

## Online Newsletters



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### Human Rights & Health Matter Most When They are Most at Risk

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***"For four and a half months, he lay in a side room of a hospital in the orthopedic ward unattended and uncared for. The doctors would run by his room with their hands covering their nose, so would the nurses and the paramedical staff. He had fractured his hip, which prevented him from sitting, standing or sleeping. His wife pleaded for an operation for his six month old injury but in vain."***

Social justice and equity are conditions necessary for health. Thus human rights and public health share a common objective - to promote and protect the rights and well-being of all individuals. Recognising the inherent dignity of all human beings, more so of people living with HIV/AIDS, will facilitate the creation of an environment wherein protection and promotion of their human rights will help in achieving the public health goals of reducing and preventing further spread of HIV infection. Protection of human rights will lessen the adverse impact of HIV/AIDS on those who are affected and also serve to empower individuals and communities to respond effectively to the HIV/AIDS epidemic.

Ignorance and fear about HIV have often lead to calls for discriminatory laws and measures. Such laws and measures (e.g. mandatory testing of high risk groups, isolation of people living with HIV/AIDS) not only violate the rights and freedoms of people living with HIV/AIDS and those affected with HIV/AIDS but these laws are also arbitrary, impracticable and serve no purpose. They are also counter-productive to public health objectives. One essential lesson that has been learned from the HIV/AIDS epidemic is that universally recognised human rights standards should guide all HIV- related health policies and program interventions.

#### **Health Care & Discrimination**

The current state of health in India, where epidemics are a recurring phenomena, calls for urgent introspection and action. Despite the fact that the Indian Government evolved a Health Policy as far back as 1983, health care services have been deteriorating and do not provide effective, preventive and curative care. Public health care services do not meet people's expectations thus, they turn to private health care, which is not regulated by any statute or laws unlike the public health care sector. According to the National Sample Survey conducted by the National Council for Applied Economic Research, sixty to eighty percent of health care is sought in the private sector for which households contribute four to six percent of their total income. This fact speaks volumes about the inadequacies of the public/government run health care institutions. With the numbers of HIV infections on the rise daily, there will arise a pressing and urgent need for the private health care infrastructure to provide treatment for people living with HIV/AIDS also. As of today very few private hospitals are willing to admit and treat people living with HIV/AIDS, most of whom are shunted to the public hospitals.

The problem is exacerbated by the disproportionate development of private and public health care services which have expanded mostly in the urban areas, while the access of the rural population to such care has decreased over the years. Today, eighty four percent of hospital beds are in urban areas while seventy five percent of the population resides in the rural areas. The basic health care needs of the population including people living with HIV/AIDS often go undressed due to unavailability of adequate health care services.

For people living with HIV/AIDS the health care setting is the most conspicuous environment for HIV/AIDS-related discrimination. The denial of services vis-à-vis care and support represents one of the most immediate and pressing concerns of people living with HIV/AIDS. There are innumerable instances of discrimination against people living with HIV/AIDS viz. refusal of doctors to 'touch' patients during routine medical examination, delays in treatment, breach of confidentiality, mandatory or routine testing without informed consent, wrapping dead bodies of HIV-positive people in plastic sheets etc. If there is a slight suspicion that a patient requiring surgery may be HIV-positive then often the patient is refused surgery, usually on some false pretext. There are also instances of exploitation of people living with HIV/AIDS in the context of health care. For example, they are often asked to pay more than HIV-negative patients do for the same services like delivering babies, ambulances, etc. This systemic discrimination against people with HIV/AIDS in the health care sector jeopardizes prevention and care efforts and will only have long-term negative public health implications.

## Legal Issues

The right to health is enshrined in various international instruments to which India is a signatory. The Universal Declaration of Human Rights (Article 25) states a right to "a standard of living adequate for the health and the well-being of the individuals and their families." Article 12.1 of the International Covenant on Economic, Social and Cultural Rights recognizes the right to the enjoyment of the highest attainable standard of physical and mental health. In terms of HIV, this means that people living with HIV or who are at risk of contracting HIV can safely seek information, voluntary testing, counselling and medical care. The concept of discrimination is incorporated in Articles 14, 15 and 16 of the Constitution of India. These principles form part of the Fundamental Rights Chapter (Part III) of the Constitution. Under Article 21 of the Constitution of India the right to health is inherent to the right to life. Under Article 47 it is the duty of the state to raise the level of nutrition and the standard of living and to improve public health. So Article 21 read along with Article 47 states that the right to health can be described as 'the duty of the state, within its available resources, to ensure the conditions necessary for the health of its population.' (*Vincent Parikulangara v. Union of India* 1987 (2) SCC 165 AIR 1987 SC 990) It imposes the duty on the State to ensure that practices, policies, and laws create conditions in which people can be healthy. Fundamental rights are available only against the State (Article 12). By law, State health care institutions/providers are obliged to provide medical treatment to all persons in emergency and non-emergency situations. They cannot discriminate on the basis of HIV status. However fundamental rights are not available against the private sector. Private sector may refuse to provide medical treatment except in the case of a medical emergency (*Parmanand Kataria v Union of India* AIR 1989 SC 2039). In the case of an emergency a private sector health care institution/provider must provide medical attention until alternative arrangements for medical care can be made. Given that the majority of people access health care in the private sector and the sheer numbers of HIV-positive people, the private health care sector will have to provide medical services for people living with HIV/AIDS. Clearly there is a need for anti-discrimination legislation which will apply to the private sector. Such regulations have now been passed in countries like Australia, Hong Kong, Phillipines etc.

Very often discrimination in the health care sector stems from ignorance about the route of HIV/AIDS transmission and unwarranted fears of occupational exposure. There is an urgent need to educate all levels of health care workers about HIV/AIDS and about the risk of occupational exposure. Studies indicate that the risk of exposure from HIV-positive patient to health care workers is fairly negligible and can be successfully mitigated by observing universal precautions and Post Exposure Prophylaxis (PEP). In law, there is a duty cast on the public sector employers to provide a safe working environment for their employees. Thus the public health care institution, in the context of its duty to provide a safe working environment for its employees, should make available the required resources for universal precautions. The public health care institution should also make PEP available and accessible to all levels of healthcare workers. The National AIDS Control Organization (NACO) has recently updated its policy on PEP and stated the two-drug PEP should be made available at the institutional level. Unfortunately, most health care workers are unaware about PEP and it is not yet readily available in health care institutions.

## Advocacy

Though the legal position is clear that public sector health care institution/providers cannot refuse to provide medical care for people living with HIV/AIDS, people living with HIV/AIDS encounter much discrimination vis-à-vis their access to health care. There is an urgent need for advocacy with the health care sector in order to improve the quality of health care available to HIV-positive people. Gaps in information and available medical treatment do exist and they must be addressed in a manner that will promote and protect the rights of people living with HIV/AIDS and the rights of healthcare workers. As a part of its on-going advocacy efforts on the issue of access to health care, Lawyers Collective HIV/AIDS Unit has been conducting seminars with doctors from key hospitals in the Mumbai region. The seminars focus on legal and ethical issues relating to HIV/AIDS in the health care setting. At these seminars the need for a protocol that would address HIV/AIDS-related legal and ethical issues has been articulated. Lawyers Collective HIV/AIDS Unit, in a participatory process with health care workers, lawyers, AIDS activists and people living with HIV/AIDS, has developed draft protocols on patient management relating to health care services for those affected by HIV/AIDS. The protocols have been developed with a view to improving the access and quality of health care services available to people living with HIV/AIDS whilst respecting the rights of health care workers. The participatory learning process will ensure the implementation of the protocols. The protocols are in consonance with the National Testing Policy, National AIDS Policy of NACO and the Government of India and the WHO Testing Policies & Guidelines. The protocol covers the issues of testing, confidentiality, admission and treatment and PEP. The protocol document will be widely circulated and scrutinized before it is finalized. For a copy of the draft protocol document, please contact the Lawyers Collective HIV/AIDS Unit. Your constructive comments will be appreciated. If adopted,

Cases relating to discrimination in the health care sector are now coming to the fore:

- A Delhi based NGO, Sahara, filed a petition in the Supreme Court on the issue of denial of treatment. People living with HIV/AIDS were denied medical treatment in public sector hospitals. The case will be coming up for hearing shortly.
- A PIL was filed in the Guwahati High Court in response to several incidents of denial of care by public sector health care institutions. The case is being heard for final hearing in November, 1999.
- A complaint was filed before the National Human Rights Commission on the behalf of a man who was denied medical treatment in a public sector hospital in Delhi. The National Human Rights Commission has called for a report.

these protocols will represent a milestone for patient advocacy in India.

### **Quackery – A Flourishing Trade!!**

Quacks have proliferated since the advent of the HIV/AIDS epidemic, making a fast buck at the expense of those most vulnerable. Many quacks claim to have cures for HIV/AIDS. Unsuspecting individuals fall prey to them in the desperate hope of being cured. People living with HIV/AIDS report having spent large amounts of money for these 'false cures'. Quacks do not have sound knowledge or educational qualifications to examine patients or prescribe any medicines. Nor are they registered with the Indian Medical Council as practitioners. Quacks use methods that are not scientifically accepted and promote quackery by the use of misleading advertisements and other methods of promotion. Since the press has such a wide and universal access to the general public it is crucial that steps be taken to stop these harmful advertisements and practices.

How quackery harms:

- Financial loss – the medicines are expensive, people living with HIV/AIDS can hardly afford them and in fact steep them in further debts
- Direct Harm – the medicines may have deleterious side effects
- False Hope – Quacks give a false promise of becoming sero-negative on taking these medicines which may endanger the lives of others. It may also cause psychological harm to the person who lives in the hope of being cured

Legal remedies against quackery are available under the following:

1. Drugs and Magic Remedies Act, 1954
2. Monopolies and Restrictive Trade Practices Act, 1969
3. Drugs and Cosmetic Act, 1940
4. Consumer Protection Act, 1986

For quacks who advertise cures for HIV/AIDS, a complaint may be made to the Advertising Standards Council of India, who may in turn issue a warning to the concerned media agency or the advertiser. The Advertising Council of India cannot take any legal action.

If you have any information or evidence regarding quacks claiming to have a cure for HIV/AIDS, do write in to us with full information so that we may pursue the matter.

### **In Conversation with Dr. Prakash Bora...**

Dr. Prakash Bora is a private medical practitioner and the director of the Mumbai-based NGO *HIV/AIDS Information and Guidance Centre and Clinic*. Dr. Bora has been providing care and support for people living with HIV/AIDS in Mumbai for many years.

*What do you feel about the present situation of discrimination against people living with HIV/AIDS in health care sector?*

There is wide discrimination prevailing in health care today. The epidemic is spreading at an alarming rate. Unfortunately society treats people with HIV/AIDS with hatred and dislike. It's a pity that when such people should be given love, care, sympathy and support they are ill-treated and isolated.

*Would you share some instances of discrimination practiced the in health care sector?*

There are many instances of discrimination in health care institutions for instance people living with HIV/AIDS are denied admission in hospitals, not provided proper attention and care for example, nurses get angry if they are called again and again. There is an instance from a very renowned hospital where the patient was admitted and when his HIV positive status was revealed, the attitude of the staff towards him completely changed. The ward boys refused to clean the dustbin and even give the bedpan to the patient. The 'aayas' did not change the bedsheets for two days. Nurses said it was not their duty to take care of such patients. This particular incident took place in a hospital where all the necessary precautions and facilities are provided. Eventually the patient was asked to leave the hospital.

*What do you think is the level of awareness of paramedical staff in regards to HIV/AIDS?*

There is a lack of awareness amongst the paramedical staff. It is obligatory on the part of the health care institution to provide safe working environment. Universal precautions should be followed. Many times discrimination arises out of ignorance and fears of infection. So there is a need to address the fears and ignorance of medical staff.

*Have you come across any positive changes in the attitude over the years?*

There is definitely a positive change in the attitude of the family members of the people with HIV/AIDS. They are more supportive and caring. As far as the health care sector is considered there is a positive change but very marginal. There are some hospitals and some doctors who are accepting the patients and providing treatment, but not nearly enough.

*What steps do you think should be taken to improve the present scenario and provide better health care services to the positive people?*

I think there is a need to create awareness and educate medical and paramedical staff. All levels of medical staff must be given adequate training. There is a need for positive role models in the medical community viz. doctors who are sensitized should come forward and inform and educate others. It is important for people living with HIV/AIDS and their families who require a non-stressful environment.

***Contributors: Nidhi Dubey, Jai Wadia & Dr. Mandeep Dhaliwal***

***Edited by Dr. Mandeep Dhaliwal***

### ***Campaign Against the Suspension of the Right of People Living With HIV/AIDS to Marry***

**21<sup>st</sup> August, 1999** - Dr. M.J. Kikani, Project Manager (in charge) Surat Municipal Corporation DFID project, organised a public meeting in Surat to create awareness about the suspended right of people living with HIV/AIDS to marry. The meeting was addressed by Mr. Anand Grover, Advocate and Director, Lawyers Collective HIV/AIDS Unit.

**4<sup>th</sup> September, 1999** - Sevadhan, a Narcotics Rehabilitation Centre organised a public meeting in Mumbai. The meeting was attended by lawyers, NGOs working in the field of HIV/AIDS and women rights activists. The meeting was addressed by Justice Suresh, retired judge of the Bombay High Court and Mr. Anand Grover, Advocate and Director Lawyers Collective HIV/AIDS Unit.

**30<sup>th</sup> September, 1999** - A public debate on the right of people living with HIV/AIDS to marry was jointly organised by India Centre for Human Rights and Law and the Bombay YMCA Central Branch. The debate was chaired by Ms. Mani Mistry, a social activist. The panel of speakers comprised Dr. Prakash Bora – Director of a Mumbai-based NGO HIV/AIDS Information and Guidance Centre and Clinic, Mr. Anand Grover, Advocate and Director Lawyers

Collective HIV/AIDS Unit, Dr. Arshad Ghulam Mohammed, President of the Indian Medical Association (Bombay West Suburban Branch), and Ms. Flavia Agnes, Advocate and women's right activist.

**10<sup>th</sup> October, 1999** – Indian Network of Positive People (INP+), Chennai organised a meeting this issue of right to marry. Mr. Ashok Pillai of INP + spoke on HIV/AIDS and Human Rights, Mr. Pramod Kumar, Senior Reporter from *The Hindu* spoke about the role of the Media regarding the Supreme Court Judgement, and Mr. Anand Grover, Advocate and Director Lawyers Collective HIV/AIDS Unit spoke about the judgment.

**October 15<sup>th</sup>, 1999** - A Petitioner, a person living with HIV/AIDS, has filed a petition in the Supreme Court. The Petitioner is seeking clarification on the substantive issues arising from the judgment of *Mr. X v. Hospital Z* (1998) 8 SCC 296 according to which the law imposes a duty on a person living with HIV/AIDS not to marry.

**29<sup>th</sup> October, 1999** - The case of *AC & Others v. Union of India & Others* (Writ Petition No. 1322 of 1999) was heard for final hearing by the division bench of Justice Ghodeshwar and Justice Radhakrishnan. The judgment is due to be given on November 15<sup>th</sup>, 1999.

The suspension of the right to of people living with HIV/AIDS to marry is a violation of their human rights. We, at the Lawyers Collective HIV/AIDS Unit, hope that these public meetings will generate public opinion on this issue and motivate people to make a concerted effort to reverse this judgement. The public meetings so far have been by and large well attended and a collective voice advocating the restoration of people living with HIV/AIDS is emerging. Similar meetings are also being planned in Goa, Rajkot, Lucknow and Delhi.

A **signature campaign** to challenge the decision of the Supreme Court of India has also been initiated. A form letter for the signature campaign is available from the Lawyers Collective HIV/AIDS Unit via fax, e-mail or the website. The signatures will be sent as a formal representation to the Supreme Court of India on the behalf of concerned individuals who oppose the judgment of the Supreme Court and want to restore the fundamental right of people living with HIV/AIDS to marry.

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, 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.

Lawyers Collective HIV/AIDS Unit holds monthly drop-in meeting on the first Thursday of each month at 5:00 p.m. The objective of the meeting is to share experiences, information and discuss issues of concern. We invite your active participation in these meetings.

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

Lawyers Collective HIV/AIDS Unit  
7/10, BOTAWALLA BUILDING, 2<sup>ND</sup> FLOOR  
HORNIMAN CIRCLE, FORT  
MUMBAI - 400 023  
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Hours : Monday – Friday : 10:00 a.m. – 7:00 p.m.  
Saturday : 10:00 a.m. – 4:00 p.m.