Lawyers Collective HIV / AIDS Unit
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"AIDS is the great moral challenge of our time, and we are clearly at a crossroads in the global fight. Which path will we take? Will we act to save millions of lives? To preserve families, communities, & countries? To protect international & economic security? The choices we make now will define generations to come. Let us rise to the challenge, finally get ahead of the epidemic, and change the course of history."

- Peter Piot, UNAIDS Executive Director

THE HIV/AIDS BILL 2007

Children are thrown out of schools because of their association with HIV; NGO interventions on HIV/AIDS with sex workers & men who have sex with men are shut down; Workers & patients are removed from jobs or refused treatment due to their HIV+ status; Healthcare workers cannot demand universal precautions; Women face increased neglect, discrimination & a vicious cycle of violence that not only leaves them vulnerable to HIV but that intensifies if they are HIV+. This, despite constitutional guarantees of life, health and equality and government policies that espouse a humane response, is the HIV epidemic in India. The law has offered little redress and India needs a clearly articulated legal response to these unjustifiable circumstances if we are to successfully tackle this epidemic.

To this end, in 2007, a unique joint initiative of the government & civil society will see the introduction of the HIV/AIDS Bill 2007 in Parliament. Drafted by the Lawyers Collective HIV/AIDS Unit (LCHAU) after rigorous consultations across the country, this Bill embodies principles of human rights & seeks to establish a humane & egalitarian legal regime to support India's prevention, treatment, care & support efforts vis-à-vis the epidemic

Background

The three-year long process of drafting the HIV/AIDS Bill began in May 2002, with an 'International Policymakers Conference on HIV/AIDS' in New Delhi where the then Prime Minister & Leader of Opposition in the Lok Sabha highlighted the need for an effective response to the epidemic. At this meeting, LCHAU emphasised the need for legislation on HIV/AIDS. Then Rajya Sabha member & currently Minister for Science & Technology, Kapil Sibal supported this idea & convened an Advisory Working Group (AWG) on the Draft Legislation on HIV/AIDS chaired by the Project Director of NACO. The AWG requested LCHAU to draft the legislation; a task LCHAU undertook on two conditions:

- that thorough research, preparation & analysis of background information including laws in various countries would precede the drafting; and
- that the process would include involvement of all stake holders through consultations.

The Need for a Law on HIV/AIDS

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

Protecting human rights – a sound public health strategy: Justice Michael Kirby of the Australian High Court has observed that, paradoxically, protecting the rights of those infected by the epidemic & those most vulnerable to it is the best public health strategy in controlling the spread of HIV/AIDS. Why do the rights of affected individuals need to be protected? Primarily because HIV/AIDS has highlighted such vast inequities, violent abuse & widespread stigma that human rights have been violated in a manner & on a scale rarely witnessed in the public health sphere. Additionally, it has been widely experienced & accepted that laws & policies with a human rights perspective create an environment whereby stigma, violence & inequity will be lessened thereby decreasing vulnerability to HIV & bringing it into the open, making it easier to treat & control.

The need for statutory law: We need a specific statute to address HIV/AIDS for several reasons:

1. *The vagaries of common law*: The various legal issues that arise in the context of HIV/AIDS (consent, confidentiality etc.) are mostly governed by common law i.e. where law is defined by principles set down in case law by judges. This allows for the personal predilections of judges to impact cases of HIV/AIDS, an approach that lends itself to extreme inconsistency, resulting, at times, in opposition to the existing, well thought out policy of the government. Obviously it does not promote a strong, reliable or universal enabling legal environment.
2. *Addressing discrimination*: The violation of rights in the context of the epidemic are widespread & detrimentally impact access to various services & sectors for HIV+ persons or those vulnerable to HIV/AIDS. The guarantee of equality in the Indian Constitution is available only against state entities & there is no restriction on discriminatory practices in the private sector, be it in healthcare, employment, or education. Most countries have, to ensure a universally applicable legal system, enacted anti-discrimination laws applicable to the private sector.
3. *The insufficiency of policies*: Although India has a National AIDS Prevention & Control Policy it does not have the status of law & is not binding on or enforceable in court. A person claiming that she has lost her job because she is HIV+ cannot ask for a remedy by urging that this goes against national policy. The presence of a nationally applicable statute would lend consistency, clarity & predictability in order for courts to effectively pass judgment in HIV/AIDS cases.

Law reform: There are various interventions amongst marginalised populations in India that effectively check the spread of HIV/AIDS, notably, condom promotion & needle exchange programmes. Existing legislation could set these initiatives at naught and the interventions have to be legally protected to ensure that they continue providing services & information that empower persons to protect themselves & others from HIV/AIDS.

Fulfilling international obligations & commitments: In 2001, the United Nations General Assembly adopted the UN Declaration of Commitment on HIV/AIDS. India as a signatory to this Declaration is committed to general obligations such as the prohibition of discrimination & specific obligations such as ensuring that by 2005, at least 90% of young persons aged 15 to 24 have access to information, education, & services necessary to reduce their vulnerability to HIV. The HIV/AIDS Bill aims at fulfilling many of these obligations while also fulfilling obligations under other international agreements such as the International Covenant on Economic, Social & Cultural Rights & the Convention on the Elimination of all forms of Discrimination Against Women.

Process

Preparation of background materials: Work on the Bill commenced with extensive research on laws, policies & practices on HIV/AIDS in different jurisdictions. This research was presented & discussed at numerous AWG meetings & subsequently published in a book entitled *'Legislating an Epidemic: HIV/AIDS in India'*. This book embodies fundamental principles of public health & human rights, which form the basis of the Bill.

Consultations: HIV/AIDS is a health crisis, which impacts populations not only in terms of their health but economically, socially, culturally & legally. This has also been the Indian experience, & in response, the Indian government & civil society have put in place strategies to address HIV/AIDS holistically. India now has a large community of persons working on various aspects of the epidemic who over the last decade have gained rich, vital experiences & insights into the epidemic.

Any legislative measure addressing HIV/AIDS must be informed by these realities. With this in mind, LCHAU conducted nation-wide consultations on the Bill, involving & learning from representatives of various sectors including HIV+ persons, marginalised populations, healthcare workers, children's organisations, women's groups, etc. Regional level consultations organised in co-ordination with SACS were held in the North, South, East, West & the Northeast of the country. The consultation process is outlined in Table 1.

Sound Bites from Consultations

The WHO guidelines say that if a person's CD4 count is below 200, they will have access to treatment. But if we don't even have a CD4 count machine, what's the use of telling us about ARVs? – *Participant, North East Consultation, Imphal*

We have found in our study in Delhi that between 30-50% of adolescents between the ages of 10 & 19 years are sexually active – this should be an important factor in deciding communication needs. – *Participant, North Consultation, New Delhi*

A PLHA in the unorganised sector made a leave application before going for treatment. When the hospital became aware of his HIV+ status, they informed the employer. The employer then tore up the leave application, & sacked the employee for taking leave without permission. – *Participant, Consultation with HIV+ persons, Mumbai*

The source of discrimination arises from the people who are supposed to uphold the law, viz., the police & other law enforcement agencies. – *Participant, Consultation with marginalized populations, New Delhi*

Partner notification for women will be dangerous, as they will face discrimination & violence if their partners are told. Moreover, they always get tested first during pregnancy & get blamed. – *Participant, Women's Consultation, Agra*

After my father died, I have been working at a coconut shop to take care of my two sisters & myself. Our house is in our father's name. He has a bank account with some money, which we wanted to use to repair the house. But the bank won't let us take out the money saying we are minors so our signatures are not valid. We have no other family or relatives to help us. – *Participant, Consultation with Children, Vijaywada*

TABLE 1- CONSULTATIONS

Dates	Consultation	Venue
6-7 Sept 2003	HIV+ persons	Mumbai
13-14 Sept 2003	Marginalized populations (Sex workers, IDUs & MSM)	New Delhi
22-23 Nov 2003	Healthcare Workers	Mumbai
12-13 Dec 2003	World of Work	New Delhi
28-29 Feb 2004	Regional - *Maharashtra, Gujarat, Madhya Pradesh, Dadra & Nagar Havelli, Daman & Diu*	Mumbai MDACS
13-14 Mar 2004	Regional - *Karnataka, Goa, Lakshadweep & Kerala*	Bangalore KSAPS
27-28 Mar 2004	Regional - *West Bengal, Orissa, Bihar, Chhattisgarh, Jharkhand & Sikkim*	Kolkata WBSACS
17-18 Apr 2004	Women's Groups	Agra
5-6 June 2004	Regional - *Manipur, Assam, Meghalaya, Mizoram, Nagaland, Tripura & Arunachal Pradesh*	Imphal Manipur SACS
8 June 2004	NGOs providing care, support & treatment	New Delhi
5-6 July 2004	Regional - *Delhi, Uttar Pradesh, Rajasthan, Himachal Pradesh, Punjab, Chandigarh, Haryana, Uttaranchal & Jammu & Kashmir*	New Delhi DSACS
31 July-1 Aug 2004	Children's Groups	Mumbai
7-8 Aug 2004	Regional - *Tamil Nadu, Andaman & Nicobar Islands, Pondicherry & Andhra Pradesh*	Hyderabad APSACS
6 Nov 2004	Lawyers	Mumbai
21 Nov 2004	Children	Vijaywada

Drafting: Spread over two years, the drafting of the HIV/AIDS Bill commenced with the holding of two consultations with HIV+ persons and vulnerable communities as the most important stakeholders in the bill. With inputs from these meetings and after extensive research into the various aspects of the epidemic, ethics, law, human rights & national & international experiences, LCHAU as a team across three offices convened several times to draft, discuss & debate various provisions. The drafting, amending & finalisation of the provisions of the HIV/AIDS Bill have been informed by debates, discussions & facts presented at the various consultations.

Critical Recommendations (Broader Health & Human Rights Concerns)

The mandate given to LCHAU was to draft legislation on HIV/AIDS. In performing this very specific task, LCHAU began to receive vital feedback that sought a far wider approach in effectively dealing with the epidemic. Although unable to incorporate this feedback due to the narrowness of its mandate, LCHAU will put before government certain recommendations made by various stakeholders as areas that require immediate attention including:

1. The need for a broader health law on lines of the HIV/AIDS Bill.
2. The need for a general anti discrimination law that covers the private sector & prohibits discrimination based on sex, class, caste, religion, sexual orientation etc.

3. The need for law reform in the context of S.377 of the Indian Penal Code, the Immoral Traffic Prevention Act, the Narcotics Drugs & Psychotropic Substances Act, the Juvenile Justice Act, all of which needlessly impose a criminal regime that exacerbates the vulnerability of individuals impacted by these draconian laws to HIV by denying them access to healthcare & other services.
4. The need for law reform, particularly of personal laws, to empower women & fully recognise & guarantee their rights.
5. The need to introduce effective legal regimes that prohibit quackery & unethical biomedical & behavioural research.
6. The need to seriously re-examine health delivery in India & increase financial allocations to the public health sector.

Highlights of the HIV/AIDS Bill 2007

Rights Recognised in the HIV/AIDS Bill

1. **Right to Equality.** – No person shall be subject to discrimination in any form by the State or any other person.
2. **Right to Autonomy.** – Every person has the right to bodily & psychological integrity including the right not to be subject to medical treatment, interventions or research without her or his informed consent.
3. **Right to Privacy.** – Every person has the right to privacy.
4. **Right to Health.** – Every person has the right to enjoy the highest attainable standard of physical & mental health.
5. **Right to Safe Working Environment.** – Every person has the right to a safe working environment.
6. **Right to Information.** – Every person has the right to information & education relating to health & the protection of health from the State.

Prohibition of Discrimination: The HIV/AIDS Bill specifically prohibits *discrimination* related to HIV/AIDS in public & private spheres. Under the Bill, no person may be discriminated against in employment, education, healthcare, travel, insurance etc. based on their HIV-related status. Discrimination in healthcare settings is attributed largely to the lack of any right to a safe working environment for healthcare workers; a right recognised by the Bill which imposes an obligation on healthcare institutions to provide universal precautions & training for all healthcare workers. The Bill also addresses hate & discriminatory speech.

Informed consent for testing treatment & research: The Bill requires specific, free & *informed consent* for HIV related testing, treatment & research. This chapter statutorises existing standards of informed consent & exceptions to it while also increasing access to healthcare services for children & young persons.

Disclosure of Information: The Bill guarantees the *confidentiality* of HIV-related information (including the HIV status of a person) & outlines the few exceptions for disclosure. Two important provisions relating to disclosure are 'partner notification' & the 'duty to prevent transmission.' The Bill specifies the exact protocol for & circumstances in which a healthcare provider can notify the partner of an HIV+ person of such person's status. It recognises the particular vulnerability of women to violence in such situations & specifies that partner notification should not take place if there is an apprehension of violence. The Bill also imposes a duty on all HIV+ persons to prevent transmission through various measures like using safer sex practices or informing their partners. Here again the duty does not exist if there is a threat of violence.

Right to access treatment: The *right to access treatment* related to HIV/AIDS as part of the right to health is recognised under the Indian Constitution & International Conventions to which India is a signatory. The Bill provides for access to comprehensive HIV related treatment including diagnostics, ARVs, nutritional supplements etc.

Risk Reduction: Strategies for risk reduction are actions that minimise a person's risk of exposure to HIV/AIDS and include programmes that promote safer sex behaviour, provide clean needles or provide information to children. Typically they are provided to communities & persons often subject to criminal sanction under various laws like sex workers, injecting drug users etc. Their criminalisation severely hampers access to healthcare services & information exacerbating their vulnerability to HIV. The Bill specifically protects these strategies from civil and criminal liability and law enforcement harassment. This does not mean, for instance, that injecting drug use is legalized. It simply means that the provision of clean needles to protect a person from HIV cannot be stopped by claiming that this promotes drug use.

Information, Education & Communication: Information is the key to any successful prevention programme. The Bill treats the Government IEC programme as an essential component of the fight against HIV/AIDS. Feedback from all the consultations rejected fear & morality based messages & supported positive & evidence based messages that speak, not just about prevention but also care, support & rights. The Bill focuses particular attention on women & young persons & IEC specific to their needs.

Implementation & grievance redressal: The HIV/AIDS Bill creates innovative *implementation mechanisms* including *institutional grievance redressal machinery*, *Health Ombuds* in each district & *HIV/AIDS Authorities* that will take over from NACO & SACS with an independent & accountable structure & expanded policy & programme base. The Bill also specifies *special court procedures,* including suppression of identity, speedy trials etc. The emphasis is on quick trials & creative redressal. Thus a case related to discrimination could see a court awarding damages & directing the person who discriminated to undergo sensitisation & training & doing community service.

Special Provisions: The Bill specifically recognises certain rights for *women, children & persons in the care & custody of the State* who due to social, economic, legal & other factors find themselves more vulnerable to HIV and are disproportionately affected by the epidemic. Prisoners are provided with specific access to risk reduction strategies, counselling & healthcare services. The Bill addresses some underlying causes of the vulnerability of women to HIV & provides for the registration of marriages, the provision of maintenance & the right of residence for HIV+ women. The Bill also mandates a review of all laws & policies that leave women vulnerable to HIV; any such review will show that discrimination & violence, inequities of personal laws, lack of knowledge & education are at the heart of the failure to protect women from HIV/AIDS. The right of women who are pregnant to proper counselling & to decide on treatment options is specifically recognised. The Bill also recognises the link between sexual violence & HIV & provides for counselling & treatment of sexual assault survivors & directs the setting up of sexual assault crisis centres.

Special provisions addressed at children & young persons include the right against discrimination in education and to access healthcare services & information in their own right. This is particularly important for street children & those living on their own. It also provides for protection of inheritance &

property rights & recognizes community-based alternatives to institutionalisation for vulnerable & affected children; provisions that were a direct result of feedback from the consultation with children's groups.

The HIV/AIDS Bill 2007 envisages a detailed & carefully planned strategy to address the HIV epidemic through an extensive prevention, care, treatment & support programme that entails widely disseminated & easily accessible IEC, an accountable & accessible government response, access to healthcare services & treatment & the protection & promotion of the rights of persons who are HIV+ & those affected by HIV.

One of the key visions of the Bill is to establish a government initiative on HIV/AIDS that is completely accountable & that is implemented at every stage with consultations. Key appointments require nominations & widespread consultation. The Bill also recognises the right to information of all persons from the HIV/AIDS Authorities. The Bill thus provides the foundation for civil society, particularly HIV+ persons, to be fully involved in HIV/AIDS programmes & policy.

So who is this law for?

One important misconception about the rights based approach needs to be clarified at this point. There is a belief that this approach is ultimately an individualistic expression & in the HIV/AIDS context this would mean that a law based on a human rights approach would be only for HIV+ persons. *This is incorrect.*

It is worth reiterating that in the HIV context, only by protecting the rights of those most vulnerable can we hope to tackle the epidemic & thereby protect all. By providing for a right against discrimination, to informed consent, to confidentiality & to access treatment, we encourage people to come forward for testing with the understanding that there will be no adverse consequences to their HIV+ status & if there are, the law will offer protection. By recognising the rights of women, we empower them to demand information & safer sexual practices from their partners. By premising the IEC programme on the right to information, we empower all persons to demand IEC in their languages, regions & to suit their specific needs. By protecting needle exchange, condom promotion & sexual health information programmes, we help those most marginalized in society by morality & law to protect themselves & others from HIV. By recognising the right of all citizens to question their government we make government bodies accountable, consultative & democratic, creating a strategy to tackle the HIV epidemic where every person is a stakeholder, every voice is included & no one is left behind. We help the epidemic emerge from the underground so that HIV/AIDS is no longer a synonym for fear, neglect, discrimination & violence but for empowerment, compassion, united action & triumph.

Finalisation & Presentation to Government

"The Final version of the HIV/AIDS Bill was presented to NACO in August 2006. It is likely to be tabled in Parliament in 2007."

ACTION!!!!

The HIV/AIDS Bill will be available on our website www.lawyerscollective.org from September. If you would like your own copy, please write to us. If you would like to join the campaign to get the HIV/AIDS Bill passed, you can write to:

1. The President of India, Mr. APJ Abdul Kalam at Rastrapathi Bhavan, New Delhi 110001 or send an e-mail to **presidentofindia@rb.nic.in** or send a message at http://presidentofindia.nic.in/scripts/writetopresident.jsp.
2. The Prime Minister, Mr. Manmohan Singh at 7, Race Course Road, New Delhi 110011 or send a message at http://pmindia.nic.in/write.htm.
3. The Minister of Health & Family Welfare, Mr. Anbumani Ramdoss at 144, A Wing, Nirman Bhawan, New Delhi 110011 or send an email to hfm@alpha.nic.in.

You can also write to your local representative or to your political party expressing support for the Bill.

Contributions: Kajal Bhardwaj and Vivek Divan

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