



# **NATIONAL CONFERENCE ON HUMAN RIGHTS AND HIV/AIDS**

**24-25 November 2000  
New Delhi**

*Organised by*  
**National Human Rights Commission**

*in partnership with*

**National AIDS Control Organisation,  
Lawyers Collective,  
UN Children's Fund and UN Joint Programme on  
HIV/AIDS**



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## Foreword

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HIV/AIDS<sup>1</sup> is not merely a medical problem: the manner in which the virus is impacting upon society reveals the intricate way in which social, economic, cultural, political and legal factors act together to make certain sections of society more vulnerable. The epidemic exposes the method and the impact of marginalisation and inequality in clear terms.

Marginalised groups in our society have little or no access to basic fundamental and Human Rights such as food, medical services and information. Many of these groups are ostracised by society at large, and their lifestyles criminalized, making it practically impossible for them to participate in mainstream processes whereby they could demand their rights. Coupled with this dismal situation, there is minimal awareness about HIV and no real options for safer lifestyles. The stark reality of the HIV/AIDS epidemic is thus that people are becoming HIV positive because they have no access to basic fundamental Human Rights. For the same reasons, the impact of infection is a lot graver for those with no access to rights. It is time to recognise this link between marginalisation, Human Rights and vulnerability.

It is also time to recognise that the HIV/AIDS epidemic itself has given rise to a range of Human Rights violations. The refusal of treatment, denial of access to essential drugs including antiretroviral therapy, discrimination in the health care and employment sectors, women being deprived of their rights and thrown out of their homes etc are just some examples of these violations. Apart from having a serious impact on the lives of people living with HIV, these violations are pushing the epidemic underground. Unless these Human Rights violations are addressed, there cannot be the creation of an enabling environment, where people come forward to access health and other services, or even get tested.

There is also a need to understand the exact manner in which factors of gender, caste, region, class, sexual orientation influence the impact of these Human Rights issues for different sections of society. Along with social and economic factors, there are laws, which complicate the influence of these factors. To understand these different contexts would be the first step in addressing the problems they entail.

HIV can today be made a manageable condition, with the use of antiretroviral treatment, along with other mechanisms. These treatments are, however, almost absolutely unaffordable to most people who need them. It is a shocking proposition that the right to live a healthy life should depend on the ability of a person to pay for treatment. This proposition is, sadly, a truth at present. The State is under an obligation to ensure that treatment is available, accessible and affordable to all people who need it. Laws that impact on the cost of treatment, such as drug price control laws and patent laws need to be moulded to fulfil this obligation. This is as much a Human Rights issue as any other.

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<sup>1</sup> Human Immunodeficiency Virus / Acquired Immunodeficiency Syndrome.

In order to bring all these realities to the fore, to understand them and to address them effectively, there must be the development of an enabling legal environment which respects and protects the fundamental and Human Rights of those worst affected. It is keeping this in mind that the National Human Rights Commission decided to take up the exercise of starting dialogue with the Human Rights community on a wide range of issues that link the HIV/AIDS epidemic to Human Rights. The National Conference was the first step in this regard. Representatives from the Human Rights machinery, police personnel, non-governmental organisations (NGOs), AIDS Control Societies and people living with HIV/AIDS from all over the country, came together for the first time to discuss these issues at length.

The conference was conducted by the National Human Rights Commission (NHRC) in partnership with the National AIDS Control Organisation (NACO), Lawyers Collective, United Nations Children's Fund (UNICEF) and Joint United Nations Programme on HIV/AIDS (UNAIDS), all of whom must be commended for the hard work that went into making the conference a success. I am glad to note that the deliberations of the conference were fruitful and informed. The success of the conference may be seen from the insightful recommendations that came out of the deliberations.

The idea of the Conference as I have stated earlier, was to start the process of developing a rights-based response to the HIV/AIDS epidemic within the country. I sincerely hope that the various State Human Rights Commissions, Police departments, representatives from the health sector and State AIDS Control Societies will now take the process forward in close collaboration with civil society.

JUSTICE J.S. VERMA  
Chairperson  
National Human Rights Commission

**“Dignity is the entitlement of *all* as long as life exists”**

Justice J.S. Verma, Chairperson  
National Human Rights Commission  
25 November 2000



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## **Recommendations**

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The recommendations emerging from the group discussions are presented as a series of **action points** that seek to feed into the response to HIV/AIDS both on national and State levels, and in reference to all partners, including the international and domestic non-governmental organisations, foreign governments and multilateral agencies, credit institutions, the business community/ private sector, employers' and workers' associations, religious associations and communities.

Another purpose of the action points is to complement the International Guidelines on HIV/AIDS and Human Rights<sup>1</sup> with practical solutions in Indian context.

### **Consent and testing**

- All staff of testing centres and hospitals, both in public and private sector should be trained and sensitised, on the added value of the right of any person or patient to make an informed decision about consenting to test for HIV. Further the same staff need to be sensitised on universal precautions, provided with an appropriate infrastructure and conducive environment enabling them to respect the right of any person or patient to decide whether to test for HIV or not. This right to self-autonomy must be combined with the provision of the best possible services of pre-test and post-test counselling.
- Persons detected at routine HIV screening at blood banks, should be referred to counselling centres at nearby health care facilities, for further evaluation and advice.
- The physical environment in which counselling and testing is carried out needs to be conducive and enabling to prepare HIV positive people physically, mentally, with accurate information on how to 'live positively'. An important component of the enabling environment is sufficient *time* to internalise and consider the counselling and information provided to make an informed decision on consent to testing.
- Official ethical guidelines and a comprehensive protocol should be developed on how to counsel and best protect the rights of the people who according to current legislation, or the practice of diminished authority, may not have legal, or social, autonomy to provide or withhold give their consent. This would include inter alia children, mentally disadvantaged persons, prisoners, refugees, and special ethnic groups.
- A comprehensive protocol on informed consent and counselling should be developed and be applicable in *all* medical interventions including HIV/AIDS. It needs to include testing facilities and processes in normal hospital setting.

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<sup>1</sup> See Annex D.

emergency setting and voluntary testing that take into consideration the window period.<sup>2</sup> Although the counselling offered aims to advise testing for those who might feel they have been engaging in unsafe practices, the right to refuse testing must be respected.

- The availability and/or accessibility to voluntary testing and counselling facilities needs to be increased throughout India, including rural/remote areas, in an immediate or phased manner within previously defined and agreed timelines.
- Guidelines for written consent procedures in the case of HIV/AIDS research need to be explored and developed.

***'The right to self-autonomy is a positive right to protect yourself -  
Protecting the rights of the infected, protects the rights of the non-infected'<sup>3</sup>***

## **Confidentiality**

- Train and sensitise all staff in testing settings, blood banks, and care and support settings, both in public and private sector, on the right of any person or patient to enjoy privacy and decide with whom medical records are to be shared.
- Explore innovative and practical ways to implement respect for confidentiality in different settings: location for disclosure of diagnosis, specific procedures for the handling of medical journals and correspondence, reporting procedures, and confidential disclosure of status without the presence and pressure of family members, which is particularly relevant to infected women.
- The legal framework, administrative procedures, and professional norms should be revised to ensure enabling environments, which foster and respect confidentiality.
- Develop guidelines/regulations for beneficial disclosure of testing results. Disclosure without consent should only be permitted in exceptional circumstances defined by law.

## **Discrimination in Health Care**

- Train and sensitise care providers and patients on their respective rights in the context of HIV/AIDS, and combine it with training on universal precautions and with the supply of means of protection including post exposure prophylaxis (PEP)

<sup>2</sup> The standardised three-month period between time of infection and time of possible detection of HIV in the blood.

<sup>3</sup> Quote from the group discussion on 'consent and testing'.

and essential drugs for all health care settings. Include to a greater extent trained and sensitised health care workers as trainers and role models to other health care workers. Information on HIV/AIDS should be available at all health care institutions for the public as well as for the staff, and should be most user-friendly.

- Implement stigma reduction programmes and campaigns among health care professionals that prohibit isolation of HIV positive patients, provide appropriately prescribed treatment of opportunistic infections, and offer standard procedure for the protection of confidentiality. Include to a greater extent people living with HIV/AIDS in the design of stigma reducing campaigns, awareness programmes and care and support services.
- Develop anti-discrimination legislation that practically enables protection of the rights of health care workers and patients, and that makes both the public and the private sectors accountable.
- Establish a multi-sectoral consultative body on HIV/AIDS to provide advice and dissemination of information to health care workers.

## **Discrimination in Employment**

- Adoption of national and State anti-discrimination legislation that should apply equally to both the public and private sectors and should prohibit discrimination in relation to work. This should include prohibition of pre-employment HIV testing, routine health checkups with mandatory HIV testing, reasonable accommodation, HIV friendly sickness schemes, entitlements, regulation on subsidised treatment costs, and compassionate employment.
- Train and sensitise both employers/corporate leaders and employees/workers at formal and informal work places, and expand the awareness programmes to the surrounding communities, on the issues of HIV/AIDS, stigma and discrimination, leading to adoption of private and public corporate regulations on HIV/AIDS.
- Train and sensitise law enforcement authorities or other authorities/sections of the community that might be closely connected with the workplace on the issues of HIV/AIDS, stigma and discrimination.
- Raise awareness about the existing CII<sup>4</sup> policy on HIV/AIDS and training in legal literacy related to both HIV/AIDS in the workplace as well as other work place regulations in force. Media could be of great use to such a campaign.

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<sup>4</sup> Confederation of Indian Industry.

- Commission an investigation on the anticipated costs for large and small Indian companies in the context of HIV, to prepare employers and workers in dealing with the consequences of HIV/AIDS.
- Introduce affirmative action/positive discrimination in the form of insurance and health care benefits and introduce medical insurance schemes to cover HIV positive employees.
- Increase focus on workplaces with special vulnerabilities: introduce interventions training and sensitisation programmes within the armed forces, and design training and sensitisation programmes that are child- youth- and women friendly to be used in the workplaces where they are represented.

### **Women in Vulnerable Environments**

- Effectively share accurate information on HIV (including transmission modes, sexually transmitted diseases (STD), preventive and curable aspects, treatment, drugs and counselling) to different categories of women in varied innovative, culturally adapted ways all over India.
- Adopt legal changes to empower women for equality in areas such as property rights, domestic violence and marital rape, and protect the right to association for any groups of women working for collective interests.
- The rights of women to provide or withhold informed consent, for HIV testing, must be protected. Social barriers that limit the free exercise of such a right by women must be overcome through appropriate educational and administrative measures.
- All pregnant women should be provided an opportunity to have an HIV test, since vertical transmission of HIV can be effectively stopped by the use of low cost drugs in pregnant women who test positive. Women, who test positive for HIV, during pregnancy, should be offered such treatment.
- Start alternate media communication programmes to reach out to as many groups of women as possible on the issue of empowerment of girls and women and elimination of misconceptions, myths and stereotyping related to male and female sexuality. Remove silence about sexuality in the development of policies, guidelines, project management and programming as well as within prevention messages.
- Increase programmes directed at informing and involving men in the response to HIV/AIDS by opening up discussion on sexuality and gender differences, challenging cultures of shame and blame.

## **Children and Young People**

- Ensure that the response to children and young people is shaped and driven by their rights guaranteed under the CRC<sup>5</sup>, and also, their overall health needs as well as health education requirements. Train government officials, policy-makers, and healthcare providers to fully familiarise them with the contents of CRC.
- Create innovative mechanisms to inform children and youth on safe sex and other sexual health issues and ensure that such information is related to their cultural context and age groups. Extensively use mass media and the education system to disseminate relevant information. The information and advocacy campaign should be subsidised by the Government.
- Redesign the health care services, including contact points/counselling services, to become more child- and youth friendly, and accessible.
- The limitations of the legislation related to children and young people need to be addressed. For instance, the Juvenile Justice Act (JJA) should be revised to facilitate the shift to alternate methods of providing non-custodial care. A law covering sexual abuse of boys and girls should be adopted. Legal remedies need to be made accessible to children and youth.
- Develop a clear policy for how young people wishing to go through an HIV test can do so voluntarily and without breach of confidentiality vis-à-vis legal guardians or others.

## **People Living with or Affected by HIV/AIDS (PWHAs)**

- Formulate institutional guidelines with standards placing the issues of PWHAs in a larger framework.
- Scale up availability and access to appropriate health care for PWHAs within mainstream services (including increase in availability of voluntary testing centres). Explore practical ways to ensure that the right of PWHAs to treatment of opportunistic infections is promoted, respected and protected in practice. This should include efforts to reduce stigma and discrimination in the health care system, reduction of the cost as well as increase of availability and affordability of drugs.
- Commission a study on the WTO<sup>6</sup> regime post 2004. Lobby with the UN agencies, including the OHCHR<sup>7</sup> to work for affordable drugs, and lobby towards Indian capacity building and opportunities for domestic drug manufacturing.

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<sup>5</sup> International Convention on the Rights of the Child, 1989.

<sup>6</sup> World Trade Organisation, Geneva.

<sup>7</sup> Office of the [UN] High Commissioner for Human Rights, Geneva.

Organise a workshop on WTO and TRIPS<sup>8</sup> with reference to the issue of future access to drugs and anti-retrovirals.

- Ensure ways to protect everyone's right to information about HIV/AIDS, means of protection and support available for 'positive living, among others, by strengthening the quality control of the services and drugs, and access to information on policy of all partners. This includes the training of testing technicians and physicians on HIV/AIDS technical aspects.
- Increase legal literacy among PWHA and communities by community training programmes and integration of legal literacy messages in prevention messages. Ensure access to legal remedy in case of violations of the rights guaranteed
- Review information, education and communication (IEC) strategies with the aim of reducing stigma while preventing HIV/AIDS. For this purpose, explore the role of public broadcasting companies, and introduce tax relief for private broadcasting channels to allow public broadcasting on issues related to HIV/AIDS. Train and sensitise the media through workshops. Lobby for the inclusion of HIV/AIDS issues in the Right to Information Bill.
- Immediately review legislation that impedes interventions (such as Section 377 IPC<sup>9</sup>), as well as feasible anti-discrimination legislation, health legislation and disability legislation to be more supportive to people living with HIV/AIDS, prevention, care and support initiatives. Include HIV/AIDS issues in the Right to Information Bill. Introduce affirmative action for HIV positive people in the employment sector.

## **Marginalised Populations**

- Revise and reformulate laws and processes (such as Section 377 of the Indian Penal Code and the NDPS Act<sup>10</sup>) to enable the empowerment of marginalised populations and reach them with HIV/AIDS prevention messages as well as care and support mechanisms.
- The revision of the legislation must seek to mitigate the socio-economic factors that cause people's marginalisation as well as unsafe practices.
- Legalise any sexual activities undertaken with consent between adults, and in connection with this adopt a clearly defined age for sexual consent.
- Legitimise and expand innovative harm reduction programmes to reduce harmful practices including needle exchange and unsafe sexual activities, and expand condom distribution among all marginalised populations.

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<sup>8</sup> Trade Related Aspects of Intellectual Property Rights (WTO TRIPS Agreement).

<sup>9</sup> Indian Penal Code.

<sup>10</sup> Narcotic and Psychotropic Substance Act.



## **General**

- A comprehensive strategy to prevent and control HIV-AIDS should combine a population based approach of education and awareness enhancement with strategies for early detection and effective protection of persons at high risk.
- An Action Plan for implementation of these recommendations should be developed with focus on specific areas of action and prioritised sequencing of recommendations for early implementation within each of them. This may be done through a working group comprising of representatives from the NHRC, Ministry of Health and Family Welfare, Government of India and UNAIDS who will identify the pathways of action and the agencies for implementation.

### **Respecting Human Rights - crucial in dealing with HIV/AIDS**

‘Respect for Human Rights helps to reduce vulnerability to HIV/AIDS, to ensure that those living with or affected by HIV/AIDS live a life of dignity without discrimination and to alleviate the personal and societal impact of HIV infection. Conversely, violations of Human Rights are primary forces in the spread of HIV/AIDS. ... Implementing a Human Rights approach is an essential step in dealing with this catastrophic threat to human development.’<sup>11</sup>

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<sup>11</sup> Source: Human Development Report Office; Mann and Tarantola 1996; UNHCHR and UNAIDS 1998.

## **Acronyms and Abbreviations**

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AIDS	Acquired Immune Deficiency Syndrome
ASO	AIDS Service Organisation
ANC	Ante Natal Care
AZT	Zidovudine
CDC	Centre for Disease Control (in Atlanta, USA)
CII	Confederation of Indian Industry
CRC	Convention on the Rights of the Child, 1989
CEDAW	International Convention on the Elimination of All Forms of Discrimination Against Women, 1979
HIV	Human Immunodeficiency Virus
ICPD	International Conference on Population and Development, Cairo 1994
IEC	Information, Education and Communication
IDU	Injecting Drug Use [er, -ers]
IMA	Indian Medical Association
INP+	Indian Network for Positive People
IPC	Indian Penal Code
ITPA	Immoral Traffic in Women and Girls Prevention Act, 1986
JJA	Juvenile Justice Act
KNP+	Karnataka Network for Positive People
NACO	National AIDS Control Organisation
NDPS	Narcotic and Psychotropic Substances Act
NGO	Non Governmental Organisation
NFHS	National Family Health Survey
NHRC	National Human Rights Commission
OHCHR	Office of the [UN] High Commissioner for Human Rights
PEP	Post Exposure Prophylaxis
PHC	Primary Health Care Centres
PWHA	Person/People Living with HIV/AIDS
RTI	Reproductive Tract Infections
SACS	State AIDS Control Societies
STD	Sexually Transmitted Disease
STI	Sexually Transmitted Infection
TB	Tuberculosis
TRIPS	Trade Related Aspects of Intellectual Property Rights (WTO Agreement)
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNHCHR	United Nations High Commissioner for Human Rights
UNICEF	United Nations Children's Fund
UNIFEM	United Nations Development Fund for Women
VCT	Voluntary Counselling and Testing
WTO	World Trade Organisation

## **Introduction**

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### **Background and Objectives**

The first 'National Conference on Human Rights and HIV/AIDS' was held in New Delhi on 24-25 November 2000. The conference was aimed at initiating a dialogue between concerned agencies and groups on the linkage between Human Rights and HIV/AIDS prevention and management.

India has 3.86 million<sup>12</sup> people living with HIV/AIDS, the highest in any country after South Africa. HIV in India is mainly transmitted through heterosexual contacts placing large parts of the population at risk of infection. The stigma surrounding HIV/AIDS, and certain vulnerable groups affected such as injecting drug users, often leads to discrimination, which constitutes a serious obstacle to HIV/AIDS control and management. It has been established that understanding of Human Rights issues enhances protection against HIV on both the individual and community level. At the same time, promotion and protection of Human Rights as a central component of the response to HIV/AIDS makes people and communities less vulnerable to HIV/AIDS and mitigates the impact on affected and infected persons.

Organised by the National Human Rights Commission (NHRC) in collaboration with the National AIDS Control Organisation (NACO), Lawyers Collective, UNICEF and UNAIDS, the conference brought together Members of the NHRC and State Human Rights Commissions (SHRC), officers from NACO and State AIDS Control Societies (SACS), Inspectors General of Police in-charge of the Human Rights Cells, UN agencies, NGOs, People Living with HIV/AIDS, and Human Rights activists.

The objectives of the conference were to:

- (i) Discuss and identify major issues in the HIV/AIDS related Human Rights framework
- (ii) Build linkages between SHRC and SACS
- (iii) Identify future interventions to create an enabling environment at various levels, and
- (iv) Delineate measures to expand the response within a Rights-based approach.

The conference was part of a series of consultations on "Health and Human Rights" planned by the NHRC, which elicited broad-based participation (including the Chairperson and members of NHRC) and enabled participants to scrutinise the status of HIV/AIDS protection, control and healthcare within the framework of Human Rights. Partnering groups and individuals were able to fully consider the immense value of recognising, promoting and protecting Human Rights, creating an enabling environment, and recognising the central role of law as essential components of the response strategies to prevent and manage HIV/AIDS in India.

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<sup>12</sup> NACO, 2001.

## **Consultative Process**

The background materials used as basis for the conference group discussions were the product of a consultative process. A variety of stakeholders were consulted to spell out the key issues governing ethics, law, and Human Rights in relation to HIV/AIDS. All background materials were distributed twice prior to the conference to a number of experts and consultants all over India, including NACO and NHRC, for comments and input. The invaluable feedback from this process has been carefully considered and incorporated to the extent possible.

The papers on *Consent and Testing, Confidentiality, Discrimination in Health Care and Employment* were written on the basis of the information and experiences shared during a consultation jointly held with PWHA, health care workers, AIDS Service Organisations (ASOs), Non Governmental Organisations (NGOs), counsellors, trade unionists, Mumbai District AIDS Control Society, UNAIDS and representatives of the legal community (Mumbai). The paper on *Women* was based on the same process as described above, but was complemented with additional interviews and consultations with women's NGOs, health care workers, lawyers, UNIFEM<sup>13</sup> and UNICEF staff. (Mumbai and Jaipur). *Children and Young People* and their vulnerability to HIV was mainly a research product, based on UN documents, national and international data, conference reports and doctrine. Three background papers were based on reports and feedback from meetings and conferences: A report from the national meet launching the 'National Forum for Advocacy and Support for Sex Workers' (Chennai, 28-30 April 2000), served as basis for the backgrounder on *Sex Workers'* vulnerability to HIV/AIDS. The paper on *People Infected/Affected* was based on the 1999 Needs Assessment Study of People Living With HIV/AIDS conducted by INP+<sup>14</sup>, as well as the INP+ Strategic Plan for 2000-2002, while the vulnerabilities of *Sexual Minorities* were discussed mainly on the basis of a conference held in May 2000 organised by the Humsafar Centre, Mumbai ('Looking into the next Millennium'). The paper on *Injecting Drug Users* was largely based on the information and experience shared by NGO representatives from Manipur and Delhi during a consultation held in Delhi.

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<sup>13</sup> UN Development Fund for Women.

<sup>14</sup> Indian Network for People Living with HIV/AIDS.

## **Recount of the Proceedings**

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### **The Inaugural Session**

The inaugural session pointed to a clear link between Human Rights, HIV/AIDS, and Development. It emphasized the necessity for harmonization between individual rights and community interests, ready access to drugs as an assertion of Human Rights, and the involvement of civil society and central and State governments in the response to HIV/AIDS.

Shri N. Gopalaswami, Secretary General of the NHRC, welcomed the guests and participants.

The Union Minister of Law, Justice and Company Affairs, Shri Arun Jaitley inaugurated the Conference. Justice Shri JS Verma, Chairperson of the NHRC presided over the function. Shri Javed Ahmed Choudhary, Secretary (Health), Ministry of Health and Family Welfare and Dr Brenda Mc Sweeney, UN Resident Co-ordinator addressed the Conference and articulated issues that provided a basis for the deliberations over the next two days.

Shri Javed Choudhary emphasised that respect for Human Rights is important in the management of any disease, and a balance needs to be found between individual rights and community rights. On the issue of access to drugs, he suggested international support should focus on enabling purchase of patents of drugs instead of disease control programmes. He also pointed to a need for much greater investment in vaccine research. With respect to groups in vulnerable situations such as sex work, he stated there is a need for the recognition and acceptance of the existence of such contexts. He felt that the opposition to such recognition was misplaced in as much as it did not consider the contextual realities.

Dr Brenda McSweeney expressed a sense of happiness that HIV is finally being viewed within the Rights framework. She considered the decentralisation of the national programme as a positive development. She articulated three significant issues in the HIV/AIDS context. Firstly, she pointed out that the HIV/AIDS epidemic is a development issue and focus needs to be brought on issues of gender, mobility, economics and marginalisation. Secondly, HIV/AIDS is significantly different from other diseases because of the stigma and discrimination attached to it. Pointing to the seriousness of ostracism in health services and employment, she emphasised that the right to dignity should be central in the response to the epidemic. Finally, she emphasised the significance of a proper system of law and ethics in the HIV/AIDS context. While pointing out that the present international guidelines were based on experiences worldwide, she cautioned the gathering that the contextual sensitivity of these guidelines should be tested. At the same time, she stated that the rights of every group affected by

the epidemic need to be recognised and respected, and any coercive action would be counterproductive.

In his inaugural address, Shri Arun Jaitley first outlined the progress of the human rights movement and the development in the conceptualisation of rights. He opined that the meaning and content of rights have been fine-tuned in the last two decades to a commendable extent, whereby today we find that rights have specific meanings and are not merely abstractions. Shri Jaitley went on to identify a few of the significant and contentious legal issues that have been raised in the HIV/AIDS context, which include confidentiality, consent in testing, and the right to marry. Recognising that the interests of the community and the individual's rights both need to be respected, he urged more debate on these issues. In the context of consent to testing, he suggested that the element of persuasion would clearly be essential in the legal response but that it may not be sufficient, considering the population of the country. Finally, Shri Jaitley pointed out that other legal and policy issues that need greater focus in the HIV/AIDS context include information and broadcasting, fundamental rights and economics.

Justice Verma, in his presidential address, emphasised that HIV/AIDS is one of the most pressing Human Rights issues. He said that the right to health under Article 21 of the Constitution puts a responsibility on the State to devise a response. At the same time, he pointed out that the responsibility was not the State's alone, the involvement of the community was equally important. In addition to the Constitutional mandate of protecting fundamental rights, Justice Verma pointed to the international obligations that apply in dealing with the problem. The focus of the State's response, Justice Verma stated, must be two-fold. The first objective should be to ensure that there is no more transmission of HIV infection, and the second to ensure that drugs are available. He further pointed out that it is time for the dialogue and activity around these issues to shift from conference rooms to the streets. He suggested that interventions, including those by NGOs, must be sensitive to the cultural context and each step should be strategically decided so that it is not counterproductive.

## **The Plenary Presentations**

Additional Secretary of Health and Project Director of the National AIDS Control Organisation (NACO), Mr JVR Prasada Rao, offered an overview of the HIV/AIDS scenario in India. The priorities of the Response to HIV/AIDS are outlined in Phase II of the National AIDS Control Programme (NACP II). It has the twin goals of reducing the transmission of HIV, and increasing India's capacity to respond to the epidemic. Based on epidemiological observations, the programme focuses on preventive strategies in States with low-level epidemics, while dual strategy of prevention and control is the focus in the remaining States.



The plenary presentation on the global situation by Mr Gordon Alexander, Senior Country Programme Adviser for UNAIDS India, provided a useful perspective for the participants on the urgency of the situation, the importance of drawing on lessons learnt in other countries, and the urgency to identify Indian solutions *-now*.

Reading out a letter to a friend and HIV/AIDS activist Dominic D'Souza, Mr Anand Grover, Lawyers Collective, highlighted the importance of law and promotion of human rights to effectively control the spread of HIV/AIDS. He also urged the participants to empathise with people living with HIV/AIDS, and act humanely but urgently to stem the spread of the epidemic.

## **Group Discussions**

Professionals, experts and activists with extensive experience on HIV/AIDS from within the national and State governments, academic institutions as well as from civil society deliberated on the critical issues to be addressed along two broad themes: issues crosscutting HIV/AIDS and Human Rights issues, and those relating to vulnerable groups and environments. The first day of group deliberations was devoted to Human Rights issues within the public health framework especially for those affected by HIV, and issues of informed voluntary consent and testing, confidentiality, and discrimination in employment. Marginalized groups such as women in vulnerable environments, children and young people, people living with HIV/AIDS, and discrimination affecting marginalized communities were the focus of deliberations during the second day of the conference.

### ***Consent and Testing***

The Human Rights issues identified by the group regarding the problem area of 'Consent and Testing' included the right to health and safety, the right to information, the right to make autonomous choices without coercion, the right to refuse, and informed consent for testing including counselling procedures. An initial discussion on the right to self-autonomy identified the basic principles of and established guidelines to biomedical ethics, the code of conduct for physicians and researchers, as well as justice, beneficence – non-maleficence and other principles, required in support of the right.

The group started by discussing *consent to testing* in the blood bank setting where both the donor's and recipient's rights need to be considered. It was argued that the safety of the recipient and not the status of the donor should be the primary concern in a blood bank, and counselling centres need to be set up if the blood bank's duty is to extend to informing donors of their HIV status.

The extent to which facilities for *voluntary testing* should be made available was also discussed. Recognising the added value of HIV testing as a source of knowledge that can be beneficial to both the individual and the community, the group agreed upon the optimal situation in which every citizen should have access to voluntary testing. Also, it would give the individual the autonomy, to choose whether or not to undergo testing. Not

allowing the individual to make informed autonomous choices would be a violation of the right to self-autonomy. The group expressed concern over a concept of diminished autonomy applied in the case of women, children, mentally disadvantaged prisoners, refugees, and ethnic groups. It questioned the right of others to give consent on their behalf.

The group felt that a comprehensive protocol is needed. For testing in the *hospital setting*, the opinion that consent to testing should be applicable to **all** medical interventions and not only to HIV tests prevailed. There was also a discussion on the need to differ from normal hospital care settings and emergency settings in the context of universal precautions and the window period.

The group further discussed the advantages of respecting consent to testing. As stigma is attached to HIV status, people do not come forward for testing. A conducive and enabling environment should be present for this to happen. This entails preparation of the patient both physically and psychologically to face the trauma of social ostracism. Also, it would include counselling on safe practices to prevent transmission. It was felt that testing without consent should occur only in exceptional cases, and that a comprehensive protocol regulating such testing is needed, as well as awareness generation to prevent its non-intended use.

The major concern, however, was the question of making rights operational and the issue of strengthening infrastructure and training staff to enable them to know when to use protection measures. For the operationalising of rights, the provision of adequate time and information for the individual to enable him/her to reflect and make an informed decision on testing was considered a prerequisite. In addition, the need to obtain written consent for research/drug testing was recognized.

### ***Confidentiality***

The starting point of the group discussion was that HIV/AIDS is a Human Rights issue involving health care and social problems. During the discussion, the group identified several instances when breach of confidentiality actually makes both prevention and management of HIV/AIDS difficult as such breach is not covered by any law.

It was argued that to bring both infected and affected persons closer to health care services, confidentiality would need to be guaranteed. Otherwise, the risk is that people will avoid health care services, and HIV/AIDS will remain beyond the control of public health.

It was concluded that health care professionals need more clarity through formal guidelines/regulations as to when it is necessary to allow the release of information on a patient's sero-status. This might be in relation to partner notification or in the interest of adequate further health care.

The group felt that respect for confidentiality plays a paramount role in HIV/AIDS response as guaranteed confidentiality motivates people to come forward and trust health care services. Disclosure of HIV status should therefore only be made in exceptional circumstances, to be specified in law.

### ***Discrimination in Health Care***

The right to equal treatment and the right to health are fundamental rights. Patients and care providers must both be made aware of rights and risks of HIV/AIDS. An anti-discrimination law covering not only public institutions, as presently provided by the Constitution, but also private institutions would be needed to ensure minimum standards of non-discrimination, and to put all health care within the framework of the rule of law. For both public and private institutions, providing safe working conditions/universal precautions and PEP would encourage non-discrimination, as would adequate supply of essential drugs. Ongoing orientation and training of health care workers at all levels would be useful to fight discrimination in the health care setting. There is no valid reason why HIV/AIDS patients should be isolated or why they should not have access to treatment provided for any other illness.

Role models in all disciplines must be motivated and encouraged. It would be advisable for health care professionals to train other health care professionals, as it would strengthen their profession from within, and at the same time, contribute to both de-stigmatisation as well as a more enabling environment to manage HIV/AIDS in health care settings.

Another recommendation for increasing the awareness and knowledge among health care professionals about HIV/AIDS is for each State to set up a multi-sectoral consultative body on HIV/AIDS in health care for advice and dissemination of information to health care workers. Such a consultative body could consist of members of State Human Rights Commissions, State AIDS Control Societies, Directorates of Health Services, Human Rights Cells in Police head quarters, PWHA, NGOs, Indian Medical Association (IMA), and the Law Department. This body may also look into the overall Human Rights issues relating to HIV/AIDS and suggest practical solutions.

People have very little knowledge about HIV/AIDS and other STD. Information on HIV/AIDS could be made available at all health care institutions – not only the ones relevant to STD or ante natal care (ANC). This information should be simple and practical and make the people aware of the risks and the rights, if exposed or infected.

An additional way of dealing with and eventually reducing discrimination that is based on HIV/AIDS, would be to offer a legal framework which includes anti discrimination clauses that have jurisdiction both in the public and private sphere and are valid in both emergency and non-emergency situations.

At the same time, resources should be made available for both State and private health care institutions to ensure a safe working environment for health care workers, so that

they can contribute in the best way to the prevention and management of HIV/AIDS. This should aim at non-isolation of HIV/AIDS patients, a standard procedure for the protection of confidentiality of sero-status, accessibility to treatment of opportunistic infections, as well as anti-retroviral medication.

### ***Discrimination in Employment***

Articles 14 and 16 of the Constitution guarantee equal treatment before the law, but only have jurisdiction in the public sector. Although one could argue that the guarantee stretches into the private sector, more concrete legislation on non-discrimination would be useful. There is need and a constitutional obligation for the State to regulate the private sector also.

The group identified several urgent issues for discussion including (i) pre-employment testing, (ii) sensitisation of employers (a positive climate has to be created among corporate leaders), (iii) armed forces as a particularly vulnerable work place, (iv) child labour, and (v) women in employment.

In the Indian HIV/AIDS scenario, main work-place concerns were identified as follows:

- a) **Pre-employment check-up:** Should pre-employment check-up be allowed, given the fact that it might lead to difficulty for those not qualifying health-wise to earn a living (which is guaranteed in the Constitution)? The group agreed that this scenario would constitute discrimination and should be specially prohibited through national and State legislation as well as within corporate regulations.
- b) **Routine health check-up:** Should employers be able to terminate the employee's contract if a routine health check-up reveals HIV status? The group agreed that it should not, and that employment in spite of positive HIV status should be protected through national and State legislation, as well as through corporate regulations.
- c) **Reasonable accommodation:** The group agreed that as reasonable accommodation is granted people affected by other diseases<sup>15</sup>, it should be granted also in the case of HIV.
- d) **Benefits to HIV positive employees and families:** As employees who suffer from other illnesses are entitled to benefits such as provision of medical services and compensation of medication expenditure by the employer, the same should be the entitlement of employees suffering from HIV, and their families. National and State legislation as well as corporate regulations should guarantee these benefits.
- e) **Treatment costs:** There is most likely an increased need among HIV positive employees to undergo different treatments for opportunistic diseases. It would be advisable that the costs of such treatment be subsidised by either the State or the

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<sup>15</sup> Anand Bihari vs. Rajasthan S.R.T.C., (1991) 1SCC731.

employer so that the employee can continue to serve the employer as well as earn a living.

It was mentioned that the employers already approached claim that the workforce and the police will not allow HIV awareness in the workplace, as it touches upon socially unaccepted topics. Finding ways of involving the workforce in HIV prevention would be useful, although this would entail difficulties due to the fact that only about five per cent of the workforce is organised enough to be easily addressed.

The group felt that the presence of representatives of the ministry of labour and the Confederation of Indian Industry (CII) would have been most useful to the discussion. Having these institutions on board as partners within the response strategy is crucial to reaching out to the large mass of the Indian workforce. The group was informed that complaints concerning compassionate employment related to HIV/AIDS are already on the rise.

Confusion about, or lack of information on, CII policy on HIV/AIDS was noted as a persistent problem. Unless it is known, a policy cannot be implemented. The group was informed that there are more than hundred laws related to the well being of the workforce, or the standards of workplace, but they are rarely implemented. A large reason for this is that there is no awareness of the laws. A person's right to such information could be successfully conveyed through the media, as it is a good way to empower groups. The cost of HIV to large and small companies would be useful to know, to motivate employers to plan for the impact and consequences of HIV/AIDS.

Affirmative action or positive discrimination would be beneficial in the form of insurance benefits and health care benefits, which is the norm with diseases other than HIV/AIDS.

In the long-term perspective, protecting against discrimination in employment would make both the employers and the employees better prepared for the future and to respond to HIV/AIDS.

### ***Women in vulnerable environments***

Not only are sex workers in vulnerable situations but also single women, those living on the streets, married young women, college students, female migrant workers, women survivors of sexual abuse and rape, etc. There was discussion on the issues of poverty, sexual abuse, neglect of the girl child, and forced marriages, which could result in girls being trafficked into prostitution. Further, police harassment, denial of health care and other services add to women's vulnerabilities.

While HIV/AIDS is seen as a multi-sectoral issue, there are contentious issues with respect to law, matrimonial relations, and female sexuality, which are based on power structures and certain cultural sanctions regulating women in society. Cross cutting issues of class, gender, sexuality and poverty deprive women of their Human Rights. Silence around issues of sex and sexuality, comes in the way of HIV related education, making

informed and responsible choices difficult. It also contributes to sex workers being seen as aberrations, deviants and dissidents, which heighten their vulnerabilities.

HIV/AIDS has also thrown up areas of conflict over rights such as informed consent, confidentiality and partner notification, which work differently for men and women. The gender dimensions in these areas need further investigation, understanding, and tackling.

In the group there were divergent opinions on sex work. This included the *terminology* used to define it, the *decriminalisation* of sex work, and the right of sex workers to *organise*. Some expressed the view that prostitution, increasingly replaced by the term sex work, is a derogatory term that violates human dignity and Human Rights. They urged that laws that target men and pimps should be framed instead of recognising sex work and the status of sex workers. The majority of the group participants argued however that such an approach would cause constraints on preventive and curative strategies adopted for HIV/AIDS. Using concept of morality within HIV prevention strategies results in the construction of women as good and bad, and shifts attention away from sexual behaviours, attitudes and practices. If the focus were premised on Human Rights, it would instead lead to empowerment, which has proven useful in HIV prevention efforts.

The group discussed Human Rights violations with reference to access to health care and treatment, access to information, bodily integrity and violence against women, and made the following recommendations:

1. **Right to information and communication:** Accurate messages on transmission should be available to different categories of women. Information should not be moralistic and must address both preventive and curative aspects. Information about the costs of treatment, including treatment of STDs, drugs and counselling should also be available. Different packages should be evolved and available for different population groups.
2. **Right to association** (form groups) and to work collective for common issues should be fostered.
3. **Need to work with Men:** There is urgent need to remove the silence around sexuality and to challenge the culture of shame and blame linked to issues of female and male sexuality, contraception choice and women's right to bodily integrity
4. **Legal changes** for empowering women to achieve equality: Laws governing property, marital rape, domestic violence and other areas that perpetuate inequality need to be amended. There is need to advocate for the Domestic Violence Bill and Marital Rape Bill.
5. **Decriminalise sex work and focus on the perpetrators:** The group noted that a Bill is pending on ITPA. There is need to decriminalise the prostitute not prostitution. This would reduce the harassment and atrocities against sex workers by police and law enforcement agencies.
6. **Rehabilitation and reintegration of sex workers:** This needs to be done with their participation and consultation.



7. **Education for life skills:** This is necessary in order to empower girls and women.
8. **Use of alternative media:** For communication and reaching out to as many groups as possible, effective use needs to be made of alternative along with mainstream media.

## ***Children and Young People***

The starting point of discussion at the session on children and young people was that even though the rights of children have been articulated in the Convention on the Rights of the Child (CRC), there is a need to change law and strategy of intervention in such a way that children and young people are seen as people *capable of exercising their rights*. In this context, the following issues were debated:

- Society's obligation to children
- Whether children have Rights and can demand Rights, specifically in the context of the Right to information.

A link between the inability to access Rights and vulnerability to HIV/AIDS was emphasised. Discussions dealt with children's right to information, and making services, especially reproductive health services accessible and available to them.

*The right to information:* It was stated that:

- Although the CRC recognises the right to information of children, there is a low awareness of the existence and content of the CRC amongst government officials and policy makers
- The right to information is cardinal in the context of HIV/AIDS, as it is seen that with information about sexual health, the rates of sexually transmitted infections have gone down in some groups of children.
- There is a need for subsidisation of advocacy and information dissemination by the Government.
- There is too much focus on the electronic media. Alternative channels of information dissemination that are culturally suited for dissemination of information related to sex and sexuality should be used. In this context it was suggested that the right to information should be linked with the Right to education.

The strategy to realise the right to information, especially in the context of HIV/AIDS should address the many different contexts in which children live, such as streets, villages, urban centres, schools, children involved in labour etc. In this regard there is a need for a clear policy that recognises the limitations of social viewing of TV programmes and of other modes of information dissemination. Similarly, it is necessary to consider the particular requirements of different contexts in designing the strategy. For example, information dissemination to children living on the street may be effective only

through outreach programmes. It was also recognised that the use of existing social structures, such as the family, may be made to get information across to children in different settings.

The policy should be clear as to what age group of children is targeted and the language and information should be suited to the age. The policy should be focussed on the various age groups beginning with the youngest (between age 5 – 6).

On information dissemination, some suggested modes include telephone-counselling services, actual counselling, programmes through educational institutions, etc.

It was suggested that the media should be used as a *connecting* agency that shares practical information (such as at which locations services and information are available), rather than as an agency that spreads mainly general messages. The group recognized that social constraints hamper actual access to sensitive information: such as when children/youth watch TV together with other family members who might influence the information flow. A carefully structured strategy could ensure that social constraints do not come in the way of children accessing information and services.

*Access to services:* The following issues were highlighted:

Children in various circumstances need access to a range of friendly services, including health care, sexual health services, night shelters, counselling, etc. There is a need to have structures in place to provide support systems for children. Presently, health care services are not suited to access by children, especially with respect to sexual health. It is therefore necessary to make the present health care sector more children friendly and at the same time create a series of appropriate contact points that are children and young people friendly.

There is a need for a co-ordinated response to children's health needs, especially in situations such as child sexual abuse. In this context it was suggested that paediatric wings should have special facilities to deal with Child Sexual Abuse that would make single point services such as counselling, health care, legal assistance, etc., available to the child.

*Other legal issues:*

The Juvenile Justice Act (JJA) was discussed along with its limitations. The Juvenile Justice System presently focuses on the institutionalisation of neglected children. This strategy has been seen to be ineffective and has given rise to the perception amongst children that the State is an enemy. It was felt that the JJA is sorely inadequate and needs to be reviewed in order to facilitate the shift to alternate methods of providing care (non-custodial care). In this regard, the 'Juvenile Justice (Care and Protection of Children) Bill 2000', (which has since been passed by the parliament and has received the assent of the President) was mentioned.

There is a need for a comprehensive law to deal with child sexual abuse. Such a law should cover sexual abuse of boys as well as girls. Presently, it is only the rape laws and the provision dealing with sodomy that provides criminal sanction to sexual abuse. These substantive laws and the procedural laws, such as the Indian Evidence Act and the Code of Criminal Procedure, are inadequate and inappropriate in dealing with cases of child sexual abuse. Along with the new law, systems must be put in place to provide support and services.

There is a need to make legal remedies accessible to children, to empower them to demand their rights. This would include, among others, the recognition of children as *capable* of giving valid consent.

Representatives from the medical sector raised the issue of young people's capacity to give valid consent to an HIV test. In the absence of the recognition of the capacity of a young person to give valid consent, consent has to be taken from the legal guardian. This implies that a young person who may have information about HIV and would like to get tested would not be in a position to do so without the guardian's approval. This has serious implications for willingness to get tested and access to services by adolescents. This issue also has implications for the right to confidentiality. There is need for a clear policy to deal with this dilemma.

### ***People Living with or Affected by HIV/AIDS (PWHAs)***

For people living with or affected by HIV/AIDS, the key issues of concern were identified as follows:

- I. The Right to treatment (which arises out of the right to life)
- II. The Right to information
- III. The Right to legal remedy

The discussion concluded with the suggestion for placing the issues of people living with or affected by HIV/AIDS in a larger framework, with far reaching standards that could be made available in terms of institutional guidelines.

#### **I. Right to treatment**

In terms of the right to treatment, the main concerns identified were the limited access to medicines at affordable prices. Access to appropriate health care is a concern, not only for HIV/AIDS patients, but also for others. The group therefore suggested both long term and short-term recommendations to all partners with reference to HIV/AIDS. These recommendations not only pertain to the immediate concerns of the PWHAs, but also to the concerns of preventing and managing HIV/AIDS:

##### *Short term steps:*

- (i) The cost of drugs should be reduced and drugs should be made affordable by a waiver of all taxes/duties; (ii) CD4 testing is available only in few places and needs to be

increased commensurate with need; (iii) The number of voluntary testing centres should be increased; (iv) Quality control measures should be strengthened; (v) Technical and HIV/AIDS training for technicians is needed; (vi) Training of private physicians should be undertaken in collaboration with IMA; and (vii) Workshop on WTO/TRIPS with special reference to availability and access to drugs should be organised.

*Long term steps:*

a) The government could build up State capacity for manufacturing drugs for HIV (Public Sector Undertakings); b) There is a need for a study of WTO regime for post 2004 scenario, and c) The Office of the High Commissioner for Human Rights and UN agencies could be approached for proactively informing and impacting drug trade negotiations

## **II. Access to Information**

Increased access to information on policy positions is needed among all partners, to act and react to HIV/AIDS in a proper and confident way, and for PWHA to lead an informed 'positive life'.

*Short term steps:*

(i) Review IEC to make it more positive, enabling it to reduce stigma with the purpose of preventing HIV/AIDS transmission; (ii) Examine the role of Doordarshan (and other Public Broadcasting companies) for IEC purposes; and (iii) Arrange media workshops.

*Long term steps:*

(i) Negotiate public broadcasting on HIV/AIDS by private channels by introducing tax relief; and (ii) Include HIV/AIDS aspects in the Right to Information Bill.

## **III. Legal remedy**

For enhanced availability and access to legal remedies, proactive action is recommended as follows:

*Short-term steps:*

(i) Introduce legal aid cells; (ii) Spread legal education; and (iii) Guarantee anonymity in case of HIV positive status.

*Long-term steps:*

(i) Review all legislation impeding effective HIV interventions; (ii) Examine anti-discrimination, health legislation and disability legislation; and (iii) Introduce affirmative action (positive discrimination) of PWHA.

## ***Marginalized populations***

The particulars of marginalized populations such as Intravenous Drug Users (IDU) and Men Having Sex with Men (MSM) were discussed. The difficulties in carrying out

prevention work among these groups are reinforced by the existing legal framework within which they live and the stereotyping that masks this reality.

There is a rapid conversion to injecting drug use especially among socio-economically marginalized populations. The environment within which both IDU and MSM exist is to a large extent 'underground'. This is due to the existing legislation, which prescribes heavy penalties on very small possession of illegal drugs (which has led to increased misuse of prescription drugs), and makes homosexual acts illegal. These groups also report harassment by the law enforcers as a result of stereotyping and stigma. The consequence of this situation is that these populations are difficult to reach with information and HIV/AIDS prevention work: unsafe practices not only in drug use but also in sexual activities of both groups are carried out 'underground'.

Therefore, to more successfully prevent and manage HIV/AIDS among these marginalized populations, a revision of the existing laws and processes is strongly recommended. This would include both the NDPS Act, and Section 377 of the IPC. In terms of preventing HIV/AIDS among men who have sex with men, it would be most useful to make section 377 IPC obsolete, and instead review the legislation and endeavour to define more clearly the age of sexual consent.

For HIV/AIDS interventions among drug users, especially IDU, stronger legal and political support for innovative harm reduction programmes of needle exchange and condom distribution is necessary. If the injecting drug users are out of reach of prevention programmes because of fear from being arrested or harassed, the problem of HIV/AIDS is pushed under ground.

In a nutshell, the protection of Human Rights and the empowerment of marginalized populations would, in the context of HIV/AIDS prevention, create an environment that would enable India to reach the most vulnerable with HIV/AIDS messages and supporting mechanisms.

## **Options for the Future**

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The recommendations emerging from this conference clearly point out that inter-ministerial collaboration and a joint response would facilitate the control of HIV/AIDS in our country. The majority of ministerial departments have a role to play in HIV/AIDS prevention, and this report emphasises the importance of their doing so as soon as possible.

The socio-economic impact of HIV/AIDS in some other countries clearly indicate to us in India that we need to work together to create the best environment for HIV/AIDS prevention and management. Promotion and protection of Human Rights for all is a necessary component of such an enabling environment, not only in the context of HIV/AIDS, but in the context of handling other Public Health issues, poverty reduction and human development in general.

Protecting Human Rights in a country with over 1 billion people, dispersed in 35 States/Union Territories, is bound to be a challenging process. But we all agree that the process of protecting Human Rights needs to move forward quickly and be strengthened.

The realisation of rights will be possible, if adequate resources are made available for both HIV/AIDS control and Human Rights protection. As the Conference participants have reconfirmed, these two issues go, hand in hand. In the global environment within which India finds herself today, the responsibility of allocation of resources lies not only with the Indian Government, but also with the International Community. That is why I call upon all partners to India (foreign and domestic governments, non-governmental foreign and local organisations, as well as the business community) to support the follow-up of the recommended actions emerging from this Conference.

In light of NHRC's role as the Defender of those experiencing Human Rights violations (mainly the marginalized and vulnerable populations), the observations of this conference and those of NHRC in the future, should be included in the overall framework governing the response to effectively tackle HIV/AIDS in India.

Let us control HIV/AIDS together!

J V R PRASADA RAO  
Special Secretary (Health)  
Project Director, NACO

29 June 2001



# **Annexes**

## ***Annex A***

## **A Tryst with Dominic**

*By Mr Anand Grover<sup>1</sup>*

This is a letter to Dominic D'Souza, the celebrated and the first HIV positive activist in India who brought me into the field of HIV and in whose memory I continue to work on the rights of Persons Living With HIV/AIDS. He left us for the other world on 26<sup>th</sup> May 1992.

Dear Dominic,

It is a long time since we met. We have communicated often, though it will be difficult for me to explain to this audience how that happened.

Do you remember the last time we met, at the Breach Candy Hospital on the Friday, 22<sup>nd</sup> May 1992? Afflicted with HIV you were in your last days. But you did not bother to tell me or Claude that you would not be with us for long. You were interested only in knowing about what I was doing about HIV issues. And then you extracted a promise from me. A promise that I did not realize would have such a profound impact on me. Some say that I am used to handing out promises, like politicians in the present India, with no real intentions of keeping them. Well, this was not one of them. You extracted from me, whether by design or accident, a promise that I would keep on doing legal work in the field of HIV.

You were insistent that once rights of HIV positive persons are secured the battle against the spread of the HIV pandemic would be easier. That was the last we spoke. Then you were gone. Like Jonathan Mann, who spoke the same language. He also argued that the HIV pandemic was not a medical or social issue alone. It was as much an issue of rights of HIV positive persons.

It was at your funeral the Monday following, when I unwittingly repeated your promise that I realized the import of it. The promise, without my willing, became the mission in my life. That promise became an obsession and has dominated my life ever since. I exorcised your ghost when we in the Lawyers Collective won a significant victory in the *MX v. ZY*<sup>2</sup> case decided by Justice Tipnis of the Bombay High Court. That day I redeemed myself in your eyes and have been able to be at peace with myself.

Well, your words and the message of Jonathan Mann have always been the guiding principles in our work at the Lawyers Collective.

When one thinks of it, it is indeed surprising that it was non-lawyers who thought of the issues in terms of rights. And now, HIV, the world over is also being thought of in terms of rights and not only as a medical and social issue. Lawyers are perhaps not the best of

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<sup>2</sup> AIR 1997 Bom 406.

theoreticians. They are good only at propounding ideas articulated by others. That is what they are paid for and that is what they are good at. You will have to excuse my tribe for not being the first in thinking of the HIV issue in terms of rights. However now that the idea has been articulated we have been propounding it with all resources at our command.

Let me tell this audience what you already know. Why rights are so important?

Jonathan Mann analysed the changing demography of the epidemic in the US. In the initial period, in the early eighties, the epidemic was concentrated mainly among white, male, homosexual and upper class of society. It has now spread to the black and the Hispanic population, heterosexuals, women, and poor of their society. Jonathan asked himself why this had happened. His answer was very clear. The epidemic had spread to the other sections because they were vulnerable. They were vulnerable on a number of fronts: biological, social, economic and most importantly legal. That is why he repeatedly emphasized that HIV is not only a medical or social issue. It is also very much a legal issue.

So what are rights? I always compare them to the green leaves of a tree in a forest. The green leaves of a tree are its rights. The tree without the green leaves is devoid of rights. If a fire is lit in the forest, which of the trees will catch fire and perish? Obviously, the one without the green leaves. The one with the green leaves, with the rights, will survive. Those without rights are therefore most vulnerable.

The trees without the leaves are like the vulnerable groups in our society, women, children, sex workers, injecting drug users, sex workers, men having sex with men, prisoners etc. They are already stigmatised and marginalized by society. They are often poor and illiterate. Either they do not have rights, or, even if they have them, they are not able to exercise them.

What has been the traditional method of dealing with issues that affect the marginalized communities? The issues of testing with or without consent, preserving confidentiality, treating a patient without discrimination. They can be summed up in a series of statements that one hears often about them at different fora.

What does it matter, you are told, if you test a sex worker for HIV without her consent? What does it matter if one discloses the HIV status of an injecting drug user? After all, others should know and be aware of the danger they pose. What does it matter if a doctor doesn't treat homosexuals for their ailments? After all, what can they do about it? They are not going to court. If they do go to court, they shall do so at the cost of their own reputation. In reality they cannot exercise their rights. In effect they do not have any rights.

Why, you are asked, should patients know about the types of treatment that a doctor may resort to? More so if they are poor and illiterate. What do they know about medicine? After all the doctors know best. Even patients say so.

Why should a doctor take consent from a patient for an HIV test? What is the need to take informed consent? Isn't that a bit of a luxury in a country like India with a scarcity of health care workers? Imagine how much time the doctor would have to spend for getting informed consent? What is the use if the patient does not understand and ultimately tells the doctor: Doctor *saab*, *aap jo thik samjo*. [Doctor sahib, do whatever you think is right]

That is what we used to think before the HIV era. That is when doctors stopped playing God.

In the initial stages of the epidemic an HIV positive person faced certain death. Faced with this, patients started demanding treatment which conventional medical wisdom would have denied them. Drugs started being administered during the clinical trials. Drug regimes were evolved by intense participation of the patients, especially in the United States. Patients became conscious of their rights. They started asserting them. The relationship between the doctor and the patient started changing. A patient could no longer be treated as a dumb and stupid person taking whatever the doctor threw at her/him. Even the doctor's perception started changing. No longer able to treat by known means, the doctor became reliant on the patient's own reading of the symptoms. The patient's knowledge came to be recognized as an important asset to the treatment protocol; especially where compliance was a key factor and drug reaction had to be closely monitored. A patient with rights, being informed, being able to consent to treatment on being given proper information and knowledge, to participate in the treatment with such informed consent became a central factor in public health responses. An informed patient was better able to take care of her/himself and was less of a drain on the busy doctor's time. Counselling, therefore, came to be seen as a necessary public health tool. It became the medium through which information was imparted to the patient valuable for her/his compliance, emotional well-being and eliciting responses to treatment. Thus the *praxis* of informed consent for treatment in the matrix of counselling not only became a good public health tool for better management of patients but it also grew into a recognized right out of the well settled common law doctrines recognizing the right of an individual to control her/his autonomy, bodily integrity and privacy.

HIV has thus forced us to change our thinking on several issues. Conventional public health wisdom dictated either the isolation of patients who had communicable diseases or contact tracing. The HIV pandemic forced analyses of earlier isolationist strategies and their failures. The major lessons being that mandatory testing, breach of confidentiality, discrimination in treatment and isolation (the isolationist strategy) forced persons who were most vulnerable not to avail of the medical services, thus forcing the epidemic underground. This isolationist strategy only stoked the epidemic, it did not halt it. Thus rights of a person are directly linked to the success or failure in the fight against the epidemic.

The isolationist strategy has been tried in several countries. It was tried in the erstwhile Soviet states. It failed miserably. A version of that was also tried in Goa. It is now recognized that it has no utility.

It is no wonder that countries which have respected the rights of HIV positive persons are those whose rates of HIV sero-prevalence are lower. Thus in Australia the HIV sero-prevalence amongst injecting drug users has stayed at about 5% for a very long time. This is primarily because the clean needle exchange strategy was recognized as an effective tool to combat infection amongst injecting drug users. Started as an informal practice with the tacit consent of the police and other authorities, it is now recognized and protected by law. Contrast this with Manipur, where the rates have been increasing exponentially. Injecting drug users were simply thrown in jail with no legal procedures being followed. Now the clean needle exchange has been adopted as a tool there also. With an indication of success there is a demand for that to be protected by law.

Very similar is the experience in Sonagachi, in Calcutta. Because of promotion of the dignity and the rights of the sex workers coupled with increasing condom promotion, the HIV sero-prevalence has only moved up from 1% to 7% from 1992 to 1998. The STD rates have actually come down from 21% to about 11% in the same period. Contrast this with the sex workers in Mumbai. There was no programme until recently to protect the rights and the dignity of sex workers. The rates of STD and HIV have been increasing exponentially and are now in the sixties and seventies percentage wise. Thus there is a link that can be drawn between the levels of the HIV pandemic and the protection of rights of vulnerable groups.

The lesson is clear. Rights are a very important part of the programme of HIV prevention. They have to part and parcel of the programme of awareness and sensitisation.

What is the situation in India? Since you have been away from us mortals for some time, let me tell you what has happened since you have been away.

Well, things are a lot different from the 1992 days.

Today, there are about 3.5 to 4 million estimated HIV positive persons in India. There has been a debate about the exact numbers but there is little doubt that we have the dubious distinction of having the largest population of HIV positive persons in the world. The rate at which the number of HIV positive persons is increasing will mean that there will be nearly 10 million HIV positive persons at the end of the decade.

Though the treatment meted out to HIV positive persons is not the same as when you were quarantined under the Goa law, they are still discriminated against and stigmatised. As recently as this week an HIV positive woman with a child was not admitted to any hospital in Mumbai and driven from pillar to post and for some time was left to fend for herself on the streets of Mumbai. After a lot of press coverage she was ultimately admitted in hospital. Fortunately in that case the local persons were quite supportive. That was a case of a family, again in Mumbai, which attempted to commit suicide. The

mother and the two children died. The father was not successful in taking his life. He survived. Now he is charged under Section 302 (Murder) and 306 (Abetment to suicide) of the Indian Penal Code. He is critically ill. There are court proceedings initiated for administering treatment to him along with an application for bail. The Sessions Court has directed that Anti-Retroviral Treatment be administered if advised by doctors. Quite evidently even now there is a lot of stigma against Persons living with HIV/AIDS. This is despite the awareness campaigns about HIV launched by the Central Government and the various State Governments.

Discrimination is even meted out by doctors. It is fairly common that doctors refuse to treat patients whom they suspect are HIV positive. However the good thing is that they are increasingly in a minority. But a lot of doctors insist that an HIV test is carried out before any medical intervention is carried out. They insist on a mandatory test without the consent of the patient. They don't realize that insisting on mandatory testing is driving the patients to quacks or underground. Those who claim that they are not discriminating say that they are more cautious when they know that the person is HIV positive. Little do the doctors who insist on such tests know that they have a false sense of security with an HIV negative test. For if the patient tests negative, s/he may be in the window period, the doctor may not take any precautions, when in fact the patient in the window period is in the most infective stage. Those who simply refuse to treat because of the HIV positive status need to be counselled and taken to task if they don't improve their practices. Fortunately this realization is dawning in the medical fraternity itself.

Unfortunately when a patient is found to be HIV positive, it is quite common that her/his status is not kept confidential. Doctors and Health Care Workers are in a quandary over this issue. There is a growing realization that it is important to maintain the confidentiality of the status of the HIV positive person. But this duty is put under severe strain when the HIV positive person is likely to marry or is already married. There the question of informing the spouse becomes a major issue. Unfortunately the Supreme Court decision in *Mr. X v. Hospital Z*<sup>3</sup> has not helped.

The Goa Public Health Amendment Act, under which you were kept in quarantine in the TB sanatorium, and which we challenged and which was upheld by the Bombay High Court in your case, is no longer being enforced. That type of isolationist law, providing for mandatorily testing a person on suspicion that s/he is HIV positive, breaching her/his confidentiality on testing positive and isolating and discriminating against her/him was sought to be enacted in your time nationally but because of efforts by all of us, you included, was stopped. The Goa Government has benefited from the wisdom of your campaign and struggle. However the law is still in the statute books, although it is a dead letter.

In some States, Karnataka and Maharashtra, private members sought to introduce similar provisions but the campaigns of the NGOs, positive peoples organizations and the stand of the Government itself has ensured that we don't have a Goa type law elsewhere in the country.

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<sup>3</sup> (1998) 8 SCC 296

The sad thing is that there are a lot of statutes affecting vulnerable groups which act as impediments to the fight against the prevention of the spread of HIV. Section 377 IPC (unnatural offences, directed against homosexuals), the Immoral Trafficking Prevention Act, the Narcotic Drugs and Psychotropic Substances Act and 376 IPC, which does not recognize rape of wife by her husband, are some such laws. They need to be repealed to launch effective HIV campaigns and programmes within these vulnerable communities.

You will be happy to know that after your case there have been some successes for the HIV positive peoples movement. First, there was great success in the *MX v. ZY*<sup>4</sup> case. This was a case of a casual labourer who was refused confirmation in a public sector undertaking on account of his HIV status. A petition was filed in the Bombay High Court challenging the denial of confirmation and recruitment as being violative of the worker's Fundamental Rights of Equality (Articles 14 and 16) and Life (Article 21). In a seminal judgement Justice Tipnis of the Bombay High Court held that a person cannot be denied recruitment in a public sector company only on account of the HIV positive status provided s/he is fit to do the work (that is able to perform the functions of the job) and does not pose a substantial risk to his co-workers, customers and consumers. More importantly the Court allowed that an HIV positive person could approach the Court by suppressing his identity from the public. Thus a Court would allow the person to file the case with his/her name and substitute it with a pseudonym with an order that there be a ban on publication of any matter by any person leading to the identity of the person being discovered. This judgement is being followed all over India. Following *MX*, the Bombay High Court has given compassionate appointments to widows who are HIV positive and whose husbands died while in service on account HIV.

The judgement has been followed abroad also. Recently the South African Supreme Court in the *Hoffman*<sup>5</sup> case following the *MX* case struck down the decision of the South African Airways disallowing the petitioner in that case from being recruited as a Flight Attendant.

The Bombay High Court recently on a petition filed by an association of HIV persons, MNP+, restrained quacks by an interim order<sup>6</sup> from advertising that they had cure for treating HIV.

The Guwahati High Court has recently directed<sup>7</sup> that the Government agencies be more accountable and transparent in their work in HIV.

However there have been failures too. The Supreme Court in *Mr X v. Hospital Z*<sup>8</sup> ruled that there is nothing wrong with a hospital disclosing the HIV status of a person to his

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<sup>4</sup> See footnote 2

<sup>5</sup> *Jacques Charl Hoffmann v/s South African Airways* Case CCT 17/00

<sup>6</sup> *MNP+ v/s Union of India & ors.* W.P. No. 346 of 2000

<sup>7</sup> *Subodh Sarma v/s State of Assam & ors.* Civil Rule No. 3984 of 1996

<sup>8</sup> See footnote 3

prospective spouse. More importantly it suspended the right of all HIV positive persons to marry.

Recently, a group of activists were detained under Preventive Detention law in Uttar Pradesh and their offices sealed under section 133 CrPC on the ground that their literature relating to sexual practices in the local area where there were working was obscene.

Dominic, there has been a major change in the last two years in the treatment of HIV positive persons. Remember, when you were around the treatment was using a single drug to increase the survival of HIV positive persons. After 1992, because of the drug resistance with single drug regimes, combinations were resorted to. Recently it is found that Anti Retroviral (ARV) therapy, a combination of 2 drugs (2 NRTIs) or three drugs (2 NRTIs and PI or 2 NRTIs and NNRTIs) administered over a year reduces the viral load to undetectable levels.<sup>9</sup> With these drugs, life can be prolonged for a very long period of time. An HIV positive person can lead a healthy life like any other person. The problem is that these drugs are very expensive. In India the double drug combination therapy costs anywhere from Rs. 5 to 7,500 and a triple drug combination therapy costs anywhere from Rs. 12,000 to 15,000.<sup>10</sup> Most HIV positive persons are from the poor strata and cannot afford these expensive drugs.

Most of the HIV positive persons are the poor in the developing countries. The HIV positive persons in the developed world in the USA, North America, Europe and Australia are getting ARVs either through insurance or through the State either free or at highly subsidized rates. On that account there are practically no deaths of HIV persons in the developed countries. In contrast in developing countries HIV positive persons are dying a silent death. No notice is taken of this by the Government.

Our Constitution guarantees all persons the Fundamental Right to Health under Article 21 read with various Directive Principles (Articles 39 and 47) of the Constitution. The State has an obligation to fulfil this right. Can the State deny this right to its own citizens and let them die?

Other developing countries are facing similar problems. The Brazilian Government has taken a bold step of actually manufacturing ARVs through State controlled companies and providing them to about 90,000 HIV positive persons free of charge. In other South American countries Supreme Courts have passed orders and judgements<sup>11</sup> directing the State to provide ARVs to HIV positive persons. This is seen as a Constitutional obligation and/or an obligation under Human Rights instruments.

Until now the government of India has been able to ignore the rising demand of the HIV positive persons for access to effective treatment and affordable drugs. The demand has not been vociferous. This is partly because the HIV positive community did not have

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<sup>9</sup> Monthly Index of Medical Specialities, May, 2000

<sup>10</sup> See footnote 9

<sup>11</sup> *Cruz Bermudez, et al v/s Ministerio de Sanidad y Asistencia Social (MSAS)* Case No. 15789, July 17, 1999



enough information about the ARV combination therapy and therefore did not articulate the demand effectively. With growing consciousness and growing organization of the HIV community the demand will be put on the national agenda. The Government cannot ignore it any longer. The State has a positive obligation to provide treatment through drugs at affordable prices. That is an issue of rights, and human and fundamental rights in particular, which the State is duty bound to fulfil.

Today we pledge to make the life of HIV positive persons to live with dignity. Today we renew the pledge to ensure that the rights of HIV persons are not violated. Today we commit ourselves to ensuring that all HIV positive persons have access to medical treatment and drugs at affordable prices.

Dominic, we shall not fail you and will carry on the work that you started with all the strength at our command.

With love,

Anand  
New Delhi 24<sup>th</sup> November 2000

## **Annex B**

# **Vulnerability, AIDS and Human Rights**

*by Ms Sonam Yangchen Rana<sup>1</sup>*

- I have been asked to share with you some thoughts on the areas of convergence between Vulnerability, HIV/AIDS and Human Rights. ....and provide a context for discussions that will take place today. We heard interesting and useful presentations on various issues related to HIV/AIDS and Human Rights and Law supported by a wealth of data and statistics yesterday.
- I will start off by reiterating what has touched upon yesterday that the HIV/AIDS epidemic in India is inextricably linked with the social and cultural values and economic relationships between individuals and within communities.
- We know that HIV is a virus that can infect a person regardless of sex, race or social status. We also know that HIV virus is not random in its spread and impact. In its impact, the poor and marginalized people and communities – be they sex workers, trafficked persons, migrant populations or drug users - are the most affected.
- This is because social inequalities facilitates the spread of the virus and the virus in turn reflects and reinforces those inequalities. The virus differentiates not only in its medical manifestations but also in its disproportionate impact on those who are socially, sexually and economically **vulnerable**.
- What makes people vulnerable? – Absence of defenses. In the context of HIV we can take this to mean absence of choices. We know that HIV transmission is preventable, but this involves a series of choices at the systemic and personal levels, whether it is the choice to provide uninfected blood or the choice to use a condom or even have sex.
- Those who are vulnerable are therefore those individuals and societies whose capacities to make the necessary choices are limited by constraints, which can include: for **individuals** –lack of knowledge and awareness, their social and economic position within societies, lack of personal freedom resulting from cultural, social and legal structures and even physical location. **For societies** – lack of political will, lack of resources, lack of knowledge and skills, lack of implementing capacity and denial.
- In order to understand the vulnerability factors of people especially those that are poor and marginalized to HIV/AIDS, an understanding of the role of the socio-economic and cultural factors in the spread of HIV is essential.

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<sup>1</sup> Regional Program Coordinator, UNDP HIV & Development Programme.

- This requires an appreciation of more than just the statistics of HIV/AIDS which demonstrate the magnitude of the problem in India today. Surveillance systems tell us where the virus has been but we need to better understand where it is likely to go and assessing vulnerability provides some of these road maps.
- An understanding of the epidemic must therefore include not only how people are infected/affected and but also the **why** they have been infected/affected. The social, cultural and economic determinants of HIV infection is very different among different groups of people including between the rich and poor, between men and women, between different ethnic and marginalized groups.
- The epidemic in India manifests itself both as a **specific** problem but also as a pervasive one. It is specific in its association with the disease, death and the increasing numbers of people infected by HIV. Most of the responses in India in the past years addressed this dimension of the epidemic. It focused on the epidemic as a health crisis and its ramifications.
- The repercussions of the HIV infections is pervasive and affects every aspect of human life and national development and threatens human rights as much as public health. The causes and consequences of the virus embrace poverty, livelihoods, gender, governance, rights and ethical issues.
- The main risk factors for HIV infection in the future may not be sexual activity or drug use as such but rather **social and economic dependency**. Because HIV AIDS is preventable, people who have access to information and choices, will in the future be able to protect themselves against infection. The people who remain vulnerable are those who are denied the means of protecting themselves against HIV infection, for example because of powerlessness to control the basis of sexual relationships.
- An improved understanding of the patterns of socioeconomic dependency, legal frameworks and other cultural factors and links with powerlessness that makes people vulnerable to HIV is essential. This will facilitate the creation of conditions in which all individuals may be empowered to exercise choice to protect themselves from infection.
- We heard yesterday of the success stories that show from experiences in the past years that people do act to reduce the spread of HIV when they have the knowledge and the means to do so and a supportive environment.
- I will now touch very briefly upon some socio-economic issues related to **poverty and livelihood, mobility, gender and rights** that need to be addressed to meet the challenges posed by HIV/AIDS. There will be more time for indepth discussions in the other sessions that will follow.
- The uneven distribution of wealth and power between people, structural poverty and lack of sustainable livelihoods provide the main impetus for the rapid spread of HIV

in India and this region .....creating, nurturing conditions which increase the vulnerability and susceptibility of people, particularly poor people to HIV and AIDS. Economic and human poverty reduce the power of people to control their circumstances and make informed choices.

- In the day to day struggle with poverty and alienation, the risk of HIV infection can be perceived as a low priority when compared with immediate threats to individual or family survival. The impact of this on the effectiveness of programmes seeking to promote public awareness of HIV and AIDS has now being acknowledged.
- For example, one constraint to the implementation of the first phase of the national project for HIV/AIDS in India has been identified as " ... *the unwillingness of groups practising risk behaviour to either perceive or care about their risks in the presence of a great many other social and economic risks*"
- We know that families affected by illness and death from HIV/AIDS suffer from the loss of livelihoods of both those who fall sick and those who care for them, while at the same time expenses for treatment increase. As a result children may be neglected, malnourished, and withdrawn from school, further compromising the health and livelihood choices of the next generation, sucking them deeper into the poverty trap and increasing their vulnerability to HIV/AIDS.
- I should of course add that all this does not mean that the rich, powerful and often mobile people or those of us sitting in this room are not at risk of infection. People less constrained by community norms and those who can afford the lifestyles they choose are also at risk of infection.
- An important characteristic of this region and India in particular is the high mobility of people in search of livelihoods or opportunities. While migration in itself is not a risk factor for HIV, it can create conditions in which people are more vulnerable.
- Separated from spouse, family and socio-cultural norms, isolated and lonely, and a sense of anonymity, can lead to sexual practices which make migrants and mobile workers more susceptible to HIV. It is then carried back to their families, the intended beneficiaries of the income from the migration. Migrants may be subjected to mandatory testing, often without counselling, while their own vulnerability to infection as a result of displacement is overlooked.
- As men migrate in search of work, women are increasingly becoming de facto heads of households. Yet they lack the legal rights, social recognition and economic means to fulfil their practical responsibilities, thus exposing them to vulnerable situations resulting often in social, economic, and sexual exploitation.
- Poor women and children who migrate are particularly vulnerable to abuse and exploitation. The lack of safe, secure and legal channels for migration drive women and girls into the hands of unscrupulous agents and traffickers who promise them

'good jobs' and 'safe travel' to sites of work. Caught in the web of trafficking, those affected face an increased risk of HIV/AIDS as they are unable to control their working and living conditions.

- The low economic and social status of women as well as endemic abuse and violence against women, lack of recourse measures and of limited legal and social protection increase their vulnerability to HIV/AIDS. For many women in India and this region sexual intercourse is not a question of choice but rather a question of survival and duty. A woman's fertility and her relationship to her husband is often the source of her social identity.
- Dominant social constructs also dictate that a married woman has little or no power to negotiate the nature of her sexual relationship with her husband. We also know that increased income alone does not lead to empowerment and autonomy of women in the absence of legal, ethical and social environment that will allow women to gain better control of their lives.
- Unless the interaction between HIV infection, cultural values and the rights and needs of women are recognized, the fundamental changes required to **stem** the epidemic will be unattainable. Where women are denied dignity and respect, HIV/AIDS spreads.
- We heard yesterday that half of all new HIV infections globally are to people in the **age group 15-24**. In all countries, young women are the group facing the highest risk of contracting HIV through sexual contact. Young women are often forced or lured into having sex, within or without marriage, and have little power to negotiate safe sex.
- One of the worst ironies of the epidemic in this region is that increasingly younger girls are being forced into sexual relations and prostitution in the attempt by men to avoid infection, and even from a mistaken belief that intercourse with a virgin can cure the virus.
- We will all agree here that respect for Human rights is critical in the context of the epidemic. As Justice Kirby from Australia often says human **rights matters most when they are most under threat**.
- The fact that those under threat most are those who are **already** socially and economically vulnerable means that the need to incorporate human rights concerns into HIV policy becomes an **imperative**. Similar issues arise in relation to drug users, gay men and sex workers, and people living with HIV/AIDS for whom **discrimination and social stigmatisation** are daily realities. People need protection against the abuse of their rights threatened by the epidemic.
- The most important and urgent task at hand is to contain the epidemic through **reconciliation** rather than **conflict** including when dealing for example with issues

related to individual vs public rights/interests. Alienation of people with HIV from society does not help to contain the epidemic. A protective and supportive legal framework is essential complemented by careful and informed ethical considerations.

- Policies and laws that reduce stigma and build self-esteem of affected people create the environment for mutual trust. The general lack of understanding of a human rights approach is due in large part to the lack of involvement, participation and ownership of infected and affected communities and groups in HIV strategies.
- We need human rights standards, systems to document and monitor legal, ethical and human rights practices, supportive policies and law, education and information dissemination and strengthened partnerships and voices.
- Human rights should not merely provide the backdrop against which HIV/AIDS strategies should be planned but rather act as a powerful tool that can be actively used to help people to protect themselves from HIV/AIDS.
- This requires that human rights considerations must address the immediate and important concerns such as stigma and discrimination against people with HIV and access to health care and employment. It must also address the fundamentally unequal social and economic position of women and poor and marginalized people within societies.
- Those living with the epidemic, those at the forefront of change must be encouraged to come out and make visible the invisible... the realities of life in the post HIV era.

Thank You

*Annex C*

*Background Material  
for the Group Discussions*

## **Consent and Testing<sup>1</sup>**

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*(Group I – Day 1)*

### **Background**

Any discussion in support of Human Rights is based on the fundamental notion that every individual has certain inalienable rights, which, if protected, permit that individual and society at large to flourish.

One such right is that of self-autonomy – where every adult of sound mind has the right to determine what can be done to his/her body. This deals with the very essence of having the right to lead a life and take decisions for oneself in one's best interests without coercion or force.

In the HIV/AIDS context this issue manifests itself in the form of informed consent, in two critical scenarios, one of currently greater occurrence than the other.

### **Consent and Testing**

The first is a situation where a person is tested for his/her positive status. It is a widely held belief that before a health care worker/testing facility tests a person for HIV the person must be fully informed of various issues related to the test and result prior to taking his/her consent for testing. This is a concept that is applicable in medical practice generally but assumes even greater significance in the HIV/AIDS scenario where far greater stigma and persecution exists. The consequences of finding oneself to be positive can be dire – great personal trauma and emotional distress and an inability to share it with others due to stigma. Therefore, it is felt that before a person is tested his/her voluntary, full and informed consent be taken which would include s/he being counselled both before and after testing.

Not only is it the right of every person to agree to the intervention that s/he is being subjected to, but it has also been felt that voluntary testing based on informed consent is a beneficial public health strategy. However, public health management held the classical view that the only way to control the spread of contagious diseases was to mandatorily test all persons. Although this view was initially adopted in India (the Goa Public Health Amendment Act, 1986) government policy now clearly favours a policy of voluntary testing. The argument for voluntary testing is based on the premise that (apart from the

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<sup>1</sup> This paper has been written after a process of consultation organised by the Lawyers Collective HIV/AIDS Unit in Mumbai on 29<sup>th</sup> July 2000. To incorporate as wide a spectrum of views and concerns as possible, the consultation was held with people living with HIV/AIDS, members of the medical community, NGOs working in the HIV/AIDS field including those working with vulnerable populations, counsellors, members of trade unions, a representative of the Mumbai District AIDS Control Society, a representative of UNAIDS and lawyers. The consultation was an opportunity for participants to articulate their concerns and express their views with respect to the issues of consent, confidentiality and discrimination vis-à-vis HIV/AIDS. The consultative process is limited to the extent that most of the participants shared their experiences as felt in and peculiar to Mumbai. To overcome this limitation, the paper was circulated nationally to experts for their feedbacks and inputs, which have been incorporated to the extent possible.



human rights aspect) people will only come forward, act responsibly and test themselves if a conducive atmosphere is created whereby they are fully informed and consent to the procedures being carried out on them is taken. If, instead, an approach of mandatory testing is imposed, apart from the financial ramifications it would entail (3 ELISA/ Rapid/ Spot tests are required to confirm the positive status of a person) and the difficulties it would pose in being implemented, such an approach would only further stigmatise an already marginalized population and discourage honesty and personal responsibility thereby driving the pandemic further underground. This has been the experience in most parts of the world where mandatory testing has been enforced. It has been seen that such a policy has done damage to efforts in trying to curtail the spread of HIV/AIDS.

In India, where mandatory testing of all is impracticality, any policy on such lines would be likely to confine itself to only certain populations – populations that are misconceived to be vectors of transmission and are already marginalized. Besides violating their human rights, such a selective policy would then only further marginalize such populations. This would have serious public health repercussions.

The right to self-autonomy, as already stated, forms the basis of consent. However, this right is further compromised for many persons, especially women for whom consent becomes an even more remote ideal. Women's access to health services is compromised by numerous structural factors including mobility, prevalent decision-making processes, health priorities of the family etc. Further many women find themselves undergoing medical procedures after having given consent that is far from free, full and informed. Such consent is often given on the basis of pressure, coercion or force, overt or covert, exerted by a dominant male. This applies in a general sense and also manifests itself in the HIV/AIDS context. It is necessary then, to address the issue of self-autonomy of women in this larger context while specifically looking at consent for conducting HIV/AIDS tests.

Consent is an issue that has many ramifications in law. These include the use of undue influence in a fiduciary relationship (e.g. healthcare worker – patient) to obtain consent, forced testing, exceptions to consent in emergency situations and the extent of disclosure of information required to obtain proper consent.

Another dimension regarding the issue of consent is one concerning the testing of children. The complications in this regard are with respect to obtaining consent of a child in the absence of a parent or legal guardian. It is the experience of several health care institutions that adolescents often arrive either unaccompanied or along with a representative of an NGO which they get shelter from, to seek testing. The law permits proxy consent from parents or legal guardians but the legality of testing a child who voluntarily seeks testing is an area, which needs to be addressed. Further issues arise in relation to children. For instance, in the adoption scenario, whether an adoption home can insist on the testing of a child before giving him/her shelter is an area where laws relating to discrimination will be tested. If such an insistence were permissible, the further question would be as to who could give consent on behalf of a destitute child. Related to

these issues is whether an adoption agency may make HIV testing a pre-condition for prospective adoptive parents.

The NACO policy encourages voluntary testing and mandates pre- and post-test counselling. However, the reality differs, both because of infra-structural reasons and because of a low priority being given to counselling and consent. It has been a wide experience that many individuals including pregnant women, prospective and current employees, and children, are often tested for HIV (in a routine manner) without even being informed of the same.

Consent in the employment scenario is another serious issue. Although NACO policy states that mandatory pre-employment and post-employment testing should be discouraged, there is no law to cover private employers who often pursue such a policy. Such testing is done without the knowledge of the prospective or current employee and without his/her consent.

Counselling is a vital aspect in the process of testing. It can be a successful method to encourage responsible behaviour change, empower patients and act as a support mechanism. However, counselling protocols are mostly absent and if present, rarely followed. Health care institutions do not have the resources or inclination to have a counselling department and students of medicine are not taught counselling as part of their curriculum.

A view is held that pre-test counselling, instead of being beneficial to patients, often causes more harm because it creates fear and discourages a person from testing. It is felt that the same should then be avoided, especially for Voluntary Testing Centres (VTC) where it is of the patient's own volition that the test is being conducted. However, accessing a VTC does not necessarily imply that a person is fully informed of the ramifications of an HIV test. For his full informed consent to be given it is necessary that a person is given pre-test counselling.

An issue that requires mentioning is the current policy of testing blood within the Indian blood banking system. Currently the duty of the blood bank is only to check whether blood is safe, based on 1 ELISA/ Rapid/ Spot test without the responsibility of informing the donor of the result. Whether this policy should be pursued or a blood bank should inform the donor is an issue that needs consideration. It is to be noted that informing a donor would require 3 tests for confirmation and pre- and post-test counselling.

### **Consent & HIV/AIDS Research**

The second situation in which the issue of consent arises in the HIV/AIDS scenario is for purposes of research. There are mainly two types of research – biomedical and behavioural. In both, consent plays a vital role. For a researcher to seek a person's participation in research it is important that the prospective participant be fully informed of various factors such as the risks and benefits that the research may expose the participant to, the absence of any monetary or material inducement, the purposes of the research, the organisations funding and conducting the research, the duties and

responsibilities of the researcher, the manner of keeping records and the guarantee of confidentiality. Vaccine Development Programs also require the researcher to lay down his/her responsibilities to a participant who becomes positive during the course of research. An obligation on the researcher to provide anti retroviral treatment to a participant, who, if not for the research, may not have known his/her status, may have to be articulated. To what extent is such provision should be made and whether this would amount to undue inducement are issues, which will have to be dealt with.

## **Confidentiality<sup>2</sup>**

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*(Group II - day I)*

### **Background**

The concept of confidentiality is rooted in the fundamental human right of privacy - every person has the right to a sphere of activity and personal information that is exclusive to him/herself and that s/he has the right to disclose as s/he pleases. This is a right that has been guaranteed by both international human rights documents and under the Indian Constitution.

Confidentiality is an extension of this right of privacy and plays an important role in the HIV/AIDS scenario where stigma and discrimination are rampant. As discussed later, this is not only an issue of the individual interest but also one that actually serves the general public interest. In the context of confidentiality the main issue that requires to be addressed is whether a positive person has the right to confidentiality about his/her HIV status. It is important to note that confidentiality is fundamental in any public health strategy and especially important in a physician-patient relationship where trust is a foundation. After all, if such a relationship cannot guarantee confidentiality it will only lead to fewer and fewer people accessing health services.

### **Approaches to the Issues Around Confidentiality**

The debate over this issue has taken the form wherein two apparently polarised views have emerged – the rights of the individual versus the rights of the community. It is argued that by protecting the right of confidentiality of an individual the larger community is not made aware of the prevalence of the pandemic and is therefore at greater risk of getting infected. This should be remedied by full disclosure of the positive status of all persons.

The counter-argument states that the debate on the individual versus the community is a false debate and in reality protecting the rights of the individual strengthens the community itself. This argument posits that if confidentiality is maintained it engenders trust and faith in the public health system and assures people that they will not be exposed to stigma and discrimination. This in turn encourages greater numbers to test themselves and access counselling and allied services thus having a positive impact on behaviour change and awareness. On the other hand if disclosure is made it will only

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discourage persons from accessing health care and testing themselves thus suppressing the pandemic and creating greater hurdles for control efforts.

It is therefore contended that maintaining confidentiality does not contribute to the spread of HIV/AIDS. Indeed, if employed in the appropriate context and in creative and culturally sensitive ways, confidentiality can help to decrease the spread of HIV/AIDS. For instance, in the Indian context, the principle of confidentiality may require to be adapted where voluntary testing centres function under tremendous space constraints and do not have the luxury of separate counselling areas/rooms. Systems need to be evolved to ensure that confidentiality is respected even in circumstances where a counsellor/healthcare worker is forced to discuss a patient's status in the presence of others, as is often the case.

Also, it is sometimes seen that a woman's test result is not collected by her, but by a male member of the family. Sometimes a patient is too ill to go to collect the test result him/herself and a friend or relative does so instead. In these circumstances the question whether the healthcare worker should give the results to the relative or whether s/he should insist on the patient collecting the results. Either choice raises different issues. For example, the situation at the patient's home may not be amenable to maintaining confidentiality. If the policy is that the relative may be given the result, a method of monitoring whether she/he has the informed consent of the patient to collect the result will have to be evolved.

Whether it is appropriate for the counsellor to make home visits despite the likelihood that family members may become aware of the patient's condition is a question that will have to be addressed in a culturally sensitive manner. This dilemma is compounded in cases where AZT is being provided to pregnant women and follow up treatment is necessary, but where the person does not return for treatment.

### **Breach of Confidentiality**

Breach of confidentiality manifests itself in many ways. Due to the stigma and fear surrounding HIV/AIDS, it is the experience of many positive persons that once their status is disclosed they are denied many services especially in the healthcare and employment setting. Often test results are shared, without the HIV positive patient's consent, with other healthcare personnel, family members, relatives, neighbours, friends, colleagues and employers. Instead, maintaining confidentiality is seen to benefit and integrate positive people into mainstream society.

In the healthcare setting, it is seen that government hospitals have a practice of writing HIV in block letters on patient case papers. These papers go from department to department for tests etc. Also, it is common that these case papers are attached to the patient's bed. These practices are ostensibly to warn healthcare workers to be more wary of occupational exposure when providing services to PLWHA, but often result in discriminatory practices. Strategies need to be evolved so that the health services may be provided to PLWHA without compromising on either the right of health care workers to a safe working environment or the duty of confidentiality. Such strategies, it is suggested,

would include mechanisms of ensuring availability of universal precautions to health care workers and clear and enforceable rules regarding confidentiality.

Often hospitals assign separate wards to HIV/AIDS patients. This exposes positive persons to breach of confidentiality and discriminatory practices.

In the employment setting confidentiality is breached at various stages. During recruitment employers often insist on knowing the status of the prospective employee and doctors, working for the employer, divulge the same. This occurs even at stages of routine medical examinations during employment. The question that arises in such circumstances is whether a doctor is obliged to inform the employer and how this is balanced with the duty of confidentiality towards the patient. Some employers argue that the employee's immediate superior should be informed of her/his HIV status, to facilitate informed action in emergency situations. It has also been argued that the duty to maintain confidentiality would vary in circumstances where the employee remains regularly absent from work. Policy and rules with respect to these issues need to be clearly identified.

Breach of confidentiality is also seen in other situations such as at the time of an insurance claim. The question that arises often in this context is whether a healthcare worker is under an obligation to disclose the HIV status of a person to an insurance company enquiring into the cause of death or whether an alternative answer would suffice.

The issue of confidentiality also arises in adoption cases. Adoption homes ask for the status of the child and often do not take in HIV positive orphans. They also insist on the status of prospective parents and refuse adoption if the parents are found to be positive.

### **Exceptions to Confidentiality**

The case for maintaining confidentiality limits non-disclosure. Although confidentiality is maintained between the healthcare worker and patient it is the duty of the positive person to notify his/her spouse/sexual partner/needle-sharing partner of his/her positive status. This is where counselling plays a vital role. However the argument in favour of disclosure sometimes goes to the extent of contending that the duty to notify the partner is not just the positive person's obligation but also extends to the healthcare worker.

It is important to note that the law does recognise exceptions to the rule of confidentiality. Such exceptions arise in a situation when the public interest to disclose outweighs the public interest to maintain confidentiality. It has also been held that disclosure is permissible (to another doctor) if it is for the treatment/interest of the patient. Confidentiality can also be breached when a person is compelled by law to breach it. Although there is no clear policy, some courts have held that where a special relationship exists and there is a foreseeable danger to an identifiable third party, confidentiality can be breached by a healthcare worker. This reasoning could be applicable in a situation where, despite extensive counselling, a person continues to indulge in high-risk behaviour and refuses to practice safe sex with his/her sexual partner.

### **Beneficial Disclosure**

Closely linked to the principle of confidentiality is the notion of beneficial disclosure. This implies disclosure that is made for the benefit of the affected individuals including the PLWHA, his/her sexual and drug-injecting partners and family. Beneficial disclosure is voluntary, respects the autonomy and dignity of the affected individuals and maintains confidentiality as appropriate. Apart from beneficial results for the people affected, it is intended to lead to greater openness about HIV/AIDS in the community and meets the ethical imperatives of the situation where there is need to prevent onward transmission of HIV. Such beneficial disclosure maintains individuals' human rights, prevents discrimination, and improves public health in the form of prevention and care efforts.

Promoting beneficial disclosure with its elements of voluntariness and confidentiality serves a direct public health function, because it encourages people to access HIV prevention and care services. Beneficial disclosure also serves the purpose of opening up the HIV/AIDS pandemic. As more people feel able and willing to disclose their status, there grows a critical mass of individuals and families within a community, and indeed within a nation, who are openly involved in dealing with the pandemic in positive and supportive ways. The challenge is to create an environment in which people will come forward for testing, counselling, prevention and care.

## **Discrimination in Health Care<sup>3</sup>**

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*(Group III – Day 1)*

### **Background**

Discrimination lies at the root of all legal and human rights issues in the HIV/AIDS context. It is because of the fear, ignorance and stigma associated with HIV/AIDS that PLWHA are treated prejudicially and unequally.

However the reality is quite different and discrimination is rampant vis-à-vis PLWHA in the healthcare setting. This is further accentuated for certain marginalized populations. For instance women, commercial sex workers, drug users and prisoners find themselves discriminated in healthcare irrespective of their HIV status. Their positive status, however, further marginalizes them and decreases access to health services even more. Those who do not fall within these populations but are HIV+ also suffer immense discrimination in healthcare. Not only would increased access to healthcare benefit PLWHA, it would have a positive public health impact on society at large in preventing the spread of the pandemic.

### **The Right to Healthcare**

The right to be treated equally and the right to health are fundamental rights guaranteed under the Indian Constitution and basic human rights found in all international human rights documents. In the Indian constitutional context it is the State's obligation to provide healthcare for all. However, the right of equality and healthcare is available only against the State and not against private bodies. Therefore, it is the widely felt experience of many PLWHA that they are discriminated against and refused treatment by private healthcare institutions due to their positive status. Even state-run healthcare institutions discriminate against PLWHA in many ways. These include an outright refusal to treat, physical isolation in wards, early and inappropriate discharges, delays in treatment, treatment on condition of higher charges being levied and prejudicial comments and behaviour.

It has been held by the Indian Supreme Court, however, that both public and private healthcare institutions have a duty to treat all those in emergency situations although the latter is not obliged to treat persons in other circumstances. Yet, both public and private healthcare institutions continue to discriminate based on HIV/AIDS status.

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<sup>3</sup> This paper has been written after a process of consultation organised by the Lawyers Collective HIV/AIDS Unit in Mumbai on 29<sup>th</sup> July 2000. To incorporate as wide a spectrum of views and concerns as possible, the consultation was held with people living with HIV/AIDS, members of the medical community, NGOs working in the HIV/AIDS field including those working with vulnerable populations, counsellors, members of trade unions, a representative of the Mumbai District AIDS Control Society, a representative of UNAIDS and lawyers. The consultation was an opportunity for participants to articulate their concerns and express their views with respect to the issues of consent, confidentiality and discrimination vis-à-vis HIV/AIDS. The consultative process is limited to the extent that most of the participants shared their experiences as felt in and peculiar to Mumbai. To overcome this limitation, the paper was circulated nationally to experts for their feedbacks and inputs, which have been incorporated to the extent possible.



### **Anti-discrimination Legislation**

In certain jurisdictions medical standards prescribe that a healthcare worker must treat every patient as HIV positive and carry out medical procedures and take precautions based on this assumption. These jurisdictions also prescribe anti-discrimination legislation that makes treatment of PLWHA obligatory even on private healthcare.

In India however, there is an absence of anti-discrimination legislation. Therefore, private healthcare is free to refuse treatment to PLWHA, as it almost always does.

### **Manifestations of Discriminatory Practices**

As mentioned above, many PLWHA are denied their basic fundamental right to health due to the discriminatory practices carried on by healthcare institutions. Discrimination manifests itself in many ways in a healthcare setting. For instance, PLWHA have their case papers often hung on their beds with bold and conspicuous notations on them indicating their positive status. This is done in order to 'warn' others and leads to prejudicial comments and mistreatment by healthcare staff.

Bodies of people deceased due to HIV/AIDS-related causes are treated in a horrific manner. Often healthcare staff refuses to handle such bodies. If they do, then the bodies are often dumped in plastic bags with 'HIV' written across the bags, which is unnecessary. Even after this the unclaimed bodies are not disposed off with dignity but are left to decay. Sometimes relatives are charged extortionate amounts for handling of such bodies.

Public hospitals too deny treatment to PLWHA. They often try to avoid surgical procedures on some pretext. This includes suggesting a non-invasive but inappropriate course of treatment. This method of treatment, and sometimes outright refusal, is often meted out to PLWHA from certain marginalized communities such as injecting drug users and commercial sex workers on the basis of their appearance. The only statistical study done on patient-to-healthcare worker transmission by the Centre for Disease Control, United States Government indicates that the chances of such transmission are remote and the paramedical staffs is more at risk than the physician or surgeon. (CDC data shows that of the 52 cases 48 were of paramedical staff.) There are no similar studies in the Indian context and it may be pointed out that the results may be different considering the difference in the manner and context in which the health care sector functions.

Hospitals have been seen to refuse treatment to PLWHA stating that PLWHA can be treated from home and that admission in the institution is unnecessary. PLWHA are also discharged early by hospitals, prior to completion of treatment, on the pretext that the PLWHA health is improving and does not require supervision. Healthcare institutions sometimes grant a bed to the PLWHA but discharge him/her in a few days without having analysed his/her condition or prescribed any treatment.

It was reported that doctors, well informed about the manner in which HIV may be transmitted, refuse to touch HIV+ patients, thereby increasing the stigma among less trained personnel and attending family members. Healthcare workers sometimes disclose the status of PLWHA to colleagues although the same is not necessary. This sharing of information leads to discrimination by the entire healthcare staff due to the stigma surrounding the infection and already marginalized populations; separate wards, which can be in most shabby conditions, are maintained for PLWHA and also labelled as such.

Sometimes PLWHA are treated by healthcare institutions and in the middle of treatment are asked to do an HIV test. Once the test results are seen as positive the PLWHA is removed from the institution in the middle of treatment.

Pregnant women in private nursing homes are tested for HIV by a single, non-confirmatory ELISA test. If found positive, they are on this basis refused treatment at the nursing home, and are directed for delivery to public hospitals.

User charges are being imposed by public hospitals even though treatment in such institutions is meant to be free. Accessibility to treatment, therefore, is further reduced. Inaccessibility or denial of treatment causes PLWHA to access quacks instead, and to rely on spurious medications. The long-term consequence of this will be their worsened health condition and the increase of society's overall vulnerability to HIV infection.

### **Concerns of Healthcare Workers**

It is important to consider another right in the context of HIV/AIDS and discrimination and this is the right to a safe working environment. Due to the fear and ignorance around HIV/AIDS, many healthcare workers are afraid to treat PLWHA. Such fear can be mitigated if healthcare workers are provided a safe working environment. This in turn may reduce the discrimination suffered by PLWHA.

It has been argued, even by public healthcare institutions, that providing basic universal precautions to healthcare workers is not a matter of priority. As such, it has been seen that these universal precautions, (including gloves and sheet, and in the HIV context, post-exposure prophylaxis (PEP<sup>4</sup>)), which ought to be considered an essential part of the functioning of healthcare institutions, whether dealing with HIV or any other condition, are not provided to healthcare workers. In these circumstances, it is contended that they are free to deny treatment to PLWHA.

It is important to note that NACO has assured the reimbursement of expenses incurred on PEP to public healthcare institutions. At the same time although precautions such as gloves and sheets are basic and to a large extent inexpensive requirements, they are not provided to public hospitals. There is no proper government policy on universal precautions and this is not treated as a priority issue.

The healthcare workers argue that the institution owes them a standard of care, which necessitates provision of universal precautions. In the absence of these precautions would

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<sup>4</sup> PEP is a combination drug regimen, which if administered within a certain time, can prevent the healthcare worker infected by needle stick injury from becoming HIV+.)

a healthcare worker be justified in refusing treatment, especially with public hospitals and their emergency wards being burdened as they are?

Even though NACO policy envisages provision of PEP, in reality, the same is not available for needle-stick injuries suffered by healthcare workers. Where available, red tapism prevents reimbursement of costs as assured.

Certain other issues that require discussion arise in the healthcare context. For instance, whether the healthcare worker have a right to refuse treatment to a person who shows symptoms of HIV/AIDS but is unwilling to be tested. This is of special significance especially in the public healthcare setting where the duty of the state to provide health care is of paramount importance.

What are the rights of the healthcare worker in the event of being infected in the course of employment? In such an event the institution is bound to take care of the worker's medical needs, especially in light of the fact that the healthcare workers have a right to a safe working environment including universal precautions.

It is the experience of many persons that because of their positive status, healthcare institutions charge them large amounts of money, which are otherwise not charged to those with other illnesses. This is often done on the pretext that the healthcare worker needs to spend an extra amount for protective gear. Thus the burden of providing universal precautions falls on the PLWHA, making access to care even more remote.

## **Discrimination in Employment<sup>5</sup>**

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*(Group IV – Day 1)*

### **Background**

Article 14 of the Indian Constitution mandates that the state shall not deny to any person, equality before the law or the equal protection of laws in India. This means that the state<sup>6</sup> cannot discriminate between one person or groups of people and other persons, except on constitutionally valid grounds. Constitutionally valid grounds include principles of affirmative action and the doctrines of non-arbitrariness and classification. This means that the state may differentiate between people on the existence of intelligible differentia i.e. an objective criteria, and where such criteria has/have a rational relationship with the object of making the differentiation. This is based on the principle that equals should not be treated unequally and unequals should not be treated equally. The restriction also implies that all state action should be reasonable, fair and just, in substance and in procedure.

Discrimination implies any action that is in opposition to the principles mentioned above. In basic terms it means treating a person or a group of people differently from others without any rational and permissible reason. An example that has been observed to be common in the HIV/AIDS context is the termination of the employment of a person on the basis that she/he is HIV positive. Discrimination in terms of denial of rights accruing due to employment and non-employment of HIV positive persons are other major examples of discrimination in the context of HIV/AIDS.

Estimates in India have found that approximately 3.5 million people are HIV positive of which a major portion is between the ages of 15 and 40. This represents a population which is either employed or of employable age. The implications of this on the economy and the well-being of the nation and its people cannot be ignored, either by the government or the private sector, which is fast creating the most significant employment base in India.

Within employment the most significant impact of HIV/AIDS has been seen in a number of cases where people living with HIV/AIDS (PLWHA) have been denied jobs or been terminated from employment because of their positive status. Apart from discrimination

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<sup>5</sup> This paper has been written after a process of consultation organised by the Lawyers Collective HIV/AIDS Unit in Mumbai on 29<sup>th</sup> July 2000. To incorporate as wide a spectrum of views and concerns as possible, the consultation was held with people living with HIV/AIDS, members of the medical community, NGOs working in the HIV/AIDS field including those working with vulnerable populations, counsellors, members of trade unions, a representative of the Mumbai District AIDS Control Society, a representative of UNAIDS and lawyers. The consultation was an opportunity for participants to articulate their concerns and express their views with respect to the issues of consent, confidentiality and discrimination vis-à-vis HIV/AIDS. The consultative process is limited to the extent that most of the participants shared their experiences as felt in and peculiar to Mumbai. To overcome this limitation, the paper was circulated nationally to experts for their feedbacks and inputs, which have been incorporated to the extent possible.

<sup>6</sup> State refers to government, parliament, legislatures, and municipal bodies, state controlled bodies & corporations & bodies created by statute.

by the employer one must also recognise discrimination and isolation by co-workers. Employers have in fact, considered pressure by co-workers as one of the bases for discrimination. There is a need to provide information to employees in this regard and to take positive steps to prevent such discrimination at the workplace.

Public sector undertakings have been directed by the courts not to discriminate in employment on the ground of HIV/AIDS. (If the employee is otherwise qualified and fit to perform his functions and if s/he does not pose a significant risk to his/her colleagues – as held in the Mumbai High Court judgement of *MX v ZY*). The private sector, however, does not fall within the rigours of the constitutional guarantee of equality. Yet, industrial and labour laws could give relief to a PLWHA. In the constitutional context, however, private sector companies are free to discriminate against PLWHA and in the absence of anti-discriminatory legislation this situation will persist. However a few private sector corporations have taken certain positive anti-discriminatory initiatives. But these are few and far between. A far more comprehensive policy on HIV/AIDS in the workplace requires to be evolved if the negative impact of this pandemic is to be curbed.

It is important also, to consider the plight of unorganised labour such as migrant workers and those who are not part of unions. This sector forms the vast majority of those Indians who are employed. In these circumstances discrimination is even greater due to lack of organised support and legal recognition. The need to address discrimination in the unorganised sector is to be seen as a part of the larger issue of recognition of and intervention with unorganised labour especially with respect to general healthcare services and employment benefits.

Closely related to the issue of discrimination in employment are the issues of consent and confidentiality. Some of the questions that arise in the context of the latter two issues are:

- a. Can an employer insist on an HIV/AIDS test at the recruitment stage?
- b. Can an employer mandatorily test members of his/her workforce?
- c. Can an employer insist on the test results being disclosed to him/her?
- d. Is a testing physician duty-bound to disclose employees' test results to their employer?
- e. To what extent is confidentiality to be maintained at the workplace?

These questions are closely linked to the issue of discrimination for if discrimination were mitigated other issues would be of far lesser adverse impact.

Several issues arise in the context of discrimination in employment, which necessitate the examination of law, human rights and corporate policies.

### **Pre-employment Discrimination**

NACO policy clearly discourages pre-employment testing. However, at the recruitment stage, the employer often subjects a prospective employee to an HIV test as part of a medical fitness test. The objective of such a test is to ascertain the general fitness of the prospective employee as it may have implications on the productivity a person is capable

of. It has been the experience in most cases, however, that if the person is found to be HIV+ s/he is denied employment. In most cases such a test is irrelevant in judging a person's fitness for a job. It is necessary to test a person's specific fitness for the particular job and not the general fitness.

Another issue that arises in the context of fitness is whether a fitness certificate should be based on a time period, i.e. a person is deemed fit to work for a particular duration of time, and whether a physician would be competent to give such a certificate.

### **Discrimination in Employment**

Judging medical fitness also occurs after the person has been given employment. Here too, the aforementioned issues of consent and confidentiality arise. Often employees are made to undergo an HIV test without consent and their status is divulged to the employer and co-workers, which ultimately leads to discrimination at the workplace and termination of employment. This even occurs in the healthcare sector, where an HIV+ worker is discriminated against and removed from employment due to the employer's belief that the worker poses a risk to others. It is important therefore to assess 'risk' and evolve policy that lays down when risk can be considered 'significant'. The only study on healthcare worker-to-patient transmission by the CDC (United States' Government) indicates that the chances of such transmission are extremely remote. (CDC studies showed the chances to be 1 in 41,667 to 1 in 416,667 through cut or needle stick injury. However, the CDC is re-evaluating its data based on epidemiological evidence that transmission even through invasive procedures is negligible.)

Often a PLWHA is kept on the pay roll of the employer but is asked not to report to work. This is a form of discrimination that impinges on the PLWHA fundamental right to work.

During employment a PLWHA may remain absent with greater frequency during the later stages of the illness. At such time special care and support is required. The issue that arises is whether a duty is cast upon the employer to provide such special care to the PLWHA and his/her family.

Medical insurance (such as the Employees' State Insurance Scheme) is an option that could be suggested in order to facilitate such care and support provided by the employer. This would assist the employee in coping with the economic burden of the illness. At the moment, however, people living with HIV/AIDS are denied insurance as insurance schemes exclude liability for HIV related expenses. This issue is dealt with in more detail in the background paper on People Affected by HIV/AIDS.

### **'Reasonable Accommodation'**

The law has provided certain innovations that would be useful in the HIV/AIDS context. For instance, the concept of 'reasonable accommodation' provides that an employee can be given alternate employment within the same organisation if such a measure does not pose undue financial and administrative hardship to the employer. The issue that arises is whether 'reasonable accommodation' could be used in the HIV/AIDS context to mitigate

the discrimination suffered by a PLWHA. Indian courts in circumstances other than HIV/AIDS have used 'Reasonable accommodation'.

In addition, it may be suggested that the practice of providing 'reasonable accommodation' should include shifting an employee from a heavy and strenuous duty to alternate light duty, especially when the illness has progressed.

#### **Other Issues**

Several closely related issues need to be addressed when creating a legal and human rights strategy in the area of employment discrimination vis-à-vis HIV/AIDS.

They include the issue of compassionate appointment, i.e. whether compassionate appointment can be denied to a widow on the ground that she is HIV+. This is linked to the question of whether compassionate appointment can be denied to a widow on the ground that her husband was HIV+. Indian labour courts have, in some cases, passed orders favourable to the widow in such instances.

Experience, however, also shows that at present, corporations deny widows of workers their rightful share in employment benefits such as provident funds and gratuity on the ground that the deceased worker was HIV+.

Another widely experienced fallout in this context is that often her in-laws throw the widow out of her matrimonial home and the corporation makes payment of benefits to them, depriving the widow of her legal share.

Clear policy guidelines are needed to deal with these circumstances.

## **Women**

*(Group 1 - Day 2)*

### **Background**

According to recent estimates, the HIV virus is increasingly affecting younger and poorer populations of which women form the largest group. Today heterosexual transmission accounts for 80 percent of HIV infection in India. Further, the data also indicates that 7 out of 10 women affected by HIV are from poor rural and urban communities. The recent data on the spread of HIV/AIDS is transcending the boundaries of high-risk groups thereby enlarging the definition of risk-groups by including into its fold; a) adolescents girls (married and single) b) married women in their reproductive age c) single women d) sex workers at various sites including marital homes e) college and university students f) pregnant women g) women survivors of sexual abuse and rape. In addition, women in need of blood transfusion and those who use drugs are also at risk.

While the virus affects both men and women, there is a significant difference in the way gender identities; roles and gender relations have an impact on the spread of the infection. Gender refers to the widely shared expectations and norms within a society about appropriate male and female behaviour, characteristics and roles. The social construction of gender devalues the feminine and subordinates it to the masculine, which results in a power imbalance between men and women. The social construction of gender increases gender inequalities. Gender differences are based on patriarchal stereotyping which has been more harmful and discriminatory towards women. Women are disadvantaged because of their subordinate positions in all spheres of their life including the family. By virtue of their sex, women have lesser control, lesser choices and lesser rights vis-à-vis men. However, women and men are not a homogenous group; the other identities such as class, caste, tribal, rural, educational and others have a significant impact on their rights and vulnerabilities.

Central to the construction of gender relations is the issue of male-female sexuality, in terms of how a society allows or denies its expression. Various institutions reinforce very different perceptions about male-female sexuality, and notions of aggressive masculinity and passive femininity. Power is fundamental both to sexuality and gender. The unequal power balance in gender relations curtails women's sexual autonomy and expands male sexual freedom, thereby increasing women's and men's risk and vulnerability to HIV.<sup>7</sup> The culture of silence around women's sexuality and the denial of women's bodily integrity form the foundation of violations against the Human Rights of women.

### **HIV in the Gendered Context**

As far as HIV/AIDS is concerned, the present data and research points to two important aspects: first the gender dimension of the virus per se and second, the highly gendered impact of the infection. Women's physiological, social, sexual and economic vulnerabilities intensify the risks to women's lives. Therefore, it is imperative to

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<sup>7</sup> Weiss, E. and G. Rao Gupta 1988 Bridging the Gap; Addressing Gender and Sexuality in HIV Prevention. Washington, DC.



approach the issue of HIV/AIDS from the perspective of gender vulnerability and Human Rights violations.

In India, the situation of women vis-à-vis HIV/AIDS infection is specially precarious owing to: a) feminisation of poverty and diminishing food security, b) high incidence of compromised health status of the majority female population, c) poor women's inaccessibility to public health care services, d) patriarchal control of women's bodies and sexuality, e) high incidence of sexual abuse and violence against women, f) adolescents marriages and child births, and g) thousands of illegal abortions.

Women's vulnerabilities are further compounded if they are single or widowed; with discriminatory access to inheritance, shelter and other care facilities. When husband dies, the wife might face a tragic set of circumstances in terms of loss of social support, ostracism from the family and community, lack of legal protection to inherit land and property.

The HIV/AIDS discourse and preventive strategies have become more complex and difficult to deal with as they have opened up issues of sexuality, morality, matrimony, religion and legislation simultaneously. It has brought to surface glaring human rights violations in the day to day lives of women and other marginalized communities such as migrant men from poorer class and caste backgrounds, tribal people, lesbian and gays and other sexual minorities etc. Therefore, HIV/AIDS is more than a health issue; it is, in fact, a cross cutting and inter-sectoral challenge to any society.

The future prevention and treatment strategies must be able to address this whole range of issues affecting diverse people. In the case of women it is worthwhile to re-examine past assumptions and revise future strategies for the prevention and care of women at large at risk of HIV infection.

### **Women's Right to Life and Health**

As far as prevention, care and treatment services are concerned, addressing women's health concerns needs to be at the very centre of HIV/AIDS control programs. The increasing HIV susceptibility can only be seen as a continuum of a range of vulnerabilities that women experience as care seekers and care providers within closely interacting institutions, namely the Marriage (family) and the State (health care system). In both the institutions, women are primarily seen in their roles as mothers and wives and not as women in their own right. Therefore women outside these identities tend to lose out on their health rights due to discriminatory treatment.

The recent mortality and morbidity data clearly indicates a very serious situation that women are faced with: a) TB continues to be the biggest killer; b) deaths due to injury and violence are on the rise; c) unsafe abortions take a big toll of women's lives (70000 women die of unsafe abortion every year) d) low nutritional status and anaemic conditions are of epidemic proportions (Indian Council for Medical Research reported the prevalence of anaemia among pregnant women as high as 87.6 percent ), and e) very

high incidence of STI and RTI.<sup>8</sup> This larger picture is framed within the precariously low sex ratio (927 women per 1000 men). It is clear that poor women are faced with multiple epidemics in their lives.

In addition, women tend to seek care and treatment of their ailments last and often too late, prioritising the health concerns of the family. An overall neglect of women's health needs, cultural practices that look at women's bodies as dirty and impure, the increasing loss of women's knowledge systems and silence around sex and sexuality, all must be seen as interrelated factors obstructing women's quest for their right to highest attainable health status and care.

The gender division of roles and responsibilities also predetermine women's role as *providers* rather than *receivers* of care and treatment. There is emerging evidence that HIV+ women's and HIV+ men's needs are very different. This has a direct implication in the way services for women have to be designed.<sup>9</sup>

### **Universal Right to Knowledge and Information**

Consultations revealed that political leaders, bureaucrats, medical and legal professionals are concerned about the level of literacy of the country as it is seen as one of the major obstacles for effective prevention of HIV/AIDS. As poor women and men form a large part of this pool, there is a danger of seeing them as potential cause of the spread of the infection. This itself displays a bias against people without literacy skills. The overall perception of seeing illiterate people as ignorant and stupid violates people's sense of dignity. Illiteracy is not synonymous to lack of education. The (implicit) assumption that poor illiterate women are not worthy of receiving and interpreting information and knowledge to their advantage constitutes a violation of women's right to information. It also has a significant impact on future prevention strategies.

In the case of HIV/AIDS it is clear that the fear and ignorance about the disease cuts across class and education levels; the consultations clearly indicated that people with high level of literacy and academic qualifications revealed fear, ignorance and stigma. The consultations further reinforced that the HIV positive people faced discrimination in many hospital settings.

Regardless of literacy level, marital and maternal status, class and caste, occupation, age, gender, sexual orientation/preference and geographic location (urban/rural), the right to information must be upheld.

### **Confidentiality, Partner Notification and Consent**

According to the present NACO guidelines, the HIV positive person is the only one to be notified of her/his status. She/he is also entitled to counselling that would encourage beneficial disclosure. However, within the Indian socio-cultural context, it is difficult to

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<sup>8</sup> National Profile on Women, Health and Development - Country Profile - India, edited by Dr. Sarla Gopalan and Dr. Mira Shiva, Voluntary Health Association of India, WHO April 2000.

<sup>9</sup> Shalini Bharat: 'HIV/AIDS Related Discrimination, Stigmatisation and Denial in India - a study in Mumbai and Bangalore', Unit for Family Studies, Tata Institute of Social Sciences, Mumbai, India (1999).

assume women's autonomy, as they are seen as dependent on their men and the larger maternal/marital families. Someone from the family often accompanies women to the hospitals and PHC (Primary Health Centres). The notion of the individual privacy and individual decision-making is culturally alien, especially for women.

Further, most women and men do not have a choice regarding marital partner, as marriages are arranged for them; for women, it is often before they reach puberty. Therefore, the issue of HIV/AIDS in relation to the right to marry affects women and men differently.

Recognizing women's unequal social status, lack of female marital decision making power, parents marrying off their daughters at a young and vulnerable age to any man of their choice and the general lack of awareness in society regarding the implication of HIV infection, terms like 'disclosure' and 'consent' need to be investigated and implemented with this awareness. The Human Rights discourse must be contextualised in this larger reality. So far no socio-legal mechanism exists to ensure that any consent given by a woman would be informed and valid without any overt or subvert pressure or coercion.

Within our socio-cultural and legal context, for the majority of women, the obligation to marry in itself is a violation of the right to privacy and reduces their control over their bodies; A married woman has little opportunity to deny her husband sex, and as marital rape is not recognized by law, for women, 'consent to marriage' often equals 'consent to sex'. Changing the criminal law by recognizing marital rape could provide increased protection against violence against women and HIV infection. Similarly there is no law to address the issue of incest, which also is relevant in the context of HIV/AIDS and children.

From a human rights perspective, it is important to recognize existing partner inequalities. Further, different compulsions inform women's and men's decision to marry, to disclose or to give consent to marry. It is not an uncommon experience of women that men marry, remarry, desert and abandon women at their will. By and large, men do not feel compelled to disclose their marital, social, economic status at the time of marriage. The apprehension that men may or may not disclose their health status including their HIV status must be placed in this context. However, it is extremely difficult for a woman to hide her health or HIV status at the time of marriage.

Therefore, the consequences for her life, once her positive status is discovered, are very different than for a man; if a man subsequent to the marriage comes to know that the woman is HIV positive, in all probability the woman would be abandoned, subjected to violence, deprived of her rights to marital property or lose her right to the children (especially male children), or to be left to care for children if they are positive. In addition, once married to an HIV positive man, a woman is forced to perform all prescribed roles such as caring for her sick husband, doing all household work, bear children at his will and have sex with or without ensuring safety. Hence it is clear that the impact of the same infection is significantly different on the lives of men and women.

This is borne out by a number of community based qualitative research findings through the voices of HIV positive women.<sup>10</sup>

Within the context of HIV/AIDS and legal implications surrounding the discourse, the issue of 'conflicting rights' has surfaced. In the case of HIV positive pregnant women the rights of the mother are pitched against the rights of the child, thus making it difficult for women to exercise their decision without guilt. Therefore, effort needs to be made to understand the potential for conflict of rights and commit to developing strategies for resolving them so as not to undermine the core agenda of gender equality and non-discrimination. While no one should be denied the right to marry and no ruling or policy should put the rights of the infected person against the right of the uninfected person, it is imperative for the Human Rights framework to incorporate a gender perspective.

### **Strategies for Prevention and Protection**

The key issue for discussion is to evolve policies and programmes that are designed to empower women. For future prevention strategies it is relevant to incorporate international blueprints such as the Cairo ICPD<sup>11</sup> Agenda ensuring reproductive rights and the Beijing Platform for Action, as well as the CEDAW<sup>12</sup> that delineate specific policy actions essential for ensuring women's empowerment.

The Indian government is signatory to these documents and therefore needs to play a more pro-active role in ensuring their implementation. Creating a supportive policy and appropriate legislative changes for women is crucial for containing the spread of the HIV infection and mitigating its impact.

There is a strong need to address issues of sexuality for both women and men. In innumerable cases male violence is an associated factor for women in their sexual, intimate encounters. This constitutes a serious violation of women's bodily integrity and right to privacy. The issues surrounding gender violence have to be located within the Rights' framework and integrated into HIV/AIDS education, prevention and care programmes. Gender violence jeopardizes women's health and well being (including sexual and reproductive health) which increases HIV susceptibility. Here it is relevant to ensure the finalization of the Draft on the Domestic Violence Bill.

The HIV infection needs to be seen as a symptom as well as the outcome of women's multiple vulnerabilities. The prevention and protection strategies need to evolve a multi-pronged approach. Care policy makers and implementers need to look at women's health requirements as a composite rather than divided in parts.

By and large, the past prevention strategies have focussed attention on male condom promotion, monogamy and partner fidelity. Due to systemic gender inequality and powerlessness, women have not found difficulties in enforcing these strategies vis-à-vis

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<sup>10</sup> Community Based Research on Gender and HIV/AIDS ISST, 2000 sponsored by UNIFEM

<sup>11</sup> International Conference on Population and Development, Cairo 1994.

<sup>12</sup> Convention Against the Elimination of Discrimination Against Women (UN 1979).

their male partners. Some of the women's empowerment programs for HIV prevention have added to the existing burden of women's lives, as safe sex negotiation strategies have become the exclusive responsibility of women. This historical context needs a conceptual and programmatic shift; *boys and men must be made responsible for their social and sexual behaviour*. Thus, it would be useful to strengthen interventions and strategies that increase male involvement and understanding of their responsibilities/roles in preventing the spread of HIV.

In the light of very low condom use within marital and more permanent partner relationships, it is evident that newer strategies are required to empower women. Until attitudinal changes among boys and men are brought about, women need safety measures in their own control. In Brazil, a project encouraged the use of female condoms by providing them at accessible prices. It showed good results in some regions (80 percent of the women and their partners in Sao Paulo were satisfied with this method).<sup>13</sup>

Another consideration that is extremely important is to acknowledge that any disadvantaged group such as women and other marginalized communities cannot be empowered if they are continuously blamed for the spread of the infection. It is not a violation of their right to life and dignity, but also deprivation of their social citizenship. HIV/AIDS campaigns exclusively targeting sex workers or similarly vulnerable groups have added to their stigma and neglected protection to other people by creating a false sense of safety/security.

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Differently adapted and specially designed communication programmes and services for different groups of people have the possibility of reaching the general population as well as addressing the specific needs of more vulnerable groups. It would be more strategic to use a rational approach to communication rather than a fear-and-morality based as it often increases stigma and discrimination of HIV positive people; it reinforces the perception that HIV only hits those who behave immorally.

Due to the disproportionate discriminatory factors obstructing women's assertion of their Human Rights, the women's rights advocates world-over are engaged with issues of affirmative action/positive discrimination. This is based on the understanding that the prevailing gender inequalities cannot be changed within the discourse on *formal equality*. For empowering all marginalized and discriminated groups, it is imperative, to promote and apply the concept of *substantive equality*. As far as the fundamental rights are concerned, this principle is clearly enshrined in the constitution of the country. This is pertinent in view of the gendered nature of HIV/AIDS. The gendered reality determines the nature and circumstances of the Human Right's violations specific to women, as well as the availability and accessibility of remedies for them.

### Key Issues for Discussion

- 1) How do we reach women at large and in specific circumstances with HIV/AIDS related information and care needs?
- 2) How do we address women's multiple health needs including HIV vulnerabilities?

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- 3) How do we resolve the issue of conflicts of rights in the context of legal and ethical issues such as confidentiality, partner notification, free and informed consent?
- 4) How to introduce innovative strategies in order to gender sensitise planners, policy makers, the judiciary and various functionaries involved in the HIV/AIDS prevention and care work?
- 5) How do we best reduce the stereotyping and discriminatory attitudes that both men and women live with?
- 6) How do we reduce stigma, AIDS related discrimination and Human Rights violations of infected and affected women and men?

## **Sex Workers<sup>14</sup>**

*(Group I – Day 2)*

### **Context**

Epidemiological studies following the spread of the HIV pandemic focussed attention on certain 'high-risk' groups of which sex workers were considered a significant constituency. Intervention efforts by NGOs and other welfare organisations brought to light the fact that the threat of HIV transmission was a reflection of the more serious and hitherto unaddressed issue of denial of basic human rights.

Sex work exists in varying contexts, across geographical, religious, caste and class boundaries. These include brothel based, street based, and home based sex work. The issues of relevance are thus as varied. The following paper attempts to articulate the issues that seem common to these contexts.

### **Human Rights and Sex Work**

At the heart of the matter lies the stigma and marginalisation associated with sex work and oppression and exploitation that the sex workers are subjected to. Sex work is not recognized as work; it is seen as a sin or a crime, posing a threat to morality, public health and social order. A natural outcome of this is the denial of basic human rights such as health, housing, and the right to self worth and dignity. The right to bear and rear children, to a large extent eludes them, as they are not granted the status as other single or adoptive mothers are. Discrimination and stigma for their children is all pervasive, debarring a future for them. Harassment at the hands of the law enforcing authorities in the form of police raids, eviction, forced testing, threats and torture is also a matter of grave concern within the human rights paradigm. Further, proposed bills such as the Maharashtra Protection of Sex Workers Bill, 1994, show insensitivity that could lead to even more serious human rights violations such as branding and identification of women as sex workers for the purpose of negative discrimination.

### **Statement of the Problem**

These grave human rights violations must be understood in the context of vulnerability to HIV/AIDS. The oppressive milieu makes access to health care, negotiation for safer sex and any sort of move towards empowerment that would protect sex workers from HIV transmission practically impossible. Further, there is a lack of knowledge with respect to

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<sup>14</sup> This paper is largely based on the deliberations of the national meet organised between 28<sup>th</sup> – 30<sup>th</sup> April 2000 at Chennai to launch the National Forum for Advocacy and Support for Sex Workers. The meeting was attended by participants from various parts of the country. The commonality between the participants cannot be overemphasised; while some belonged to organised and relatively articulate groups, others came from contexts where such organisation and group processes are unheard of. It may be pointed out that this paper may not adequately articulate issues in certain unorganised contexts such as street-based, home-based and flying sex workers. Thus, the views presented herein may not be representative of the entire group in question. To address this limitation, this paper was sent out to various experts and consultants in the field for their comments and inputs. These have been considered and incorporated to the extent possible.

safer options and the virus itself. The hostile legal and social environment makes effective intervention difficult.

Following are some of the common experiences of sex workers from all over the country, which contribute towards the vulnerability to HIV/AIDS:

- Non-availability of Health care and services. The stigma linked with sex work makes even the services that are available practically inaccessible to sex workers as well as their families.
- Arbitrary Police raids; seizure of money and material belongings
- Physical assault, torture and rape by police personnel. These violent actions make sex workers even more vulnerable to STI/STD and HIV, in social and actual physical terms.
- Forced testing and detention of sex workers
- Harassment of workers and clients including extortion and blackmail
- While some groups such as those in Calcutta, Pondicherry and Tamil Nadu have been able to organise themselves successfully, often at a national level like the National Forum for Advocacy and Support for sex workers, others have found it difficult to come out open as sex workers and form collectives owing to stigma and the fear of oppression and torture from the police.
- Coercive Rehabilitation programs have been ineffective, misplaced and insensitive to the needs of the communities. Enforcement of the same has led to more human rights violations than actually helping sex workers. This has had the effect of validating the perception among sex workers that the state is more of an adversary than a supporter.
- Discrimination in housing, education of children, care and support

*The statement of the problem* is thus in terms of the creation of an enabling environment whereby, factors which push girls and women into involuntary sex work are addressed and the rights of sex workers are respected and protected, health services are made accessible, discrimination against sex workers and their children is done away with and in short, sex workers are considered as human beings.

### **Social Hurdles**

- Sex work is considered as “immoral” and a sin by the same society that creates the demand for it and puts women in a position whereby they are abused and exploited.
- Due to the stigma, sex workers are forced to ghettoise into areas and situations where basic human rights do not exist and basic living requirements including health care, education, information etc. are denied. This is particularly true in the context of brothel-based sex workers.
- Where there is information as to the risks of unprotected sex, there is no negotiating power, except where sex workers have been able to form collectives and fight for their rights.
- The culture of silence around sex and the link made between STI/STD and sex work makes health care facilities (where available) inaccessible.
- Media, political and legal responses to problems faced by sex workers have been insensitive and adverse.



- The children of sex workers carry the stigma with them and are discriminated against with respect to education, shelter and other essential aspects of living. This leaves them with no future.
- Inability of sex workers to take recourse to legal action owing to fear, stigma and various socio-economic factors.
- The silence and stigma around STI/STD, even within the sex workers communities, further enhances the risk to HIV transmission.
- There is a lack of care and support systems for HIV positive sex workers and their children.

### **Legal Hurdles**

Laws, which are intended to be protective of women, have in practice worked against their interests, especially sex workers. In addition to the laws that make women vulnerable to HIV in general, sex workers have to contend with the use, abuse and misuse of The Immoral Traffic in Women and Girls Prevention Act, 1986

- At the same time, all the necessary concomitants, such as soliciting, keeping of a brothel etc. are punishable by law. As such, sex work is effectively criminalized.
- Ambiguity in the provisions of ITPA, including the meanings of terms such as "Immoral Traffic", "tender age", "moral danger" make the law all the more subject to abuse.
- The ITPA espouses mandatory testing, which is detrimental to public health and the National AIDS Policy.
- The ITPA provides the police with power that have been misused and manipulated in such a manner that the law itself is an instrument of oppression.
- Attempts at law reform, such as the Maharashtra Protection of Sex Workers Bill, 1994, have been insensitive and violative of basic rights. (The Bill proposed steps such as mandatory testing, branding with indelible ink and quarantining of sex workers)

### **Options**

Two main options have been suggested in the context of the legal status of sex work: *decriminalisation* would imply removal of penalties against the practice of sex work and its necessary concomitants, as far as it relates to consenting adults, and *legalisation* would imply recognition and regulation of sex work through licensing and other government controls that would permit sex work in specific (and usually limited) ways. A third option is that of *criminalisation* and subsequent abolition of sex work and related activities. This argument is largely based on the view that prostitution itself is a form of violence perpetrated by society against women and any move towards legalisation will legitimise an exploitative set-up.

### **Experiences Articulating Best Practices**

Amidst the negative social attitudes and hostilities towards sex work, there have been successful experiences, which generate hope in the years to come. In West Bengal, groups were able to organise a national conference for sex workers in 1992, which was attended by representatives of communities such as doctors, academicians and media

representatives. The event enabled sex workers to sensitise and gather support from health care providers, which led to positive action such as recognition of the right to respectable treatment. Recognition of self worth i.e. sex workers looking at their lives positively was a marked step forward in the long drawn process of empowerment.

Organised groups from Sonagachi and Tamil Nadu have been able to promote condom usage to prevent transmission of HIV by employing peer education strategies and collective action. Organised groups have been in a better position to regulate and minimise the inflow of children into sex work in these areas by putting in place self-regulatory mechanisms. There has also been an increase in bargaining power vis-à-vis state agencies such as the police and the capacity to deal with atrocities by state and civil society alike.

### **Sex Worker's Demands and Felt Needs**

- Recognise sex work as 'work', just as any other work and all the rights and obligations rendered to other kinds of work, should be rendered towards sex work too.
- Decriminalise sex work. This will minimise the misuse of power by the law enforcers and safeguard the worker's against all forms of exploitation and oppression. Legalisation, it is feared, will grant more powers to the authorities in the form of licenses and regulations and will be detrimental to the interests of the sex workers.
- Scrap/ amend ITPA and remove the existing loopholes that allow the police to inflict torture on the sex workers.
- Recognise the fact that the sex worker's fight for their rights is taking place within the gamut of the wider struggle for women's empowerment. Seek support from existing women's collectives and initiatives towards the rights of sex workers.
- Recognise the sex worker's right to bear and rear children in a non-discriminatory and least restrictive environment. Provide them access to services such as health and education, which will improve the quality of their lives.
- Address the need to improve existing (if any) health care services for sex workers. Health care to be provided in a non-judgmental and non-stigmatised environment, thus respecting the worker's rights to dignity, consent and confidentiality.
- Provide effective education on HIV/AIDS through creative media strategies such as song and dance sequences and peer education.
- Messages promoting prevention of HIV transmission must be sensitive to the socio-cultural context of sex workers.
- Facilitate the creation of an Enabling Environment, which allows for openly talking about condom use and openly promoting condom use. An enabling environment would also promote open discussion as to diseases and health problems and thus access to medical services.
- Promote the formation of collectives. This is the only way in which problems such as police harassment can be addressed. In many parts of the country, formation of collectives is difficult as there is a constant fear of police torture and coming out in the open as a sex worker has daunting implications.

- Promote strategies that empower the sex workers community, enabling them to establish their own self-regulatory systems for their collectives. This may prove to be one of the remedies for child trafficking and exploitation within themselves.
- Create a forum for support and advocacy both within and outside the sex worker's community.
- Ensure that the media deals with sex workers with utmost sensitivity and confidentiality.

**Suggested Points for Discussion**

- 1) What should be the strategy to prevent human rights violations of sex workers, especially by state agencies, such as the police?
- 2) What should be done to increase sex workers' access to basic services such as health care and education?
- 3) What steps can be taken to integrate sex workers and their children into mainstream society, to remove stigma and prevent discrimination?
- 4) What strategy should be adopted to create an enabling environment, especially in the context of vulnerability to HIV/AIDS?
- 5) What should the legal status of sex work be?

## **Children and Young People<sup>15</sup>**

*(Group II - Day 2)*

### **Facts and Figures<sup>16</sup>**

- Adolescents account for one-fifth of the world's population. In India adolescents comprise 21.4 % of the total population. These include school going and non school going, drop outs, sexually exploited children, working adolescents-both paid and unpaid, unmarried adolescents and married males and females with experience of motherhood and fatherhood.
- The figures for working children in India range from 5% (1991 census) to more than 50 %(NGO estimates) of the 200 million children in the age group 10-14 years.
- Gross school enrolment rates for children between 11-14 years are 65% for males and 49 % for females. This is further exacerbated by drop out rates of 54% for males and 60% for females in middle school.
- With respect to HIV/AIDS, more than half of all new infections globally are in young people below 25 years. Global data indicate that during 1999 alone, 620,000 children under 15 became infected with HIV.
- In India, current available data, limited as they are, indicate that youth are increasingly at the centre of the HIV/AIDS pandemic both in terms of transmission and impact. Over 50% of all new infections in India take place among young adults below 29 years. The disease has now entered the stage where both parents are dying leaving behind an increasing number of AIDS orphans and infected children. The stigma and discrimination faced is accentuated if the children themselves are infected, and they grow up in a hostile environment without parental or community support.

### **Key Findings and Critical Issues<sup>17</sup>**

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<sup>15</sup> The 'Convention on the Rights of the Child (UN, 1989)' defines 'children' as 'all persons up to the age of 18 years'. WHO defines 'adolescents' as 'between the ages 10-19 ' and 'young people' as 'between the ages 10-24'. As per GOI, youth in India are defined to be between 15 - 35 years. In this document 'adolescents', 'youth' and 'young people' have been used interchangeably

<sup>16</sup> Main sources of data are: MOHFW, Country Paper, 1998; Adolescent in India – A Profile, UNFPA 2000; MOHRD 1998-99; Report on the global HIV/AIDS pandemic in India-UNAIDS 2000; NACO – Country Scenario 1999-2000 & India Responds to HIV/AIDS.

<sup>17</sup> Synthesis of UNICEF Consultations conducted with young people, NGOs working with young people and currently available data. UNICEF held state level consultations (in Maharashtra, Andhra Pradesh, Karnataka, Tamil Nadu, and Rajasthan) with State AIDS Societies, NGO, CBO and other stakeholders. These were followed by a national level consultation. The participatory process at the state level provided a significant opportunity for discussing current programs, exploring practical ways of addressing rights of children and young people and identified critical issues for discussion.

Children and youth in all socio-economic groups in India are especially vulnerable to HIV infection as indicated by key findings of recent studies<sup>18</sup>:

- 1) The limited data available suggests a fairly high level of sexual activity amongst youth with boys being more sexually active than girls. This includes both peer sex and sex with adults. However knowledge of HIV/AIDS, safe sex and preventive behaviour (use of condoms) is low across all ages and education levels.<sup>19</sup> Majority of the information is obtained from peers, which may be inaccurate or misleading, as many misconceptions and myths related to adolescent sexuality proliferate. Girls especially have almost no information and conservative attitudes and lack of openness in matters relating to youth leads to further the perseverance of unsafe practices.
- 2) Although the prevalence of Reproductive Tract Infections (RTI) and gynaecological morbidities is alarmingly high, existing reproductive health services do not serve adolescents, let alone providing adolescent friendly services - making it difficult for them to approach health care centres for counselling and services (testing or abortion).
- 3) Street children and child labourers are particularly vulnerable due to high incidence of sexual abuse and exploitation. All these children have little or no family support, no access to services without the welfare and social safety nets of the organised sector
  - There are an estimated 100,000 street children in the metropolitan cities like Mumbai, Delhi and Calcutta, and the numbers are increasing due to rapid urbanisation.
  - Street children are especially vulnerable to HIV infection due to lack of awareness and an absence of safety nets. Many of them, as young as 8, report having sex for companionship or as being victims of regular sexual abuse.
  - It is estimated that 60-90 % of street children in Mumbai are sexually active. About 20% of street boys in the 16-20 age group visit commercial sex workers regularly and 80% periodically.
  - Government of India data indicates 17.5 million children in the 5-14 age group as being in the labour force. The most exploitative forms of child labour include child prostitution, forced and bonded labour. These child labourers work and some live in conditions of extreme marginalisation and fall prey to sexual exploitation increasing their vulnerability to HIV/AIDS. In this context, the situation of the girl child labourer calls for particular attention, with life on the street for the girl child is twice as oppressive and exploitative than that of a boy.

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<sup>9</sup> Main sources of data are: Adolescent Sexuality and Fertility in India: Preliminary findings of four studies undertaken in India by International Centre for Research on Women, Presented at the Workshop, Bangalore 1998; other data are from studies conducted by UNFPA, Commonwealth Youth Programme, Field Research conducted by the NAZ Foundation, 65 City Risk Behaviour Survey, NACO; Report on the six regional workshops on Sexual Trafficking of Children. Social Welfare Board. 1992

<sup>19</sup> NHFS survey

- 4) Child prostitution, child trafficking and sexual abuse leading to forced and coerced sex further increase the vulnerability of children to HIV:
  - A 1990 study conducted by the Central Social Welfare Board in six metros reported that roughly 40% of the total commercial sex worker population is below 18 years of age, many of them as young as 8 or 9 years. With every year, about 50,000 more are forced into prostitution. The average age of children in brothels is as low as 13.
  - The children of sex workers are an especially vulnerable group since they are easy victims to the sex trade.
  - Recent studies indicate that the incidence of rape in the under-10 age group has increased by 84% between 1990 and 1994, while the general incidence of reported rape in all age groups has increased from 20,194 in 1990 to 21,500 as of October 1995. These figures represent only the tip of the iceberg.
  - Studies in 1993 estimates that 15% of secondary school girls have been sexually abused. The Social Welfare Board reports increased molestation, rape, and sexual abuse of progressively younger children occurs more within the family than outside.
- 5) Given the predominantly patriarchal set up and ideology of sex preference, adolescent girls are especially vulnerable. Their vulnerability is further enhanced considering that increasingly, adult males are targeting younger children for sex in the belief that they are free from HIV and STDs or that sex with a virgin will increase their virility or cure them of STI. Weaker immune systems due to poor nutrition (as many as 55% of adolescent girls may suffer for anaemia) and underdeveloped genital and anal tracts increase susceptibility to HIV/AIDS.
- 6) In many countries children resort to drug use for recreational purposes.
  - The UNDCP reports of a close relationship between living on the street and use of drugs.
  - Injecting drug users (IDU) is a major concern especially in the Northeast and in the metropolitan areas of the country.
- 7) Mother-to-child transmission: The rising prevalence of HIV among women attending antenatal clinics increases the probability of more children being born with HIV and dying from their infection.

#### **Additional issues**

- Lack of adequate and reliable data-disaggregated by age and gender. This is a major impediment to planning, especially the expansion of the current response to HIV/AIDS.
- Lack of enabling environment and inadequate opportunity to develop life and livelihood skills.

- Early age of marriage, high adolescent fertility and maternal mortality - In India, the official age for marriage for girls is 18 years and for boys is 21 years. However certain personal laws permit marriage for a female at the age of puberty/15 years. 54% of females are married by the age of 18<sup>20</sup> and 64% of married adolescent girls between 17-19 years are already pregnant with their first child. This does not include the large number of unwed mothers for which no data is available. (1 of every 10 births is to an adolescent).<sup>21</sup>

### **The Rights of the Child in a World with HIV/AIDS**

There is a global consensus that children's rights need special protection. In a rights based framework 'all rights apply to all children without exception. It is the State's obligation to protect children from any form of discrimination and to take positive action to promote their rights'. (CRC, Art. 2) The Convention on the Rights of the Child ensures every child the right to survival and development, the highest attainable standard of health and health services, and if disabled, special care that ensures dignity, promotes self-reliance and facilitates active participation in the community. (CRC, Art. 24)

In the context of HIV/AIDS, the CRC has spelt out principles for reducing children's vulnerability to infection and to protect them from discrimination because of their real or perceived HIV/AIDS status:

- Children should have access to HIV/AIDS prevention education, information and to the means of prevention. Measures should be taken to remove social, cultural, political or religious barriers that block children's access to these.
- Children's right to confidentiality and privacy in regard to their HIV status should be recognised. This includes the recognition that HIV testing should be voluntary and done with the informed consent of the person involved which should be obtained in the context of pre-test counselling (keeping in mind the evolving capacities of the child).
- All children should receive adequate care and treatment for HIV/AIDS, including those children for whom this may require additional costs because of their circumstances, such as orphans. States should include HIV/AIDS as a disability, if disability laws exist, to strengthen the protection of people living with HIV/AIDS against discrimination.
- Children should have access to HIV/AIDS prevention education and information both in school and out of school, irrespective of their HIV/AIDS status.
- Children should suffer no discrimination in leisure, recreational, sport and cultural activities because of their HIV/AIDS status.
- Special measures should be taken by Government to minimise and prevent the impact of HIV/AIDS caused by trafficking, forced prostitution, sexual exploitation, inability to negotiate safe sex, sexual abuse, use of injecting drugs and harmful traditional practices.

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<sup>20</sup> NHFS 1998-99

<sup>21</sup> Adolescent Profile in India – UNFPA (2000)

## **Indian Law**

The Indian Constitution mandates the State under Article 39 to ensure that “children are not abused and that childhood and youth are protected against exploitation and against moral and material abandonment”. India ratified the CRC on 11th Dec. 1992. When countries ratify the convention, they agree to review their laws relating to children. This involves assessing social services, legal, health and educational systems as well as the level of funding for these services.

- The Indian Supreme Court expanded the concept of Fundamental Rights to use the provisions made in the Directive Principles in implementation. Social Sanction Litigation has expanded the scope for Constitutional redress for violation of Child's Rights in many areas, with the right to life being recently interpreted as the positive duty of the state to provide the basic conditions for survival.
- The State's response to its obligation towards children is contained largely in the Juvenile Justice Act.<sup>22</sup> Although it makes provision for educational and vocational training and rehabilitation, character development and protection from exploitation, in practice the focus is on institutionalisation. These are generally perceived as jails for children leading to harassment, extortion and vulnerability for street children. In light of reports of human rights violations and cases of children running away from the homes, empowerment of children through other interventions needs to be reconsidered (e.g., street based interventions). In addition, the rules and regulations made under the Juvenile Justice Act need to be reconsidered so as to make them compliant with the CRC.
- There is an absence of any specific laws to deal with the issue of child sexual abuse. Related criminal laws (Sections 376, 377 and 354 of the IPC) are inadequate and provisions relating to evidence and criminal procedures are not suited to deal with such cases. Civil courts also often deal with related cases and provisions of family law and Civil Procedure, if used creatively, can be very effective in dealing with sexual abuse etc.
- According to the provision of the Immoral Trafficking Act (prevention) 1956, presumptions are created with respect to certain offences against a child (less than 16 years) and a minor (between 16-18 years) and severe punishments are prescribed for procurement of prostitutes and prostitution in public places. These provisions need to be re-evaluated in light of experiences that show that empowerment of sex workers is effective in restricting entry of children into sex work.
- The IPC has provisions for dealing with obscenity, including provisions dealing specifically with dissemination of “obscene” material to young persons<sup>23</sup>. ‘The Young Persons’ (Harmful Publications’) Act 1956 also lays down provisions to prevent dissemination of certain publication harmful to young persons (under the

<sup>22</sup> Juvenile Justice Act (1986) deals with neglected and delinquent juveniles. Juveniles are defined as girls under 18 and boys under 16

<sup>23</sup> Section 292 and 293 of the Indian Penal Code



age of 20). In the absence of clear thinking, and ambiguity in the meaning of "obscenity", these provisions may hinder dissemination of information, which is a prerequisite in empowering young persons to protect themselves.

Prevention of transmission among young people and women is a crucial component of the National AIDS Policy (2000). The Young people - School Talk AIDS (Ministry of Youth and Sports Affairs, soon to be launched is another program which taps into youth and their potential as educators for HIV/AIDS prevention and awareness. Children's communities committees and Bal panchayat bodies voicing children's demands on rights continue to function at a local level – creating potential platforms for children's participation in larger rights based issues, which will positively impact responses to HIV/AIDS.

### **Key issues for Discussion<sup>24</sup>**

- 1) How can we protect children's right to information, particularly about issues and safe practices related to adolescent development and sexuality, STD/HIV and substance use?
- 2) Children are vulnerable in multiple settings. How can schools, families, peers, health care facilities, streets, villages, and work places be used to reach them with the relevant information?
- 3) How do we promote and protect the rights of AIDS orphans, to treatment, health care, support, employment, education, life without discrimination etc? - How does this relate to the prevalent testing practices in adoption homes? - A child being a minor has no access to courts of law. How do we address the right to litigate for a child orphaned on account to both parents dying of HIV/AIDS? Minors often approach health care centres alone for testing or abortion. How does this affect response to HIV/AIDS?
- 4) How can young people be involved and mobilized as agents of change, especially on the issue of stigma surrounding HIV in particular and in order to promote safe practices?
- 5) How can the loopholes in and the insensitivity of law (especially criminal law) with respect to child sexual abuse and incest be rectified? (Especially when perpetuated by a family member/ trusted person). Also the Indian Penal Code does not penalize sexual intercourse by a man with his wife who is above the age of 15 without her consent. There is no legal age for consent to sex by boys. There is, in fact, no recognition of sexual abuse of males. How can these be addressed in the context of HIV/AIDS?

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<sup>24</sup> The discussion and results of the key issues should aim at identifying and determining the use of the above described existing laws and mechanisms in order to optimally expand the response/reach children and youth to remedy their vulnerabilities

## People Infected and Affected<sup>25</sup>

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(Group III – Day 2)

### Context

India does not yet have a complete picture as to the magnitude of the HIV pandemic especially considering the lack of surveillance data in vast regions in the country. But in areas where surveillance has taken place it is seen that the pandemic follows its unbridled path and is beginning to surface in all spheres of life including homes, the workplace and the health care sector. It is now quite clear that HIV/AIDS in India is not just a medical issue but also an issue that cuts across all economic, social and cultural realms. It is also an issue that does not affect particular groups but has an impact on all. It is important, therefore, that the tendency to blame a certain section of society needs to be combated if prevention and control efforts are to be effective.

As the pandemic has grown, experiences reflect a consistent pattern through which discrimination, marginalisation, stigmatisation and more generally, a lack of respect for the human rights and dignity of individuals and groups heighten their vulnerability to HIV/AIDS. Very often such discrimination stems from ignorance about the route of HIV/AIDS transmission and unwarranted fears of infection. The ignorance and fear has led to harsh laws and measures that violate the rights and freedoms of those trying to avoid HIV infection and of those already living with HIV/AIDS.

No one has experienced fear and courage, ignorance and insight, prejudice and acceptance, despair and hope more fully or intensely than people living with HIV/AIDS (PLWHA). Yet, this experience is not confined to just PLWHA but also those who are dependent on, related to or associated with a PLWHA. These persons include spouse, partners, children, widow (-er) s, orphans, parents, other family members and friends of PLWHA. Clearly, this is a vast and significant segment of society. While developing any response and implementing any strategy vis-à-vis HIV/AIDS the needs and experiences of this entire group of people affected must also be considered.

### Human Rights and People Affected

The main human rights issues concerning PLWHA include:

- *Denial of healthcare and treatment* – The most common human rights violation is refusal to medical treatment. For instance, first aid and emergency services like surgery are denied once the sero-status of the patient is disclosed. PLWHA have difficulty in accessing medication even for opportunistic infections. They require health care providers who are well trained, sensitive and knowledgeable about care and treatment but it is commonly found that healthcare workers actively discriminate against PLWHA, due to several misconceptions about HIV/AIDS. Further the cost of the treatment is prohibitive. (Refer to the background papers on Consent, Confidentiality and Discrimination in Healthcare).

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<sup>25</sup> This background paper is partly based on the 1999 Needs Assessment Study of People Living With HIV/AIDS by the Indian Network For People Living With HIV/AIDS and the INP+ Strategic Plan for 2000-2002.

- *Denial of and/or removal from employment* - PLWHA commonly experience various forms of discrimination in the employment sector. These include refusal to employ PLWHA, termination of employment, refusal to grant various benefits to both the PLWHA employee and his/her dependants or family members and denial of compassionate appointment for dependants. (Refer to the background paper on Discrimination and Employment).
- *Access to and Availability of Drugs* – Access to drugs is a critical emerging issue in the HIV/AIDS context. With a new patent law likely to be enforced in India by 2005 under the Trade Related aspects of Intellectual Property (TRIPS) of the World Trade Organisation, effectively product patents for new drugs will be recognised under Indian law as compared to the hitherto followed process patent system. Thus, Indian pharmaceutical companies will be prevented from manufacturing new and effective HIV/AIDS drugs whose patents would lie with foreign inventors/patent holders and manufacturers. This will result in foreign monopoly rights in pharmaceutical manufacture and sale of drugs. Consequently India is likely to see a drastic increase in prices, which would make drugs prohibitively expensive and inaccessible to a vast majority. This would have adversely affected the fundamental right to health of PLWHA.

However, TRIPS gives grounds under which a government could combat unaffordable prices. This method of compulsory licensing could be exercised in cases of national emergency, extreme urgency, anti-competition or for public non-commercial use – these are widely defined grounds that are left to individual governments to incorporate into their national legislations more specifically. It is left, then, to the Indian government to give full meaning to its peoples fundamental right to health by incorporating such grounds meaningfully and in a manner that makes essential drugs and those required for serious health crises freely and easily available. Clearly, this is an issue of grave concern in HIV/AIDS context.

In light of a new legal regime, apart from the access to drugs, certain drugs that do not fall under the new patent regime, and should therefore be freely available (drugs for opportunistic infections, post exposure prophylaxis for needle stick injuries, drugs preventing mother-to-child transmission) are not available.

- *Denial of various services including insurance, medical benefits etc* - Insurance systems exclude such services to PLWHA and their dependants. Apart from the Employees State Insurance Scheme, which is applicable only to corporations or employers that use this scheme, there is no medical insurance scheme that provides insurance benefits to PLWHA and their dependants. All other medical insurance schemes in the country such as Mediclaim and Jana Arogya Bima policies specifically exclude PLWHA and any illnesses arising out of HIV/AIDS. This makes accessibility to health services even more difficult for PLWHA and their dependants. The issue which needs to be addressed in this context is whether in a low sero-prevalence setting currently existing in India, if an insurance policy for HIV/AIDS

were introduced, a sufficient fund could be created for the future, whereby medical expenses that are bound to increase could be subsidised and covered at a later date, when the need arises. Actuarial studies require to be undertaken immediately, so that the viability of such insurance schemes can be properly examined.

Apart from medical insurance, it has been experienced that life insurance policies are denied to PLWHA. Their dependants are also denied their rightful dues under such policies on the death of the policyholder due to causes related to HIV/AIDS. These are critical issues that need to be addressed if the human rights of all people affected by HIV/AIDS are to be upheld.

- *Access to Information* – PLWHA have little access to information about HIV/AIDS and life after the infection. Primarily, most of the information is targeted at people who are not infected, because prevention appears to be the media priority. As such, much of the available information is fear based. Much media reporting is irresponsible, blame-oriented and insensitive. At the same time media responses ignore the needs of people already affected; they are as much, if not more, in need of accurate information. PLWHA are poorly informed about even the basic issues like hygiene, nutrition, diet, behavioural change and legal rights relating to HIV/AIDS. Not many of them have information on prevention of opportunistic infections. The key constraint to accessing information is the prevalence of misconceptions and misinformation about HIV/AIDS that deceive the PLWHA into thinking he or she is adequately informed. Other constraints include poor literacy levels, ill-planned and ill-targeted media campaigns and the lack of a non-judgmental, safe environment to access information. Information providers such as the media, health care workers, and other PLWHA themselves have little or no accurate information to share with the PLWHA.
- *Legal remedy* - Another significant issue of concern is that PLWHA have no knowledge about where to address human rights violations. There is a severe lack of information about fora that could address the issues of human rights violations and related grievances. Even if legal aid and services are available there is sometimes a delayed response from PLWHA. A key reason for this is that most respondents fear that their sero-status would become public knowledge while trying to address human rights violations against them. Therefore, PLWHA need to be informed about legal innovations such as 'suppression of identity' orders that are issued by courts, whereby parties to litigation are given pseudonyms.
- *Lack of strong support systems* – Misconceptions about HIV lead to lack of support for PLWHA. Sources of support include family, spouses, friends and relatives. Support makes a considerable difference to the quality of life of PLWHA. Sometimes gender biases also exist i.e. women provide support to their male partners men but men seldom offer support to HIV+ women. It is commonly seen that many joint families ask PLWHA to move out once their sero-status has been disclosed. Family members and relatives physically isolate PLWHA by forcing them to use separate soaps, towels and utensils, by not talking to the person and by not touching their

clothes. Children in the household are prevented from playing, interacting or eating with the PLWHA.

Many women with HIV who have been widowed by the death of their HIV+ spouses are thrown out of their matrimonial house and forced to return to their maternal homes.

HIV- children of HIV+ parents suffer various forms of discrimination and lack support structures. Schools refuse to admit the children of HIV+ parents. The real problem arises when they are orphaned, as even the extended families do not want to keep HIV+ children. This is an issue that needs urgent addressing. With an increasing number of deaths related to HIV/AIDS likely to occur in the coming years there is distinct likelihood that many children will be left destitute – children who may or may not be HIV+. There is an abject lack of capacity to support children in such circumstances. Measures to protect their human rights need to be taken expeditiously. Amongst children also there is an increase in the rate of HIV+ children.

Different studies highlight the intensity of stigma and discrimination faced by PLWHA. PLWHA feel demoralized by constant discrimination. Some withdraw from the community and family. Most of them do not wish to disclose their status to anyone. A few develop suicidal tendencies. Low self-esteem is a universal feature. All this can only be overcome by promoting social acceptance of PLWHA. Sensitive media campaigns can play a very crucial role as they can encourage PLWHA to come forward, educate the general public about HIV/ AIDS and promote social acceptance of PLWHA. Human rights should be included as an integral part of prevention programs.

Law, ethics and human rights are means to ensure that human dignity is universally respected (in all situations and contexts). Further they are crucial aspects of any comprehensive response developed to deal with the HIV/AIDS pandemic. In this context, experience has shown that intervention strategies that protect and promote the rights of people affected are far more effective and acceptable than those violating the human rights of affected populations. Some of the issues that arise in this context may be thus identified:

#### Key Issues for Discussion

- 1) What specific measures, including legal measures should be taken to ensure that the rights of people affected are not violated?
- 2) Specifically, what steps should be taken to ensure that PLWHA have access to health care (including drugs), employment, insurance and other community resources and services?
- 3) What strategies should be evolved to provide PLWHA access to accurate information on life after infection including information about various drug and treatment options?
- 4) How can family and community support systems be strengthened for people affected by HIV/AIDS?

## Sexual Minorities<sup>26</sup>

(Group IV - Day 2)

### Context

The phrase "Sexual Minorities" refers to an entire range of people comprising of groups and individuals whose sexual orientation or gender identity sets them apart from the majority mainstream population, which is predominantly heterosexual. Sexual minority does not imply any homogeneity of character and there is no common or universal identity amongst sexual minorities. The phrase includes:

- People who are attracted to members of their same sex (whether men or women)
- Those who identify themselves with or as the opposite sex
- Those who identify themselves as a third sex
- Traditional communities such as *hijras*, *jogtas* and *kothis*
- People who are forced into same sex behaviour due to economic compulsions (e.g. male commercial sex workers, masseurs, bar boys)
- People who indulge in situational same sex behaviour, but may not identify with any of the sexual minority groups (same sex behaviour in predominantly male concentrated populations such as, boys hostels, prisons or the armed forces)

Documented evidence of same sex behaviour may be seen from the Vedic era, through the generations, and up to the present date. Some studies estimate that 5 to 8% of any given population is homosexual. Very few behavioural studies have been conducted on same-sex behaviour in India. Amongst these, most studies have focussed on same sex behaviour/orientation amongst men while not much work has been done on same sex behaviour/orientation amongst women.

Rough estimates point out that there are about 50 million men, in India, who have sex with men. Owing to the culture of silence around women's sexuality, similar estimates would not be accurate.

### Human Rights and Sexual Minorities

All sexual minorities are stigmatised and disempowered – socially, culturally, politically, legally and often, economically. The manner and extent of the disempowerment, however differs from group to group and from region to region. The fundamental right to life, which has been construed by our Supreme Court to mean the right to a wholesome life, is denied to sexual minorities by virtue of there being no safe spaces where alternate sexual and gender identities may exist. The freedom of speech and expression does not exist for these populations and access to basic services such as health, are denied. In the case of some populations, such as *hijras*, there is no legal recognition of their very existence.

<sup>26</sup> This background paper is based on the deliberations at the "Looking into the next Millennium" conference conducted by the Humsafar Trust at Mumbai in the month of May 2000. Sexual minority groups and individuals attended this conference from all over the country, including Andhra Pradesh, Bihar, Delhi, Karnataka, Maharashtra, Orissa, Tamil Nadu and West Bengal. The process may not, however, be considered to be representative of all sections of sexual minorities. Hijras, for example, were represented only to a limited extent. Similarly, participation of lesbian groups at this meeting was limited. To address this limitation, this paper was sent out to various experts and consultants in the field for their comments and inputs. These have been considered and incorporated to the extent possible.

These invisible populations are denied the most basic social, cultural and civil rights contemplated by the human rights regime, not just by civil society, but also by positive state action.

Although our Constitution does not specifically recognise sexual orientation as a basis of non-discrimination, it does prohibit discrimination on the ground of sex. If sex is construed to include 'sexual orientation' in its ambit, then clearly there is a bar on such discrimination.

### **Statement of the Problem**

It is today an accepted hypothesis that unless the rights of those who are most affected by the pandemic are protected and actively promoted their vulnerability to the pandemic cannot be reduced. In addition, this approach will help in making prevention efforts more effective in the larger community. The fact that sexual minorities are denied basic rights makes them vulnerable to HIV.

- The social context, in which sexual minorities exist, along with the hostile legal regime, pushes sexual minorities into risky behaviour and also limits access to health and support.
- Harassment, extortion, blackmail and coercive sex under the threat of disclosure or prosecution are direct results of the hostile environment.
- The creation of safe spaces for interaction of sexual minorities is actively discouraged, thereby rendering sexual contact possible only in public spaces. Such sexual interaction is often hurried and furtive. In such circumstances there is often no space for considering and/or negotiating safer sex options. These problems are compounded by identification by certain groups with female gender stereotypes, which decreases their power to negotiate safer options.
- Such a context actively discourages the setting up of medical and care services targeted at the specific needs of sexual minorities. People do not access medical services (where available) to deal with STI/STD owing to the fear of same sex behaviour being discovered and stigmatisation/prosecution. The existence of and the problems related to male sex work also need to be understood in this context.
- Criminal provisions with respect to same sex behaviour directly impede access to information regarding safer sexual practices. Such lack of information enhances the possibility of risky behaviour and further complicates the situation.
- Vulnerability of sexual minorities is also an issue of concern vis-à-vis transmission amongst the heterosexual population as there is a significant amount of heterosexual interaction amongst sexual minorities. For example, there are a large number of bisexual men and women. There also are other sexual minorities who face and often succumb to considerable social pressure to conform to the heterosexual norm and to get married.

A strategy that focuses on behaviour and on safer sex information is clearly insufficient. Two approaches have recently emerged that have looked beyond just behaviour. One attempts at organising already existing traditional identities, such as the *kothi* identity (which implies effeminate males, usually from the more economically depressed segments) and to empower this most disempowered of groups, so that they become

capable of negotiating safer options and protecting themselves. Owing to the culture of silence around women's sexuality, similar identities have not been identified and categorised. The other focuses on empowerment through promoting the development of more concrete identities, such as gay (self-identified MSM usually from economically stable backgrounds) or lesbian identities, which in turn acts against vulnerability.

The statement of the problem would therefore be in identifying and addressing factors that lead to disempowerment of sexual minorities and therefore to their vulnerability, in the context of emerging identities based on sexual orientation and gender.

### **Social Hurdles**

- Minimal social acceptance of sexual minorities and pressures to conform with heterosexual norms
- Silence with respect to sexuality in general, which makes dialogue on rights issues related to sexuality difficult if not impossible
- No space for alternative sexual identities to develop. Empowerment is not possible without the evolution of identities
- Economic compulsion pushes men and boys into sex work
- Identification with female gender stereotypes by certain segments puts them in unequal power relationships
- Difficult to access medical and legal services due to stigma and social attitudes
- Groups such as *hijras* are assigned particular roles and accorded particular stereotypes in society. These roles disallow such groups from social, cultural or economic empowerment.
- Condoms are culturally associated with contraception and not safer sex. As such, condoms are not generally linked with same sex behaviour.
- Discrimination at places of employment, in housing and other sites is rampant.

### **Legal Hurdles**

- Section 377 of the Indian Penal Code, which reproduces 19<sup>th</sup> century anti-sodomy laws from England, criminalizes "carnal intercourse against the order of nature". The punishment prescribed under this provision is imprisonment for a maximum of ten years and fine. The offence does not differentiate between consensual and non-consensual same sex behaviour.
- There is no legal recourse against sexual abuse and violence within same sex behaviour. A complaint under Section 377 would implicate the person offended as well. As such, the law does not recognise male rape and child sexual abuse of boys.
- Section 377 is the basis of harassment of sexual minorities. The police pick up people from public spaces, such as parks and public toilets. Extortion, violence, sexual harassment and other violations of basic rights occur frequently. Harassment is even more severe when the person is an effeminate male.
- The laws relating to Obscenity and Public Nuisance, under the Indian Penal Code and the local Police Acts are also used to harass people from sexual minorities.
- Health interventions with sexual minorities may be construed as abetment of these offences. This has been a source of harassment of organisations and groups working



with sexual minorities. HIV focused interventions are thus not possible without fear of persecution and violence from the police.

- Publication of material focused on safer sex and the above-mentioned laws may hit HIV/AIDS in the same-sex context. Access to resource material is also restricted due to these laws. This makes spreading of information, intervention and empowerment even more difficult.
- The law does not even recognise the existence of trans-gendered people. It is difficult for them to get ration cards, voter identity cards and passports. In such circumstances, it is not possible for them to access their rights.
- *Hijras* are often harassed and abused under the laws relating to sex work.
- There are and have been sensitive police officials who have co-operated with the intervention programs, but this is dependent on individual sensitivity and one transfer can alter the real life situations of sexual minorities.
- Due to the illegality and stigma surrounding same sex behaviours, registration of organisations working on sexual health and sexual minorities is difficult. This hinders intervention efforts.
- As long as Section 377 criminalizes same-sex behaviour there may be no legitimate intervention or development of any support structures for sexual minorities. Despite this many States have taken cognisance of some issues related to sexual minorities in their response to HIV/AIDS.

### **Suggested Points for Discussion**

- 1) Should Section 377 of the Indian Penal Code be done away with? The Law Commission has recently recommended that rape laws should be made gender neutral so as to include male rape and child sexual abuse of male children along with the repeal of Section 377. Is this a positive recommendation from a public health perspective?
- 2) Should the Constitution be amended to clearly recognise sexual orientation/gender identity as a prohibited marker for discrimination like sex, caste, religion etc?
- 3) Should there be a move towards a positive anti-discrimination statute with respect to sexual minorities such as in the South African Constitution?
- 4) What strategies could be developed for the empowerment of sexual minorities and the creation of an enabling environment?
- 5) Should there be a Constitutional / legal recognition of the third sex?
- 6) What can be done in order to change the social attitudes towards sexual minorities?
- 7) What can be done to stop police harassment of sexual minorities?

## **Injecting Drug Users<sup>27</sup>**

*(Group IV – Day 2)*

### **Context**

Drug use is prevalent in all parts of the country and across classifications of class, caste, religion and gender. Owing to the traditional culture of drug use, ganja, charas, bhang and opium have been linked with religious functions and also have been used for medicinal and recreational purposes for centuries.

The shift from these traditional drugs to life endangering drugs such as heroin and brown sugar and further, to pharmaceutical drugs, is linked with the legal, social and economic developments in the last few decades.

The introduction of the Narcotic and Psychotropic Substances Act (NDPS Act) in 1985, which did not reflect the socio-cultural realities of drug use patterns in India, criminalized possession, manufacture and sale of certain drugs, including those that were traditionally used. The impact on availability and quality of ganja and charas pushed more people into use of Heroin and Brown Sugar, which around this time were flooding the drug market.

The initial use of these drugs was mostly by smoking, but the fall in availability and quality, and the rise in prices encouraged the use of these drugs in the injectable form. Non-access to heroin also made people seek treatment. Injectable pharmaceutical drugs, such as Tidigesic, were used for the purpose of providing relief from heroin withdrawal symptoms. This, on one hand, made injecting a more popular mode of drug use, and on the other, introduced drug users to pharmaceutical drugs.

At present, the commonly used drugs include pharmaceutical drugs that are available across the counter at Chemist shops at affordable prices and without the fears and restrictions of criminal law.

The impact of drug use on the health and economic status of individuals as well as the community at large is one significant concern. The other major concern is that intravenous drug use is the third largest mode of transmission of HIV in India. As a matter of fact, in some states such as Manipur, it has been recognised as the most common mode of transmission. Intravenous drug use and the vulnerability of drug users to HIV/AIDS has become an issue of concern in other parts of the country as well, particularly in urban areas.

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<sup>27</sup> This paper is based on interactions with groups and individuals working with injecting drug users in the states of Manipur and Delhi. As such, the identification of issues may not be exhaustive and in the case of some states, may not be reflective of the actual situation. At the same time, the paper attempts to provide an overview of issues of concern that are general in nature, while only referring to the specific contexts of Manipur and Delhi. This paper also does not deal exhaustively with specific issues around drug use and women, owing to the limitations of the consultative process. To address this limitation, this paper was sent out to various experts and consultants in the field for their comments and inputs. These have been considered and incorporated to the extent possible.

### **Human Rights and Drug Use**

The human rights of drug users, especially from the lowest economic strata are constantly violated, owing, firstly to the social constructions around certain forms of drug use and secondly, to the abuse of laws by law enforcement agencies. Intravenous drug users, being an easily identifiable group, are harassed by the police (atrocities include physical abuse, extortion and illegal detention), denied access to and discriminated against in health care and employment sectors and denied access to services that may aid in effective rehabilitation.

Intravenous drug use gives rise to serious health problems such as abscesses, gangrenes, tuberculosis and other respiratory diseases. These problems require immediate treatment and may be fatal if services are not provided. Intravenous drug users of the lowest economic sections have no access to such services. Even where services are available, they are not accessed until the last moment, due to discrimination and the fear of it. This drives the community underground and along with it, a significant portion of people who are more vulnerable to HIV.

The onslaught of the HIV/AIDS pandemic has given rise to further discrimination in the health care sector. Identification of a person as an intravenous drug user often implies total refusal of treatment. In other circumstances, identification as an intravenous drug user implies forced testing without pre- or post-test counselling and subsequent denial of health care, sometimes even emergency services.

The vulnerability to HIV/AIDS due to drug use is also linked with vulnerability due to other circumstances. There is a link between drug use and sex work. Often, people do sex work to support their habit and vice versa. There is a link between child sexual abuse on the street and drug use. Younger children are often encouraged to take drugs by adults/older children so as to do away with resistance.

Vulnerability to HIV/AIDS is thus linked with this denial of basic human rights.

### **Problem Statement**

In dealing with problems around drug use, the two important objectives are to provide effective rehabilitation options and the prevention of HIV transmission.

With respect to rehabilitation strategies:

- There are no real options available to drug users other than abstinence and piecemeal rehabilitation programs. The success of these strategies has been minimal as compared to the grave human rights violations that they entail, such as chaining and beating of drug users as part of "therapy".
- There is a lack of understanding with respect to the experience of addiction and de-addiction.
- Social support is not given importance in rehabilitation strategies, whereas it is impossible for a person to break out of the habit without support due to stigma and discrimination

- Where attempts have been made to come out of the habit, the lack of support structures to absorb those “rehabilitated” and the absence of an enabling environment push people into relapses.
- Many people begin drug use during adolescence and as such may not have had the opportunity to develop particular skills that may support any sort of lifestyle.
- There is no support for people who are affected by Drug use but may not themselves use drugs. Links between violence against women and drug use, the predicament of widows, orphans, destitute children etc need to be understood and addressed.
- Applying a comprehensive strategy, linking harm reduction to long-term rehabilitation could be a more viable option as experience has shown that neither can work in isolation.

With respect to strategies focussing on prevention of HIV transmission:

Sharing of needles/syringes is the main form of high-risk behaviour related to injecting drug use. The reasons why people engage in such behaviour include:

- Lack of awareness as to HIV and of the fact that transmission is possible though sharing of needles
- The fear of police harassment discourages access to clean needles and carrying of personal equipment.
- For poorer drug users, personal or clean needles are often not affordable
- Drug use is often a group activity where sharing of equipment is a source of bonding.

To counter these problems, needle exchange programmes have been introduced in some parts of the country. Whereas such initiatives may be considered abetment of offences under the NDPS Act, some states have attempted to implement and support such programmes. In addition to legal concerns, questions have been raised about the sustainability and community support for these programmes.

Other possibilities of state supported and community based initiatives for not only harm reduction but also drug-demand reduction may be explored.

*The problem statement is thus with respect to the creation of an enabling environment that addresses social stigma and discrimination, legal strategies to deal effectively with the inflow of drugs, support structures for intravenous drug users and strategies that find a balance between harm reduction and rehabilitation. Such strategy must be based on respect for human rights of the affected communities.*

### **Social Hurdles**

Stigma sticks to a person once she/he is identified as a “drug addict”. Termination of employment and social rejection (including rejection by family members) and isolation are common experiences of drug users. Apart from a moral basis for such a stigma, drug users are often suspected to be thieves involved in petty crimes in order to sustain the habit. Such stereotypes make reintegration into society very difficult.

In the context of Delhi, the intravenous drug users are a floating population. As such, continuity of interventions is difficult. In such circumstances, medical services and harm reduction programs gain importance.

The fear of stigma is a cause for people not accessing health care, especially in the context of HIV/AIDS. This is more so in the case of needle exchange programs. This is to say that in order to provide effective solutions, there must also be a larger change in the way that drug use and drug users are perceived. Counselling of families has been suggested along with the counselling of drug users in this context.

### **Legal hurdles**

The NDPS Act provides for the prohibition and regulation of cultivation, collection, production, manufacture, transport, export, import inter-state and in and out of India, transshipment, possession, use, consumption, sale, purchase, warehousing, trafficking etc. of narcotic drugs and psychotropic substances which are enlisted in schedules to the Act.

The Act is amongst the strictest laws in India. The punishments prescribed in the Act include death penalty in certain cases, imprisonment up to 20 years and fines up to the sum of the Rupees 2 lakh. Rules of evidence and procedure are also changed in order to make conviction more probable. All offences under the Act are cognisable and there may be no bail except under certain circumstances. A large population of under-trials in prisons all over the country is detained under this Act.

The Act recognises a difference between a drug dealer and a drug "addict". There is provision for an addict to be released on probation if she/he undertakes to undergo medical treatment at a hospital maintained or recognised by the government.

In practice, the NDPS Act is rarely used in the manner envisaged. Drug dealers and peddlers are rarely prosecuted, while the user is often subjected to harassment, physical violence, and extortion of money and drugs. Apart from the abuse of the powers under the NDPS Act, other criminal laws are used to harass intravenous drug users from the lower economic strata. The reason is that drug users living on the streets, close to temples and other sources of free food are the easiest targets of the misuse of law. People are picked up on a regular basis and booked for petty crimes to show that action has been taken on any given complaint. In such circumstances, drug users have no help at all, no access to legal services and no knowledge of rights.

Police harassment has a serious impact on the efficacy of health and rehabilitation interventions. Police often pick up (arrest or illegally detain) people in the process of rehabilitation. This problem is compounded in areas where intravenous drug users are a floating population. Police harassment and the fear of police harassment literally chase drug users away from health services. This problem is even worse in the context of needle exchange programs. Even where a needle exchange program is supported by a State AIDS Control Society, there is no co-operation from the law enforcement agencies and harassment continues to be a hurdle.

The fact that the laws relating to drugs are not sensitive to the fact that a large percentage of drugs being abused are available easily at low prices at Chemists shops is another shortcoming of the legal response. In Delhi it has been observed that older people use drugs such as heroin whereas younger people use pharmaceutical drugs, perhaps due to the perception that pharmaceutical drugs are not “drugs” and due to the fact that buying them is not illegal.

Corruption in the criminal justice system ensures that the bigger dealers and retailers do not face any trouble whereas drug users off the streets have to face harassment and extortion.

There is an urgent need to take a fresh look at the legal regime around drugs and drug use.

### **Points for Discussion**

- 1) What legal reforms could be initiated so as to reduce drug demand and alter drug-using patterns?
- 2) What strategies may be evolved in order to ensure access to medical and other services to IDU?
- 3) What steps may be taken to prevent the abuse of laws against intravenous drug users?
- 4) What steps need to be taken in order to provide an enabling environment for rehabilitation and integration of IDU in society?
- 5) On the basis of a human rights approach, could harm reduction programmes be a part of the state’s response to HIV/AIDS?
- 6) The therapeutic community approach, based on self-help groups, whereby peers organise themselves to support each other have been seen to be successful. What can the state do to encourage such initiatives?

## ***Annex D***

# **International Guidelines on Human Rights and HIV/AIDS<sup>1</sup>**

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**GUIDELINE 1:** States should establish an effective national framework for their response to HIV/AIDS which ensures a coordinated, participatory, transparent and accountable approach, integrating HIV/AIDS policy and programme responsibilities across all branches of government.

**GUIDELINE 2:** States should ensure, through political and financial support, that community consultation occurs in all phases of HIV/AIDS policy design, programme implementation and evaluation and that community organizations are enabled to carry out their activities, including in the field of ethics, law and human rights, effectively.

**GUIDELINE 3:** States should review and reform public health laws to ensure that they adequately address public health issues raised by HIV/AIDS, that their provisions applicable to casually transmitted diseases are not inappropriately applied to HIV/AIDS and that they are consistent with international human rights obligations.

**GUIDELINE 4:** States should review and reform criminal laws and correctional systems to ensure that they are consistent with international human rights obligations and are not misused in the context of HIV/AIDS or targeted against vulnerable groups.

**GUIDELINE 5:** States should enact or strengthen anti-discrimination and other protective laws that protect vulnerable groups, people living with HIV/AIDS and people with disabilities from discrimination in both the public and private sectors, ensure privacy and confidentiality and ethics in research involving human subjects, emphasize education and conciliation, and provide for speedy and effective administrative and civil remedies.

**GUIDELINE 6:** States should enact legislation to provide for the regulation of HIV-related goods, services and information, so as to ensure widespread availability of qualitative prevention measures and services, adequate HIV prevention and care information and safe and effective medication at an affordable price.

**GUIDELINE 7:** States should implement and support legal support services that will educate people affected by HIV/AIDS about their rights, provide free legal services to enforce those rights, develop expertise on HIV-related legal issues and utilize means of protection in addition to the courts, such as offices of ministries of justice, ombudspersons, health complaint units and human rights commissions.

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<sup>1</sup> Source: <[www.unaids.org](http://www.unaids.org)>, UNAIDS, 08 December 2000. Second Consultation of

- GUIDELINE 8:** States, in collaboration with and through the community, should promote a supportive and enabling environment for women, children and other vulnerable groups by addressing underlying prejudices and inequalities through community dialogue, specially designed social and health services and support to community groups.
- GUIDELINE 9:** States should promote the wide and ongoing distribution of creative education, training and media programmes explicitly designed to change attitudes of discrimination and stigmatization associated with HIV/AIDS to understanding and acceptance.
- GUIDELINE 10:** States should ensure that government and the private sector develop codes of conduct regarding HIV/AIDS issues that translate human rights principles into codes of professional responsibility and practice, with accompanying mechanisms to implement and enforce these codes.
- GUIDELINE 11:** States should ensure monitoring and enforcement mechanisms to guarantee the protection of HIV-related human rights, including those of people living with HIV/AIDS, their families and communities.
- GUIDELINE 12:** States should cooperate through all relevant programmes and agencies of the United Nations system, including UNAIDS, to share knowledge and experience concerning HIV-related human rights issues and should ensure effective mechanisms to protect human rights in the context of HIV/AIDS at international level.



## **Annex E**

# **Children living in a world with HIV/AIDS**

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*Committee on the Rights of the Child, General Discussion, 5 October 1998*

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The Committee on the Rights of the Child periodically devotes one day of general discussion during its official sessions to a specific article of the Convention on the Rights of the Child (CRC) or to a theme in the area of the rights of the child in order to enhance understanding of the contents and implications of the Convention.

The Committee decided to devote one day of general discussion to the issue of “Children living in a World with HIV/AIDS” on 5 October 1998.

In an **outline** prepared to guide the general discussion, the Committee pointed out that the HIV/AIDS epidemic has drastically changed the world in which all children live. Millions of children have been infected and died worldwide since the beginning of the epidemic. Initially considered to be only marginally affected, later research has pointed out that women and children are increasingly becoming infected, with the majority of new infections in many parts of the world taking place in young people between the ages of 15 and 24. Younger children are predominantly infected by HIV-positive mothers who are not aware of their infection and transmit the virus to their children before or during birth or through breast-feeding. Adolescents are also highly vulnerable to HIV/AIDS, and more so because their early sexual experiences often take place without access to proper information. The epidemic has also increased victimization of children living in particularly difficult circumstances, who are at greater risk of infection, which in turn leads to stigmatization and greater discrimination.

The Committee also stressed the relevance of the CRC to prevention efforts, recalling that HIV/AIDS is often seen primarily as a medical problem, while the holistic, rights-centered approach, required by the Convention, is more appropriate to tackle the much broader range of issues involved.

The Committee identified five main areas to be considered during the day of general discussion:

- Identifying and understanding the rights of children living in a world with HIV/AIDS and evaluating their status at national level;
- Promoting the general principles of the Convention in the context of HIV/AIDS, including non-discrimination and participation;
- Identifying best practices in the implementation of rights related to the prevention of HIV/AIDS infection and the care for, and protection of, children infected or affected by the epidemic;
- Contributing to the formulation and promotion of child-oriented policies, strategies, and programmes to prevent and combat HIV/AIDS;
- Promoting the adoption at the national level of approaches inspired by the International Guidelines on HIV/AIDS and Human Rights, jointly issued by the

Office of the United Nations High Commissioner for Human Rights and the Joint United Nations Programme on HIV/AIDS.

On the basis of the recommendations of the discussion groups and the general discussion that followed on the various issues, the Committee formulated the following recommendations:

- (a) States, programmes and agencies of the United Nations system, and NGOs should be encouraged to adopt a child's rights approach to HIV/AIDS. States should incorporate the rights of the child in their national HIV/AIDS policies and programmes, and include national HIV/AIDS programme structures into the national monitoring and coordinating mechanisms for children's rights.
- (b) States should adopt and disseminate the International Guidelines on HIV/AIDS and Human Rights and ensure their implementation at the national level. Programmes and agencies of the United Nations system as well as NGOs should contribute to the dissemination and implementation of the Guidelines.
- (c) The right of children to participate fully and actively in the formulation and implementation of HIV/AIDS strategies, programmes and policies should be fully recognized. A supportive and enabling environment should be provided, in which children are allowed to participate and receive support for their own initiatives. The proven effectiveness of peer education strategies, in particular, should be recognized and taken into account for its potential contribution to the mitigation of the impact of the HIV/AIDS epidemic. The key objective of HIV/AIDS policies should be to empower children to protect themselves.
- (d) Access to information as a fundamental right of the child should become the key element in HIV/AIDS prevention strategies. States should review existing laws or enact new legislation to guarantee the right of children to have access to HIV/AIDS related information, including to voluntary testing.
- (e) Information campaigns targeting children should take into account the diversity of audience groups and be structured accordingly. Information on HIV/AIDS should be adapted to the social, cultural and economic context, and it should be made available through age-appropriate media and channels of dissemination. In the selection of target groups, attention should be given to the special needs of children who experience discrimination or who are in need of special protection. Information strategies should be evaluated for their effectiveness in leading to a change of attitudes. Information on the Convention of the Rights of the Child and on HIV/AIDS issues, including the teaching of life-skills, should be incorporated into school curricula, while different strategies should be designed to distribute such information to children who cannot be reached through the school system.
- (f) HIV/AIDS data collected by States, and by programmes and agencies of the United Nations system, should reflect the Convention's definition of a child (human beings

under eighteen years of age). Data on HIV/AIDS should be disaggregated by age and gender and reflect the situation of children living in different circumstances and of children in need of special protection. Such data should inform the design of programmes and policies targeted to address the needs of different groups of children.

- (g) More information should be collected and disseminated on best practices, in particular on community-based approaches to HIV/AIDS which have positive outcomes.
- (h) More research should be carried out on mother-to-child transmission, and in particular on the risk and alternatives to breast-feeding.
- (i) Information designed to raise awareness about the epidemic should avoid dramatizing HIV/AIDS in ways that can lead to further stigmatization for those affected by the epidemic.
- (j) States should review existing laws or enact new legislation to fully implement article 2 of the Convention on the Rights of the Child, in particular to prohibit expressly discrimination based on real or perceived HIV status and to prohibit mandatory testing.
- (k) Urgent attention should be given to the ways in which gender-based discrimination places girls at higher risk in relation to HIV/AIDS. Girls should be specifically targeted for access to services, information, and participation in HIV/AIDS related programmes, while the gender-based roles predominant in each situation should be carefully considered when planning strategies for specific communities. States should also review existing laws or enact new legislation to guarantee inheritance rights and security of tenure for children irrespective of their gender.
- (l) Prevention and care strategies designed to deal with the epidemic should focus on children in need of special protection, including those living in institutions (whether social welfare ones or detention centres), those living or working in the streets, those suffering from sexual or other types of exploitation, those suffering from sexual or other forms of abuse and neglect, those involved in armed conflict, etc. States should, in particular, review existing laws or enact new legislation to protect children against sexual exploitation and abuse and to ensure rehabilitation of victims and the prosecution of perpetrators. Particular attention should also be given to discrimination based on sexual orientation, as homosexual boys and girls often face acute discrimination while being a particularly vulnerable group in the context of HIV/AIDS.
- (m) HIV/AIDS care should be defined broadly and inclusively to cover not only the provision of medical treatment, but also of psychological attention and social reintegration as well as protection and support, including of a legal nature.

- (n) Barriers to the provision of youth friendly health services should be identified and removed. States should review existing laws or enact new legislation to regulate the minimum age for access to health counselling, care and welfare benefits. The formulation of adolescent reproductive health policies should be based on the right of children to have access to information and services, including those designed to prevent sexually transmitted diseases or teen-age pregnancy.
- (o) States should review existing laws or enact new legislation to recognize the specific rights of the child to privacy and confidentiality with respect to HIV/AIDS, including the need for the media to respect these rights while contributing to the dissemination of information on HIV/AIDS.
- (p) States, programmes and agencies of the United Nations system, and NGOs should explore the possibilities for new partnerships which could bring together organizations that deal with human rights, children-centred ones and AIDS-focused ones to look together for ways to respond to the epidemic, and to work together in reporting to the Committee on the Rights of the Child.

## ***Annex F***

## **India's status of ratifications<sup>1</sup>**

<b>Legal Instrument</b>	<b>Status</b>	<b>Sign. Date</b>	<b>EIF date</b>	<b>Rec. of Instrument</b>
Convention Against Torture and Other Cruel Inhuman or Degrading Treatment or Punishment (CAT)	Signed	14/10/97		
Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)	Ratification	30/07/80	08/08/93	09/07/93
Convention on the Rights of the Child (CRC)	Accession		11/01/93	11/12/92
International Convention on the Elimination of All Forms of Racial Discrimination (CERD)	Ratification	02/03/67	04/01/69	03/12/68
International Covenant on Civil and Political Rights (ICCPR)	Accession		10/07/79	10/04/79
International Covenant on Economic, Social and Cultural Rights (CESCR)	Accession		10/07/79	10/04/79

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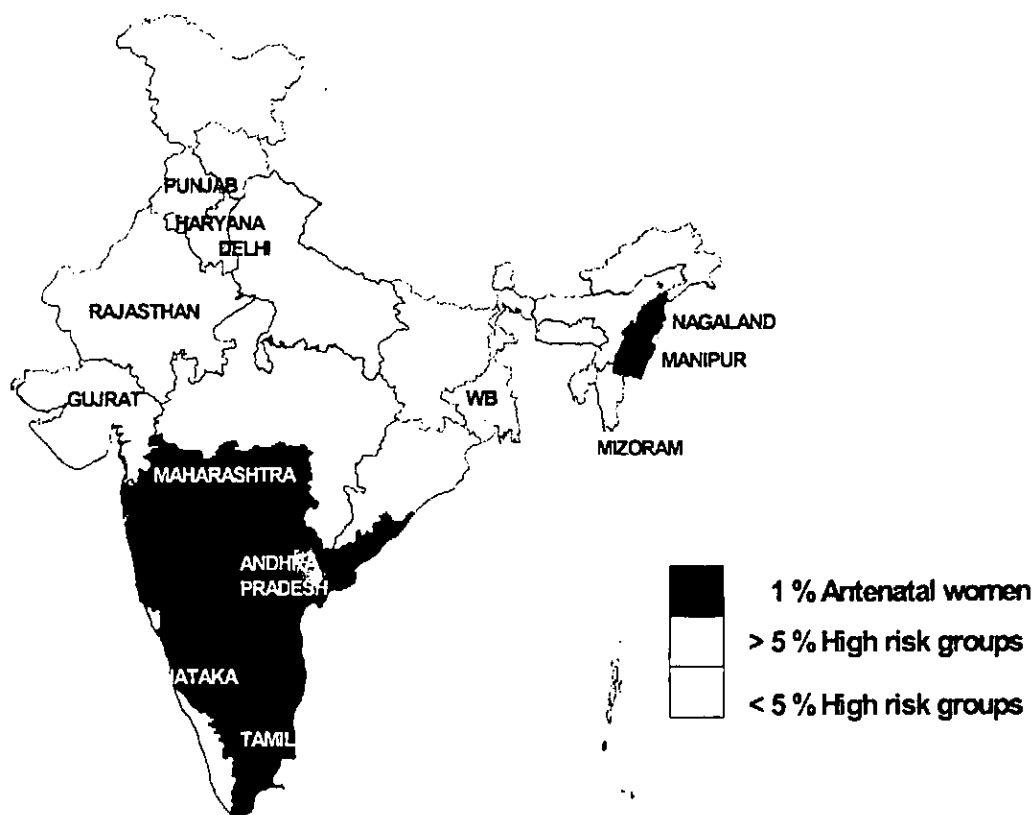
<sup>1</sup> Source: URL: <[www.unhchr.ch](http://www.unhchr.ch)>, UN High Commissioner for Human Rights, 08 December 2000.

## Annex G

## Status of HIV Epidemic in India



Estimated 3.6 million infected (1999)



Source : Surveillance data from NACO, 1999

**Annex H**

## **Adults & children living with HIV/AIDS (World)**



**Estimate as of end 1999**



Source : UNAIDS, 2000

## **Annex I**

## **Conference Agenda**

### **Friday**

08.30 – 09.30 hrs.	Registration	
09.30 – 10.30 hrs.	Opening Session	- <i>Lighting of the Lamp</i>
	<i>Welcome:</i>	Shri N. Gopalaswami, Secretary General, NHRC
	<i>Address:</i>	Shri Javed Ahmed Chowdhury, Secretary (Health), Ministry of Health & Family Welfare
	<i>Address:</i>	Dr Brenda Gael McSweeney, UN Resident Co-ordinator
	<i>Inaugural Address:</i>	Shri Arun Jaitley, Union Minister of Law, Justice & Company Affairs
	<i>Presidential Address:</i>	Justice Shri J.S. Verma, Chairperson, NHRC
	<i>Vote of Thanks:</i>	Dr P.L. Joshi, Joint Director, NACO
10.45 – 11.15 hrs.	Plenary Session and Discussion	
	<i>Theme:</i>	<i>Global Trends of the HIV/AIDS Epidemic - Social and Human Rights Implications</i>
	<i>Chair:</i>	Shri Sudarshan Agarwal, Member, NHRC
	<i>Presenter:</i>	Mr Gordon Alexander, UNAIDS
11.15 – 11.45 hrs.	Plenary Session and Discussion (Cont.)	
	<i>Theme:</i>	<i>HIV/AIDS Epidemic in India – The Community Response</i>
	<i>Presenter:</i>	Shri J.V.R. Prasada Rao, Additional Secretary & Project Director, NACO
11.45 – 12.15 hrs.	Plenary Session and Discussion (Cont.)	
	<i>Theme:</i>	<i>Public Health within a Human Rights Framework with special reference to HIV/AIDS</i>
	<i>Presenter:</i>	Shri Anand Grover, Lawyers Collective
12.15 – 12.30 hrs.	Briefing for working group sessions	Shri Vivek Divan, Lawyers Collective
12.30 – 13.00 hrs.	Parallel Working Group Sessions	
	Group I – Consent and Testing	
	<i>Chair:</i>	Dr P.L. Joshi, NACO
	<i>Discussant:</i>	Dr (Mrs) V. Muthuswami, ICMR
	Group II – Confidentiality	
	<i>Chair:</i>	Dr Bhanu Verma
	<i>Discussant:</i>	Shri Anand Grover, Lawyers Collective



**Group III – Discrimination-Health Care**

*Chair:* Dr Kusum Sehgal, Former Principal, Lady  
Harding Medical College  
*Discussant:* Ms Anandi Yuvarai, INP+

**Group IV – Discrimination-Employment**

*Chair:* Prof Joga Rao, National Law School of  
India University, Bangalore  
*Discussants:* Ms Shalini Bharat, TISS  
Ms Anjali Gopalan, NAZ Foundation

13.00 – 13.45 hrs. Lunch

13.45 – 16.00 hrs. Working Group Sessions (cont.)

16.00 – 17.00 hrs. Plenary Session

*Theme:* Reports by Working Groups followed by  
discussions  
*Chair:* Justice Shri Tipnis, Hon'ble Lok Ayukta of  
Maharashtra  
*Presenters:* Working Group Rapporteurs

19.00 – 21.00 hrs Reception

**Saturday**

09.00 – 09.15 hrs. Review of Day 1  
Mr Gordon Alexander, UNAIDS

09.15 – 09.45 hrs. Plenary Session  
*Theme:* 'Vulnerability, HIV/AIDS and Human  
Rights'  
*Chair:* Dr K.S. Reddy, WHO Consultant  
*Co-chair:* Prof. V.S. Rekhi, National Law Institute  
University, Bhopal  
*Presenter:* Ms Sonam Yangchen Rana, Programme  
Co-ordinator, UNDP HIV and Development  
Programme

09.45 – 10.00 hrs. Briefing for Working Group sessions  
Shri Vivek Divan, Lawyers Collective

10.00 – 13.00 hrs. Parallel Working Group Sessions

**Group I – Women in Vulnerable Environments**

*Chair:* Ms Chandni Joshi, Regional Programme  
Director, UNIFEM  
*Discussants:* Ms Abha Bhaiya, Jagori  
Ms Nandinee Bandhupanhaya, DMSC/POP  
Council

**Group II – Children and Young People**

*Chair:* Ms Neelam Kapoor, NACO

*Discussant:* Dr Radhika Chopra, Dep. of Sociology,  
Delhi School of Economics, Univ. of Delhi

**Group III - People Infected/Affected**

*Chair:* Dr Shalini Bharat, TISS

*Discussants:* Ms Roma Jana  
Shri R. Elango, KNP+

**Group IV – Vulnerability of Marginalised Populations**

*Chair:* Ms Anjali Gopalan, NAZ Foundation

*Discussants:* Shri Luke Samson, Sharan  
Shri Ashok Row Kavi, Humsafar Trust

13.00 – 13.45 hrs.

Lunch

13.45 – 15.00 hrs.

Plenary Session

Report of working groups followed by discussions

*Chair:* Prof Bhanu Verma

15.00 – 16.00 hrs.

Panel Discussion

*Theme:* 'Strategies for Enabling Environment and  
its Implementation'

*Chair:* Justice Ms Sujata V Manohar, Member,  
NHRC

*Discussant:* Mr Gordon Alexander, UNAIDS

*Panellists:* Dr Radhika Ramasubban, Centre for Social  
and Technological Change  
Shri A. Sengupta, Principal Secretary,  
Health & Family Welfare Department  
Govt. of Karnataka Karnataka  
Dr Srinath Reddy, Prof. of Cardiology,  
AIIMS  
Shri Anand Grover, Lawyers Collective  
Shri R. Elango, KNP+

16.15 – 17.00 hrs.

Closing Session

*Theme:* 'Feedback and Recommendations for a Plan  
of Action for Human Rights and HIV/AIDS  
in India'

*Chair:* Justice Shri J.S. Verma,  
Chairperson, NHRC

*Rapporteur:* Shri Akshay Khanna, Lawyers Collective

*Speaker:* Shri J.V.R. Prasada Rao, Additional  
Secretary & Project Director, NACO

*Chief Guest:* Shri Dr C.P. Thakur,  
Union Minister of Health & Family Welfare

*'Concluding Remarks'* Justice Shri J.S. Verma, Chairperson, NHRC  
*Vote of thanks* Ms Pernilla Berlin, UNAIDS

## **Annex J**

## **List of Participants**

### **National Conference on Human Rights and HIV/AIDS, 24-25 November 2000**

<b>Name</b>	<b>Designation</b>	<b>Organisation/agency</b>
1. Ms. Renu C. Deshpande	Deputy Secretary (Admn & DP)	Ministry for Social justice and Empowerment, Delhi
2. Shri A. Sengupta	Principal Secretary	Health & Family Welfare Department, Govt. of Karnataka
3. Dr A.K. Khokhar	Dy. Medical Commissioner & Project Incharge, AIDS Cell	Employees State Insurance Corporation, Delhi
4. Dr (Ms) Sangeeta Narang	Nodal Director	Employees State Insurance Corporation, Delhi
5. Shri Maurya	Director	National Commission for Scheduled Casts and Scheduled Tribes, Delhi
6. Shri Hasib Ahmad	Deputy Secretary	National Commission for Minorities, Delhi
7. Shri M.P.S. Sethi	Joint Director (Child Welfare)	Ministry of Human Resource Development (Dept. of Women & Children), Delhi
8. Shri S.M. Imran Ali	Law Officer	National Commission for Women, Delhi
9. Justice Shri J.S. Verma	Chairperson	National Human Rights Commission, Delhi
10. Dr Justice K. Ramaswamy	Member	National Human Rights Commission, Delhi
11. Justice Ms Sujata V. Manohar	Member	National Human Rights Commission, Delhi
12. Shri Sudarshan Agarwal	Member	National Human Rights Commission, Delhi
13. Shri Virendra Dayal	Member	National Human Rights Commission, Delhi
14. Shri N. Gopalaswami	Secretary General	National Human Rights Commission, Delhi
15. Shri Y.N. Srivastava	Director General	National Human Rights Commission, Delhi
16. Ms S. Jalaja	Joint Secretary	National Human Rights Commission, Delhi
17. Shri C. Jawa	Presenting Officer cum Registrar General in charge	National Human Rights Commission, Delhi
18. Shri B.S. Kallur	Senior Superintendent of Police	National Human Rights Commission, Delhi
19. Shri K.N. Gupta	Senior Superintendent of Police	National Human Rights Commission, Delhi
20. Shri Y.S.R. Murthy	PS to Chairperson –cum-OSD (Research)	National Human Rights Commission, Delhi
21. Shri E.I. Malekar	Assistant Registrar (Law)	National Human Rights Commission, Delhi
22. Dr Savita Bhakhry	Senior Research Officer	National Human Rights Commission, Delhi

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23. Ms Maushumi Chakravathy	Information Officer	National Human Rights Commission, Delhi
24. Shri Gautam Ghosh Moulik	Deputy Registrar	West Bengal State Human Rights Commission, Calcutta
25. Ms. Ranjana Chowdhury	Secretary	Madhya Pradesh State Human Rights Commission, Bhopal
26. Shri G.N. Wani	Administrative Officer	Jammu & Kashmir State Human Rights Commission, Srinagar
27. Dr A.R. Basu	Commissioner-cum-Secretary	Himachal Pradesh State Human Rights Commission, Shimla
28. Shri Lalit Kothari	Secretary	Rajasthan State Human Rights Commission, Jaipur
29. Shri A.P. Bhatnagar	Additional Director General of Police	Punjab State Human Rights Commission, Chandigarh
30. Shri Ramesh Chandra Bhanu	Chief Investigation Officer	Kerala State Human Rights Commission, Thiruvananthapuram
31. Shri Kuldeep Khoda	Inspector General of Police, Crime and Railways	Jammu & Kashmir Headquarters Crime & Railways, Srinagar
32. Shri Bhattacharyya	Inspector General of Police	West Bengal State Police Headquarters, Calcutta
33. Shri Thiru K.R. Shyam Sundar	Inspector General of Police, Human Rights / Social Justice	Tamil Nadu Office of Director General of Police, Chennai
34. Shri J.S. Ghungesh	Inspector General of Police	Uttar Pradesh State Police Human Rights Cell, Lucknow
35. Shri J. Changkija	Inspector General of Police	Nagaland State Police Human Rights Cell, Kohima
36. Shri K. Kumaraswamy	Inspector General of Police	Gujarat State Human Rights Cell, Ahmedabad
37. Shri B.K. Gupta	Inspector General of Police	Mizoram State Director General's Office, Aizawl
38. Dr P.R. Mathur	Inspector General of Police, (Complaints / Human Rights)	Madhya Pradesh Police Headquarters, Bhopal
39. Shri M.L. Sharma	Inspector General of Police (Crimes)	Rajasthan Office of Director General of Police, Jaipur
40. Shri R.K. Sharma	Inspector General of Police (Litigation)	Punjab Police Headquarters, Chandigarh
41. Shri G.M. Srivastava	Additional Director General of Police & Head of Human Rights Cell	Assam Office of Director General of Police
42. Shri Jasbir Singh	Inspector General of Police & Director of Vigilance	Sikkim Vigilance Police, Gagtok
43. Shri Prem Singh	Inspector General of Police, Armed Police and Training	Himachal Pradesh State Police Headquarters, Shimla
44. Shri J.V.R Prasada Rao	Additional Secretary & Project Director	National AIDS Control Organisation, Delhi
45. Dr P.L. Joshi	Joint Director (Tech.)	National AIDS Control Organisation, Delhi
46. Ms Neelam Kapur	Joint Director (IEC)	National AIDS Control Organisation, Delhi
47. Shri Trilochan Singh	Project Director	West Bengal State Prevention and Control Society, Calcutta
48. Dr D. Thimmaiah	Additional Project Director	Karnataka State AIDS Prevention Society, Bangalore
49. Justice Tipnis	Hon'ble Lok Ayukta of Maharashtra	Mumbai High Court
50. Prof Joga Rao	Chairperson	Technical Resource Group on Legal & Ethical Issues, Bangalore

51. Prof V.S. Rekhi	Director	National Law Institute University, Bhopal
52. Shri Anand Grover		Lawyers Collective, Mumbai
53. Shri Vivek Divan		Lawyers Collective, Mumbai
54. Ms Veena Johari		Lawyers Collective, Mumbai
55. Ms Kiran Sharma	Senior Project Officer	Lawyers Collective, Delhi
56. Shri Akshay Khanna	Legal Officer	Lawyers Collective, Delhi
57. Ms Sonam Yangchen Rana	Programme Co-ordinator	UNDP HIV and Development Programme, Delhi
58. Ms Madhu Deshmukh	Programme Officer	UNDP, Delhi
59.		
60. Ms Alka Narang	Programme Officer	UNDP, Delhi
61. Smt Chandni Joshi	Regional Programme Adviser	UNIFEM, Delhi
62. Ms Suneeta Dhar	Programme Officer	UNIFEM, Delhi
63. Ms Veera Mendonca	Programme Officer	UNICEF, Delhi
64. Mr Richard Young	Chief, Child Rights & Community Processes	UNICEF, Delhi
65. Ms Anne Vincent	Project Officer, Health	UNICEF, Delhi
66. Shri Shankar Chowdhury	Consultant	UNESCO, Delhi
67. Dr K. Sudhakar	Health Adviser	WORLD BANK, Delhi
68. Dr A.B. Chaudhuri	Consultant	UNDCP, Delhi
69. Ms Ashita Mittal	Programme Officer	UNDCP, Delhi
70. Ms Carin Hakansta	Junior Professional Officer	ILO, Delhi
71. Dr Swarup Sarkar	Team Leader	UNAIDS South Asia Inter-country Technical Team, Delhi
72. Ms Anne Bergenstrom	Associate Professional Officer (VCT & MTCT)	UNAIDS South Asia Inter-country Technical Team, Delhi
73. Mr Gordon Alexander	Senior Country Programme Advisor	UNAIDS India, Delhi
74. Shri K Pradeep	Officer-in-Charge/ Strategic Planning Officer	UNAIDS India, Delhi
75. Ms Pernilla Berlin	Associate Professional Officer (Law, Ethics & Human Rights)	UNAIDS India, Delhi
76. Prof Bhanu Verma	Private practitioner	Gujarat, Baroda
77. Dr K Srinath Reddy	Professor of Cardiology	All India Institute of Medical Sciences, Delhi
78. Prof L.M. Nath		All India Institute of Medical Sciences, Delhi
79. Dr Kusum Schgal	Former Principal	Lady Harding Medical College and Hospital, Noida
80. Dr Jayashree Ramakrishna	Additional Professor & Head Department of Health Education (Project Coordinator, NIMHANS Small Grants Programme for Research on Sexuality & Sexual Behaviour)	National Institute of Mental Health & Neuro Sciences (NIMHANS), Bangalore
81. Dr Maninder Setia	Professor & Head of Department	Department of Dermatology, STI & Leprosy, Sion Hospital, Mumbai
82. Dr Radhika Ramasubban	Director	Centre for Social and Technological Change, Mumbai

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83. Dr Shalini Bharat	Professor	Tata Institute of Social Sciences, Mumbai
84. Dr V. Muthuswami	Additional Director General	Indian Centre for Medical Research (ICMR), Delhi
85. Ms Shyamala Ashok	Secretary	Society for Development Research and Training (SFDRT), Chennai
86. Ms Nandinee Bandyopadhyay	Consultant	DMSA/POP Council, Calcutta
87. Dr Radhika Chopra	Professor	Department of Sociology, Delhi School of Economics, University of Delhi
88. Shri Ashok Row Kavi	Chairperson	The Humsafar Trust, Mumbai
89. Ms Anjali Gopalan	Director	NAZ Foundation, Delhi
90. Ms Abha Bhaiya	Consultant	Jagori, Delhi
91. Dr Tokugha	Physician	YRG Care, Chennai
92. Shri Luke Samson	Director	SHARAN Society for Services to Urban Poverty, Delhi
93. Shri Deepak Singh	Secretary	Manipur Network of Positive People (MNP+), Imphal
94. Mr R. Elango	President	Karnataka Network for Positive People (KNP+), Bangalore
95. Ms Anandi Yuvaraj	Member	Indian Network for People Living with HIV/AIDS (INP+), Chennai
96. Ms Roma Jana		Mumbai
97. Shri S.V. Sreevan	Treasurer	Women's Initiatives, Hyderabad
98. Shri Eldrid Tellis	Consultant	Sevadhan, Mumbai
99. Shri Frank Krishner	Co-ordinator	AASRA, Patna
100. Dr A. Bansal		Medical Council of India, Delhi
101. Ms Brinda Adige	Co-ordinator	Makkala Sahaya Vani, Bangalore
102. Dr Alka K. Deshpande	Prof and Head	Grant Medical College, Mumbai
103. Dr Pradeep		Butterflies, Delhi
104. Ms. Ashima		PRAYAS, Delhi
105. Shri Rami Chhabra		ALNA, Delhi
106. Shri Bimal Charles		AIDS Prevention and Control Projects, Chennai
107. Dr Makroo		Apollo Hospital, Delhi
108. Dr Bona Chowdhary		Apollo Hospital, Delhi
109. Dr. R.M. Pal		PUCL, Delhi
110. Mr Joe Thomas		Deakin University, Melbourne, Australia
111. Mr. A.H. Barmaki	Programme Manager	FPA/IRI (IPPF), Tehran, Iran

