIDS research be addressed?*
- *Who should be held liable for violations?*
- *Should penalties be imposed?*

- *How can VCTCs, path labs, blood banks, home test kits be regulated?*

When reference was made to CEDAW in the presentation, a participant noted that CEDAW has issued guiding principles that are obligatory and there are lots of interpretations.

The LCHAU newsletter on pre-marital testing was also distributed to the participants and participants were informed that the governments of Goa and Andhra Pradesh were considering laws to make pre-marital testing mandatory.

Open House Discussions

Pregnant women and consent for testing: A participant noted that pregnant women are always asked to test when they go to antenatal clinics. Without test results Gynaecologist does not attend to the patient. Even if the whole procedure of counselling, filling up of form, signing etc. is followed, can it be said that she has given a consent if she is not going to be attended by the doctor in absence of the test results?

Another participant felt that the current environment is coercive and everybody is aware of practical problems in enforcing and ensuring informed consent. However, she noted, this should not deter us from making laws.

A participant working with PPTCT programmes noted that positive women who come to their clinic may not have symptoms of STIs. She asked if she, as a HCW would be violating the provisions of consent if she asks the woman to test for HIV? She also clarified the manner in which group counselling is conducted in their clinic i.e. first, group counselling is provided and then the individual who wants to test can go for actual testing. She asked where the law and the DL stand in such a situation? She also asked if a husband could be coerced to test if he refuses to give his consent. Taking up this issue, another participant asked whether LCHAU considers the choice of husband to refuse a test as correct? Would it help if law provides room for this? LCHAU felt that the issue is a difficult one as unless the husband is also tested along with his wife, he is likely to blame her for the infection. Proper and effective counselling rather than mandatory testing which would push men away from ANCs would be the most appropriate mechanism to ensure that both husband and wife test themselves.

Research and consent: A participant noted that even ICMR conducted research does not give full information as regards the consequences of research and all. It is a practical problem. She asked if consent is possible in these cases and felt that these things must be kept in mind while making provisions on Consent.

Informed Consent: A participant asked what kind of information should form part of counselling to fulfil the requirements of informed consent – contraceptives, testing,

ARVs. She noted that the word ‘information’ is very subjective and asked if it would include for instance, menstrual problems etc. She asked if there is a definition of ‘informed consent’ and felt that the doctors’ dominating position in relation to that of the patients who are usually poor, mentally incapable or illiterate allows them to test without giving much/any information.

Echoing her concerns, another participant asked when using the phrase ‘adequate information,’ who would decide what is adequate? She felt that the definition/provision of the DL should incorporate views of PLHAs in determining what constitutes satisfactory information in areas of consent aside from bio-medical standpoints. Concurring with this, another participant said the doctor giving information usually believes that patients are incapable of understanding medical advice and matters.

Private sector: One participant felt that the provisions of the DL may not hold good for the private sector.

Age of consent: A participant felt that the age for capacity to consent that the draft proposes would have implications on other laws and that will be dangerous. She also felt that having gender neutrality in case of sexual assault would percolate in other civil laws. She feared that the provisions relating to HIV may also come in other laws and may affect women adversely.

Group Discussions on Consent

Group 1 (Facilitator: Anand Grover Rapporteur: Shalini, Rajesh)

Children and Consent

- What if mother and 12 year old child, both infected by HIV, and mother did not want to reveal the result of test to the child and child is curious as to why s/he falls ill often. In such a situation, what should be the role of a social worker?
 - Disclosure comes after testing. Firstly, did the minor consent to testing? We are considering social workers & NGOs as a homogeneous entity. Who is accountable? We need to lay down definitions
 - Are NGOs sensitive enough to all the issues?
 - Can *Gharwali* act as bonafide caretaker and thus in a position to consent on behalf of minor girl child?

Counselling

- The quality of counselling is bad. Counsellors use very bad language and behave in such a way that it would appear that they want to break the marriage.

- In case of counselling the accountability should not be shifted from the State and it should serve as the most important link. There should be accountability on all the parties concerned.
- Counsellors ask bad, probing and insensitive questions and reveal things about an individual.
- Checklist required for counselling: something that reiterates that consent should be taken in a manner that is understood by the woman. There is the danger of family interest versus woman's interest taking precedent.
- Qualification should not be a consideration in recruiting counsellors.

Marriages, consent and mandatory testing

- Can any modifications be made in the law to wherein a husband who refuses to take an HIV test can be mandatorily tested?
- How can the registration of marriages be implemented and what should be the entry point for pre-marriage counselling as in rural setting the marriages take place at a very early age like 7-8 years and the girl actually goes to husband's place at the age of 13-14.
- Can pre marital counselling be made mandatory? Don't agree on registration of marriage & counselling

Consent generally

- What would be the impact on private practitioners?
- In VCTC settings, there is no privacy, the questionnaire is lengthy and it has to be filled in then and there (relating to confidentiality). Consent is slip shod in VCTC.
- The language such as 'the manner in which she understands' should be done away with as doctors explain HIV in a language such as 'your blood has become bad' etc. We also have to appreciate the role of family and family doctor as they play a major role in care and support and patient is closely associated with this class.
- If a person is very ill it is very difficult to get consent and all.

Women and consent

- Consent is looked at in a limited manner as the position of woman in Indian context is different. There is classification of women depending there marital status – married / unmarried – and age wise - adolescent / grown up.
- There should be separate provisions as regards consent for women.

HCWs and HIV testing

- Person suffering from bronchial asthma & TB & doctor did not suggest testing. In the process, family incurred Rs.20, 000/- as expenditure. When they approached another doctor, an HIV test was recommended. Husband tested positive. Shouldn't the doctor have a duty to atleast suggest a test if not impose it?

Women and DL generally

- Structuring of the draft is problematic. Limited way in which gender has been looked at. Doesn't run in all sections. Adolescents, girls & non-married women do not feature in the draft. Need to provide for youth friendly services & consent for adolescents & girls. Women are only looked at in the context of marriage.
- IEC and gender should be included on all issues.

Group 2: (Facilitators: Veena & Kajal Rapporteur: Kajal)

Informed Consent - Section 15(1):

- Is the definition of informed consent really practical and operational? The person providing the information/counselling can influence decisions just by the way the information is given. For instance, women in rural India implicitly trust their doctors and don't ask questions.
- Who decides how the information is given? Does consent have to be taken in writing? What about the environment around it? We need to specify all this.
 - In reply another participant noted that the operative word is that consent must be 'free' assumes that the environment must also be free.
 - Another participant noted that the word 'free' is adequate. It has different interpretations in courts. The concern is that consent will be influenced because doctors are treated like gods and they don't inform of risks. It should be ensured that basic information is given, even if people are illiterate.
- How will written consent be taken in the case of illiterate persons? They tend to put their thumbprints on documents without really understating what they are agreeing to?
- In case of women in institutional settings such as trafficked girls, it is very difficult to obtain free informed consent.
- This opportunity should be used to specify what is adequate information.
 - Some participants disagreed stating that the provisions should not get restrictive and strict since the nature and content of the 'information' will change with time and circumstance.
- What about something like the essential medicines list of the WHO?
- LCHAU noted that the WHO list is also problematic. It may be possible however to specify some guidelines in the rules and regulations.

Capacity to consent

- Does an individual who has no money and is sponsored by an NGO, have the capacity to consent to an HIV test?
- How will the DL deal with women victims of sexual violence and their consent for HIV testing or treatment (PEP)?
 - In case of sexual violence, victim may need PEP. So there should be mandatory testing for perpetrator and not of victim.

- If mental capacity is absent then whether PEP permission is an issue?
- Who will give consent for cross border/trafficked girls and abused children with no family set up?
- We need to consider the issue of lowering the age of consent and its impact on other laws – would courts look at this and extend it to other situations like in the Goa case where the Courts held that a girl under the age of 16 had consented to the sex (because there were no signs of resistance) –we need to consider implications
 - Some safeguards have to be built in to make sure that the law is not extended in this manner.
 - Would this impact child labour laws?
- Generally in the case of abused children, parents will not allow even medical tests, let alone HIV tests. How can we obtain consent in such cases? How do we provide for children in such situations?
- What about the consent of a pregnant women?
- What about consent from illiterate populations?
 - Thumbprints on the informed consent forms are considered legal signatures.
- What about refugee women? Refugee camps in Gujarat – who gives consent there?
- Women in the North East – particularly Bangladeshi women lack access to medical treatment etc. There is a problem as illegal migrants (also have sex workers among them) are considered to be ‘high risk’ – how do we provide for them?

Counselling - Section 15(4)

- Principally if we agree that pre and post test counselling is required, the exception should be removed as it leaves room for circumventing, for example, in the airlines, you don’t pay attention to the safety messages anymore so you can do the same for counselling – but it should be mandatory.

Informed consent for HIV research - Section 15(5)

- What is adequate information in counselling?
- We should also address the issue of research since there is testing in research – this law should address it.
- What about surveillance – isn’t collecting data, a kind of research? We need safeguards in that too.
 - Yes, but epidemiology is critical in an epidemic, so details should not be given.
 - HIV is not a notifiable disease so details are not given

Informed consent is not required - Section 15(6)(b)

- ‘if authorised by another law’ – by adding this clause DL allow situations of mandatory testing – so what is the point?

- Don't start with a watered down version – you must delete it.
- There should be some special provisions for women
- Well before the DL there was nothing – at least now we have this much.

Group 3: Facilitator: Tripti, Shehzad Rapporteur: Valmiki

Right to autonomy

- Right to autonomy should be the right not to be subjected without informed consent; include a right to be informed, enabling clause, i.e. via mass media. The phrasing right now emphasises “right not to be tested,” cross-reference this with the right to be informed prior to subjective testing in medical settings.

Rural and urban settings

- What concerns do rural women have that differ from urban women's concerns?
- Guidelines should be set on training for quality of information irrespective of rural versus urban settings to solicit consent.

Mandatory testing and counselling of partners/husbands

- Whether there should be mandatory testing for husbands who transmit? Should we do away with their consent?
- We can include educative (preventive) provisions to mediate improved informed consent. Then set rigid outlines on counselling, for partner and women counselling.
 - Could it backfire? Men might prevent women from testing.
- If woman tests positive, then recommend that the husband go to voluntary counselling, then voluntarily test. The option should be available for men, should not be compulsory counselling.
- There is already couple counselling for PPTCT and the men don't come back. And that's just trying to be biased for one circumstance. In any case, the counselor determines if a woman truly wanted to be tested or not.
- Sex workers with steady men should have the option to be counseled as well. Women should decide whom her significant partners are to invite to counselling—regardless of status, i.e. pregnant women, sex workers, WSW, etc.

Women and Consent

- Consent in your outline should specify HIV in a gender context (HIV/Gender Context). There should be a provision for a comfortable space, environment, of the patient's choice where testing/treatment/research be conducted that is friendly to women.
- Under Issues to Consider you should posit if principles of consent should be applied to partners of women in relationships. You're looking at compulsive

- situations, emotional pressure settings—so it exceeds mandatory testing, i.e. pregnant women.
- There's legalese versus legalese without informed consent leading to discrimination or mandatory/forced testing.
 - The draft law should set rigidly defined and tested guidelines to solicit consent for women in multiple circumstances. Advocacy groups should create accountability measurements for enforcement of guidelines.

Children

- In quality of counselling for doctors we should ensure they are not biased on protecting only the child's rights/future.
- Include provisions for children orphaned by AIDS—to address issues of inheritance and property of women.
- Set a judicial bypass provision for kids under 12 to get consent. It was answered that in India, such bypass is used to round up street kids for testing without consent. A minor still can't approach or file anything in court.
- Create a 3rd party authority to decide a child's right to get consent. Write it in the framework/rules. Will Lawyer's Collective do so?

Proxy Consent Age

- NACO is already actively reaching out and informing youth. Problem lies in their right/choice to test for status—currently requires parental/guardian accompaniment below age 18. This denies them access. There are lots of street/orphan children in high-risk activities just like adults.
- Between age 12-18, health care workers assess whether children have the capacity to understand the ramifications of the test. This they determine by the child's lifestyle, activities, and risks—if they're making adult decisions. Otherwise, stipulate parental consent.
- Doesn't this contradict the concept of proxy in this draft bill? For women under proxy, this is loosely defined. If you liberate the child, you should leave such a liberal option to disabled men and women. Expand beyond age this protection against proxy consent. Explain other areas of mental/physical disabilities where they still have the capacity to make choices—determined by circumstance.
- Some say age 12 is too high. Children even younger than this are engaged in high-risk behaviour. There should be an enabling proviso with specific situations for whatever age.
- In West Bengal, the state delayed sex education for 8th and 9th grades because the children are too innocent. In Kerala, it is up to the children to read material on their own.
- Consent should be based on capacity, inclusive of differing factors, of a wide scope of possibilities to explain one's capacity to decide on consent. This way health care workers and medical providers know of their client's protections, reducing discrimination.

- Collectives, like Lawyer's Collective, should be on lists of health care providers accountable to inform appropriately clients about issues of consent/confidentiality/discrimination.

Verbal consent

- Informed consent in writing isn't always feasible, thus consent can be taken verbally, in cases of illiteracy/disability. So, allow this with record-taking altogether. It is up to the health care provider to keep records confidential.
- The draft law makes no reference to health care worker's obligations. Draft focuses on right of client to consent. Incorporate this into suggestion on guidelines for quality of information to solicit consent via appropriate/sensitive means with transparency. The written/verbal/fingerprint consent is not assurance that information for consent was adequate.
- Have provisions for health care certification to be met in order to counsel, to ensure accountability of quality of information.

Exceptions to consent

- Exceptions to consent for HIV testing - determination of issues, interests of justice - give too much power to the judiciary. The courts can still misuse these exceptions. Some interests of justice are always necessary—child DNA cases, divorce—but should still be done with informed consent/confidentiality.
- Exceptions to consent for surveillance, statistics, tracking prevalence; should be anonymous and unlinked. We should impose high penalties for any breach of confidentiality, women are highly susceptible to backlash if their status is revealed. Should organizations like blood banks be registered in order to conduct HIV data collection?
- Even with false charges of HIV transmission, still the court will compel the test for the partner/spouse. No consent needed. Only the result will invalidate the charge. There is the issue of automatic stigmatization, but it is not as prevalent in personal law cases, which are very private, confidentiality retained. (Telgi's case not a confidentiality violation)

Sexual Minorities

- Sexual minorities, WSW's deserve recognition. They have no visibility, so laws will not represent them. Lesbians are ostracized for being women, for their sexuality, and the funding community ignores them. Policy should include recognition of WSW's contracting HIV, thus qualifying them as a vulnerable group. There are still many bi-sexual women infecting other women. Many are forced into marriage, widowed, and then find new female partners.

Group 4 (Facilitator: Vivek, Leena Rapporteur: Leena)

Registration of Marriages

- Registration of marriages is necessary.

- Are we allowing the State to enter areas that were not previously interfered in by the state.

DL Generally

- Is this law being drafted only for protection of the rights of PLHAs.
 - LCHAU clarified that the law was not only to protect the rights of PLHAs but also vulnerable communities & basically for everyone who goes in for an HIV test. The DL also looks at barriers that impede prevention work and addresses them. By protecting rights, the DL facilitates prevention.
- Why include a broad right in an HIV/AIDS Bill (section 14)?
 - The structure spelt out the structure of the chapters of the bill – first are the general principles and then the specific sections (nitty-gritty’s)
- Different areas such as labour, health, matrimonial etc should be dealt with in different chapters, instead of dealing with all these sectors in each chapter on consent, confidentiality & Discrimination
- Unless we address HIV/AIDS head on, it will be a health emergency. We also have to work with adolescents, sexuality activity starts at as early as 10.
- Should not address women in the marital context only, should address single women, adolescent girls.
-

Written consent

- Hospitals are jam packed - how will taking consent in writing be possible in such a setting?
 - If written consent is not possible, then contemporaneous records should be maintained. It is the best practice.

HIV Testing

- Test for HIV - make it routine for all services
- What about laws like ITPA, which legally allow health checkups including mandatory HIV testing – they have to go.
 - LCHAU explained that the phrase in section 16 i.e. “notwithstanding any law for the time being in force” will supersede current laws that allow mandatory testing

Confidentiality

- Are we driving this disease underground by insisting on confidentiality?
- Confidentiality is a western notion. Rural people are not attaching so much stigma to HIV. Stigma is an urban phenomenon.
- Access to services will be affected if confidentiality is not protected

Children

- In the context of consent of minors – these are broad principles, even applies to consent for research (case of orphans in US participating in clinical trials raised)

- In CSA, minors do not resist, interpreted as consent, there is possibility of misuse
- Restrict, tighten language in case of minors, so that it does not cover areas like research

Counselling

- Often the person thinks that the info & counselling is not important and bypasses it. On the other hand counselling is a voluntary process.
- The quality of counselling is problematic. Counsellor should have to undergo training.

Disclosure of Information

Presenter: Tripti Tandon

Overview

The principle of privacy protects the right of a person vis-à-vis the world at large while that of confidentiality protects a person vis-à-vis another person/s. The overriding principle is that “Every person has the right to privacy.” The existing law on privacy and confidentiality is derived from Article 21 of the Indian Constitution (the right to life and liberty includes the right of a person to maintain her/his privacy) and common law (courts have recognized the obligation to maintain confidentiality within certain professional relationships, in the public interest.)

Courts have permitted disclosure if required by law, for the administration of justice, in the best interest of the patient, to protect another person or if it is necessary in public interest. The Judicial Standard is that, ‘Disclosure is permissible when the public interest to disclose outweighs public interest to maintain confidentiality. In relation to HIV, disclosure has been discussed in case law mainly in relation to partner notification by HCWs which courts have permitted subject to protocols that are now reflected in the draft law. The only Indian law that discusses confidentiality is the MCI Regulations, which prohibit disclosure but remain vague due to the language used in the regulations.

Disclosure of information under the Draft Law

The Draft law recognises that every person has the right to privacy and forbids disclosure of information imparted in confidence, except with the written informed consent of that person or her/his representative when that person is incapable of consenting on grounds of death, age or incapacity. The draft law protects “HIV-related” information i.e. relating to the undertaking, performing & result of HIV test, HIV or HIV antibody status or information that may identify a person eg- address which is collected/ received/ accessed/ recorded in connection with HIV testing, treatment or research.

Disclosure is permitted to another HCW if it is necessary for treatment & in best interest of patient, by order of court, if disclosure necessary for determination of issues & in interest of justice. Whether it should be permitted if required by statute, in public interest if determined by court or prior to adoption are debatable issues. In relation to partner notification, the draft law prescribes specific protocols to be followed by the HCW, but essentially leaves the decision to the discretion of the HCWs, subject to the protocols. However, for women, partner notification poses a unique problem as if women are not informed of their partner's status, being unable already to negotiate safe sexual activity, puts them at an enormous risk of infection. On the other hand, where the woman is HIV+, revealing her status to her partner is likely to leave her vulnerable to violence, abandonment and neglect.

The Draft law also imposes a duty on every HIV+ person who is aware of her/his status and has been counselled to inform her/his needle sharing or sexual partner of such risk. The position women find themselves in under such a duty is best explained in the following examples:

Situation 1: *Rebaan*, HIV+, meets *Mallika*, a young woman at a party. They exchange phone numbers and begin dating. A few dates later, they decide to have sex. *Rebaan* does not reveal his HIV status to *Mallika*. Imagine the ***consequences of non - disclosure***.

Situation 2: *Meena*, 6 months pregnant, is informed by the doctor that she is HIV +. *Aman*, her husband, has a history of domestic violence and wife beating. *Meena* reveals her HIV status to *Aman*. Imagine the ***consequences of disclosure***.

Duty to inform: Issues to consider

- *Should duty to inform exist at all?*
- *How does it impact women – at different sites and in different spaces?*
- *Is it sufficient to protect women from HIV?*
- *Should there be exceptions – safer sex, adverse consequences etc. ?*
- *How can implementation be ensured?*
- *Consequences, if any, of not informing?*
- *Will it discourage people from seeking HIV testing ?*

Under the draft law, a person to whom disclosure is made is prohibited from making further disclosure, institutions are required to institute data protection measures and disclosure of statistical information that does not reveal identity of patient is permissible.

Other Issues to consider

- *What kinds of relationships should obligation to maintain confidentiality arise in: Fiduciary relationships only? Media? **Any others?***
- *Penalties, if any, for breach of confidentiality?*

Open House Discussions

Penalty: A participant felt that in ‘duty to inform’, if there is a failure to inform and there is no penalty then that will render the law toothless. LCHAU in response informed the participants of the provisions of sections 269/270 of the IPC and other tort laws and the implications of non-disclosure.

A participant asked if there is a duty to inform regulated without penalties, does it still become mandatory in legislation. LCHAU stated that criminal codes still apply for threatening to harm a person; but an order of injunction can be cited to compel disclosure even in statutes without penalties or remedies.

Disclosure of status to the person at risk: There was a question as regards duty of the HCW to disclose the status of the person to the person at eminent risk of transmission. LCHAU explained that the DL would allow disclosure in order to protect partners i.e. discretionary power of HCW’s to inform partners at risk if their partner is HIV+ and refuses to give written informed consent of disclosure. First the HCW must counsel the HIV+ partner to inform their spouse. If this too is refused, then the HCW may personally tell the untested spouse if there is a bona fide belief of threat of transmission to that person. In this case, the HCW must tell the HIV+ partner of his/her intention to disclose. That would be coupled with appropriate pre-counselling for that partner before information is disclosed.

Group Discussions on Confidentiality

Group 1 (Facilitator: Anand; Rapporteur: Shalini, Rajesh)

- There should be clarity between confidentiality & disclosure. In certain cases husband is unable to disclose status on time. Another problem is that concordant couples do not engage in safer sex.
- What is ‘identifiable person’?
- How can HCW ascertain partner/contact? For sex workers it is difficult to trace contact. What if the person at risk is not reachable?
- Significant risk can be interpreted wrongly. It is very broad & can be used to harass women.
- Friend has got infection from husband- can the husband be held liable under Sec 269 & 270?
- Law should protect the right of women.
- The Sex workers community in Rajasthan is the Nautch community & there has been a very interesting study that looks at choice that operates for minors in the community. Young girls are given the choice of either marrying or entering sex work. Shows that young girls are considered to have the capacity of taking decisions.

- Instance of NGO - disclosed status of a client to the media
- The duty to disclose provision can get women into a more vulnerable position. Infact will disclosure help in a situation where women are forced to have sex.
- Regarding pre-marital counselling - in rural areas access for girls is limited. They get married at a very young age & stay with their natal family still puberty. (known as gona). When will they get pre marital counselling?
- In an ideal situation registration sounds good.
- There are various socio-cultural factors to consider, like gona. Also, what about those not getting married? The law must look at right of information & education for all situations.
- “duty to disclose in doctor patient relationship” not necessary if universal precautions exist.
- There could be instances where there is no safe sex between testing and test results and non-disclosure of it to the partner could be disastrous for the partner.
- If a person is using condom, still he be considered to be exposing other person at significant risk?
- What is the extent of information needed to be disclosed in respect of Insurance cover?
- In respect of partner notification / duty to inform, it should be more voluntary than mandatory. In case of doctor-patient, is it necessary for the patient to disclose to every doctor or only where the treatment is related to HIV?

Group 2 (Facilitator: Veena, Kajal Rapporteur: Kajal)

HIV related information

- Is it separate from the HIV test? Will this be part of the overall consent that one takes for the test or will it have to be separate?

Exceptions to consent for disclosure

- General consensus: disclosure should not be allowed by other statutes – similarly, the requirement for informed consent should not be negated by other laws.
- Also what about (d) – what is ‘in the interest of justice’?
 - It was answered that if a court asks for information about HIV status – it has to be relevant to the case not otherwise. The disclosure will be made only to court – so its not really disclosure.

Fiduciary relationships

- Whether employer-employee / parent-child - fiduciary relationship? And what is private or personal information?
- GROUP SUGGESTIONS ON WHAT SHOULD BE COVERED:

• Relationships:	• What info:
• Doctor-patient	• Name
• Counsellor- client	• Address
• Employer-employee	• Employment details
• Educational settings	• Sexual orientation
• Media	• Behaviour that may have exposed one to HIV
• Law enforcement	• Occupation/livelihood (like SW)
• Landlords-tenants (?)	• Route of transmission
• Family (how to cover them?)	• Gender
•	• Marital status
•	• No. of children

- Women in families – how do we cover them?
- What if we say ‘family obligations to one another’-- problem in defining what family obligations are

Partner Notification

- The fundamental question is whether this is mandatory or discretionary?
- Should not be there at all – what do we achieve by having this section? If man is infected he already has more power so wont access healthcare facilities – if the woman is tested and it is revealed she will face discrimination – it wont work
- That’s like saying politicians are going to be corrupt or murder anyway so there should be no action/penalty
- Any other disease you would need the support of the family – but with HIV, stigma becomes a problem
- How do we define significant risk? For instance in the Tarasoff case the guy said I am going to kill her with HIV so there it was clear – but what about other cases – if the woman comes in for a test how can they tell if there is a risk or not?
- Is not there too much of a duty on the HCW? One participant commented that there should be a duty
- If the decision is taken not to inform then should record why to protect them from liability
- What is the duty on the State or the HC institution to follow up after a disclosure has been made? Like when you counsel victims of violence, you don’t have the support structure to pull them out of the situation – shouldn’t this be part of state obligations – like maybe set up shelters?

- What is the method of enforcing this? Should it be mandatory? Will the woman end up paying the price in both situations?
- Why have it at all?
- Some % of men will take care so even for that little benefit its good – the basic issue is stigma and discrimination and if we can deal with that, confidentiality will no longer be an issue

Adoption

- Should child or parents be tested?
- Well they may test the child later – how do you stop that?
- General Feeling – might be important in child’s interest to avoid being abandoned or mistreated by family – also who will bear costs? On the other hand AIDS orphans are not being adopted. HIV+ parents on the other hand should be allowed to adopt – it amounts to discrimination, as anything can always happen to the parents.

Group 3 (Facilitator: Tripti, Shebzad Rapporteur: Valmiki)

Women and disclosure

- Disclosure is always a problem for women, their protection is not guaranteed. The right to marry prohibition precluded issues of informed disclosure. Are these exaggerations of risk to women from disclosure? There are no reliable statistics / measures for this in India. In Africa, there are beneficial results for women, but there is less severity of violence to them, so it is the women’s decision, not the HCW’s. Mandatory testing would not secure a woman’s protection.

Partner notification and duty to disclose

- The draft law encourages a positive partner to disclose, and if he refuses persistently then an HCW has the option to inform partner at risk.
- The duty to disclose may dissuade high-risk agents to not test, to not know status and not have to disclose to anyone.
- Disclosure is necessary. It becomes a question of who should inform and how?
- Human rights are not clearly challenged; the draft uses language of convenient legalese.
- The draft law uses pre-existing laws, nothing innovative at this point. There is only the manner in which provisions are presented. Everyone has the right to his or her own process of voluntary disclosure. Exceptions are already there legally; just introduce them even if it gets thrown out. The language puts duties solely on HIV+ to disclose. Protection again is not guaranteed for a woman. Also, not guaranteeing dignity/productivity for people if they’re compelled to disclose.

- There should be mandatory sensitising undertaken by the government. Underscored by a positive person's choice to decide when, how, and where to disclose. Incorporate voluntary disclosure with family education counselling so a woman is not refused or thrown out of her home.

Adoption

- If an HIV+ baby is adopted without disclosure then the family will want to give them back later. By disclosing no one will want to adopt a child in the first place. Any health status is a material fact that needs to be revealed to prospective family, as well as by any HIV+ prospective adoptive parents. The agency can determine how sensitised, responsible and appropriate the family to adopt is.
- CARA does not stipulate disclosure for curable diseases. Only HIV right now, is considered incurable, but it is manageable.
- The media violate the civil liberty rights of the individual. They can't identify individual identities, but their content can identify certain groups—sex workers, MSM's—increasing stigma. There is no way to censor this, but it can be regulated.
- Vulnerable populations need protective clauses for support when they disclose. Even for adoption cases, then you need to ensure a child receives the proper institutional / home care for their health.
- Consent to media is not perpetual. You need permission to run a story, photo, or names of individuals on every occasion.
- How would you protect orphans from discrimination? It was responded that LCHAU thought about introducing protections under special provisions, but also have thought about including a chapter just for children.
- One needs to watch out for exclusion without protective clauses. The Immoral Trafficking Prevention Act (ITPA) is used for harassment; it doesn't deal with women's actual mobility.

Group 4 (Facilitator: Vivek, Leena Rapporteur: Leena)

Disclosure of information & legal duty to inform

- If patient has to disclose to the HCW – issue of refusal of treatment if disclosed to healthcare worker
- Patient's right to know must be stated in the law clearly.

Partner notification protocol

- Discretion to inform is very subjective, no objective criteria
- This is a balanced protocol, if there is no discretion, then it becomes mandatory disclosure (expressed surprise at LCHAU taking this stand)
- On the issue of women who test to prevent parent to child transmission – husbands often refuse to test, woman carries the burden of HIV+ status, often blamed. There should be couple counselling.

- Then it will become mandatory disclosure

Legal duty to inform

- Informing often made no difference –example of cases where the HIV+ status was disclosed to the woman but pressure to have child continues.
- There was a concern regarding the duty of the person informed to maintain confidentiality – what responsibility does the person have to further not disclose. A participant shared a case where the marriage counsellor in the family court had disclosed to her in a particular case that the defendant was suffering from HIV and that they should settle the matter. The participant wanted to know whether in that case she would have a responsibility to not disclose this fact to her client who was fundamentally affected by it. It was answered that the marriage counsellor according to this law could not reveal. Regarding her duty as a lawyer to disclose all facts that affect her client's case? It was also pointed out that the relevant section in the draft that required the person to whom disclosure is made to maintain confidentiality.
- Irrespective of law, if a person does not want to disclose, s/he will not do so
- It is better to inform the partner to get support
- For women, however, support cannot be taken as a given
- If duty to inform already incorporated in counselling protocols, then why do you need it in law? Also duty to inform does not factor in significant risk.
- Group also felt that there was no duty on the sex worker to inform - person going to a sex worker should know of the risks

Adoption

- Issue of disclosure to prospective parents – It was answered that if one knows the status one can inform because of the responsibility of care and support, but should all children to be given in adoption be tested for HIV?
- Parents should know before adoption, other tests are also done

Children in Institutions

- Children in institutions can be tested – home should know. It was responded that if no strict guidelines, then there could be misuse. They will test and exclude children who test HIV+ from their services.
- Should duty to maintain confidentiality be confined to fiduciary relationship? Would you like to take your family to court for disclosing?
- What about women who are threatened with disclosure by their marital family when they want to assert their rights.

Discrimination

Presenter: Anand Grover

Overview

Articles 14, 15 and 16 of the Indian Constitution guarantee equality to all persons in the territory of India. However these rights are available only against the State. There

is, no remedy against discrimination by private individuals and bodies and a specific anti-discrimination legislation is accordingly required.

However, despite the constitutional guarantee of equality, discrimination against women is widespread, based on stereotypes, traditional, cultural, religious practices and beliefs detrimental to women. Women comprise the majority of the world's poor & illiterate, face different forms of violence, are paid 30 – 40% less than men for the same work, have unequal access to property and have little control over their bodily integrity. In India the judiciary has upheld laws & policies that discriminate against women despite constitutional safeguards as in the case of personal Laws and the more recent Air India cabin crew judgment.

In the HIV context, women face increased discrimination and violence and are usually blamed as vectors, labeled as promiscuous, threatened with disclosure, abandoned by their families, face social ostracism and are the last to receive treatment. *In 2003 a woman living with HIV/AIDS was allegedly stoned to death in Andhra Pradesh.* The Constitutional protection against discrimination applies only to the public sector, while the majority of affected women face discrimination from their families and communities.

Discrimination under the Draft Law

Under the draft law, discrimination is defined as any act or omission including a policy, law, rule, practice, condition or situation, which directly or indirectly, imposes burdens, obligations or disadvantages on, or withholds benefits, opportunities or advantages, from, any person based on one or more HIV related grounds (i.e. HIV status, actual or perceived; or actual or perceived association with an HIV positive person; or actual or perceived risk of exposure to HIV infection; or any other ground where discrimination related to HIV/AIDS – (1) causes or perpetuates systemic disadvantage, (2) undermines human dignity or (3) adversely affects the equal enjoyment of a person's rights and freedoms in a serious manner). This definition is adapted from the South African anti discrimination legislation.

The draft law only prohibits 'unfair' discrimination – discrimination based on rational, objectively determinable criteria, has a legitimate purpose, or is intrinsic to the activity concerned. The law will apply to public and private actors. The law is also inclusive and does not define every situation of discrimination that is prohibited as the definition is intended to be a flexible one. Some of the specific areas that are covered by the law include discrimination in employment, healthcare, education and access to services.

Under the draft law the denial of or unfair treatment in employment is considered to be discriminatory. Termination on the grounds of HIV status is allowed only (a) when there is a significant risk of transmission or (b) the person is medically unfit and the employer is unable to provide reasonable accommodation due to undue hardship.

Discrimination in employment cannot take place on any other grounds. In healthcare settings, there is little data to support the fear of risk of transmission from a healthcare worker to a patient.

Courts have held that the practice of HIV-infected healthcare providers who pose a In India there have been no HIV/AIDS-related decisions offering alternate employment to healthcare workers but a similar concept has been applied by the Supreme Court. (*Anand Bihari v. Rajasthan S.R.T.C.*)

In healthcare settings, denial of treatment or unfair treatment generally occurs because of the fear of occupational exposure and/or the lack of resources to provide adequate treatment and protect oneself. Accordingly the draft law recognises the right of all persons to a safe working environment. Unfair treatment in healthcare settings may take the form of untimely or arbitrary discharge, charging higher rates, [imposing conditions in the form of research], public identification, pressure to leave the healthcare institution and so on. The draft law attempts to enumerate these forms of unfair treatment. It also addresses discrimination in other situations such as education, residence, travel, access to services, access to institutions, insurance, etc. The law also prohibits hate and discriminatory propaganda against HIV infected and affected persons.

Issues For Consideration

- *Does This Cover All Situations?*
 - *Women*
 - *Children*
 - *Home*
 - *Parties*
 - *NGOs*
 - *Insurance*
- *Should The Prohibition On Healthcare Discrimination Extend Beyond The HIV Context?*
- *Does This Properly Address Discrimination In The Private Sector?*

Open House Discussions

Discrimination in getting treatment: One participant asked that in government hospitals, patients are denied treatment for lack of infrastructure or they are referred to the higher institutions, will that be discriminatory? It was answered that it would depend on facts of each case. If capacity to treat is there and still treatment is denied then it would be discriminatory.

There was a question that if the HIV+ patient, who is suffering from many diseases, approaches the doctor for treatment and the doctor refers him to another doctor for treatment of TB but patient wants to be treated for other disease first. Then in such

instances will the doctor be discriminating? It was answered that it would be doctor's discretion to treat because he knows the patient's condition better and possesses medical knowledge. If there is no basis for the referral then it is discrimination. If the person is HIV+ and has TB then the first treatment has to be TB and only then the doctor would look at HIV. However, if there is a deliberate malafide intention on the part of doctor that can be proved, then only its discriminatory.

One participant shared her personal experience and stated that her husband was suffering from HIV and he visited the doctor at government hospital. The doctor gave many excuses and asked him to come to his private nursing home and get treated. LCHAU said that this is a case of malpractice by doctors and discriminatory. We need to sensitise doctors.

Inadvertent Discrimination: A participant stated that inadvertent discrimination is not accepted in India as in America. Should it be introduced in the bill? Is it the same as perceived discrimination when it is not overt discrimination? No one should be able to discriminate on health services due to corrupt practices of referring out to private providers to make more money.

There is a difference between TB clinics and general practice. Such referrals are not discrimination, especially for opportunistic infections of PLHA's. There must be established mechanisms for accountability in equal access to health care in legislation undoubtedly. There must be a bona fide reason to refuse treatment for referrals. The draft law utilizes an in-house institutional grievance mechanism. Denying ARV's or charging for them is a malpractice.

Discrimination generally: Another participant wanted to know if there is a definition of 'dignity' and do we not need to define it? What is human dignity? LCHAU answered that courts have not defined this, each case is different, and the judge bases this on objective and subjective factors. Some things are kept vague for individual assessment by courts—i.e. unfair business practices in commerce in the U.S. and U.K.

A participant suggested that the phrase 'perceived to be hated' should be included in the provision on hate propaganda.

A participant asked what are the provisions for those actions that are not discriminatory but the impact of the same is discriminatory or how will it be taken care of. Like if the doctor asks the HIV+ person to stand at the end in a queue of patients. He attends to the patient but he attends last. There could be other such forms of actions where there is no discriminatory action per se but the impact would be discriminatory. Further to this, a participant said that Dalits have been ostracised and because of its impact children stopped getting education.

DAY 2

Special Provisions: Personal Laws: Registration of marriages, residence, maintenance

Presenter: Shehzad

Overview

While the Constitution of India (Art.14) guarantees equality to women, personal laws in India today remain the foremost areas of discrimination against women – these laws which affect crucial aspects of human life are sex discriminatory exacerbating the socio-economic vulnerability of women to HIV/AIDS. India made reservations in becoming a signatory to CEDAW to modify social and cultural patterns of conduct to eliminate prejudice in customary practices to which the CEDAW committee in 2000 expressed concern due to failure by India to take steps to reform personal laws.

Personal laws relate to marriage, divorce and annulment, maintenance and alimony, custody and guardianship and inheritance of property. In spite of the Child Marriage Restraint Act and provisions of the IPC, young girls continue to be married off and bigamy continues to be a serious problem affecting the rights of many women. Although most personal laws offer the same grounds of divorce to women (except the triple talaq system in Muslim personal law), divorce is not an option due to the economic dependence on the husband. Inheritance laws and procedures make access to property difficult for women, particularly, Hindu women.

Maintenance

Women also face impediments in accessing maintenance. In the HIV context, often the husband is terminally ill and unable to pay maintenance for too long. An order for interim/ad hoc maintenance takes very long to obtain from court. The Draft Law gives courts the power to grant ad hoc maintenance and take medical and HIV related costs into account in deciding amount of maintenance.

Right of Residence

The most significant form of discrimination that women face is loss of residence and neglect. Most widows are driven out of their matrimonial homes after the deaths of their husbands and there is substantial provision for the right of residence for a woman in her matrimonial or parental home. Even under laws that give women the right to reside, women are unlikely to enforce it due to harassment from the husband/in-laws. The Draft law specifically recognises the Right of every 'protected' woman to residence in her matrimonial home and the right to use the facilities.

Registration of Marriages

The registration of marriages is an issue that has long plagued Indian polity and while it is compulsory in one way or another in the majority of religions practiced in India and even in some States it continues to be an issue to which the Indian State does not

commit resources and []. Thus, Muslims, Christians and Parsis have some form of registration of a marriage while it is compulsory under the Special Marriage Act. Hindus, however, have no procedure to register marriages. CEDAW recommends registration of marriages [].

The Draft law introduces the compulsory registration of marriages as an entry point for counselling and sexual health information to couples getting married. It may also be successful in preventing bigamy, verifying the age of parties to the marriage etc. Under the draft law, a marriage that is not registered is voidable at the option of the woman and women whose marriages are voided would be entitled to the same [benefits] as on divorce (i.e. maintenance, property rights etc.) Registration officers will be appointed in each district under this law. The draft law further provides for mandatory pre-marital counselling of which HIV related counselling would form a significant part.

Issues to Consider

- *Should the draft law spell out to what extent personal laws to be reviewed and changed?*
- *Is registration of marriages the best option to introduce pre-marital counselling?*
- *What should pre-marital counselling entail?*
- *Will registration be able to address the issue of bigamy and child marriage?*
- *Will registration be able to verify if parties to marriage are within prohibited relation to marry?*

Open House Discussions

Registration of Marriage: A participant said that Muslims and Christians permit minor's marriage with parents' consent. Even in Hindu Marriage Act (HMA) there are certain provisions, which permit child marriage, so there is no effective prohibition to child marriage. Registration of marriage may adversely impact these laws. There were issues raised about Streedhan and it was stated that it should be read in consonance with section 406 of IPC that speaks about criminal breach of trust in respect of property entrusted with someone.

A participant informed that there is no difference between Streedhan of Hindus and dowry for Muslims in Kerala. They as an organisation try to recover dowry of Muslim women back from the in-laws after the death of husband that should be made compulsory by law. She also raised issue of women who get duped in contract marriage and hence insisted that registration of marriages should be compulsory.

A participant asked how registration and pre-marital counselling is envisaged and how counselling at the point of registration of marriage would be implemented. LCHAU responded that in case of registered marriages, currently it takes one month from the date of filing application till the date of marriage, and that time should be used for counselling. Participants noted that while this practice is followed in

Christian marriages, for Hindu marriages, there is no real way to enforce the 30-day period of the intent to marry. Another participant asked who would be responsible for pre-marital counselling – the Health dept. or any other dept.

As far as registration of marriage is concerned, a participant raised the issue of inter-caste or inter-religion marriages that are not registered or where marriages happen without the consent of parents. In absence of registration, the rights of women will be taken away. She expressed that DL should ensure that it does not happen. Another participant asked if the bill address inter-family marriage, which the Hindu law already addresses.

Another participant thought that even though marriage registration is made compulsory and used as a tool of giving information it would still not cover a large population of women that are out of marriage who are also at risk of getting HIV. She asked how bigamy could be prevented unless there is online registration of marriages facilitated by computer network accessible to all. If all the personal laws allow child marriages, then what is the point in talking about the issue of minority.

Another participant noted that there are more instances of bigamy seen in Hindu men that is why court has recognised the right of second wife for maintenance. Muslim law provides for more than one marriage hence there is maintenance security for second wife. The problem of personal laws coupled with a universal solution like marital registration in the draft bill is that it conflicts with the duty to inform by an HIV positive person. So in HIV law there is ambiguity. She asked why non-registered marriages are made voidable?

LCHAU responded that the idea of making the marriages voidable is to provide some protection for women. The Unit also explained that the registration of marriage is an idea that is being thought over and more inputs are needed from the participants. LCHAU also noted that the issue of counselling is of real concern as State provided counselling is inadequate and problematic.

DL in conflict with other laws: Another participant was concerned with whether these proposed provisions are not in a way amending Hindu Marriage Act and making it applicable to everyone. She also felt that it is also logically inconsistent as in HIV law the DL is walking in some other law, thus mixing two things. She questioned as to how we could throw some provisions affecting other laws and what is the feasibility of doing this. One participant thought that DL is in a way amending other laws and asked whether it is proper to do it.

Women outside marriage: A participant felt that women's concerns are looked at in a limited manner. She stated that DL is talking about right to reside in respect of married women only, but what about women outside of marriage, their rights and counselling for them. Hindu women's concerns are looked at only in the area of

marriage, issues of maintenance and property. She also expressed that stigma that women face is not getting addressed adequately. LCHAU replied that DL looks at marriage specifically because it covers a lot of population and also look at this as an entry point where information can be imparted. The Unit has seen that monogamous women are getting infected so it is essential to give them the information that could protect them. We can have separate provisions if the language appears to be neutral.

LCHAU also felt that some of these concerns could be addressed through IEC material. The Unit said that the idea is to cover adolescent girls to get access to information and it should be provided in school education. A participant was doubtful about the comfort with which women would access or receive sexual information.

Another participant expressed that the HIV related discussion is equalising gender, which is against the interests of women. DL is an omnibus legislation that creates contradiction. Few things need to be added and few others are to be deleted. She also questioned the connection between HIV and registration of marriages. In counselling, there can not be compulsion on disclosure.

Maintenance, counselling & other issues related to women: A participant felt that the right to maintenance is a problem of all the women and asked if the HIV+ husband is spending money on his treatment and if he is not in a position to pay to his wife, then how can a 'right to maintenance' be implemented. A suggestion came from a participant saying that the State should provide for maintenance of an HIV+ woman if her husband is dead. There should be some social security measures making it obligatory on State to provide maintenance. One participant stated that women do not get interim maintenance within 3 months though there is a provision to that effect.

Child marriages: A participant noted that Despite 80 years of the HMA restricting child marriages, there is still no way to implement it. All it has done is to raise the average age of girls getting married from 7 to 16. She stated that the social aspect of why child marriages happen in rural areas should be considered i.e. because parents are concerned with virginity of a girl child. We should have provision that would cover adolescent girls who have no access to information.

Another participant said that child marriages in rural setting are common. What is the realistic chance of counselling these people in remote areas? Those will be hit by such a provision and this population will remain uncovered. Child Marriage Restraint Act has not succeeded and here we are making registration compulsory and making second marriage voidable, that will be doubly punishing for women.

Right to reside: A participant had a question that right to reside is for married women only then what about those who are outside the marriage? Does DL envisage any

penalty? Another participant asked about the definition of ‘matrimonial home’ – property of husband, father/mother in law and whether ‘protected women’ have right to matrimonial home. LCHAu agreed that the definition of matrimonial home would have to be examined.

A participant asked that what about the objection raised as to draft being ‘omnibus’? If there are fundamental differences how would we deal with it?

One participant informed that the daughters in Tamil Nadu have equal rights in property. She questioned whether marriages among cousins should be abandoned?

Definition: One participant pointed out that definition of ‘domestic violence’ is missing. When LCHAU answered that there are many terms that are to be defined, a participant asked if the DL is going to create its own definition of section 498-A.

Special Provisions: Sexual Violence

Presenter- Leena

Overview

The links between sexual violence and the risk of HIV infection, though obvious, have not the subject of any thorough []. The risk of transmission during sexual activity arises directly from penetration and indirectly from the inability to refuse sex or negotiate safe sex.

Indian women face wide spread sexual violence in India. According to the National Crime Records Bureau 16,469 cases of rape were *reported* in 2000. A study in Punjab estimated that for every crime of rape that is reported, 70 go unreported. In different studies across the country, 46% to 76% of children report child sexual abuse. In one of the few studies on sexual violence within marriages, conducted in Karnataka, 31.4% of the respondents reported marital rape. *The failure to recognise/address sexual violence leads to failure to respond to risk of HIV from sexual violence.*

Substantive and procedural laws in India, in spite of Constitutional and international obligations, hinder the reports and prosecution of sexual violence crimes. Indian law does not even recognise sexual violence within marriages as the IPC provides a specific exemption from criminal liability for non-consensual sexual activity by a husband with his wife. Where crimes are reported, healthcare and counselling services are negligible if any, with no awareness of the risk of HIV from sexual violence or the possibility of harm reduction through Post Exposure Prophylaxis (PEP) and no counselling for HIV.

The draft law, recognising the connection between the marital rape exemption and increased cases of HIV+ married women, provides for the deletion of this exemption. It further provides for treatment and counselling for sexual assault

victims, which would include HIV counselling, referrals for counselling by the police and healthcare workers and mandates the State to set up sexual assault crisis centers in every district.

Issues for Consideration

- *How can NGOs be involved in addressing risk of HIV if women, children, MSM approach for assistance*
- *Setting up Sexual Assault Centres? How?Who?*
- *Explanation of Sexual Assault could read as: includes any non – consensual contact with a sexual purpose that may expose a person to the risk of HIV transmission including peno-vaginal, peno-anal, peno–oral penetration*
- *Should Proposed Amendments in other laws include:*
 - *Reform of Sexual Assault law in accordance with 172nd Law Commission Report*

Open House Discussions

Sexual offence, rape etc.: One participant commented that changing rape to sexual assault is a good idea and asked whether it also covers the assault (may not be sexual) which leads to exchange of bodily fluids that has danger of HIV transmission. A participant pointed out the frequency of sexual violence faced by women in custodial settings and asked about specific provisions for such cases.

Another participant asked about marital rape and felt that the marital rape exemption should be removed from law. Responding to this, another participant said that marital rape comes under civil law and marriage is per se a sexual relationship and civil and criminal laws (restitution of conjugal rights) should be looked into together. She felt that DL is neutralising gender and that would not protect women. Child abuse and sexual harassment are different issues and should not be mixed up. She also asked what about the same sex rape. Law does not recognise same sex relationships and the persons who are involved are booked by police and harassed. She felt that definition of same sex relationship should also be made.

Another participant spoke of an instance where a child was raped and the mother of the child did not want to report the incident. She asked how such situations should be dealt with.

Counselling: One participant asked if there was a need for separate institutions for separate sections of people as far as counselling was concerned. She asked if counselling can be crosscutting across different groups and felt that sexual assault has a direct link to HIV transmission and DL should address sexual assault through VCTC, antenatal clinics etc.

IEC and myths: Another participant raised her concern that a lot of people believe that having sex with child cures HIV. Can this issue be addressed through IEC? Also can there be penalties for such acts?

Special Provisions: Pregnant Women

Presenter: Kajal

Overview

Concerns about HIV and pregnancy arise from the fact that a woman living with HIV/AIDS may transmit the virus to a foetus during gestation (pregnancy), labour and delivery or even after childbirth (through breast-feeding). HIV transmission during and after pregnancy may be addressed through ARV therapy (before treatment, abortion or sterilisation were common practices...), changes in delivery practices (caesarean section) and altering infant feeding patterns. All these interventions depend on testing pregnant women for HIV, providing ARV interventions to HIV+ pregnant women etc. which involves having access to women through their pregnancy. Thus, pregnant women attending antenatal clinics are viewed as a captive population where HIV transmission may be controlled/prevented. The fallacy is that most births are home births and most women attend clinics only for the actual birth.

The approach to pregnant women who are HIV+ is limited to prevention of transmission to the child with the health of the woman and the child if HIV is transmitted being ignored. Testing options include mandatory testing, routine testing and testing with free and informed consent. Routine testing is now being encouraged in many parts of the world with women being given the option to opt out. In settings like India this will border on mandatory testing. In India, arguments regarding lack of infrastructure and service providers have resulted in the adoption of group counselling or group information with one on one post test counselling only if the woman is positive. Anecdotal evidence suggests that women who are given 'information' rarely return even for their results let alone complete for antenatal care. Couple counselling where the partner is involved or disclosure of the woman's status to her partner also raise problems for women, as being tested first they are blamed for the infection and face violence and abandonment.

Treatment that is advocated for women in 'resource poor settings' like India is Nevirapine which is preferred as the regimen only requires 1 dose during delivery +1 to infant in first 3 days and is cheaper & preferred in breast feeding conditions. However, this treatment has been rejected outright in the West due to toxicity and the requirement of follow up of women who take the treatment. Also where it results in resistance in the woman and the child, the only alternative treatment to Nevirapine is considered unsafe for women, particularly those who will have children. Artificial feeding is also not promoted in India as it is considered expensive and unsafe in settings like India, due to the stigma associated with failure to breastfeed and because

the potential benefits of breast milk outweigh potential risks to infant. We need to ensure that women receive all the information to make the choice b/w breast & artificial feeding.

The prevention of transmission from a woman to her child should not be resolved or addressed by pitting the rights of the woman against those of the child as has happened. The DL accordingly recognises the right of the woman to information and services, to proper counselling to make appropriate decision about pregnancy, to treatment for mother and child and to confidentiality and against mandatory testing, abortion or sterilisation.

Issues for consideration

- *Control over information & reproductive decision making: State, society, service providers*
- *Couple counselling*
- *Can women in India truly give free consent- involvement of family?*
- *Should the partner have a right to results?*
- *Ensuring access to services for all women: age, marital status, sex workers?*
- *Permission for advertisement and promotion of infant milk substitutes?*

Open House Discussions

Partner notification and pregnant women: A participant pointed out the connections and contradictions regarding partner notification and pregnant women. She said that where women who are tested first at ANCs are likely to face violence, the provision regarding partner notification becomes problematic.

Discrimination and pregnant women: A participant asked about the accountability of a treatment provider for not providing adequate treatment to mothers/babies? LCHAU responded saying penalties could be fines, discrediting etc. but also cautioned that discrimination is usually extremely hard to prove.

PPTCT and women: Another participant spoke about why the term changed from PMTCT to PPTCT. She further commented that ‘moral wives are being infected by immoral husbands’. She said that women do not have control or have a little control over the number of children they would have. How much control can they exercise?

One participant pointed out that all the discussions on PPTCT had centered around heterosexual married couples when there are many couples outside marital relationships. She asked what are the provisions for them?

Infant Milk substitutes: Commenting on issues surrounding infant milk substitutes, a participants asked if information on baby care be left to the HCW’s responsibility or through the media and infant formula ads? Responding to this, another participant

said women must get all the information and then it would be their choice whether to breast-feed or top feed.

Ensuring information/services for women at sites other than ANCs: A participant said that 70% births take place at home. Pregnant women go to hospitals for tetanus, x-rays etc. but do not register themselves in ANC for birth at hospitals. She felt that the DL should include options for information for women who deliver at home and said that men should be made responsible for contraception but still that would not solve the entire problem. Similarly, another participant wanted to know what were women's rights at the time/site of information centres. LCHAU noted that some of these issues could be addressed through the DL provisions on IEC.

ARV treatment: A participant asked about the cost of using ARV treatment and its availability. Carrying the ARV issue further, a participant said that in the context of ARV rollout plan, confidentiality gets violated because the partner and family members get involved. It is the family's responsibility to ensure that ARVs are taken properly to ensure that no resistance develops. LCHAU explained the terms of the Government ART rollout plan and that ARV treatment costs about Rs.1200/- pm. The government plan aims at delivering free ARVs in six high prevalence states and in Delhi. Preference is given to children below 15 and pregnant women.

Counselling: A participant suggested the inclusion of women accessing abortion services for HIV counselling. While talking about counselling, one participant raised a practical problem that couple counselling is not possible in case of sex workers because the father is not identifiable. In case of pregnant woman, in the interest of the child mandatory testing should be done. If HIV+ woman gets information then she can avoid transmission to the child. Another participant was of the view that if there was no routine testing, then it was the responsibility of the State to test. Government should push for extensive antenatal counselling to check infant mortality rate and the testing decision should be such that it should be in the interest of both, mother and child. Women should be informed of possible risks and available services for HIV. A participant noted that even in marriages the husband does not come for counselling. LCHAU agreed saying couple counselling is problematic and cannot not ensure the safety of women, a man's co-operation, a woman's autonomy.

Mandatory testing: One participant asked what is the punishment if HCW asks to test mandatorily and how to fasten accountability on doctors. She said that MCI guidelines have not been changed for long. She asked as to what is the state's responsibility towards those who do not get information. She also asked a question on companies promoting infant food.

Special Provisions: Women under care and custody of state

Presenter: Kajal

Overview

Persons in the care and custody of the State include prisoners, undertrials, detainees, 'rescued' persons, institutionalised persons, persons in State run juvenile homes, rehab Centers, mental homes, adoption homes, hospices, night shelters, beggars homes etc. It is also important to recognise the differences in the nature of care and custodial settings and the vulnerabilities they create and [].

Concerns about HIV transmission in institutionalised settings have arisen with reports of higher incidences of diseases such as HIV, Hepatitis B&C, TB etc in such settings. Vulnerability of prisoners for instance increases due to potentially unsafe sexual activity (coerced & consensual), tattooing, needle & syringe sharing (large no. of convictions drug-related in Tihar etc.), floating populations of undertrials, closed, overcrowded, violent & unsafe environments. In such settings HIV infection also increases instances of discrimination & violence (mandatory testing, segregation, etc.)

For women prisoners, studies in the US at least have shown that HIV rates are *2 to 3 times higher among women prisoners* who also face increased sexual violence and other forms of abuse by prison staff. Prison health systems do not deal with health needs of women as they are designed primarily to meet the needs of male inmates. This is important to note as HIV infection manifests differently in men & women (*women present with common gynaecological problems before anything else and if no obstetrician/gynaecologist available, women inmates less likely to seek medical help*). Women also need gender-specific health education to protect themselves from HIV infection.

Studies in India, though not HIV specific, have highlighted the poor condition of women in the care and custody of the State. A 2001-02 Parliament Committee report noted the absence of basic amenities, medical aid, training etc., the lack of whole-time female medical officers, lack of medical attention for seriously ill women and the instances of violence/assault. In 1986-87 an expert committee on Women Prisoners headed by Justice Krishna Iyer noted that women in prisons...suffer unhealthy living conditions, exploitation, unnecessary severance from family, lack of gainful employment and recommended the setting up of a National custodial authority for women in prisons/mental hospital etc.

In the HIV context, discrimination faced by women in the care or custody of the State has included the following:

- HIV+ woman arrested under ITPA detained after expiration of sentence till Madras HC ruled HIV-related detention illegal
- HIV+ woman arrested under ITPA denied bail in NOIDA based on her status

Various laws allow for medical examination which law enforcement (ITPA) and judges (In Mumbai and Madras courts have ordered mandatory testing of sex workers) have interpreted to include mandatory HIV testing. The Supreme Court has

held that society has an obligation towards prisoners' health as prisoners do not enjoy access to medical expertise that free citizens have, incarceration places limitations on access; no physician of their choice, no second opinions, few, if any, specialists and conditions of incarceration expose inmates to more health hazards than free citizens. India's prison law is nearly a 100 years old and only the West Bengal Correctional Services Act 2000 speaks of sanitary toilets with separate enclosures, women doctors who specialise in women's health issues etc.

The DL makes it mandatory for the State to introduce risk reduction measures (including sexual health information/condoms/needle exchange & drug substitution programmes). It also recognises the right of persons in care/custody to HIV counselling, testing and treatment services and the right of HIV+ persons in custody to medicines, special lock up and nutrition. It provides for the referral of persons in care and custody for counselling and PEP if there is any possible exposure or risk of transmission of HIV.

Issues to Consider

- *Do the provisions address concerns of women?*
- *Should the draft law address issues for women in care & custody separately?*
- *Should issues of 'care' and custodial' settings be dealt with separately?*
- *What are women's issues in 'care' settings?*

Open House Discussions

In terms of care for women in state custody, a participant wanted to know till what time the State was responsible for providing treatment and what happens after she is released from the custody. LCHAU shared details of the case where Delhi High Court ordered to provide ARV treatment when a prisoner was released from jail. It is being figured out whose responsibility it should be. It means developing an infrastructure for treatment services with no money, network etc. Another participant wanted DL to contain specific provisions for women in custody.

One participant wanted to whether Kiran Bedi's column contributed to this draft's suggestions. LCHAU responded that some of the articles and columns could be looked at, but also pointed out that Kiran Bedi had in fact opposed the distribution of condoms to prisoners in Tihar jail on the ground that it promoted a criminal activity not recognising its importance in the protection of health.

Promotion of strategies for reduction of risk

Presenter: Tripti

Overview

The clause on risk reduction addresses problems faced by persons/NGOs providing risk reduction services (currently seen only in the form of targeted interventions) with

criminal laws and law enforcement agencies. Many of these services are provided to persons whose behaviour/actions are criminalised in some form or the other by law. Risk reduction services are thus considered abetment of crimes and this has resulted in the harassment and even arrest of peer educators and NGO staff. Thus, while the National AIDS Prevention and Control Policy encourages such HIV/AIDS interventions it does not provide them any protection from criminal liability.

The problem with HIV/AIDS interventions can be seen clearly in the case of interventions with sex workers, MSM and IDUs. The law that affects sex workers adversely is ITPA that not only hinders sex workers right to livelihood and health but also impacts HIV intervention programmes with sex workers. The criminalisation of sex work settings impedes access to services, reduces sex workers' negotiation ability & makes introduction of health and safety regulations impossible. Section 377 of the Indian Penal Code is misused by the police to harass, blackmail and extort money from MSM. The criminalisation of consensual, adult sex between men increases stigma and marginalisation, hampers HIV interventions and therefore increases their vulnerability to HIV. The NDPS Act makes consumption; possession etc. of drugs a punishable offence and therefore drives IDUs underground and affects their access to information and health. The criminalisation of drug use exacerbates their vulnerability to HIV. Law enforcement agencies have in the past used these laws to interpret the provisions of clean needles to IDUs, sexual health information to MSM and condoms to sex workers as abetment of crimes. (Sahyog, Bharosa etc.)

Risk reduction under the Draft Law

The provisions on risk reduction in the DL are based on the recognition that a *criminalised environment* has severely hampered *targeted interventions* and that existing laws have *disempowered* marginalised populations & *fuelled vulnerability* to HIV/AIDS. Risk reduction in the draft legislation means the promotion of actions and practices that minimise a person's risk of exposure to HIV/AIDS and/or to mitigate adverse impacts related to HIV/AIDS. Presently this clause is applied in the context of populations that are considered vulnerable to HIV/AIDS like sex workers, MSM and IDUs. However the clause aims to keep the category broad because in the future other vulnerable groups can be included within the purview of the law. The clause on risk reduction proposes various strategies for risk reduction and discusses existing laws that impede strategies for risk reduction.

The DL protects risk reduction measures and programmes from existing laws under which they may be illegal or considered to be abetting a crime or illegal activity. Certain strategies of risk reduction - *IEC, safe sex tools, NEPs, drug substitution* are specifically protected. Under the DL, the police and other law enforcement agencies cannot interfere with any risk reduction programme and cannot apprehend/harass persons providing/using risk reduction strategies. The implementation of risk reduction programmes is not illegal. Persons providing/possessing/utilising services of risk reduction programme will be immune from civil/criminal liability.

This provision in the DL would have different implications for different marginalized groups and would allow them to freely access services related to HIV and would also protect those carrying out HIV/AIDS intervention work. However, these provisions have certain limitations as it would only protect and create safe havens in the context of HIV/AIDS and not address larger vulnerabilities to HIV created by the criminalised status of many 'populations' and 'communities' by law.

Issues to Consider:

- *Does this go far enough to protect vulnerable groups from harassment & persecution?*
- *Should certain 'physical spaces' be created/ earmarked for carrying out risk reduction?*
- *Should NEPs & drug substitution require licensing/ certification?*
- *Can this provision be used to introduce coercive measures like mandatory testing?*
- *Will risk reduction programmes result in increased stigmatisation and isolation of SWs, MSM, IDUs?*

Open House Discussions

High-risk: One participant objected to terming some groups as high risk groups and provide for them separately, as HIV has now become the disease of the masses. She said that NGO staff were put behind bars when condoms were distributed or when condoms were found in the purses of SWs.

Safe havens: DL provides for safe havens, then does that mean that police could not enter the area where crime is being committed? She felt that people might not access 'safe havens' as they might not like to get identified as persons availing these services. As regards 'safe havens', another participant asked who would create safe havens and who would come under it? She also questioned about those people who do not identify themselves as such.

Registration of NGOs: One participant felt that the non-registration of good NGOs should not prevent them from carrying on good work. She felt that registration of safe havens would mean greater government control. She asked whether there have been instances of misuse of NSEP. In response to this, another participant felt that the government should be involved only to lay down technical standards for certain risk reduction programmes but should not have regulatory. LCHAU responded that there may be ways to ensure the regulation of NSEPs remains outside State control.

Microbicides: A participant felt that gender issues need to be considered in discussing risk reduction and the impact of certain measures on women and their empowerment. For instance, she was of the opinion that Microbicides as sex prevention tool perpetuate gender distinction and leads to further stigmatisation and hence should be dropped from the provision. LCHAU noted that there is in fact a lot

of politics around microbicides being pushed as female empowerment, though trials with them have proved very harmful in Africa.

WSW: A participant felt that WSW groups have been left out and have not been dealt with adequately and a separate meeting should be called with WSW groups.

Licensing of sex workers: A participant asked about licensing proposed for sex workers in Kolkata. Another participant from Kolkata replied to the query of licensing of sex workers saying that the mayor of Kolkata was contesting from the area and had declared licensing of sex workers as his election promise if they follow health check-ups, protocols. But since it was election promise and considering that he was from Left parties, it would be difficult to get this implemented. LCHAU pointed out that the DL does not recommend licensing. It only suggests demarcating geographic areas where intervention is protected, in high drug use sectors.

Rural settings: A participant compared the positions of rural and urban women, the prior having no access to diagnostic facilities while the later have such facilities available to access. How would risk reduction work in rural setting? Another participant noted that there is no concept of privacy in rural settings and NGO's may divulge status to family.

Drug Use interventions: One participant said that drug use was still criminal and what is the line that de-criminalises drug use and drug use for risk reduction. Another participant asked if the distribution of needles and syringes leads to the expansion/promotion of criminal drug use or enhances protective measures against greater transmission in society.

NGO accountability: Some participants felt that while interventions should be protected, NGOs should also be accountable in the provision of these services. In particular, concerns were raised regarding the maintenance of confidentiality. A participant asked whether the right to confidentiality could be violated in the provision of risk reduction. Another participant took the point further saying that risk reduction goes much beyond only the persons accessing the services and asked whether NGOs would be charged for breach of confidentiality when they undertake risk reduction work as the very setting up of such services would reveal information about persons accessing it?

Information, Education and Communication

Presenter– Shalini Singh Deo

Overview

The draft law incorporates information, education and communication (IEC) as essential in the prevention of HIV and in addressing discrimination in the HIV

context. Information in the HIV context is considered particularly important as it tends to define the epidemic and shape societal responses to it; can alleviate fear, shame & guilt related to sexuality; can equip women & girls to negotiate and say 'no' in sexual relationships; can enable people to protect themselves & others from the risk of infection; can equip women & girls to seek support for sexuality & reproductive health concerns and can create awareness of rights. It has further been seen that the lack of information and knowledge about HIV has in fact fuelled the epidemic and has also led to stigma & discrimination against PLHAs.

For women accessing information and education is already difficult and information that is intrinsically connected to sexuality and sexual activity is almost always denied. Existing IEC on HIV/AIDS is not gender sensitive and fails to capture larger social, cultural & economic factors that influence women's choices.

The right to information and education is recognised by the Indian Constitution (Article 19 (1)(a), Article 21, Article 21A and Article 14), International Conventions (ICCPR, CEDAW and the UNGASS Declaration of Commitment on HIV/AIDS). In India, however, laws and policies, particularly censorship and obscenity laws hamper women's access to information on grounds of decency and morality.

The National AIDS Prevention and Control Policy also reflects a normative, moral framework with sex within marriage seen as an all-pervasive reality while all other sites of sexual activity are seen as aberrations - usually linked with urbanisation/migration. The prevention strategy in the NAPCP includes, "reinforcing traditional Indian values & morals amongst youth & other impressionable groups." State and community responses to comprehensive HIV/AIDS IEC tend to identify IEC as promoting 'promiscuity' & 'irresponsible' sexual behaviour among adults. For women, IEC is not considered important as they are perceived to have limited sexual needs and because it is likely to lead to the initiation of sexual activity among young persons.

Not only is comprehensive HIV/AIDS related IEC not offered by the State due to these perceptions, NGOs providing this information are often penalised and targeted under criminal laws (Sahyog, Almora (2000), NFI/Bharosa, Lucknow (2001)). The State's prevention efforts have seen emphasis on the 'ABC' approach and a ban on condom advertisements.

What the Draft Legislation proposes

The DL gives statutory recognition to the right to information for the protection of a person's health. It obligates the State to institute IEC programs, which are evidence based; age appropriate; do not promote gender/sexual stereotypes; do not incite/create hate propaganda and that are developed in a participatory/consultative manner. It further obligates the State to make special efforts to promote IEC for:

girls & women, employees and other groups. It further provides for IEC at travel points, health care institutions; the inclusion of HIV education medical, legal and social work curriculum; HIV information to be provided with prophylactic materials etc. The law however, cannot ensure the creation of an enabling environment for women and girls to access information, or ensure that gender issues cut across IEC or cover non-State actors and the problematic messages that they may be promoting.

Issues for Consideration

- *Should the law prescribe contents/ minimum requirements for IEC on HIV/AIDS?*
- *Should provision of IEC be restricted on basis of age and/ or capacity to understand?*
- *Provision of IEC material for persons with disabilities?*

Open House Discussions

Language suggestions: A participant felt that IEC must be strengthened as much as possible. It should be based on the ‘capacity to understand’ rather than be ‘age specific.’ Another participant suggested the addition of the word ‘complete’ on page 28 of the DL as an essential component of the ‘right to information.’ Another participant suggested that IEC should contain ‘appropriate and sufficient information for protecting a person from transmission’. She also felt that it should give enough information that enables a person to make an informed consent.

IEC, BCC, ABC: One participant questioned the usage of term ‘IEC’ instead of BCC (Behaviour Change Communication). Another participant disagreeing with the use of the term BCC noted that BCC speaks about abstinence while IEC tends to be morally neutral. Another participant asked about the ABC strategy of the Health Ministry. She noted that though abstinence may be the best way to avoid HIV transmission, this did not allow the government to promote only abstinence messages. She asked whether IEC should be morality based or evidence based.

The importance of obscenity and censorship laws: Some participants expressed their apprehension that framing State responses such as censorship or indecent representation laws as narrow beliefs based on Victorian precepts was an oversimplified framework on public imaging of sexual roles. Similarly one participant felt that existing obscenity laws and Section 377 do play an important role in challenging child pornography etc. LCHAU clarified that the provisions of the DL do not interfere with the existing laws, they merely protect HIV/AIDS related IEC from being censored by the State. Further the problem perceived by LCHAU lay not in the purpose for which obscenity and censorship laws were enacted but with the manner in which the State uses them to control information, particularly sexuality and sexual health related information.

Sex Education: A participant asked about the status of sex education in schools, to which another participant answered that her organisation was working in that area

where volunteers are sent to schools to provide sex education. Another participant shared her experience on sex education saying that teachers often did not teach chapter on 'reproduction' and asked pupils to read it at home. She suggested that giving sex education should be put part of the B.Ed curriculum. She also felt that there should be a network of counsellors to train 1 or 2 teachers in every district with sex education information and that they should work in rural areas. [One participant felt that the provision of 180 days appears to be inadequate.] Another participant gave an example of a professor, who, when her organisation asked to include some information on lesbians in a seminar objected to it and said it was illegal.

IEC by non-State actors: One participant was concerned with the IEC materials produced by NGOs and wanted to know how these could be controlled. She also felt that the phrase 'evidence based information' in the DL chapter on IEC may be misused by the State to promote abstinence messages. Continuing the discussion on NGOs materials, another participant asked whether there are any safeguards against right wing publications promoting stereotypical modules in IEC material. She stated that HIV related IEC falls in the realm of 'safe sex' and risk and safety needs to be embodied in this IEC language to enshrine women's rights/empowerment as a principle for its objective. She also suggested the use of sensitive language in IEC.

Duty on State to discuss sexuality: One participant spoke about censorship. She asked can IEC be produced that talks about WSW/MSM and whether the government would not control it. She also asked if the government is obliged to speak about homosexuality, sexuality and gender issues. What if they choose to never address these problems because there is no incorporation of non-state actors? LCHAU said that it wants government to include all the related information including WSW, MSM and it would be under an obligation to come out with correct information.

Implementation & Grievance Redressal

Presenter: Vivek Divan

Overview

In any law, the implementation/procedural provisions are as important as substantive provisions, as the experience with many Indian laws has been their ineffectiveness due in large part to the lack of implementation. The presentation commenced with an explanation of the existing court systems and how persons access justice in civil and criminal cases. This was followed by an explanation of the grievance redressal and implementation mechanisms in the DL.

The DL law envisages different implementation mechanisms while maintaining the sanctity of the court system in accessing justice. Based on the experience of consumer tribunals, family courts etc. the law does not propose an alternate system for HIV related cases; it does however propose certain mechanisms such as the institutional

grievance redressal mechanisms and health ombudspersons to provide some avenues for quick redressal of complaints.

Institution Grievance Redressal Mechanism

Under the DL, every institution where 20/50 persons carry on systemic activity in co-operation for the satisfaction of human wants would have to designate a person of senior rank, holding a permanent post as a Complaints Officer. All health care institutions would have to comply with this provision. The definition of institution under the draft law is meant to apply to the organised and unorganised sectors and to all persons whether they are 'employees' or not. Any person whose rights under the law have been violated or her/his legal heir or representative can complain to the Complaints Officer. The Complaints Officer would deal with complaints on a daily basis and would take a decision within 7 days except in the case of complaints relating to healthcare discrimination, access to health care services or provision of universal precautions in which case complaints would have to be settled in one day. As most discrimination arises out of fear and myths, the Complaints Officer must first counsel the violator. Where violations continue, disciplinary action is to be initiated and in all cases the complainant is to be informed of the action taken.

Issues to Consider:

- *Grievance Redressal by individual or committee?*
- *Separate persons for internal and external complaints?*
- *Effect of non-compliance: penalties?*
- *What has the experience of sexual harassment committees been?*

Health Ombudsperson (HO)

The idea of the HO is based on the Lokayukta system. This office is envisaged as being part of the existing Indian administrative structure and would be appointed/designated at a district level. The DL provides for the appointment of a person of or above the rank of the Joint Director of Health and Family Welfare as the HO in a Union Territory and a person equal to or above the rank of the officer responsible for health in a district as the HO in a district.

As the most common, severe and life threatening discrimination that PLHAs and protected persons is in healthcare settings, the function of the HO is the immediate redressal of grievances regarding violations in the health care sector. The HO may take action based on complaints by protected persons or their representatives or when asked by a government or court or even suo moto. The HO has the power to pass orders and/or take actions to attend to immediate breaches and in cases of emergency to direct hospitals to admit a person and decide on the merits of the issue subsequently.

The HO would deal with complaints on a daily basis and would take a decision within 7 days except in the case of complaints relating to healthcare discrimination, access to health care services or provision of universal precautions in which case complaints would have to be settled in one day. Proceedings before the HO would be summary and s/he would have to pass reasoned orders, maintain proper records and report the number and nature of cases and violations to the State government every six months.

Issues to Consider:

- *What should the effect of non-compliance of Health Ombudsman order be?*
- *Complaints: letters? Telephonic? Accessibility issue.*

Special Procedures in Court

The DL makes provisions for special procedures in courts in HIV related matters or where protected persons are involved in cases. Stigma and discrimination contribute to a large extent to protected persons being unwilling to access justice through the legal system. Accordingly, the DL provides for various mechanisms allowing protected persons to conceal their identity in court proceedings such as the suppression of identity (i.e. substituting the name of the HIV positive party in a court proceeding with a pseudonym), in camera trials (i.e. apart from the parties in the case no other persons/media would be allowed in court) and restraining any person from publishing any matter relating to the disclosure of identity. It also provides for the expediting of proceedings with HIV related matters or matters involving protected persons to be taken up on a priority basis and making it mandatory for courts to prepare a daily hearing timetable for the case with only summary proceedings for interlocutory matters.

The DL also makes provision for Courts to pass orders to rectify and prevent breaches of the Act and take measures including affirmative action, damages, withdrawal of breaches, suspend/revoke license, submit a matter to concerned police station in case of criminal proceedings. In cases relating to discrimination, courts can order reinstatement, payment of salary/wages/benefits etc. that may have been lost due to the discrimination and can order damages. In matters relating to discrimination, the DL shifts the burden of proof on the person alleged to have discriminated to show that either discrimination did not take place or the act was not discriminatory. The DL also provides for a persons HIV status to be a relevant factor in determining bail and sentencing.

Issues to Consider

- *Should HIV+ persons get special consideration in criminal matters?*

HIV/AIDS Commissions

The DL proposes to make NACO and SACS statutory bodies to ensure their accountability, independence and transparency in operations. The DL re-

conceptualises NACO (or the National HIV/AIDS Commission – NHC) and SACS (State HIV/AIDS Commission – SHC) as independent bodies with representatives from the States and Union Territories, PLHAs, NGOs, HCWs, HIV/AIDS experts etc. Appointments to the NHC will be done by a nomination committee comprising the Prime Minister, leader of opposition, PLHAs, NGOs, etc. and the NHC will be advised by an Advisory Committee comprising the Prime Minister, leader of the Opposition, other parties, Minister of Health and Family Welfare, NGO representatives, Representative of ICMR, HCWs, PLHAs, etc.

The ‘Primary Functions’ of NHC/SHC shall be to prevent and control the spread of HIV; promote and protect the rights of protected persons; provide care, support and treatment to those infected and affected by HIV/AIDS; reduce the vulnerability of individuals and communities to HIV/AIDS; promote awareness, information and education about HIV/AIDS; and alleviate the socio-economic and human impact of HIV/AIDS. Among the NHC’s functions are the formulation and review every 3 years of the National HIV/AIDS Policy after widespread consultation; supervision of SHCs, formulation of standards for HIV tests, blood safety, medication, etc., guidelines for registration & support of NGOs etc. SHC functions include the translation and dissemination of the National HIV/AIDS policy, setting up VCTCs, formulating guidelines to prevent violations of the DL, advise and report to the government and importantly to conduct investigations into violations of the Act, review laws and policies that discriminate against protected persons and maintain a particular focus on women and gender issues, etc.

Most importantly, the DL imposes a clear duty on the Commissions to Consult governmental and non-governmental organisations including calling upon public health, human rights, law, HIV etc. to assist in inquiries, community consultation in all phases of HIV/AIDS policy design, programme implementation, establishment of formal and regular mechanisms to facilitate ongoing dialogue with community representatives and supporting the greater involvement of persons living with HIV/AIDS – GIPA.

Issues to Consider

- *What should their composition be – NGO, civil society, PLHA representation? Who should appoint them?*
- *What functions – programmes, IEC, conciliation – consultation with*
- *NGOs/civil society?*
- *Should the SHCs have the power to conciliate?*
- *How to ensure financial commitment from the government?*
- *How can accountability and transparency be ensured?*

Open House Discussions

Institutional Grievance Redressal: One participant had the following suggestions and questions - 1) instead of a single Complaints Officer, forming a committee would be a better option; 2) can committees be formed under existing labour law provisions?; and 3) whether orders from the Complaint Officer would be directives or recommendations?

Ombud: One participant asked if the ombud institution could be a committee rather than an individual. She also wondered whether harassment complaints could be worked into existing labour laws. LCHAU felt it was possible to consider the health ombud as a committee rather than an individual and while harassment complaints could be dealt with through the labour laws, the effect on the organised and unorganised sectors as well as unions would have to be researched.

Court procedures: One participant asked if the provision for ‘in camera trials’ was mandatory or optional and who would decide - the aggrieved PLHA or the court? There are disadvantages also of having such a trial as lawyers ask very probing questions. Women NGOs have a bad experience of this as the questions lack sensitivity and women have no support systems within the court. Public scrutiny sometimes can provide that support. She also noted that there have been bad experiences with speedy trials as people are lined up for petty trials also. The wording has to be cautious so the matter is not decided hastily.

Another participant also felt it was important to maintain a balance between open courts and in-camera trials.

One participant noted that often the person who discriminates also sits as the judge. She also asked if there was sufficient evidence to show widespread discrimination that justified the shifting of the burden of proof as the DL proposes. A participant also felt that other laws may have to be reviewed and the cabinet of ministers, labor, health, etc should see the DL, so they may consider revising existing laws. She felt that the provisions relating to special procedures etc in the DL were very ambitious.

One participant asked whether family courts could be used for issues of maintenance and divorce.

PLHAs and leniency in criminal matters: Most participants felt that PLHAs should not be given special consideration in criminal matters. While one participant felt it would be a bad idea to grant bail based on a person’s HIV status, another felt that leniency to an HIV+ person in criminal matters, whether in relation to bail or sentencing should depend on the merits of the case.

Commissions: A participant pointed out that in setting up the NHC and SHC we should look to other structures and commissions that have not worked and determine the cause of their failures. Important issues that need to be looked at

include insuring financial independence and determining the extent of the power of the Commissions. Another participant suggested that the name of the PM should be dropped from the advisory committee as if s/he were unable to attend, the body would become non-functional.

A participant expressed her concern at the statutorising of NACO and SACS saying that being a statutory body does not necessarily ensure accountability or efficiency; it just ensures permanence to HIV commission. She felt that the Commissions should be given teeth; clear responsibility and should not be a mere advisory body. With regard to child rights, she recommended a look at critiques of other commissions like the NHRC - they lack financial independence, transparency in dealing with grievance redressal to cite a few potential problems. She foresaw the government perceiving the NHC and SHCs as previous commissions and structure them as such without the drafters' intention. Another participant recommended that 50% of the members on the commission should be women.

On the issue of setting up committees, one participant said that NACO has set up 2/3 advisory committees where NGOs are also represented. These committees, however, do not invite the NGOs for discussions. She questioned who decides and what are the criteria for selecting an NGO representative. She also asked about the functioning of sexual harassment committees and felt that these committees are non-functional. Summing up she said that it is the experience that committees do not function properly.

Unorganised Sector: Some participants felt that the proposed grievance redressal mechanisms do not adequately account for the unorganised sector. A participant asked how persons working in the unorganized sector would lodge their complaints - Through courts or with district-level officers? Another participant spoke about the tripartite boards in Tamil Nadu for construction workers against contractors, which were set up after sustained pressure from NGOs and other sections of society and said that these boards were working well.

Another participant shared the experience of her NGO that was harassed by the State government. Nine cases were filed against her organisation (directors, employees for charges of rape, murder etc for which they work) 8 of them being non-bailable. She explained how NGOs are victimised under false cases. She raised questions about the role of funding agency as the funding agency can fund for projects and not for fighting cases.

Emerging Issues

The final session at the women's consultation outlined emerging issues in the HIV context in India. Participants were given brief overviews on issues related to access to treatment and the Government of India ART rollout plan, vaccine research in India and Microbicides.

Agenda
 Consultation on the Draft Legislation on HIV/AIDS
 17-18 April 2004, Hotel Taj View, Agra

DAY 1

9 – 9.30 am	Registration
9.30 –10 am	Welcome and Introduction of participants
10 – 10.15 am	Introduction to the Draft law
10.15 – 10.45am	<i>Vulnerability of Women to HIV/AIDS</i> <i>(A legal and human rights perspective)</i>
10.45 – 11 am	Open House
11 – 11.15 am	TEA
11.15 – 11.45 am	Consent (Chapter IV)
11.45 am – 12 pm	<i>Open House</i>
12 – 1 pm	Group Discussions on Consent
1 – 2 pm	LUNCH
2 – 2.30 pm	Disclosure of Information (Chapter V)
2.30 – 2.45 pm	<i>Open House</i>
2.45 – 3.45 pm	Group Discussions on Disclosure of Information
3.45 – 4.15 pm	Discrimination (with TEA) (Chapter III)
4.15 – 4.30 pm	<i>Open House</i>
4.30 – 5.30 pm	Group Discussions on Discrimination
5.30 – 5.45 pm	<i>Feedback and wrap-up</i>

DAY 2

9 – 10 am	<p>Special Provisions <i>Personal Laws: Registration of marriages, residence, maintenance Sexual violence and sexual assault protocols</i> Pregnant Women <i>Women in the care and custody of the State</i> (Chapter XVI)</p>
10 – 11 am	<i>Open House</i>
11 – 11.15 am	TEA
11.15 – 11.40 am	<p>Risk Reduction <i>(in the context of sex work, drug use and men who have sex with men)</i> (Chapter VIII)</p>
11.40 – 12 pm	<i>Open House</i>
12 – 12.30 pm	<p>Information, Education & Communication <i>(Right to Information on Sexuality, Reproductive Health and Gender)</i> (Chapter XI)</p>
12.30 – 1.15 pm	<i>Open House</i>
1.15 – 2 pm	LUNCH
2 – 2.45 pm	<p>Implementation <i>(Health Ombudsperson, Institutional Obligations, HIV Commissions, Courts)</i> (Chapters XII, XIV, XIII and XVII)</p>
2.45 – 3.15 pm	Open House
3.15 – 4 pm	<p>Emerging Issues <i>(ART rollout plan and vaccines)</i></p>
4 – 4 .30 pm	Wrap Up & TEA

Glossary of terms

LCHAU: Lawyers Collective HIV/AIDS Unit
PLHA: Persons living with HIV/AIDS
DL: Draft Legislation on HIV/AIDS
NGO: Non Governmental Organisation
NHC: National HIV/AIDS Commission
SHC: State HIV/AIDS Commission
HCW: Healthcare Worker
ITPA: Immoral traffic Prevention Act
MSM: Men who have Sex with Men
IDU: Injecting Drug Users
NSEP: Needle Syringe Exchange Programme
NDPS Act: narcotic Drugs and Psychotropic Substances Act