

Online Newsletters



NEWSLETTER#11
December 2001

~SUBSCRIBE FOR NEWSLETTERS~

"The supposed dichotomy between public health and civil rights is a spurious one; an effective public health policy to combat AIDS in India will depend on civil rights"

Siddhartha Gautam, HIV/AIDS activist

INFORMED CONSENT & MANDATORY TESTING

Do medical authorities have the right to mandatorily test a person for HIV/AIDS disregarding the person's right to give consent? Will detaining sex workers in rescue homes on the ground that they are infected with HIV/AIDS violate their fundamental right under Article 21 of the Constitution of India? Is the right not to be tested without full and informed consent in conflict with public health interests? These questions were among the several considered by a 5-judge Bench of the Andhra Pradesh High Court in a recent judgement (2001 (5) ALD 522 LB). This edition of Positive Dialogue focuses on the issues raised by the judgement and its ramifications in the context of HIV/AIDS.

Facts of the case

The petitioner, a woman diagnosed with chronic cervicitis, underwent a hysterectomy operation performed in the Maternity Hospital of Singhereni Collieries Company Ltd., (SCCL), where her husband was working. During the course of the surgery she required two units of blood, one of which was donated by her brother. Fifteen days after discharge, she started suffering from fever and approached the hospital again. Since the fever did not abate, the petitioner made the rounds of a number of private hospitals for treatment before being diagnosed as HIV positive .

In a letter to the Chief Justice of Andhra Pradesh High Court, imploring him for an enquiry into the transfusion of contaminated blood during the hysterectomy operation, the petitioner asked for adequate financial compensation along with action against those responsible for the negligence. The High Court took the matter up as a Writ Petition. Considering the enormity and significance of the problem the matter was referred to a bench of five judges. Notices were issued by the High Court in various national and regional newspapers inviting intervention by NGOs and public-spirited persons.

Contentions in Court

The respondents filed their counter dismissing the contentions of the petitioner and basing their argument on the premise that the petitioner had been infected by HIV before the surgery. They took recourse to the fact that at one point the petitioner had approached a private medical practitioner for treatment when she was subjected to a procedure called Upper Gastrointestinal Endoscopy resulting in her being diagnosed as having oesophageal candidiasis, which is a common opportunistic infection affecting persons whose immunity is depressed. The respondents contended that oesophageal candidiasis occurs in a patient with AIDS after few years of entry of HIV into her body thereby suggesting that the petitioner had not contracted HIV by the transfusion of blood performed recently. Moreover, before transfusion, the blood had been subjected to all the mandatory tests and it was found to be HIV negative.

The respondents further elucidated on the facilities and amenities provided to their workforce in the context of HIV/AIDS. Counter affidavits were also filed on behalf of the Andhra Pradesh State Aids Control Society and the Advocate General appearing on behalf of the State, explaining the measures taken by the State to counter the HIV/AIDS epidemic, including the focus on creation of awareness, introduction of blood screening at blood banks and conducting surveillance activities.

The intervenors, including NGOs and human rights organisations, raised the plea that no provisions for the treatment and rehabilitation of AIDS patients had been made. Further issues raised included the fact that blood banks were not registered, despite a legal requirement to do so, and that a family faced ostracism if any member was found to be positive. The intervenors also contended that right to health was a part of the right to life included in Article 21 of the Constitution and that the state was thus under an obligation to provide requisite medical facilities including tests before blood transfusion. Interestingly, the Court accepted the contention of one of the intervenors, that the slogans to promote usage of condoms encourage indiscriminate sex though no mention was made of education and promotion of safe sex.

The Judgement

After hearing the pleadings, the Court granted compensation of rupees one lakh to the petitioner while dismissing the contentions of the respondents as being based on surmises and conjectures. The Court found it shocking that the respondents did not test the petitioner before operating on her and considered it negligence on their part. The petitioner had in fact argued that the negligence was in terms of non-testing of blood before it had been transfused. The Court accepted the contention of the respondents in this regard, that the blood had been tested. No concern was expressed on the issue of whether the legally required donor questionnaire/counselling protocols had been conducted before considering the blood safe. No question was raised as to whether the petitioner had given informed consent to the transfusion, i.e. after being informed of the risk that the donor may be in the window period.

The Court laid down certain guidelines for better management and control of HIV/AIDS in Andhra Pradesh in the wake of various control programmes undertaken by the State through Governmental and Non-Governmental organisations. The exact impact of these guidelines is unclear since the court itself chose to call them 'suggestions/directions'. These directions emphasised that sufficient and state of the art testing facilities be made available in all hospitals, institutions and blood banks. The Court also insisted that government hospitals use only disposable syringes, monitor strict adherence to the Bio-Medical Waste (Management and Handling) Rules, 1998, and keep a strict vigil on licensed blood banks.

Significantly, the directions envisage the supply of 'anti-AIDS drugs'. Whether this refers to anti-retroviral treatment is unclear in view of objection to anti-retroviral treatment by one of the intervenors on account of their toxicity. In a linked direction, the Court suggested to the Andhra Pradesh Government that it grant sales tax exemption on drugs used in treatment of HIV.

Another aspect of the judgement was the formulation of rehabilitation schemes for people living with HIV/AIDS purportedly to save them from social ostracism. A "compensatory mechanism" to deal with transmission due to negligence was also suggested through the creation of free facilities and free access to state funded health institutions. This direction is confusing since the right to healthcare is already a part of the right to life and provision of treatment and facilities is not a matter of 'compensation', but a matter of right.

(Based on the latest information available it appears that SCCL has recently appealed to the Supreme Court against the judgement and the apex court has admitted the appeal and granted a stay of the judgement.)

Critique

It is a positive development that the Indian Judiciary is taking a proactive role in the response to the HIV/AIDS epidemic. The right to treatment and the obligation on the state to ensure its availability have been clearly articulated in this judgement. There are, however, some apparent gaps in the understanding of the epidemic from a public health perspective. For instance the

Court's states that "it was incumbent upon the medical staff of the hospital, to carry on the requisite tests on the victim for detecting AIDS at the time when blood was transfused for hysterectomy operation". The Court is, in no uncertain terms, directing medical authorities to test each person before surgery. The Court goes on to suggest that the State should take active measures to identify people living with HIV. It further endorses an older decision of a Division Bench of the same Court, (P.N. Swamy v. SHO, Hyderabad, 1998 (10) ALD 75 (DB)), in which mandatory testing and isolation of sex workers was justified. The Court is very clearly prescribing mandatory testing and isolation of people living with HIV and seems to suggest the testing of persons from marginalised groups such as prisoners, sex workers, truckers etc.

In debating the issue of whether such an isolationist approach is permissible or desirable, the point considered was the apparent conflict envisaged between the 'individual right' and the 'public right'. The HIV/AIDS context has shown this to be a false debate. It is only by protecting the rights of those affected and those most vulnerable that the epidemic can be effectively dealt with. Policies giving teeth to mandatory testing, breach of confidentiality and discrimination in the name of community health would only succeed in driving the epidemic underground. Does this indicate an isolationist approach as exemplified by the case of Lucy S. D'Souza v. State of Goa (AIR 1990 Bom 335) in which isolationist policies in the Goa Public Health Amendment Act were held to be constitutionally valid? The Court has resisted going deeper into the debate and recognising that it is not merely an issue of individual right versus public interest, but one of public health policy.

With respect to the particular facts of this case, significant issues, such as the need for informed consent of the recipient of blood before transfusion and strict adherence to blood banking protocols and donor questionnaires, were not addressed. Had these issues been tackled, the judgement could have had a far more positive impact on the predicament we are in.

The significance of Siddhartha Gautam's prophetic words could not be more relevant. The Constitution of India guarantees the right to life encompassing the right to health along with the right against discrimination and right to privacy. These rights are directly linked to the success or failure of the campaign against the pandemic. Breaching a person's rights apparently in the interests of public health would help only in stoking the pandemic. The need of the hour is for the stakeholders to realise that HIV/AIDS can be arrested only by sensitisation, increase in the level of awareness and a commitment towards protection of rights of those most affected. Judicial activism based firmly in a holistic public health perspective can be a key component in the realisation of these needs.

Affordable Medicines and Treatment Campaign

A national campaign on accessibility and affordability of medicines and treatment has recently started and is on the verge of its formal launch around the country. The Affordable Medicines and Treatment Campaign (AMTC) will symbolically begin on World AIDS Day, 1st December 2001 this year. The campaign finds its origin at a workshop organised by the Lawyers Collective HIV/AIDS Unit in Mumbai, where over 35 organisations/participants from different parts of the country came together and discussed the issues and strategies to be adopted. The Mission Statement of the AMTC reads:

The right to life and health is a fundamental right guaranteed to every person living in India and is non-negotiable.

This campaign aims to demand and create an environment that will ensure sustained

Indian patent law, which protects the invention of new products. The 'process patent' system used in India so far will be replaced by a more restrictive 'product patent' system. The impact of this change on new medicines is unimaginable. Foreign pharmaceutical companies will have sole rights to determine the production, distribution, pricing and, therefore, availability of new medicines. It is feared that such a situation will raise the prices of new medicines to amounts that are unaffordable to most Indians. This is one of the main issues taken up by the campaign.

This campaign lays special emphasis on access to HIV/AIDS medicines for opportunistic infections (OIs) and Anti-Retroviral Therapy (ART). People with HIV/AIDS can prolong their lives with the help of these medicines, which are already very expensive (minimum Rs.1800 per month for ART). New medicines for the treatment of HIV/AIDS are going to be even more expensive. If we do not stand up against TRIPS now, many more lives will be lost to this epidemic.

The main priorities of the campaign include:

- •Bringing about legal reform within the country
- •Advocacy and lobbying for changes at the international level - WTO, TRIPS Council etc.
- •Awareness creation amongst organisations, civil society, policy makers, legislators, media personnel etc.
- •Making medicines available to PLWHA
- •Creation and practice of effective service delivery modules and protocols for treatment of PLWHA
- •Interventions to bring about change in NACO policy to provide ARVs, OI, PEP, MTCT medicines at affordable rates/free

To this end, the campaign has set up a series of working groups that will focus on specific tasks such as law reform, media advocacy, technical inputs on treatment etc. The campaign shall also set up an email discussion forum in order to facilitate dialogue on the various issues involved.

Groups around the country are planning programs to commemorate the launch of the campaign on December 1st. These include public meetings, marches, candle light vigils etc.

For further information about the campaign and what you can do, write to:

Affordable Medicines and Treatment Campaign
7/10, 2nd Floor, Botawala Building,
Horniman Circle, Fort,
Mumbai - 400023.
Tel: 022- 2676213/19
Email: aidslaw@vsnl.com

The Draft National Health Policy 2001

In September 2001, the Ministry of Health and Family Welfare released the Draft National Health Policy 2001 and asked for public comments on its contents. The previous such policy dates back to 1983. Some of the interesting features of the policy are:

- •A (meagre) increase in spending on public health by the centre
- •A gradual change from vertical programs that deal with specific epidemics (such as TB, HIV/AIDS etc.) to a more integrated public health system, which would presumably be more cost effective
- •A recognition that there is a need for an increase in services that address mental health needs
- •A commitment to providing "some essential drugs" at public health service outlets · A commitment that the government shall ensure that the patent laws that are brought in compliance with the TRIPS agreement shall use all opportunities to secure affordable access to medicines
- • An increased participation of local self government institutions in the implementation of national disease control programmes

- Encouragement of specialisation in public health and family medicine
- Focus on further privatisation of health services
- Fiscal incentives to the health sector to provide services to foreigners, by declaring health services as 'deemed exports'

Many of these prescriptions are bound to have a negative impact on public health. The insistent drive towards privatisation in a manner that makes health an industry that brings in foreign currency is one of the most serious flaws. Already private healthcare, although being subsidised by the state in many ways, refuses to provide treatment to disadvantaged sections of society. Making health a market is only going to make matters worse. Another serious drawback is in the non-recognition of serious problems in the health sector, such as the lack of infrastructure that could allow for practice of universal precautions, non-adherence to ethics and legal requirements such as informed consent, confidentiality and non-discrimination and the lack of services for sexual health problems. The policy, in fact, does not even mention sexual health. There is a need for responses to be sent, especially from members of the health sector, to the Government, before this policy is finalised. The draft can be downloaded from the Ministry's web site www.mohfw.nic.in. Details of how responses are to be made are also provided.

Report of National Conference on Human Rights and HIV/AIDS organised by the National Human Rights Commission (NHRC)

The Report of the National Conference on Human Rights and HIV/AIDS, organised by the National Human Rights Commission in partnership with NACO, Lawyers Collective, UNICEF and UNAIDS on 24-25 November 2000, New Delhi, was released. The Report articulates the need for a human rights based response to HIV/AIDS and in this context presents the recommendations that emerged from the Conference. The recommendations encompass changes in institutional practices, policies, programmes and legislations on issues pertaining to Consent and Testing, Confidentiality, Discrimination in Healthcare and Employment settings. In addition, it lays down specific recommendations for addressing vulnerabilities of women, children and young people, people living with or affected by HIV/AIDS and marginalised populations. Significant amongst these are the revision of laws such as Section 377 of the Indian Penal Code and the Narcotic Drugs & Psychotropic Substances Act that exacerbate vulnerability of marginalised communities and impede interventions, legalisation of all consensual sexual activities between adults, decriminalisation of needle exchange programmes, adoption of legislative changes to deal with situations of marital rape and domestic violence and the introduction of anti-discrimination to cover all health care and employment settings. The report puts together the deliberations of representatives from the Human Rights Machinery, police personnel, NGOs, AIDS Control Societies and people living with HIV/AIDS from all over the country. In his introduction the Chairperson of the NHRC, former Chief Justice of India JS Verma calls upon the State Human Rights Commissions, Police Departments, representatives of the health sector and the State AIDS Control Societies to take this process forward.

Contributions: Diva Saxena and Akshay Khanna

Monthly Drop-in meeting

Lawyers Collective HIV/AIDS Unit holds monthly drop in meetings on the first Thursday of each month. The meetings start at 3.30 p.m. at the Delhi Office and at 5.00 p.m. at the Mumbai Office. The objective of the meeting is to share experiences, information and discuss issues of concern. We invite your active participation in these meetings.

Lawyers Collective HIV/AIDS Unit provides legal aid and allied services for people affected by HIV/AIDS. The main objective of the Unit is to protect and promote the fundamental rights of persons living with HIV/AIDS, who have been denied their rights in areas such as:

- Health care
- Employment
- Terminal dues like gratuity, pension
- Marital rights relating to maintenance, custody etc

•Housing

The Unit is involved in initiating public interest litigation on issues like the right to marry, confidentiality, access to health care, safe blood supply, quacks, etc. Lawyers Collective HIV/AIDS Unit also conducts workshops on legal and ethical issues relating to HIV/AIDS for people living with HIV/AIDS, lawyers, judges, health care providers, NGOs etc.

Please send your comments and queries to the addresses given below. Those affected by HIV/AIDS seeking legal aid, advice and support are welcome to contact us at:

Lawyers Collective HIV/AIDS Unit

Programme Management Unit
7/10, BOTAWALLA BUILDING, 2ND FLOOR
HORNIMAN CIRLCE, FORT
MUMBAI - 400 023

TEL: 022 267 6213/9 FAX: 022 270 2563
E-MAIL: aidslaw@vsnl.com
Website: www.hri.ca/partners/lc

New Delhi Project Office
63/2 MASJID ROAD, 1st FLOOR, JANGPURA
NEW DELHI - 110014

TEL/FAX: 011 4321101/2 or 011 4316925
E-MAIL: aidslaw1@ndb.vsnl.net.in
Hours: Monday - Friday: 10:00 a.m. - 7:00 p.m.
Saturday: 10:00 a.m. - 4:00 p.m.