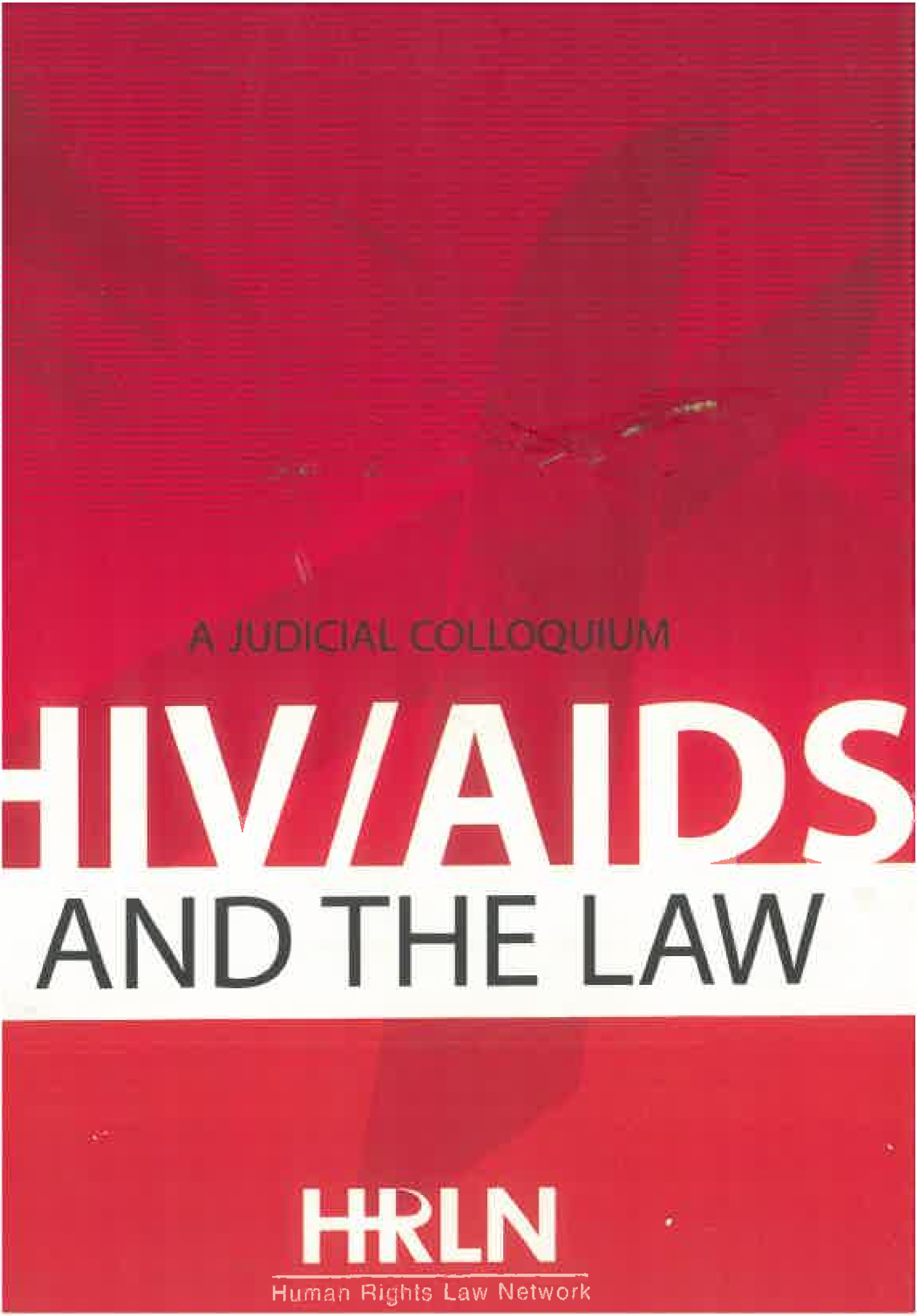
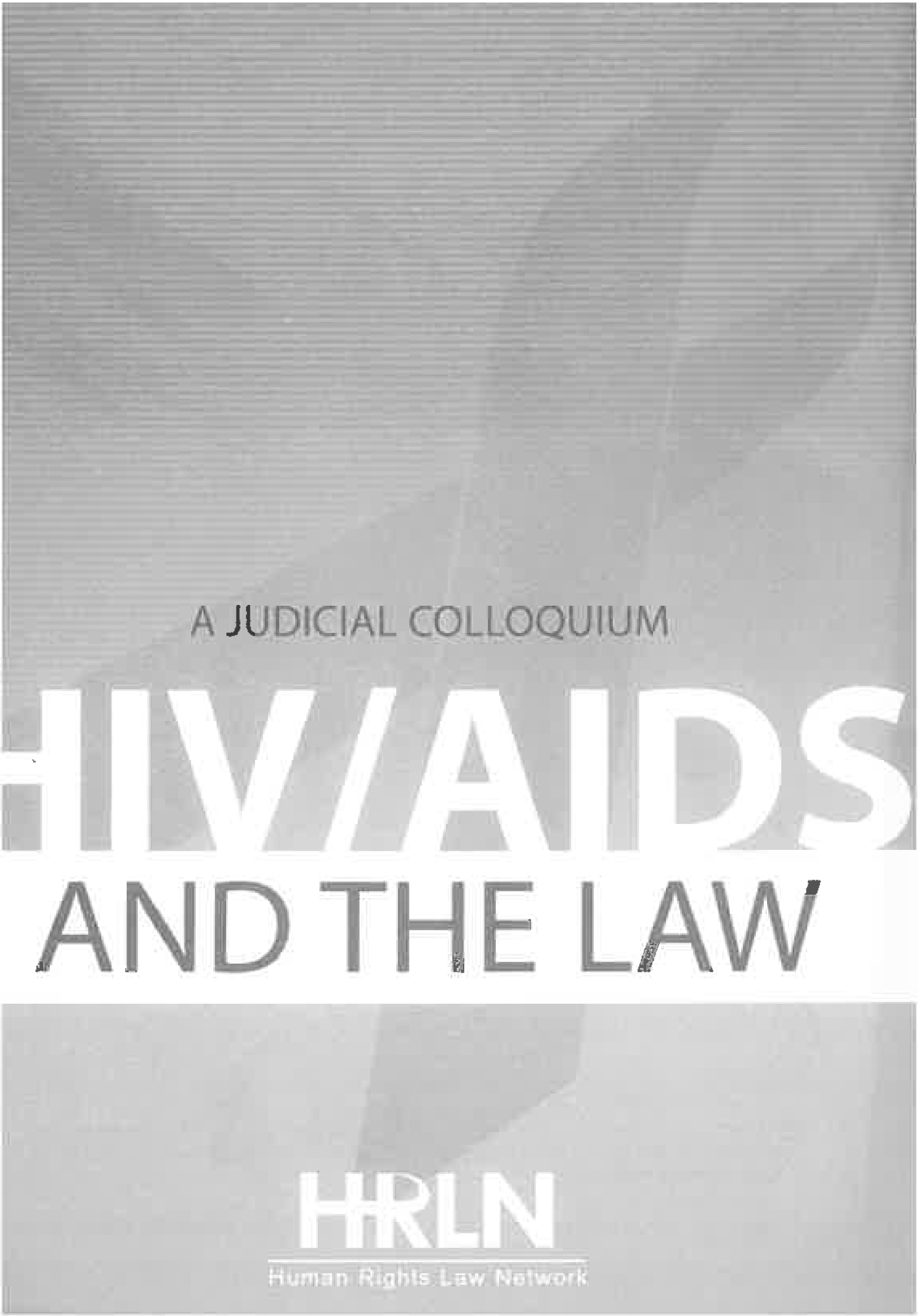


A JUDICIAL COLLOQUIUM

HIV/AIDS AND THE LAW

HRLN
Human Rights Law Network



A JUDICIAL COLLOQUIUM

HIV/AIDS AND THE LAW

HRLN
Human Rights Law Network

Human Rights Law Network Vision

To protect fundamental human rights, increase access to basic resources for the marginalised communities, and eliminate discrimination.

To create a justice delivery system that is accessible, accountable, transparent, efficient and affordable, and works for the underprivileged Raise the level of pro bona legal expertise for the poor to make the work uniformly competent as well as compassionate.

Professionally train a new generation of public interest lawyers and paralegals who are comfortable in the world of law as well as in social movements, and who learn from social movements to refine legal concepts and strategies.

A Judicial Colloquium – HIV/AIDS and the Law

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Disclaimer

Hon'ble Mr. Justice Deepak Mishra, Judge of the Madhya Pradesh High Court

There are two motives for making people aware of HIV/AIDS. One is prevention, and one is to encourage an appropriate response. There should be a legal literacy camp held, involving doctors, lawyers and other people to educate people about their rights and about how to avoid HIV infection. The right to health is a fundamental right, as interpreted by the Supreme Court.

Hon'ble Mr. Justice Altamas Kabir - Justice of the Supreme Court

Concluding Remarks

JUSTICE
ALTAMAS KABIR

This problem is similar to global warming – as dangerous, and spreading fast. I am extremely grateful to the Human Rights Law Network for having prepared these two excellent volumes on HIV/AIDS and the Law, a wonderful collection of judgments and pronouncements.

We as judges need to use the tools available to us in fighting this epidemic. We need to consider the impact of patent law and how it can be developed. We will also shortly be considering the HIV/AIDS Bill which is on the anvil. Access to treatment and the elimination of stigma and discrimination are extremely important issues for people living with HIV/AIDS. Education needs to be given, for example, to employers about how to deal with employees living with HIV/AIDS.

Today the HIV population of the world is nearing 39 million. The HIV population in India is near 5.3 million. HIV positive status by itself does not do any harm, in the sense it is not infectious unless transmitted by very specific means. It can also be kept in check for a long time.

I first met Justice Yacoob in 2001 when he and another eminent judge of South Africa of the constitution bench, Justice Albie Sacks, had come down to Kolkata. These two gentlemen were part of the five judges who framed the South African constitution after the departure of apartheid. They are extremely sensitive people.

Thank you all for taking part.

Foreword

On the 19th and 20th of May 2007, Human Rights Law Network, together with UNAIDS, held a National Judicial Colloquium, in New Delhi.

The Colloquium was attended by close to 50 High Court Justices, Chief Justices, and Judges of the Supreme Court who heard presentations given by experts and participated in a discussion about the role of the judiciary in responding to the HIV/AIDS epidemic in India. Issues covered included technical aspects of HIV/AIDS, the state of the epidemic in India today, HIV/AIDS and the law, lessons which can be drawn from the South African experience, mandatory testing, treatment, discrimination, patents, women's rights and many more.

The panel for the inaugural session was made up by the Honourable Mr Justice Altamas Kabir (Judge of the Supreme Court, Chair and Keynote Speaker), Dr Maxine Olson (UNDP Regional Representative), Ms Sujatha Rao (Director General of the National AIDS Control Organisation), Dr Denis Broun (Country Coordinator, UNAIDS) and Mr Colin Gonsalves (HRLN).

The Honourable Mr Justice Altamas Kabir, in his keynote address, spoke of how important it was for the judiciary to understand the nature and extent of the difficulties experienced by the persons living with HIV/AIDS. He spoke of the role of the judiciary in interpreting existing legislation in an expansive and purposive manner given the current absence of HIV/AIDS-specific legislation. The keynote address highlighted the difficulties faced by the judiciary in trying to deal with issues that have a social as well as legal dimensions.

Dr Maxine Olson spoke of the UNDP's commitment to the right to access to information for everyone, and the importance of greater involvement of people living with HIV/AIDS Ms Sujatha Rao gave an update on NACO's activities and the status of the epidemic in India today, as seen by NACO. Dr Denis Broun enumerated the issues concerning estimating the extent of the epidemic around the world using existing mathematical models and spoke of some of the positive signs being seen in some parts of India today He also spoke of those factors that had worked most significantly in the global fight against HIV/AIDS.

The HRLN book, 'HIV/AIDS & The Law' was formally released by The Honourable Mr Justice Kabir.

On the second day, the Colloquium was attended by Shri Oscar Fernandes, Parliamentarians' Forum on HIV/AIDS, who took questions from the Honourable Justices.

Over the two days, a number of sessions were conducted by leaders of the positive networks - such as Mr Elango Ramachandran of Indian Network of Positive People, Mr Ashoka Row Kavi Hamsafar Trust, Mr Rahul, Naz Foundation, and Mr Firoz Khan of Lovelife Society.

A good friend of HRLN, Mr Justice Z Yacoob, Judge of the Constitutional Court of South Africa, chaired the final session of the Colloquium on the role of the judiciary and spoke warmly and eloquently about the struggles of the South African people for anti-retrovirals and the judiciary's response to the struggle.

Justice Altamas Kabir concluded the Colloquium with an inspiring Valedictory Address ending with a warning that "this is a problem which is almost similar to global warming, as dangerous and spreading fast."

Acknowledgements

We would like to thank the contribution of many colleagues and interns who worked with us to make the Judicial Colloquium on HIV/AIDS and the Law successful.

Many colleagues at HRLN Delhi- Saud Tahir, Ragini Trakroo, Sanjay Dhadwal, Rekha Srivastava, Bertyl Verma, Nick Robinson, Monideepa Bannerjee, Deepak Chamoli, Pankaj Chamoli, and Shiva Pahari were an important part of the Judicial Colloquium event and we would like to thank them for all their assistance.

Rashi Surekha, Rishi Thakur and Etika Mishra, interns with the HIV/AIDS and the Law Initiative provided crucial support leading up to and at the event, we are grateful for their effort and acknowledge the role they played in the event. Colin Gonsalves' leadership and the assistance provided by all the state units of HRLN were crucial aspects of the colloquium. We would also like to acknowledge the transcription work done by Brittany Davis, an intern with the HIV/AIDS and the Law Initiative.

NATIONAL JUDICIAL COLLOQUIUM ON HIV/AIDS AND THE LAW - MAY 2007

GLOSSARY

- Anti-retroviral Treatment or Therapy

  Drug treatment which, when taken properly, significantly increases the expected life-span of a PLHA.
- ARV Treatment or Therapy

  Anti-retroviral treatment or therapy
- CSW

  Commercial sex worker(s)
- Global Fund

  Global Fund to Fight AIDS, Tuberculosis and Malaria
- GIPA

  Greater Involvement of People Living with HIV/AIDS
- MSM

  Men who have sex with men, or a man who has sex with men
- NACO

  National AIDS Control Organisation
- NACP

  National AIDS Control Programme, a phased programme of which Phase III was announced in July 2007

- PEPFAR
  [United States] President's Emergency Plan for AIDS Relief
- PLHA/PLWHA
  Person (or people) living with HIV/AIDS
- Provider-initiated Testing
  A policy under which healthcare providers recommend to patients, presenting with symptoms indicating HIV, that they be tested for HIV.
- PTCT
  Parent to child transmission, referring to transmission of HIV from mother to child before or during birth, or through breast feeding
- TB
  Tuberculosis
- VCTC
  Voluntary Counselling and Testing Centre

Hon'ble Mr. Justice Altamas Kabir - Justice of the Supreme Court

The Hon'ble Mr. Justice Altamas Kabir was born on 19 July, 1948.

He was enrolled as an Advocate in 1973, and practised in the District Court and Calcutta High Court in Civil and Criminal matters. He was appointed as a permanent Judge to the Calcutta High Court on 6 August 1990 and was thereafter appointed as Chief Justice of the Jharkhand High Court on 1 March 2005. He was appointed as a Judge of the Supreme Court of India on 9 September 2005, and is due to retire on 19 July 2013.

HON'BLE
ALTAMAS KABIR

Key note address – We need to make people aware

HIV/AIDS is a topic where it is of utmost importance to first of all understand the problem. It is important to know exactly what we are faced with, and what we are called upon to tackle. The expressions HIV and AIDS are expressions with which we are all quite familiar, but sometimes one wonders what exactly is HIV? Human Immuno-Deficiency Virus. What does it do? A person infected with this particular virus, after a number of years, may develop AIDS. What is AIDS? Acquired Immuno-Deficiency Syndrome. And how does one get infected? Unsafe sex is the main problem faced all over the world. Transmission can also occur through sharing syringes or needles, and unsafe blood transfusions.

Many people living with HIV/AIDS do not know they are positive, which brings in another facet of this national debate: confidentiality and disclosure.

There is currently no HIV/AIDS legislation in place. Until today, what we have had is decisions of the different courts at common law, interpreting certain provisions of the Constitution of India. The decisions, on the whole, enforce certain human rights including the rights of people who are HIV positive or suffering from AIDS, which are guaranteed by the Constitution of India. It is on this basis that judgments have been delivered by the Indian judiciary.

The most important Article of the Constitution of India in this context is Article 21: The right to life. The judiciary has stretched Article 21, as well as Articles 14, 16 and even 19, to try and provide some kind of relief to those who are infected and affected.

As far back as 1989, an attempt was made to introduce legislation in Parliament addressing the HIV/AIDS epidemic. That Bill was known as the Acquired Immuno-Deficiency Syndrome (AIDS) Bill, 1989. Before it could even see the light of day, the then Minister of Health, who was piloting the Bill, sought to withdraw it. He was asked by a Member of Parliament why he was withdrawing the Bill: "Let me explain why I am withdrawing the Bill. In a nutshell, I would say that we have introduced this Bill in 1989 in this House, now the World Health Organisation has passed a resolution that HIV patients and AIDS patients should not remain isolated. The treatment towards such patients should be humane. It should not be inhuman. There should be no separate camps or compartments in any hospital. They should be treated as common human beings. The second thing is that mostly HIV patients are found in high-risk groups called, in ordinary parlance, "commercial sex workers". The Bill seeks that these people will be identified."

This was amongst the reasons given for the withdrawal of the Bill and there was then no further attempt made to introduce legislation in Parliament. I think what led to the withdrawal of the 1989 Bill was also reflected in the judgment of the Bombay High Court in Lucy R D'Souza v State of Goa and others (AIR 1990 Bom 355). At that time, there was a law in force in Goa regarding isolation of people who were found to be HIV positive. Pursuant to this law, Ms D'Souza's son was quarantined. Ms D'Souza tried to get her son out, but it was held by the Bombay High Court that, whilst such quarantined isolation did infringe the individual's human rights, public health and the public good was of more importance than the individual's right to move around freely.

One question which has arisen is whether the national Government ought to be required to provide treatment free of charge to people who are living with HIV and AIDS. This particular problem is still most prevalent among the high risk groups, that is commercial sex workers, migrant workers, men who have sex with men and injecting drug users. Once a person becomes HIV positive, there is no cure for it. A person can receive treatment to slow the effects of the virus on his or her body, but ultimately it is going to result in AIDS.

NACO is, of course, trying to contain this epidemic, through various methods including by trying to disseminate information about the use of safety measures for all people when having sex. HIV/AIDS is also a social problem. It is perhaps something which you cannot enforce by law alone. You cannot, for example, compel someone to use a condom.

That kind of behavioural change must come about through awareness, which is what NACO is also trying to bring about.

It is currently proposed that the draft HIV/AIDS Bill will be presented to Parliament in the Monsoon Session of 2007. I will look briefly at the opening provisions of the Bill. The statement of objects and reasons provides: "Whereas the spread of HIV/AIDS is a matter of concern to all, and Whereas there is a need to prevent and control the spread of HIV/AIDS, and Whereas there is a need to protect and promote the rights of those who are HIV-positive, those who are affected by HIV/AIDS and those who are most vulnerable to HIV/AIDS in order to secure their human rights and prevent the spread of HIV/AIDS, and Whereas there is a need for effective and accessible care, support and treatment for HIV/AIDS, and Whereas there is a need to protect the rights of healthcare providers and other persons in relation to HIV/AIDS..." The Bill is divided into various sections which seek to achieve these objects. But it is yet to be presented to Parliament.

It is a sense of awareness that needs to be inculcated and, as judges, in the absence of any legislation as such, we should all use our own innovative methods in trying to provide relief to those persons who are affected by this particular disease.

Question

Much has been said of the judiciary's innovative use of Articles 14 and 21.

For example, it is reported that the epidemic is spreading through rural areas, where the people affected will be looking for speedy, accessible remedies, geographically close to them. Not everyone can afford to approach the High Court with a writ petition. What is being done to disseminate information to the lower judiciary, is to educate them about how to help affected populations?

Answer

The courts, lower courts included, have to use what is available to them to help affected populations. Currently, that is the Constitution of India.

Ms. K Sujatha Rao - Additional Secretary and Director General, National Aids Control Organisation (NACO)

Ms Rao joined the Indian Administrative Service in 1974. She has worked in various posts such as District Collector and Magistrate, Commissioner and Special Officer of Hyderabad Municipality in Andhra Pradesh, Director of School Education, Secretary (Finance), etc. She was also Director and later Joint Secretary in the Ministry of Health & Family Welfare, Govt. of India in two spells, from 1988 to 1993 and from 1998 to 2003. In 2004, she was appointed as Secretary of the National Commission on Macroeconomics and Health which was co-chaired by the Union Ministers of Finance and Health. Ms Rao joined the National AIDS Control Organisation as Additional Secretary and Director General on 21 November 2005.

MS. K SUJATHA RAO

What NACO is doing

This is an overview of what we are doing at the National AIDS Control Organisation in respect of the HIV/AIDS epidemic, which is now quite a serious concern in India. First of all, I ask for your understanding that lawyers and NGOs are able to make passionate pleas on distinct issues, but that we, as implementing programmes, have to look at a broader picture, and have wider responsibilities.

The first case of HIV in India was discovered in 1986 in Chennai. Today, we estimate there may be some 5.2 million cases. The estimates are drawn up by using surveys from sentinel sites, which we have established throughout the country. At each sentinel site, we collect about 400 unlinked, anonymous blood samples from people who come to the sites over a period of three to four months. The blood samples are tested, and those which test positive for HIV go to a national reference laboratory for confirmation.

Based on those positive test results, we take into account the denominator of the population and arrive at an estimate of the prevalence level of the disease. We extrapolate that to the whole country, and from there we draw the estimated number of cases.

In India today, we have about 1,162 sentinel surveillance sites in public hospitals, as well as sites which commercial sex workers, injectable drug users and MSMs (i.e. high risk groups) are likely to attend.

The World Health Organisation, which is the international certifying body for our sentinel surveillance sites, has given India an A Grade. That means we have one of the best and most robust sentinel systems in the world for assessing the trend, and tracking the disease progression in India.

A figure of 5.2 million people living with HIV/AIDS translates into a prevalence level of approximately 0.9% amongst the adult population. This means it is still under the 1% benchmark. I think it is a very distinct achievement of NACO's to have been able to protect 99% of the citizens from this infection. There are claims that these figures are an underestimate, but our assessments are scrutinised by international bodies such as UNAIDS, the World Health Organisation, the Center for Disease Control and Prevention. They participate in the process and, in June, 2007 will again look at our figures for the 2006 data.

In absolute numbers, India is second only to South Africa. This year, you may have seen the UNAIDS estimate of 5.7 million people living with HIV/AIDS, which would put India ahead of South Africa in terms of absolute numbers. This discrepancy is due to the fact that NACO's figures include only those in the 15 to 49 year old, sexually active section of the population.

The epidemic is still characterised in India as a concentrated epidemic. It is not a general epidemic, as we see in South Africa or Sub-Saharan Africa where the prevalence rates are 18% to 20% - Botswana has a prevalence rate of 32%. The epidemic in India is concentrated in some states of the country and, within those states, within certain districts. It is largely in the developed parts of the country, such as costal Andhra Pradesh, in the Maharashtra region, and Karnataka, and in Manipur and Nagaland (because of the association with drug use).

The age and sex distribution of the reported AIDS cases in India shows that the younger population is most vulnerable to this infection. 15 to 29 year olds constitute almost one third of the total number of those infected, and that is a major cause for concern. The 30 to 49 year olds also have a large burden of disease. In India, 86% of HIV infection is passed through heterosexual sex, the rest through contaminated blood, sharing of syringes, or within the MSM community.

The HIV prevalence level is not uniform amongst different population groups. Among those who have sexually transmitted diseases, it is about 5.7% – these are averages which means it could range anywhere between 4% and 12%. In Andhra Pradesh, 22% of those with STDs are HIV positive while 8.4% of female sex workers are HIV positive. In Maharashtra, we find that 20% to 25% of the commercial sex workers are HIV positive;

recently we found a village in Punjab where the youth have been taking drugs, and there was a prevalence of almost 17% amongst the IDUs.

When we extrapolate to the general population, we use an indicator of HIV tests taken at anti-natal care, as these mothers are generally less likely to engage in high risk behaviour. This data is, therefore, extrapolated as a proxy to give the general estimates for the country as a whole.

NACO's goal for 2007-2012 is to halt and reverse the epidemic in India. The modelling exercise done for these purposes shows that if we do not do anything, and just continue to maintain the status quo, by 2012 we may have about 6 to 8.7 million cases of HIV infection. If, however, we are able to implement the interventions designed in NACP Phase III, we, in partnership with all our donors and in consultation with the states and different stakeholders of the programme, would be able to reverse the epidemic, bring it down to between 3 and 3.5 million, and after that we hope it will peter out. That is the modeling we did, and it is based on this that NACP Phase III has been developed.

There are four key strategic objectives. One is prevention. Data today shows that the Indian model is very effective, and has in fact been adopted by other countries. Our prevention policy is based on trying to saturate the high risk groups, mainly commercial sex workers, IDUs and MSMs, providing access to safe blood and testing and providing prophylaxis treatment to HIV pregnant women to ensure they do not pass on the infection to their babies.

In the prevention programme, we base our model of saturating the high risk groups on a rights-based approach. This sometimes brings us into conflict with other government departments, for example the Department of Women and Child Development which would like to bring in a law to the effect it should be a punishable offence for a male client to go to a sex worker. Our argument has been that unless and until we get these marginalised groups out into the open and get access to them to provide information, condoms, access to services etc., it will be impossible to contain the infection. Legislation such as criminalising clients of commercial sex workers would only push the infection further underground, and does not really solve the problem.

We have found the rights-based approach to be effective in the states in which we have implemented it. In Tamil Nadu for example, under NACP Phase II, we have about 92% use of condoms amongst sex workers. There is evidence to show that, over a period of three years, the epidemic has shown a decisive reversal. It is now at 0.6% and I think in the next year we should be able to declare Tamil Nadu, previously one of the highest hot spots in the country, as a low-prevalence state. The results are similar in Maharashtra and Andhra Pradesh. Andhra Pradesh continues to be a very high prevalence state, although it has come down from 3.2% to 2%.

Our second key objective is increasing the proportion of people living with HIV/AIDS who are receiving care, support and treatment. HIV positive people are prone to several opportunistic infections – surveys show they suffer double the number of infections of a person who is HIV negative. At the household level, in terms of illness episodes, visits to the hospitals etc., people living with HIV/AIDS face a lot of economic hardship.

Thirdly, we want to decentralise, at district, state and national levels, improvements to the management of the Programme.

Our focus on saturating high risk groups means we need accurate methodologies to determine the locations of these high risk groups. For example, we used to have brothels, which were much easier to approach – there was a whole hierarchy of functionaries around the brothels. Now, because the activity is illegal, all this has been breaking down and it has made it a greater challenge for us to reach out. Today, we have a large number of prostitutes on the streets, in homes. The more the police enforce the laws, and it is their duty to do so, the more you push the infection to invisible areas, making it difficult for us to access people.

Section 377 is also a huge legal barrier to us in accessing MSMs. To say that a man having sex with another man is liable to ten years' rigorous imprisonment, is a source of exploitation, a huge factor to pushing them underground, and a huge factor in which we, the programme, being unable to access them in time.

Testing is very critical to NACO because out of the estimated 5.2 million people living with HIV/AIDS, only 17% of them know they are HIV positive. A TB patient will start coughing, so he goes to a doctor. An HIV positive person, unless he or she comes forward for a test, may not know he or she is HIV positive for quite some time.

Testing was brought into the Programme in 2001, when we did about 4 million tests. This year, the target is 10 million. We want to get to 22 million people being tested next year. Our objective is to get as many HIV positive people as possible out in the open, so that we can access and treat them.

Condom promotion is also a very critical programme for us. Last year we distributed 993 million condoms, and our target is to reach at least 3 billion condoms distributed in the next two years. Blood safety is another important programme.

We have expanded from 54 ART Centres to 127. In 2007, another 48 to 50 centres will be added. Our target is about 250. Alongside this, we are developing satellite sites for the distribution of drugs closer to home. We have about 75,000 people on free ART at the moment. That means they get free diagnostics and free treatment. In addition, we have reason to believe (through the ORG, a credible survey of utilisation of pharma drugs) that another 30,000 people are receiving ART.

India was the first country to come up with treatment protocols and the right ART dosages for children. This has enabled children to access good quality treatment. We have reached about 5,200 children. We have identified 12,000 children, whose CD-4 count has been done. Those who do not currently require ART, will receive it as and when they do.

Second line treatment requires three drugs and the projections show that, by 2011, we may need to spend Rs. 450 crores on these three drugs. Today, the second line treatment costs almost Rs. 1 lakh per person per year, as opposed to Rs. 7,000 for the first line drugs. We have taken a view that, if there are 5.2 million people living with HIV/AIDS, our focus should be to try and reach those 5.2 million people. Our main target is to access as many people as possible with the first line drugs. Later on, as we stablise the programme, we will certainly get to full, comprehensive treatment.

NACP Phase III envisages a NACO spending of about Rs. 8,000 crores, of which spending on prevention is the most important.

There are certain legal barriers making NACO's work extremely difficult. There is a need for national debate, for example, on legalisation of commercial sex workers. Should we repeal Section 377? Some people say that 99% of the population has an equal right to the resources allocated to HIV/AIDS. Their argument is that a disproportionate amount of resources are allocated to 1% of the population. National debate is also required on the issue of confidentiality.

There is a globally-accepted best practice which requires confidentiality, but increasingly people living with HIV/AIDS are seeking transport subsidies, and rightly too. How can we provide this and at the same time protect confidentiality?

Increasingly, chief ministers are demanding mandatory testing, pointing to a state like Andhra Pradesh where a number of young girls have been widowed in circumstances where their husbands married them without disclosing their HIV positive status. Listening to these girls' stories makes you very sympathetic to them and their requests, but we also know of the serious drawbacks of a mandatory testing programme.

Question

Does the epidemic have a trend of being more prevalent in urban, rather than rural areas? I wish to be informed as to whether the rural area is affected more, or the urban area – so that we have an insight as to where effort has to be made.

Answer

When we first started in the early 1990s, it was focused 57-60% in urban areas. Over the last ten to fifteen years, the epidemic has been shifting to rural areas, and now the data shows that 57% of the infection can be found in rural areas. This is largely because of the bridge populations – truck drivers and migrant workers – who go in search of economic opportunities and take back the infection to their wives in the rural areas (the feminisation of the epidemic, where women faithful to their husbands are becoming infected).

Transmission of the virus amongst IDUs is seen largely in the metro cities, but we are, for example, seeing it in rural areas in Punjab, as well as in the North East states.

Question

Firstly, please provide some details on the monitoring mechanisms used by NACO. There is always a risk that a programme fails due to lack of enforcement. It has been suggested that the judiciary can play a role in enforcement of the programme, for example if the court is approached with a PIL. What else does NACO do for programme enforcement?

Secondly, what kind of media strategy is in place to ensure that information is reaching the right people?

Answer

NACO operates at state level through the State AIDS Control Societies. Most of the targeted interventions with the high risk groups and bridge populations are done by NGOs, as they have much better access to these groups. This implementation is monitored very closely – we have reviews almost every month to test, for example, actual condom use, prevalence levels of sexually transmitted diseases etc.

We also carry out a sentinel survey every three years. About 100,000 households are interviewed, this is a structured sample, and we use a questionnaire to seek information on whether there has been a behavioural change. We want to see that we reduce promiscuous behaviour, other risky behaviour, and increase use of condoms. Our latest survey, carried out last year, shows an awareness level of 86%, and that use of condoms has been steadily going up among the groups with which we are most concerned.

We run information campaigns, largely on radio and Doordarshan, which have good access in the rural areas.

Question

Financial and other constraints mean you are able to test only a percentage of the population through sentinel surveillance monitoring. Are the tests carried out one-time tests, or are you able to test periodically?

Answer

The sentinel surveillance testing is done every year, from people who are unlinked and anonymous. This is only to get data for tracking the disease. Is it going into rural areas, is it evenly spread among men and women etc. It is an academic exercise for us to get data.

We are rapidly trying to decentralise the testing sites, but the problem here is the low perception of risk. Due to the epidemic's association in people's minds with homosexuality, for example, the community may think "why is she going to a test?" In the absence of mandatory testing, low perception of risk is a big barrier, because people have to want to be tested. Pre-test counselling and post-test counselling are made available. We have about 4,200 laboratories where we have set up integrated counselling and testing centres, where there is a laboratory technician and a counsellor. It is a walk-in service, and their use is increasing.

The debate on whether we should make testing mandatory or not is becoming a big issue. With cooperation of the police, Andhra Pradesh tested the low-level police constabulary in one district, and found 2% prevalence. Many Police Constables insist on having unprotected sex, thinking they are macho and nothing will happen to them. They have power over the women, who cannot negotiate safe sex. This kind of data illustrates to some people the balance between mandatory and voluntary testing. We are trying to find that balance in the provider-initiated testing policy.

Provider-initiated testing is when a doctor sees a patient who, for example, has diarrhea, or weight loss – symptoms which could suggest HIV infection. That health care provider would then have the right to suggest the patient should taken an HIV test, in the same way you would tell a patient to get an MRI test done.

We are also looking at an opt-out policy, where if a large number of people are together – this is mainly for pregnant women – we provide them with information about HIV/AIDS and tell them we would like to do an HIV test as a routine matter, then we can see that your baby is not infected.

In both these cases, we have a problem with the human rights angle, which says we are not making the testing voluntary. It is a fine balance to be met.

Question

The situation in the North East is very complex. There are as many as 34 active insurgency operations going on. Apart from terrorism, we take HIV/AIDS as the main terrorist threat in the North East. So, in this regard we have four groups of people. The insurgency groups, truck drivers and those who are passing through the North East, migrant workers, and then those involved in the drug traffic. What study or survey has been made by NACO for these areas?

Answer

Studies show that in the North East, this problem continues to be very severe. Manipur is the highest in terms of prevalence, and the main problem is the drug trafficking from Myanmar. This is an unprotected zone and it is very difficult to control that.

We have several surveys which show that intravenous drug use is the main driver of the epidemic in the North East and we are now trying to have a comprehensive policy where we provide IDUs with oral substitution therapy, to get people away from intravenous drug use.

Dr. Maxine Olson, UNDP Regional Representative

The UNDP Approach

In India, as well as in most countries of the world, the UN operates under the three ones principle. This is: (i) one framework for the strategy of how to address HIV/AIDS within the country; (ii) one coordinating mechanism – ideally (as is certainly the case in India) under the leadership of the government itself; and (iii) one monitoring and evaluating framework, so that we all measure our challenges and successes in the same way.


DR. MAXINE OLSON

One of UNDP's core activities is to support making the tools of prevention available – information, condoms, safe blood, clean needles, treatment to prevent the unborn from becoming infected. We are committed to seeing that the right information is available to those who need it most, and that includes providing sex education. This is a hot topic in India. Some states such as Madhya Pradesh and Karnataka are in the process of banning sex education. Education is really the only vaccine we have that works, in terms of preventing HIV. If people do not know how to use condoms, if they do not know how the infection is transmitted, if they do not know the importance of safe blood and the importance of clean needles, the chances of them becoming infected become much higher. We need to find the way forward to provide this information to the most vulnerable (i.e. the young who are in schools) in a way that is acceptable to Indian society and provides the information they need.

The UNDP also works in mainstreaming. Mainstreaming is very important – HIV/AIDS is everyone's business. It is a question of seeing how each of us in both our professional and personal capacities can be in a position to halt the increase in the rate of infection.

GIPA, the greater involvement of people living with HIV/AIDS, is one of our priority principles. Positive people are an important tool, the best instrument, to carry out effective HIV/AIDS programmes. PLWHA are best able to understand and communicate to others the issues involved. To hear a positive person speak, I know in my own experience, turns the tide in terms of how one sees the issues, and how one understands their immediacy for the people of India.

The UNDP wants to be inclusive, and takes deliberate steps to see that positive people are a part of planning our programmes, as well as their implementation, monitoring and evaluation.

I want to examine briefly the context in which the HIV/AIDS epidemic has thrived and what the UNDP sees as the vital role, the judiciary plays in the way forward. It is important to understand why the numbers continue to grow. Stigma and discrimination act as a bar to the very effective work possible at the medical level. Stigma and discrimination operate in two different ways. One is that the vulnerable populations themselves are not easily reached. Therefore they do not have the information or means to prevent infection itself. Secondly, once someone is infected, the same stigma and discrimination operates to drive them and their knowledge underground, so the infection continues to spread. Stigma and discrimination are drivers of exclusion, which in turn is the single biggest driver spreading the disease.

We have all been watching and participating in the discussions about the new development plan for India for the years to 2012. The issue of inclusion is very much present in that. The understanding is there that, as a development issue, it is important to narrow the gap between the rising, fast growing India, and the part that is not growing. The traditional distinction between Indian and Bharat is still very much there, and the concern for development practitioners is to see that inclusion is the order of the day.

At the United Nations, we look at inclusion in all the work we do, to meet the needs of those who are most disadvantaged. In fact, the goal for our own development framework, which is a sub-set of what is done in the national development plan, is "to promote the social, economic and political inclusion for the most disadvantaged, especially women and girls." This is very much the way we approach the issue of HIV/AIDS. It is about inclusion and seeing that our programmes are ones which include positive people and the most vulnerable groups as important, vibrant members of society itself.

Discrimination on the basis of a disease is a violation of a person's human rights. That is why the engagement of the judiciary is so important. As the number of those living with HIV/AIDS grows, and the effects are felt at individual, household and community levels, many more cases are coming to the courts for redress, for the upholding of rights relating to access to treatment, patents, second line treatment, health, property, care and support, adoption, guardianship of children affected by HIV/AIDS, rights of a widow whose husband has died from AIDS within the extended family.

We seek three things from the judiciary. One is that when cases come before the courts, there is speedy and conscientious redress. Secondly, the enforcement of existing laws and policies. Lastly, to ensure a strong legal framework for the protection and promotion of the rights of those infected, affected and vulnerable to infection. The judiciary can certainly play a lead role in the reinterpretation of section 377, in facilitating better access to services for MSMs, and in the implementation and enforcement of any HIV/AIDS-specific legislation that is passed.

As the number of cases on enforcing the human rights of those affected by HIV/AIDS, together with the awareness of those judgments, the judiciary will be a part of the transformation of the understanding and appreciation of HIV/AIDS and the human rights of those affected. The judiciary's role is critical to ensuring individuals affected are able to lead lives of dignity and that India's prosperity means prosperity for all.

Question

Are you generating a model package of laws for universal access that could be adopted, or promoted by the treaty route?

Answer

There are a number of experiences from around the world that are considered best practice, and of course in India, there is the HIV/AIDS Bill.

Dr. Denis Broun, UNAIDS, Country Coordinator, India

Dr Broun obtained a Masters degree in Biomathematics in 1977, and his Medical Doctor Degree in 1981, from the University of Paris. He specialised in Tropical Medicine from the Institute Léon M'Ba, University of Paris, in 1982. He is diploma cum magna laude of the Paris Institute of Political Sciences, 1984.


DR. DENIS BROUN

After working as a health economist in countries in Africa and Asia, Dr. Broun joined the World Bank in 1991 and was in charge of the pharmaceuticals and vaccines sector as a Senior Health Specialist coordinating the Bank's work in the essential drugs area. Between 1996 and 1998, he was Chief of Health Section and Special Adviser to the Executive Director at UNICEF (New York). He joined the World Health Organisation in 1998, initially as a deputy director for the Control of Tropical Diseases, then as Director of Resource Mobilisation. Between 2000 and 2005, Dr. Broun worked with Management Sciences for Health, leading the franchise activities of the Gates Foundation-funded Strategies for Enhancing Access to Medicines (SEAM) to improve access to essential drugs.

Dr Broun became UNAIDS' country coordinator for India in 2005.

The state of the epidemic in the World Today

What is the situation of HIV/AIDS in the world today? The first important thing to note is that whatever figures we give for HIV/AIDS, they are estimates. We do not know the exact situation. The only way to know the exact situation would be to have everyone tested, which is of course impossible, and it would necessitate every case of

AIDS treated by doctors and hospitals declared as such, which is never the case. So, we base our figures on estimates. We have large margins of error everywhere. We do, however, probably have enough information to understand the dynamics of the epidemic, how it has been evolving and where it is going now.

To give you an example of the spread, when we speak of the number of people living with HIV/AIDS in India, we give a mid-point of a little over five and a half million. We say it is actually between three and ten million – this is the type of margin of error we have in our estimates.

In the world today, we think that, as of 2005, there were 39 million people living with HIV/AIDS. This could be as high as 46 million, and it could be lower. We estimate, based on the evolutions we have from the previous years, that in 2005, 4.1 million people became infected and that 2.8 million people lost their lives to AIDS. Since the beginning of the epidemic, close to 30 years ago, more than 60 million people have been infected and more than 20 million people have died of AIDS – the equivalent of a world war.

What is the trend today? For the first time, I think we are seeing a positive evolution. We are seeing a stabilisation, even a decrease of prevalence in several countries. From the models we have, we have good reason to believe the epidemic has peaked towards the end of the 1990s and early 2000s. There is progress, thanks to better prevention. This progress has been recorded in many countries, and it is something we in UNAIDS have been looking for for many years. We went to great efforts to check these figures that seemed to show improvements were real, when we saw the situation was improving in Zimbabwe and Kenya. We put a lot of research and resources into these countries to confirm it was indeed the case. We also know that in India there has been progress in several states. The prevalence has been decreasing in Tamil Nadu for the past four years, and Tamil Nadu is no longer a high prevalence state.

In addition, we have more than one and a half million people on anti retroviral treatment in the world today. We consider that more than 400,000 deaths were averted last year thanks to this successful treatment. This is important because when we have so many deaths averted, that means we have more people alive and living with HIV/AIDS, and the prevalence as a whole can continue to grow. It is not the same thing, though, as people living with HIV who are sure to die because there is no treatment.

What the world is showing is that AIDS is indeed a problem, but that it is a problem with a solution. It is a solution made of better awareness, better information, better prevention, better care – and this has been implemented in a large number of countries. There are many things that have made this possible. I think AIDS is unique in this respect, and it is worth looking at these facilitating factors. One has been money. Ten years ago, we had about US$200 million of international money to fight HIV/AIDS. Today it is close to US$9 billion. The countries living with a high HIV/AIDS prevalence have increased their own national budgetary spending in a way which had not been seen in previous years. We have seen major initiative created with many funds – for example, PEPFAR (the United States Presidential Initiative) which brought $15 billion dollars to the fight against

HIV/AIDS, the creation of the Global Fund Against AIDS, Tuberculosis and Malaria, the special programmes of the World Bank on treatment of HIV/AIDS and prevention; all of these elements brought additional international money, which was necessary to help countries make the best of their own investments.

Another important factor has been the big movement towards fighting the HIV/AIDS gender gap. HIV/AIDS was initially a disease of men; it is now more and more feminised in sub-Saharan Africa. Up to 60% of people living with HIV are women, in India it is more than a third – it is about 39%. Women's movements all over the world have adopted this HIV cause, as a mechanism to ensure women would be empowered, would have more capacity to access knowledge, more capacity to access prevention.

HIV/AIDS has also triggered a real movement towards the rights of minorities, especially the sexual minorities. This subject, which was often taboo, has now come out in the open, and is discussed in several countries. HIV/AIDS has been the trigger to help increase the rights of minorities, which in turn has allowed better prevention of HIV/AIDS.

Information is also important. HIV/AIDS is the first disease of the internet age, and there has been an explosion of global information about HIV/AIDS. For those familiar with the information networks, it is very difficult to imagine news about changes in HIV/AIDS in one country not being known elsewhere almost immediately. It has been interesting to see that on the issue of section 377, activists from all over the world have been making their opinions known for an issue which, in the past, would have been confined to India. This networking, this internationalisation of information and of activism, has really changed the picture. It is interesting to see how international activists have opened debates and opened minds; how, for example, this has led to the major decrease in the price of anti retroviral drugs (which has been decreasing by a factor of nearly 100), how it has helped to raise international money, how it has alerted international press and user networks.

HIV/AIDS has also seen something that we are going to see more of in public health in general, the power of people living with the disease. The power of patients not being seen as at the mercy of doctors. Patients and people living with HIV/AIDS have taken their faith in hand, and have been major actors in the whole debate on how to prevent and how to cure HIV infection. I think these changes are changes in international society, and they always have their consequence in law, national and international law.

The world community has put a major effort in to fight HIV/AIDS. It has taken some time. The first cases came at the end of the 1970s, the reaction from UN aid agencies started probably towards the end of the 1980s. It was in 1996 that UNAIDS was created, and in 2001, we finally had the first special session of the General Assembly of the United Nations on HIV/AIDS. This was the moment when the whole international community took this cause as a major cause for international cooperation, for international security, and where public health became something which concerned everybody. In 2006, five years later, we had a high-level meeting in New York of the general assembly where two major ideas came out. One was universal access. The concept of universal access to care, as well as universal access to prevention, treatment and support for people living with HIV/AIDS. This concept of universal access, contrary to some programmes which had fixed targets in the past like polio eradication by the year 2000 (which we know does not always work) has been put in a way that each country is to try and reach universal access at the pace it thinks possible for it. Each country has designed its own plans, mechanisms and targets and is responsible for monitoring them. In India, all the targets of NACP Phase III include these targets for universal access.

The second important concept that came out of that 2006 meeting was making the money work. There is much, much more money in HIV/AIDS than before, there is now more emphasis on making sure the work done is cost effective and brings as many results as possible.

So we have what I would call good news now, although we must always be very careful not to over-emphasise this. We must remember that the AIDS epidemic will not be reversed in the short term. It will take many years and a full-scale response in the long term. This response must be worldwide. Each country brings its stone to the wall, but no country can bring no stone, because then the epidemic will start again. Every step which was taken ten years ago is today bearing fruit. Every step which is taken today will contribute to the victory against HIV/AIDS. Today, after nearly 30 years, we are seeing a silver lining.

Question

Has the UN come up with any acceptable legal mechanism for skirting the patent regime for making ART drugs available, or has there been any deliberation or discussion, at the WHO or any of these fora? I understand there is some conflict going on regarding this issue in Africa, here, and also in Brazil.

Answer

The United Nations follows the issue of patents extremely closely, especially through the specialised agency for it, which is the World Health Organisation. The World Health Organisation has a standing interaction with the World Trade Organisation on the issue of patents for anti retrovirals. The UN is more a place where negotiations can take place; a careful, neutral convener of negotiations on the issue of intellectual property.

The WHO plays a major role in helping manufacturers of generics gain access to large markets. One of the most important things to have started at the WHO over the last four to five years has been the pre-qualification scheme. Under this scheme, the WHO sends inspectors to the generic manufacturers, to ensure they are manufacturing their drugs to the highest standards of quality. Once these products are pre-qualified by the WHO, they are eligible for purchase with money from the Global Fund etc. The result has been that, as of today, half the anti-retrovirals available in developing countries come from India.

Dr. Ajay Kehra, Joint Director, National Aids Control Organisation

The HIV/AIDS epidemic in India

Four colours have been used in the map to indicate that HIV epidemic is not uniformly distributed. HIV, unlike other diseases is linked with the personal behavior and habits of a person. In 2006, there are lots of dark patches in various parts of the country. Initially, India was categorized into high prevalence state, moderate states, and low prevalence states. However, even within the low prevalence states, there are areas where the problem is heightened.

Out of 610 districts in the country, 187 have been identified as high prevalence.

The overall prevalence level in the country is less than 1%. That means 99% of the people are still uninfected. Only 1% of the adult population is infected. Another important characteristic of the HIV epidemic is that it is mainly spread amongst the high risk population groups. Hence, the government of India is paying major attention to this category.

There are around 5 million HIV positive people in India. Since the beginning of the epidemic there have been 165,000 AIDS patients. AIDS deaths are usually underreported. Many people die of opportunistic infections without knowing their HIV status.

There have been efforts to track the epidemic in the past through mechanisms called sentinel surveys. In order to track the epidemic, usually the high risk groups are anonymously tested. The data in the last three years demonstrates that the prevalence which is represented by the ANC population has remained less than 1%. Whereas the prevalence rate amongst the STD population is around 5%. The female sex workers data reveals a prevalence rate of 10-30%. Hence, it is clear that the HIV epidemic is mostly spread amongst the high risk groups. Initially, IDUs were perceived to be a North Eastern phenomenon. The data now reveals, however, that it is spread to Southern and Central India. There is a large population infected with HIV amongst the IDUs. Recently, even Punjab had a huge population of infected IDUs.

There are around 2 million MSM in the country. There is a huge infected population amongst them.

The age profile of most of the infected people in the country is 30-49 years.

It is evident that HIV is related to the sexually active population. It has also been evident in recent times that a large number of women are also infected. The reasons for this are numerous. For instance, commercial sex workers could be responsible for infection of innocent house wives. This is also termed as the feminisation of the epidemic. There is no doubt in the fact that heterosexual sex is the main mode of transmission, and blood transfusion is a close second. Around 5-6 million units of blood are collected in the country. There are high chances of the blood being contaminated. Hence, NACO has a safe blood policy whereby special precautions are taken during blood donation.

Mother to child transmission is another mode of transmission.. If the mother is HIV positive, there is a 30% chance that the newborn will be HIV positive too. There are 27 million births every year in India. Even if the rough estimate of the infection transmission is 1%, there are around 270,000 positive mothers. And if 30% women give birth to positive children, around 70,000 children will be born infected.

The government, is therefore, giving special attention to the mother to child transmission and 4,000 counselling and testing centres have been set up in this regard.

Opportunistic infection is another important cause for concern. Tuberculosis is the most common opportunistic infection. Every year there are around 1.7 million new TB patients, and even if around 5% of the TB patients are HIV positive, it is a huge number. Hence, the government is making lots of collaborations on HIV-TB.

Sexual behavioural practices are the main reasons for the spread of HIV/AIDS in India. The behavioural sentinel survey which is carried out every 5 years revealed in 2006 (100,000 people were interviewed) that 7% of the population had non-regular sex partners. There were regional variations. For instance, in Andhra Pradesh it was 11-13%, whereas in Maharashtra it was 8-9%. In comparison to countries like Thailand where it is 12-13%, and South Africa where the figures exceed 50%, the Indian figures were low.

However, the female population in India having non-regular sex partners is only 2%, whereas the male population is 18%. Due to strong cultural links, the epidemic is not spreading very fast in the country. For instance, in South Africa, equal number of females have non-regular sex partners.

The use of condoms by the non-regular sex partners is another important aspect. The usage of condoms has risen from 76% in 2001 to 84% in 2006. Even amongst the high risk groups like sex workers, the usage of condoms has gone up from 76% to 87%. This is also an important determination of the direction in which the epidemic is going in India.

India is vulnerable at this point. It has the youngest population, with 50% of its population being below 25 years of age. A large section of population is sexually active. Secondly, 35% of the population is below the poverty line. The low social status of women, and the illiteracy and lack of awareness on HIV/AIDS make India extremely vulnerable. Migration is another such factor.

Stigma is an important factor driving the epidemic. The social stigma and discrimination in hospital settings etc. is driving the epidemic. Hence if we look at the data, the epidemic has moved from high risk population to the general population. Secondly, five years back HIV/AIDS was an urban phenomenon but it is now spreading to rural settings. 59-60% of the infected population is in the rural setting.

Dr. Sunil Mehra, Executive Director, MAMTA

What is HIV? HIV stands for human immuno-deficiency virus and this virus causes AIDS.

How does HIV spread? Infection with HIV occurs by the transfer of blood, semen, vaginal fluid, pre-ejaculate or breast milk. Within these bodily fluids, HIV is present as both free virus particles and virus within infected immune cells. The four major routes of transmission are unprotected sexual intercourse, contaminated needles, and transmission from an infected mother to her baby at birth, or through breast milk. Screening of blood products for HIV in the developed world has largely eliminated transmission through blood transfusions or infected blood products in these countries.

What is AIDS? AIDS stands for acquired immunodeficiency syndrome. An HIV-infected person receives a diagnosis of AIDS after developing one of the Center for Disease Control-defined AIDS indicator illnesses. An HIV-positive person who has not had any serious illnesses also can receive an AIDS diagnosis on the basis of certain blood tests (CD-4 cell counts).

A positive HIV test result does not mean that a person has AIDS. A diagnosis of AIDS is made by a physician using certain clinical criteria (e.g. AIDS indicator illnesses). Infection with HIV can weaken the immune system to the point that it has difficulty fighting off certain infections. These types of infections are known as opportunistic infections because they take the opportunity a weakened immune system gives to cause illness. Many of the infections that cause problems or may be life-threatening for people who are HIV positive are usually controlled by a healthy immune system. The immune system of a person with AIDS is weakened to the point that medical intervention may be necessary to prevent or treat serious illness.

HIV destroys a certain kind of blood cells – CD-4+ T cells (helper cells) – which are crucial to the normal function of the human immune system. In fact, loss of these cells in people with HIV is an extremely powerful predictor of the development of AIDS. Studies of thousands of people have revealed that most people infected with HIV carry the virus for years before enough damage is done to the immune system for AIDS to develop. However, recently developed sensitive tests have shown a strong connection between the amount of HIV in the blood and the decline in CD-4+ T cell numbers, and the development of AIDS. Reducing the amount of virus in the body with anti-HIV drugs can slow this immune system destruction.

Center for Disease Control defines AIDS as any HIV positive person having one or more of the 21 AIDS defining opportunistic infections.

There has been feminisation of the epidemic, and if women's empowerment issues are not given priority, India will cross the Sub-Saharan figures of 50% women infection.

It has been discussed earlier that heterosexual transmission is responsible for 86% of the infections. In such a scenario, it is imprudent to stop sex education in schools and universities. Sex education and condom promotion are two important vaccines for the prevention of HIV virus spread. According to World Bank reports, $1 invested in prevention is equal to about $67 saved on care and support. Therefore it is important to prioritise prevention.

Everyone is at equal risk, but some high risk groups like commercial sex workers, injecting drug users and men having sex with men, are more at risk. They need to be provided with support, care and access. The truck drivers and street children are equally vulnerable.

The issue of early marriage needs immediate attention. It is my request to the judiciary to look at the Early Marriage Prevention Act. Every third girl in India is married below the age of 18. Most of the rural population is mobile. Is a 17 year old girl expected to negotiate condom use with a man carrying the virus? Girls should not be allowed to marry unless they are 18 and above.

Most of the issues regarding care and prevention have been successfully addressed in NACP III. However, it is important to emphasise that condom promotion is central. As long as condoms are available and used in the remotest rural area of India, prevention to a large extent will be taken care of.

The next issue is that of anti-retroviral therapy. Out of 100,000 people, the government was able to reach only 60,000. A technically sound health system is imperative for successful implementation of the ART programme. The private sector needs to be regulated, as there has been misuse of power and the ART regime in the past.

Stigma and discrimination is a huge challenge for the judiciary. How can stigma and discrimination stop? It is important that fundamental rights become a reality for the positive people and children. Rights of every individual, including people with different sexual orientation, are important.

Further, children infected and affected with HIV/AIDS are denied their basic rights when they and their parents do not get equal opportunities. This issue, especially at the grass root level, requires immediate attention.

Dr. Binod Mohanty, World Health Organisation, India

The main entry point for universal access to prevention and treatment is counselling and testing. If a person tests positive for HIV, treatment can commence immediately. If the person tests negative, you can reinforce their negativity and make sure that person does not get infected in the future. Hence, counselling and testing is really a core entry point, and core element of any national AIDS programme.


DR. BINOD MOHANTY

The UN propagates that all HIV testing of human beings should follow the three Cs. These are counselling, confidentiality and consent. Testing has to be accompanied by counselling. There is pre-test counselling, and post-test counselling which helps someone understand their HIV status, be it positive or negative. It is important to respect someone's confidentiality because breaches can lead to discrimination and stigma. There can also be shared confidentiality, where the healthcare provider has to be informed about the HIV status of his or her patient. It is important for an HIV positive person to share his or her HIV status with his or her spouse, friends, etc. Finally, all HIV testing needs to be done with the consent of an individual. Theoretically, consent can take different forms. It can, for instance, be opt-in consent saying yes, I want to get tested; it can also be opt-out consent, where someone has to actively say they do not want to be tested.

The (Government of India) does not promote mandatory testing. Mandatory testing creates stigma and discrimination, and drives people underground. If, for instance, everyone in India were tested today, they would have to be tested again in three months. This would be a very expensive way to proceed. Mandatory testing would also create a false sense of security, as there is a window period between when someone becomes infected and when that infection would show a a positive test result. In place of mandatory testing, the government of India propagate voluntary counselling and testing, in line with the three Cs outlined above.

There are two ways that the national programme is now scaling up HIV testing an counselling. One is the client-initiated testing and counselling, where a person volunteer for counselling and testing. The other is provider-initiated testing in healthcare settings, where people who present with symptoms suggestive of HIV infection are proactively asked by their healthcare provider to be tested. Hence, these two approaches are being promoted by the WHO and they are also included in the National AIDS Control Programme Phase III.

Dr. Po Lin Chan, World Health Organisation, India

Prevention is the foundation of the HIV/AIDS management programme. However, care and treatment are also important, mainly because health is wealth and is equally important for older people as children. If one looks at the basic evidence, there are as many affected children as adults. Even if one adult in a family is infected with HIV, the entire family suffers. This also results in orphan children, who are often infected and are at the very least affected. The only way to reduce the adverse impact of HIV/AIDS on children is to provide better access to care and treatment. There have been continuous efforts towards making access to anti-retroviral treatment a reality for children.

DR. PO LIN CHAN

Mr. Colin Gonsalves, Human Rights Law Network

According to NACO, there are 5.2 million HIV positive people in the country*. Currently, 10% of the HIV positive population, i.e., 500,000 **people, have a CD-4 count of less than 200. These people are at a critical stage where they will transit from HIV to AIDS. The latest figures from NACO show that the number of people getting ARV treatment is roughly 70,000.*** Further, the drop out rate is very high. People requiring the drug are often poor and need to travel up to 200 kilometers to get tests done and drugs. They get disillusioned when it comes to choosing between the drug and food, and they drop out.

MR. COLIN
GONSALVES

If the drop out rate is 20%, the official figure of people receiving treatment would immediately drop from 1,20,000 to 1,00,000 people. The government, until 2003, had a policy of not providing the antiretroviral drugs. The essential question is, how did India have a policy of not providing the antiretroviral at all, when developing countries like Costa Rica, Colombia and Argentina were providing free drugs. The Supreme Courts of these countries called upon their respective Governments to provide free drugs. The Indian Government decided to focus only on prevention.

As a consequence of this policy, approximately one hundred persons died every day because they did not get ARV treatment. Hence the policy decision has resulted in many deaths, including the death of a large number of children.

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* Subsequently this was scaled down to 2.6 million on the basis of a survey funded by certain organisations and undertaken without involving local positive networks.

** downscaled to 300,000 as on Feb 2008.

*** updated to 1,20,000 as on Feb 2008.

Since 2004, there has been a positive change in government policy. ARV treatment is now provided free of charge in ART Centres in India. It is important to have surveys done, however, on the number of drop outs.

The following table* highlights the problems faced by various states in the country. The judiciary can play an important role here.

Delhi

Art Centres	Issues	CD 4 Machines	Issues
8-Kalawati, Safdarjung, AIIMS, RML, LNJP, GTB, DDU, LRS	1670 people have discontinued due to lack of follow up, of which 1558 are adults and 112 children. 10960 people have registered for ART. 5000 have started. 3424 are on ART as on 2007. Need a follow up mechanism. 2050 people on private ART.	5-LNJP, RML, AIIMS, Safdarjung, NICD. Available free.	In four roll out centres there are no CD4 machines. Only 1 public PCR machine for whole of Delhi in AIIMS. ART roll out centre for pediatric drugs doesn't have a PCR machine. Patients being referred to private hospitals or AIIMS. People come to Delhi from Meerut and Rohtak.

Delhi- Reasons for discontinuance

- Travel burden.
- Drug literacy and adherence literacy.
- Lack of Voluntary counseling availability, accessibility.

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* updated as on Oct 2007.

- No drinking water, places to sit available.
- In RML hospital, 3000 people come for treatment and there are 6 chairs. 2 counselors.
- In LNJP, 1 counselor. 2000 people come for treatment.
- Lack of confidentiality.

Goa

ART Centres	Issues	CD 4 Machines	Issues
1 - Goa Medical College	Traveling to the ART centre from the South to the North is expensive.	1 - not working from the past 2½ months.	Testing refused despite availability of the kits to meet the daily quotas set by the Government

Tamil Nadu

Art Centres	Issues	CD 4 Machines	Issues
19 - Chennai-3, Kanchipuram-1, Vellore-1, Villapuram-1, Salem-1, Namakal-1, Ramananthapuram-1, Tanjavur-1, Trichy-1, Madurai-1, Teni-1, Tirunalveli-1, Kuttopori-1, Karoor-1	People taking private ART have become poor and need to shift to the public system. All 19 centres have pediatric treatment 1200 children on pediatric ART.	6 - All currently working. 5 more expected.	Inaccurate results: Blood samples sent to two centres give different results.

West Bengal

ART Centres	Issues	CD 4 Machines	Issues
3 - School of Tropical Medicine, AGM, NB Medical College.	Patients made to wait for long durations for medicines. No drinking water available. 1800 people on ART.	1 - in School of Tropical Medicine.	North Bengal residents are required to travel for 2 days to get to the centre. West Bengal has 19 districts and is a high prevalence state.

Madhya Pradesh

ART Centres	Issues	CD 4 Machines	Issues
2 - Bhopal, Indore	In April 2006 there was a break in supply for 20 days. Resultantly many people became ill.	1	People from public hospitals are referred to private hospitals for the test which costs them Rs. 15,000.

Himachal Pradesh

ART Centres	Issues	CD 4 Machines	Issues
1 - Shimla	One centre for 12 districts. Not accessible.	1 Shimla	Lack of infrastructure. Tests sent to Hyderabad.

Rajasthan

ART Centres	Issues	CD 4 Machines	Issues
2 - Jodhpur, Jaipur 33 districts.	1900 people need ART only 700 are provided. 500 are on private treatment. 650 dropout out of total of 3000.	2 - Jaipur, Jodhpur	CD4 kits are invariably out of stock.

Punjab & Haryana

ART Centres	Issues	CD 4 Machines	Issues
4 1 Chandigarh 1 each in Amritsar and Jallandhar Rohrak -1 20 districts of Punjab 20 districts of Haryana.	In Haryana people requiring treatment go to Chandigarh. There were 3000 patients registered. 1615 adults and 65 children are getting treatment as of now. In Chandigarh, 10 patients need second line treatment, out of which only 6 are receiving and 4 are waiting for treatment due to lack of funds.	3 Chandigarh-1 Rohtak-1 Amritsar-1	Not Working for Two Months. Jalandhar Machine giving unreliable Test Results. Samples sent to Amritsar from Jalandhar. Waiting time 2-3 months.

Meghalya

ART Centres	Issues	CD 4 Machines	Issues
1-Shillong	30 people are receiving ART treatment. 3 children are receiving ART treatment.	1-Shillong	Blood samples sent to Kolkata and Gawahati.

Bihar

ART Centres	Issues	CD 4 Machines	Issues
2 - Patna, Muzzafarpur 36 districts.	Poor people are unable to travel to these centres from other districts. Distances are far. Each centre has 2500 people. There are no seating arrangements. 50 people need second line treatment. 10 are getting it, 40 are not.	2 - Patna, Muzzafarpur	Poor people are unable to travel to these centres from other districts.

Manipur

ART Centres	Issues	CD 4 Machines	Issues
5-active centres, 1 to be started. Ukhrul-Thoubal, Imphal West, Imphal East, Churachandrapur.	CD4 machine not working since last one month at Ukhrul. Very long distances for people to travel and access treatment services. 3912 people accessing ART. Sept 2006- 4877 people registered for treatment. 84 have dropped out. 709 IDUs accessing ART in one centre and 715 in another.	4-Ukhrul Imphal East, Imphal West, Churachandpur Thoubal	Inconsistent test results. Power supply erratic, so machine does not work. Gauhati High Court has given a judgment for CD-4 count machines to be installed in every district hospital.

Karnataka

ART Centres	Issues	CD 4 Machines	Issues
15		4 Bangalore-1, Mysore-1, Hubli-1, Gulbarga-1	Gulbarga machine is not working.

Orissa

ART Centres	Issues	CD 4 Machines	Issues
1 - Ganjam District	No trained doctors. No pre and post counseling. 7600 people require treatment and fewer than 300 receiving it. No pediatric ART available. 93 children need medicines (according to SACS).	None. 30 districts.	People have to travel to other states like West Bengal and Delhi for tests. Blood samples sent to these states. Long queues for taking of blood samples.

Nagaland

ART Centres	Issues	CD 4 Machines	Issues
3-Kohima, Dimapur, Tuensang. Dimapur centre is not working (has not functioned since it opened).	Only 13 children on ART, pediatric drugs unavailable. Required to travel long distances.	3-Kohima, Dimapur, Tuensang. 11 districts	Only 2 CD-4 count machines are working- Dimapur is not working. Hep-C also very important.

Uttar Pradesh

ART Centres	Issues	CD 4 Machines	Issues
3 Lucknow-1 Meerut-1 Varanasi-1 70 districts in UP	Not enough trained doctors. Doctors work only for 4-5 hours. There are 40-50 patients per day, but no senior doctors available. The doctors are insensitive. No drinking water.	3 Lucknow-1 Meerut-1 Varanasi-1	Lucknow machine is not working.

Kerala

ART Centres	Issues	CD 4 Machines	Issues
5 - Trivandrum, Iduki, Trissur, Calicut, Kottayam	2900 people receiving ARV treatment. 4780 registered for ARV treatment. 86 people have died in 2007. 218 people have discontinued. 250 children receiving ART. Many people are receiving ART privately.	4-Palghat, Trissur, Calicut and Trivandrum	Trivandrum machine is not working

Maharashtra

- ART Centres - 18 centres.
- CD-4 count machines- 7.
- 4 Treatment and Counseling Centres.
- Total number of people registered for ART is 11749.
- 1 Positive Living Centre.
- 350 children in Pune have not started ART.
- Problems - confidentiality of people coming to the ART centres. Government Medical College, 200 people coming per day and only 1 counselor available. People from MP, Chattisgarh and AP use the Nagpur centre.
- No proper seating arrangements and no hygiene. No drinking water.

Ms. Jhanabi Goswami, Assam Network of Positive People

There is a lot of stigma and discrimination in India. Discrimination usually takes place in hospitals, work place, private set ups, etc. There are many PHLAs who have lost their jobs due to discrimination. I would like to highlight a few cases.


MS JHANABI
GOSWAMI

Once a person discovers his/her positive status, he/she is required to go to the hospitals for CD-4 tests. CD-4 machines are available in limited hospitals and are mostly dysfunctional. Many people are discriminated against in hospitals and therefore need to stay in a hotel in order to get their tests. Moreover, if a person's HIV status is known to the healthcare personnel, they sometimes refuse to treat. Therefore, most people do not come forward for tests and treatment. Usually, people are not poor at the time their status becomes known. It is only when they start treatment they become poor. Even if the CD-4 tests are free, people need to travel from villages to cities to access ART facilities. They need to rent accommodation for two-three days. These expenditures are difficult to meet.

Even within family, an HIV positive person is discriminated against. Due to ill health, a positive person is unable to work; the family refuses to take care of the person due to financial burden.

The lack of HIV/AIDS legislations aggravates the discrimination problem. There are a number of property and employment cases. Even if these cases are taken to the court, it takes about five to eight years for the final judgment to come. The positive person may die during this period. It is our humble request to all the judges, that some mechanism should be devised for speedy trial. There are many property cases where a woman is usually thrown out of the house and not given a share in her husband's property after his death. She is in fact blamed for his death, and stigmatised. Usually, advocates who take up these cases demand a lot of money, which the HIV positive people are unable to afford. There is an urgent need for free legal services. There are organisations providing free legal aid, but one needs to take the initiative. It is because of the judiciary that we have pro-active judgments on HIV/AIDS.

There are a lot of discrimination cases reported to Human Rights Officers, but they are still languishing. I request the judiciary to look into the matter and continue to give good, positive judgments.

Open House – Questions and Answers

Comments from the Judiciary

Three legal issues seem to be coming up: (i) damages, e.g. for wrongly-transfused contaminated blood; (ii) constitutional rights of privacy and confidentiality; and (iii) isolation of patients identified as HIV positive. The issue of discrimination is also prevalent. I do not think the judiciary can stall the epidemic, or prevent its spread, but the judiciary can work on the peripheral issues. This is not a purely biological issue – AIDS is not purely a disease – it has social and political dimensions. The judiciary can deliver decisions on the rights of PLHAs.

Should we make PLHA litigants another agenda on the priority list, in the same way as we have for senior citizens, ex-servicemen and under trial prisoners? We also have years where certain cases are prioritised, such as this year of women, the year for people living with disabilities, the year for under trial prisoners etc. Perhaps we could have a year for litigants affected by HIV/AIDS?

I would like to know how many cases involving PLHAs are pending before the courts? We should not assume people are always able to file their case.

The judiciary should consider the effect on the epidemic of judgments on, for example, rape cases, or cases under the Immoral Trafficking Act.

There are two broad areas – treatment and prevention. For those people already affected by HIV/AIDS, their legal concerns generally relate to access to treatment and stigma and discrimination. In relation to the latter, the problem is compounded by the concerned person's wish to keep their HIV status confidential.

I have experience of a discrimination case which was very difficult for the court to decide. A community came to know that a ten year old child was HIV positive, and he was thrown out of school. The court passed orders that the child was to remain in school, and summoned the principal. The principal said he agreed with the court, but had 1,200 children in his school whose parents would remove them if the HIV positive boy returned to school. The court therefore passed orders to the effect that those children would not be admitted to any other school. So the boy was able to return to school, but nobody would talk to him, none of the children would play with him, or share food with him. The child died three weeks later.

This case highlights the limited role of the judiciary – we cannot pass an order requiring 1,200 children to play with someone.

In the second area – prevention – I think the judiciary can do a lot. Through the Legal Services Authority, we can educate people about HIV/AIDS prevention.

Sex is not the only mode of transmission of the virus. If you go to most villages, you find a quack treating people with the same instruments he has had for twenty years, without boiling them. Even in Delhi there are quacks, but at least in Delhi people have a choice between the quacks and qualified doctors. In remote villages, people do not even have that choice.

When cases come before it, the judiciary can have a role in the cost of treatment, in awareness and in discrimination. Our key role is therefore sensitisation of the judiciary. We have to realise that this is a human rights issue. Take, for example, a maintenance case brought by a woman thrown out of the marital home who has a young child. A three month adjournment may make such a big difference to that woman's life that, even if she gets a favorable order in three months' time, it may be too late for her. The cases need a judge sensitive to the issues. Similarly, if a right to treatment case comes up, that person may need treatment immediately, and a judge must be sensitive to those issues.

In human rights cases, the judiciary is not criticised for its over activity.

A basic issue is: which courts can give what kind of reliefs, in what kinds of circumstances. Many people affected are poor and illiterate, living in remote, inaccessible areas. Only the High Courts and Supreme Court will deal with Article 14, Article 19 and Article 21 etc. cases. Cases are not always going to reach the High Courts, so sensitisation has to take place at the lowest rung of the judiciary. The Legal Services Authorities need to hold seminars and colloquiua. I think the thrust should be at the Labour and Consumer courts, because actual relief can be granted there.

If we take this as a human rights issue, lack of specific HIV/AIDS legislation is no excuse. PLHAs and NGOs working in the area need to be made aware of the services offered by the Legal Services Authorities

We must look at the issue of patents for life-saving drugs and whether these proprietary rights are violative of the right to life.

In 1985 or 1986 the Delhi University Law Authority organised a seminar on HIV/AIDS. In those days, hardly anything was known about HIV/AIDS in India. A doctor addressing the audience said that at that time, India had only three or four cases of people who had tested positive for HIV. He said if we did not check the virus then and there, it would assume much larger proportions.

Even though the prevalence rate is just below 1%, 1% of 1.1 billion is a huge number.

Of course the judiciary have to address many issues, and I am not saying that HIV/AIDS should be given number one priority. But if we have a priority list, it should certainly appear in the top ten. The situation is definitely alarming.

Comments from Civil Society

In 2000 in Lucknow, four people from the NAZ Foundation were arrested. They were working on HIV prevention with MSMs. The state accused them of homosexual acts under section 377. At the bail application, after listening for one and a half hours about NACP and HIV prevention, the learned judge said "In my opinion, the activities of the accused are a sin on society, and therefore they do not deserve bail." In the Indian legal system, the judiciary is supposed to implement the law, not sin and virtue. Clearly in this case, though, the judge's personal prejudice was acting to deny the accused bail. They remained in jail for 45 days before the charges were dropped. I therefore think the higher judiciary has a role to play in sensitising the lower judiciary.

Where the Legal Services Authority is functioning well, it is very effective. Crucially though, PLHA need to know what our rights are.

I'll give you the example of a Mumbai High Court case and a Goa Bench case relating to commercial sex workers. In both these cases, the High Court ordered that the sex workers be mandatorily tested, overriding the objection both of the sex workers, NGOs and NACO. The government even said it was government policy not to do mandatory testing. The High Court nevertheless said it had to be done because it is an infectious disease, and on that basis directed testing. The moment the women were tested, within the establishment itself where they were being housed, they were stigmatised. Then there was no one to give them food, no one to look after them, no doctor was willing to look after them. So the first question they asked was, "Do we have a right not to be tested?"

Secondly, in the Mumbai case, as well as the Goa case, the High Court ordered deportation to the place from which the women originally came, on the presumption that it is good to send young women back to their families. The judges did not realise that in some cases, the families themselves had trafficked the girls. The women were very reluctant to go back: they said keep us in jail, but we do not want to go back, we will be trafficked again. The second question they asked is, "Do we have a right to reside in any part of India, under Article 19, or are we subject to an internal deportation order, so to speak?"

Thirdly, is the right to humane treatment inside the establishment. The women were put in a small room, 100 girls to a room, the toilets were overflowing and food was not available. Even today, the government budget for looking after a girl who has been rescued is Rs. 500/- per woman per month. That includes food, everything. So these are the three broad rights they ask if they can get by some sort of judicial process.

Speeding up cases is an important issue. For example, in Karnataka, we filed six cases against quacks who were treating HIV positive people, causing deaths. We filed a case and within one year we got a judgment. In this way, we prevented innocent people accessing the quack.

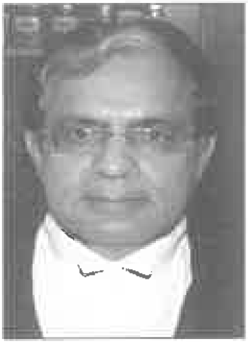
We feel very strongly that the judiciary can play a role in the reinterpretation of statutes hampering our work, such as section 377. At the least, the judiciary can raise the debate about these statutes which push people underground and make it difficult to reach them with information on treatment and prevention.

Judgments relating to discrimination against positive people can borrow a lot from international standards. The way in which judgments are written could draw out more that these are human rights violations. It seems there is still quite a gap between what the Indian judiciary has laid down and international standards.

Hon'ble Mr. Justice A K Sikri, Judge of the Delhi High Court

The Honourable Mr Justice A K Sikri took his undergraduate degree from Shriram College, Delhi University in 1974, and his LLB from the Law Faculty of Delhi University in 1977. The Honourable Mr Justice Sikri secured first position in all six semesters of his LLB and won all possible prize medals at Delhi University for his LLB course. He was President of the Campus Law Centre at Delhi University for 1976-77. He began practising in Delhi in 1977, with a specialisation in Labour – Service and Arbitration. He also lectured part time at the Campus Law Centre at Delhi University between 1984 and 1989. During 1994-5, he was Vice-President of the Delhi High Court Bar Association. On 30 September 1997, the Honourable Mr Justice A K Sikri was designated a Senior Advocate.

On 7 July 1999, the Honourable Mr Justice A K Sikri was appointed as a judge of the Delhi High Court and has given many landmark decisions since then.



JUSTICE A K SIKRI

Right to Confidentiality

PLWHA are entitled to all respect as human beings[1]. However, PLWHA face serious rights violations. It is increasingly recognised that HIV/AIDS poses great challenges to the protection and fulfillment of human rights, impacting people's civil and political rights, as well as their economic, social and cultural rights. Systematic abuses of rights[2] of PLWHA not only exacerbate the spread of HIV/AIDS, but also fuels a cycle, whereby people suspected of being infected with HIV are subjected to further human rights abuses on account of their real or perceived status. Further, stigma and discrimination are the biggest barriers in the response to HIV/AIDS prevention and control. Fear, lack of understanding, myths and misconceptions add to the stigmatisation.

Stigma translates into discrimination when HIV positive people are denied access to health care. Many are tested without their consent and their confidentiality is often breached, leading to harassment and rejection by families and communities. As soon as the fact of being HIV positive comes to the knowledge of other persons, PLWHA are discarded from society. Their friends, relatives, even children and most beloved spouse do not want to talk to them. The disclosure of the fact of infection puts a full stop on all these rights, as if PLWHA cease to be human beings[3]. Thus, in order to help patients cope with this fatal disease, stress must be placed on confidentiality and right to privacy of PLWHA. The maintenance of confidentiality of PLWHA is one of the cornerstones of public health and rights-based legal responses to HIV/AIDS. Not only does the principle rest on human rights norms of autonomy and respect for privacy, but it has also been viewed as crucial to encouraging those most at risk to come forward to HIV testing, counselling and clinical attention.

The patient-doctor relationship is, by its very nature, based on an inordinate amount of trust which the patient places in the doctor. Keeping this paradigm in mind, this article construes the countervailing concerns regarding confidentiality and privacy of PLWHA and society. On the one hand, the rights of PLWHA clearly warrant uncompromising protection due to the hysteria that surrounds the disease. It establishes necessary legal protection to the PLWHA subject to unwarranted disclosure. While the rights of the individual PLWHA must not be circumvented, they must be balanced against broader concerns. A policy that ensures patient confidentiality at any cost may deny society's right to acquire necessary information for legitimate reasons. One often-cited reason is protection of the public health. Another basis for disclosure is "the rights of employers, property owners and service providers to establish their own standards" free from intervention. When those rights are balanced against those of the patient to be treated fairly and without discrimination, a "contradiction" erupts. Section I discusses legal notions of the physician-patient privilege such as the physician's duty of confidentiality, and the patient's right to privacy. In Section II, the discussion turns to the dilemmas that erupt when the confidentiality of the patient conflicts with the need to acquire information about the patient. Section III prescribes solutions for healthcare professionals, lawyers and courts on how best to manage the competing interests of disclosure and confidentiality. The lesson: no easy solutions exist to balance the multiple interests at stake. Only through open discourse and education will all parties be protected.

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1. Justice Palok Basu, Law Relating to Protection of Human Rights under the Constitution of India and Allied Laws, Modern Law Publications (2002) p.429
2. Right to be free from discrimination, right to prevention, treatment and care, right to physical and mental integrity, and the right to freely receive and impart information.
3. Dr Surender Kumar, "Human Rights of AIDS Infected People vis-à-vis Healthy People" AIR 2000 Journal Section 1999

I. The Physician-Patient Privilege

Physician's Duty of Confidentiality and the Patient's Right to Privacy

The most important aspect in the doctor-patient relationship is the doctor's duty of maintaining secrecy. A doctor cannot disclose to a person any information regarding his patient which he has gathered in the course of treatment, nor can the doctor disclose to anyone else the mode of treatment or the advice given by him to the patient. Communication between the physician and patient must be confidential. Thus, the very nature of the relationship warrants confidentiality. Doctors have an ethical duty not to reveal information given to them in confidence by their patients[4]. The doctor's duty to maintain secrecy has a correlative right vested in the patient that whatever has come to the knowledge of the doctor would not be divulged.

Confidentiality has been recognised as a legal principle in various forms. Confidentiality inheres in privileged communications, such as between patient and doctor, client and lawyer, and protects against unauthorised disclosure of that personal information to third parties. For instance, the Indian Evidence Act 1872 protects confidential information shared by a client with their legal adviser. In the healthcare context, the concept of confidentiality and right to privacy derives its genesis from Article 21 of the Constitution of India, that every person has the right to a sphere of activity and personal information that is exclusive to him and has the right to disclose or not disclose this information as he considers in his best interest.

A physician's duty of confidentiality is an important factor, which aims at the protection of as well as assurance of dignity to PLWHA. Generally speaking, it arises when in a confidential relationship based on trust, information having the quality of confidentiality is imparted from one person to the other. Thereby, in such a relationship, if confidential information is imparted, it must be kept confidential. A form of the concept of confidentiality in medicine is ancient, based as it is on the Hippocratic Oath that dates back 2,500 years. The Hippocratic Oath is an ethical code and states:

"All that may come to my knowledge in the exercise of my profession or in daily commerce with men, which ought not to be spread abroad, I will keep secret and will never reveal."

The International Code of Medical Ethics has also been laid down as under:

"A physician shall preserve absolute confidentiality on all he knows about his patient, even after his patient has died."

The Code of Medical Ethics which has been made by the Indian Medical Council provides as under:

"Do not disclose the secrets of a patient that have been learnt in the exercise of your profession. Those may be disclosed only in a court of law under orders of the presiding judge."

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[4] C. Manickam, "Human Rights Aspects of AIDS Victims" (1993) 3 Supreme Court Journal 57

The ethical codes used by the medical profession serve as the primary source of the common law concept of the physician-patient privilege establishing the physician's duty of confidentiality.

Unfortunately, in India, when a patient is found to be HIV positive, it is quite common that her/his status is not kept confidential. Doctors and healthcare workers are in a quandary over this issue. Some hospitals reveal or fail to respect the confidentiality of patients' HIV status, sometimes by writing on prescriptions and referrals. Sometimes medical staff tell others of a patient's HIV positive status, or separate the HIV positive person from other patients, which causes others to suspect they are HIV positive. This kind of demeanor causes stigma and denial by healthcare workers to PLWHA and arises out of a lack of knowledge about HIV/AIDS; fear of exposure to infection for lack of protective equipment, and also a sense that patients are "doomed to die". In cases of children living with HIV/AIDS, discrimination by healthcare workers causes some guardians to avoid taking HIV positive children for medical care, to hide the child's HIV status if they do and, in some cases, to refrain from having the child tested at all.

There is a growing realisation that it is important to maintain confidentiality of the status of the HIV positive person. 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. Guaranteed confidentiality to PLWHA motivates them to come forward and trust healthcare services. It brings both infected and affected persons closer to healthcare services. Otherwise, the risk is that PLWHA will avoid healthcare services, and HIV/AIDS will remain beyond the control of public health.

Unwanted disclosure of intimate health information can cause patients a great deal of emotional, social and economic harm. Stigmatisation, also being the consequence of such disclosure, leads to harassment, discrimination and rejection by families and communities. Thus, it causes embarrassment, social isolation and loss of employment or ability to obtain insurance, or housing. It also makes both prevention and management of HIV/AIDS difficult as such breach is not covered by any law. Disclosure of HIV status should only be made in exceptional circumstances, to be specified in law.

The physician's duty of confidentiality has a correlated right. In interpreting confidentiality, as a corresponding duty, Courts have found that there should be a relationship between two persons, the confidante and the person who confides. The relationship should be one whose nature is dependent on factors of mutual trust or knowledge or skill or with the objective of imparting services[5]. Right of privacy, in the context of PLWHA, means that there is protection against unauthorised access to personal medical information by individuals or organisations. It is understood as an aspect of ensuring human dignity to HIV/AIDS patients. Although not expressly mentioned in the

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5. D v National Society for the Prevention of Cruelty to Children [1977] 1 All ER 589; Prince Albert v Strange (1894) 1 H & T; Lord Ashburton v Pape [1913] 2 Ch 469; Pollard v Photographic Company 40 Ch.D 345; Gilbert v Star Newspaper (1894) 11 TLR 400023

Constitution, it has been recognised as a fundamental right by the Supreme Court of India. In R Raja v State of Tamil Nadu[6] it was observed that the right to privacy is implicit in the right to life and liberty guaranteed to the citizens of this country by Article 21. It is a "right to be let alone." The Black's Law Dictionary defines right of privacy as:

> *"The right to be let alone; the right of a person to be free from unwarranted publicity; and right to live without unwarranted interference by the public in matters with which the public is not necessarily concerned ... and such right prevents governmental interference in intimate personal relationships or activities, freedoms of individual to make fundamental choices involving himself, his family, and his relationship with others."*[7]

Right to privacy is nothing more than a right to live in a particular way one chooses for himself to enjoy his life, his family life, honour and reputation. Privacy is also defined as the claim of individuals, groups or institutions to determine for themselves when, how and to what extent, information about them is communicated to others[8]. The Apex Court in Mr 'X' v Hospital 'Z'[9] addressed this issue where a hospital had disclosed a patient's HIV status to his fiancée's family. The patient challenged the hospital's action on the ground that the breach of confidentiality had irreparably damaged his right to marry, and sued for damages. It was argued by Z Hospital that the duty to keep even the true private facts confidential was not absolute and this disclosure in the interest of right to life of another person was justified. The Supreme Court rejected the contention of Mr X for tortious liability against Z Hospital. Saghir Ahmed, J. for the court observed, "The right [of confidentiality] however, is not absolute and may be lawfully restricted for the prevention of crime, disorder or protection of health or morals or protection of rights and freedoms of others." Holding that marriage was the sacred union, legally permissible, of two healthy bodies of opposite sex, the Learned Judge observed that the right to marry was not without a duty and that a person marrying was under a moral and legal duty to inform his proposed partner about his state of health, in case he suffered from venereal disease, impotency or other communicable disease. He stated, "In this situation, the right to marry and duty to inform about his ailment are vested in the same person. It is a right in respect of which a corresponding duty cannot be claimed as against some other person." Referring to Section 268 of the Indian Penal Code, which punished the persons who were negligently, or unlawfully, doing an act likely to spread infectious disease dangerous to the life of another person, the Learned Judge concluded that the statutory provisions imposed a duty upon Mr X not to marry. However, in 2003, in Mr 'X' v Hospital 'Z'[10] the Supreme Court upheld the right to marry of people living with HIV/AIDS, but dismissed the claim arising from the breach of confidentiality.

The right to privacy and confidentiality is closely linked to the other contentious issue of compulsory HIV testing. Accordingly, any challenge to compulsory HIV testing would

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[6] AIR 1994 SC 265

[7] Bryan A. Garner & Henry Campbell, Black's Law Dictionary (6th Ed. 1990), West Publishing Co., p1195

[8] Dr Surender Kumar, "Human Rights of AIDS infected people vis-à-vis Healthy People", AIR 2000 Journal Section 1999

[9] (1998) 8 SCC 296

[10] (2003) 1 SCC 500

probably need to rely upon an extension of the constitutional right to privacy. In Vijaya v Chairman and Managing Director, Singareny Collieries Ltd[11], it was held that subjecting an individual to compulsory HIV testing was not unconstitutional, even though it infringed the individual's right to privacy, because the State also had an obligation under the Constitution to take steps to improve public health.

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. Disclosure of an employee's HIV status will usually result in emotional harm to the employee, and may also result in actual or threatened physical harm. 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 his/her 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. The Bombay High Court in MX of Bombay Indian Inhabitant v M/s ZY and another[12] ruled in favour of a PLWHA who was discriminated against at his workplace. It was observed that the right to livelihood was guaranteed to all persons and could be overridden only by a procedure established by law that was just, fair and reasonable; and that persons with an ailment who are capable of performing normal job functions and who do not pose any threat to the interests of other persons at the workplace during their normal activities cannot be denied employment or be discontinued from employment. The writ petition that was filed initially disclosed the real names of both the employee and the Corporation. Subsequently, the material which might reveal the employee's identity was removed from the record, and the employee's confidentiality and right to privacy were thus preserved.

II. DILEMMA: Individual Rights & Public Welfare

The duty to maintain confidentiality is not absolute, however, and has often been subordinated to other important societal concerns, such as the protection of innocent third parties who may be at risk. The controversy over privacy rights has been clouded by the public policy goals of disclosure. The overriding public policy interest that governs this debate is protection of the public health against the spread of this deadly disease. 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

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11. AIR 2001 AP 502
12. AIR 1997 Bom 406

false debate and in reality, protecting the rights of the individual strengthens the community itself. The 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 discourage persons from accessing health care and testing themselves, thus suppressing the pandemic and creating greater hurdles for control efforts.

By observing the rule of confidentiality and privacy, the right of a person affected by HIV/AIDS is protected but, at the same time, the right of society is transgressed. Everyone in the society has a right to remain healthy. Thus there is a conflict of individual interest with social interest[13]. If a state permits authorities and healthcare workers to release the identity of an HIV positive person, it prevents the further spread of AIDS, expedites efforts to find a cure for AIDS by allowing medical researchers to chart the course of the disease, and reinforces the important value of protecting and cherishing human life. This section explains each of these rationales. However, these rationales support only limited disclosure. It is suggested that disclosure of the identity of HIV positive persons shall be prohibited unless it is reasonably necessary to prevent the spread of HIV/AIDS. The issue discussed is not whether confidentiality should be protected at all, but whether it should be protected absolutely even when such protection could seriously jeopardise the public's health.

In evaluating the potential risks and liabilities of mandating full disclosure in the physician-patient relationship, it is necessary to consider the disadvantages to the persons who must disclose their HIV positive status. Opponents of disclosure argue that mandatory testing and contact tracing would discourage HIV positive individuals from cooperating with public officials because of the stigma attached to disclosure. Ostracism and discrimination are known consequences of positive HIV status made public. Disclosure of HIV/AIDS status may result in social stigma among that person's family and friends, and may also lead to discrimination in employment, housing and insurance. Therefore, positive people have a strong ethical claim to the privacy of their medical diagnosis, records and their health status generally. However, it is sacrificed when it is necessary to reduce a risk to another person or their sex partners. Balanced against the claims of infected persons to privacy are the equally compelling claims of other people to be informed of the risk. The other people may claim a "right" to know that they have been exposed to infection because (1) knowledge empowers individuals to avoid continuing risks; (2) knowledge of infection allows for early treatment; and (3) knowledgeable partners can adapt their behaviour to prevent further transmission of infection to others.

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[13] Justice Palok Basu, Law Relating to Protection of Human Rights under the Constitution of India and Allied Laws, Modern Law Publications (2002) p. 459

Balancing of Interests

Various judicial pronouncements worldwide have recognised confidentiality and right to privacy in cases of HIV/AIDS. A fine balance is maintained between confidentiality and right to privacy on one hand and public welfare on the other. Courts have held that HIV/AIDS status falls within a legally recognised zone of privacy and that involuntary disclosure of test results could undermine the interests of PLWHA and would further discourage people from getting tested for HIV[14]. In X v Y[15] a newspaper disclosed that doctors in a hospital were HIV/AIDS positive and further threatened to disclose their names. The hospital obtained an injunction for the same from the court, and it was laid down that the confidentiality and right to privacy of doctors suffering from HIV/AIDS outweighs the freedom of press to publish such information and that the public interest would not be impeded due to non-disclosure of names.

In Anderson v Strong Memorial Hospital[16], an HIV positive hospital patient brought suit against his physician, hospital and a local newspaper. The patient had agreed to be photographed by the newspaper after his physician assured him that he would not be recognisable in the published photograph. He was in fact recognised in the photograph. The trial court found that the patient's right to confidentiality encompassed his identity, and the patient ultimately obtained damages of $35,000 from the physician and hospital for breach of confidentiality.

In Doe v Shady Grove Adventist Hospital[17], doctors diagnosed the plaintiff as having AIDS after he was hospitalised for pneumonia. The patient sued the hospital for breach of confidentiality of his medical records and invasion of privacy. He alleged that a respiratory therapist had shared his medical records with a colleague who knew the patient, and that the colleague had in turn shared the information with the patient's family and friends. The court stated that the allegations in the complaint, if true, made out a patent violation of the patient's right to privacy.

On the other hand, there are various judgments which strike a balance between the infected individual's right to keep his illness confidential and the overriding public policy concern of stemming the spread of the virus, but find that public welfare outweighs the individual interest[18]. In Doe v Roe[19], the plaintiff patient brought an action against his treating physician for revealing his HIV positive status to the Pennsylvania Bureau of Worker's Compensation[20]. The Doe Court addressed several interesting questions

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[14] Jeffrey H v Imai, Tadlock & Keeney et al 2000 Cal. App. LEXIS 932; Urbaniak v Newton 1994 Cal. LEXIS 1801

[15] [1988] 2 All ER 648, QBD

[16] 573 N.Y.S.2d 828, 829 (NY Sup. Ct. 1991)

[17] 598 A.2d 507 (Md. Ct. Spec. App. 1991)

[18] See Roe v Wade 410 US 113, 115-56 (1973) (stating that privacy rights are not violated when medical records are not kept confidential if there is compelling state interest); United States v Westinghouse Elec. Corp. 6338 F.2d 570, 577-78 (3d Cir. 1980) (asserting that disclosure of medical records for reasons of public health does not automatically infringe on privacy rights); Doe v Barrington, 729 F. Supp. 376, 385 (DNJ 1990) (Declaring privacy of medical information is not absolute and disclosure of AIDS tests results requires compelling state interest).

[19] 588 NY.S.2d. 236 (Sup. Ct. 1992)

[20] Dr Roe, complying with a request by Worker's Compensation Board, forwarded a complete copy of patient's medical records which included, among other things, his HIV positive status.

concerning privacy[21], holding that the patient has a duty to disclose HIV positive status to his physician. The court determined that the duty arises not as a result of the patient having a duty per se to a physician, but rather out of the patient's engaging in behaviour which elevates the risk of transmitting a deadly communicable disease to an unknowing healthcare provider he may further unwittingly transmit it to others. The Doe Court aptly described the ethical and equitable arguments supporting the legal duty for patients to disclose their HIV status and mandated disclosure. In requiring patient disclosure, the Doe Court acted on an issue which had not been addressed by the legislature. It was observed that the legal duty to disclose arises out of not only moral and ethical considerations, but out of logic, common sense and medical evidence as well, with regard to the general health of society and its physician caretakers. To hold otherwise would be to improvidently elevate policy and the political aspects of this fatal disease over the medically proven health dangers of exposure to HIV infected blood, semen, saliva etc., and to the demonstrated risks of transmission to unknowing and unprepared recipients.

Thus, one may say that although doctors are bound to maintain confidentiality regarding the medical status of their patients, and although patients have a right to privacy regarding their HIV status, the right is not absolute and could be restricted for the prevention of crime and the protection of health and rights and freedoms of others. The principles guiding confidentiality and right to privacy may be summed up as follows:

- PLWHA have guaranteed right to privacy, which is the right to determine for themselves when, how and to what extent information about them is communicated to others.
- On the other hand, physicians are bound by a correlated duty to maintain confidentiality of PLWHA.
- The confidentiality and right to privacy must be maintained in various settings including:
    - Diagnostic testing centres
    - Counselling services
    - Healthcare institutions
    - The workplace
    - During research
    - Educational institutions
    - The judicial system
    - Insurance sector

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[21] Plaintiff's five claims included negligence per se, breach of confidentiality, breach of oral contract, breach of implied contract and invasion of privacy.

  - Adoption and children's care homes
  - In the media
  - Any other setting that may collect, assess and record information on HIV/AIDS and/or vulnerable status.

- In case of dilemma between individual interest and public welfare, the individual interest must prevail except in the following circumstances:
  - When the PLWHA gives informed and written consent for disclosure of his/her status.
  - When disclosure is necessary for the treatment of the patient.
  - When disclosure is necessary for the administration of justice.
  - Where disclosure is necessary to protect another person.
  - Where disclosure is for the welfare of the child.
- A duty is also vested on HIV positive persons to inform the healthcare workers who treat them of their HIV positive status, as physicians bear a greater risk of accidental infection. By protecting doctors from potential exposure during their treatment of patients, we in turn protect other patients whom the doctor treats.
- An HIV positive person also has a duty to inform the same to his/her sexual partner, needle sharing partner and blood bank. It is grounded on the obligation to do no harm to others.
- Thus, an attempt is to be made to safeguard individuals' interests while also giving weight to the public interest of disclosure, only in very exceptional limited circumstances.

The Code of Medical Ethics also carves out an exception to the rule of confidentiality and permits the disclosure in the circumstances enumerated above under which public interest would override the duty of confidentiality, particularly where there is an immediate or future health risk to others. The Guidance of the General Medical Council of Great Britain on HIV infection and AIDS, reads as under:

"When diagnosis has been made by a specialist and the patient after appropriate counselling, still refuses permission for the General Practitioner to be informed of the result, that request for privacy should be respected. The only exception would be when failure to disclose would put the health of the health-care team at serious risk. All people receiving such information must consider themselves to be under the same obligations of confidentiality as the doctor principally responsible for the patient's care. Occasionally the doctor may wish to disclose a diagnosis to a third party other than a health-care professional. The Council thinks that the only grounds for this are when there is a serious and identifiable risk to a specific person who, if not so informed would be exposed to infection ... A doctor may consider it a duty to ensure that any sexual partner is informed regardless of the patient's own wishes."[22]

III. Prescription for the Future

The impact of AIDS on society is tremendous. Statistics show that the epidemic continues to surge worldwide and that the disease is rapidly spreading throughout India. As more patients are diagnosed with HIV, the nation needs to define the balance between the rights of the patient and those of society. If our nation dedicates itself to educating medical practitioners on the laws of confidentiality and to educating society on the disease itself, a balance protecting PLWHA and those in society desiring information about the patient may be achieved. Challenges similar to Doe will erupt in our courtrooms as well until legal and medical practitioners become better acquainted with the confidentiality and right to privacy. The issue is complex in that it places two fundamental precepts of law in opposition: a patient's right to privacy and society's right to uncover information in a legal system based on adversarial discovery.

The time to end the hysterical response to AIDS is now, but until the fear is replaced by rationality, society must protect the PLWHA from potential discriminatory treatment. A two-part prescription will surely relieve the tension of confidentiality and the right to privacy. First, a sound and structured public policy must be drafted that accommodates the multitude of interests in a manner that is fair and reasonable. Secondly, educational opportunities for those affected by such laws must be created. By writing tougher confidentiality laws, and by educating the medical community and those who represent it, both patient and physician will be protected. Physicians are advised to gain an understanding of the laws regarding confidentiality in order to understand what constitutes unlawful disclosure. Ultimately, the best advice is for the physician and patient to talk about the issue of confidentiality and disclosure before the exchange of any information.

Further, there is an imperative need to incorporate human rights concerns into HIV/AIDS policy to reduce discrimination and stigma to PLWHA. By creating a supportive social environment for PLWHA through legal process, the mindset of people can also be changed. Herein, law can be conceived to function in such a manner so as to modify the thinking process of society towards PLWHA. Thus, by developing a legal environment which respects and protects the fundamental and human rights of those worst affected, we can educate people at large of immediate and important concerns surrounding HIV/AIDS. So, the need of the hour is to formulate a clear and consistent policy on HIV, backed up by appropriate legislative reforms and aiming to negate the discrimination and abuses. It may nurture understanding about HIV in the society and may also broaden the thinking horizons so as to reduce the stigmatisation.

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[22] Justice Palok Basu, Law Relating to Protection of Human Rights under the Constitution of India and Allied Laws, Modern Law Publications (2002) P. 429

Mr. Rajendra Sharma, IGP National Security Guard

It is worth noting why the issue of HIV/AIDS is receiving such attention, and why so much importance is being given to it as a human rights issue, when there are other diseases in the world such as cancer and tuberculosis which also have devastating effects. One reason is that HIV/AIDS originates largely from sexual relationships, although there are other routes also. The second reason is the, so far, incurable nature of the disease. It is treatable, but not incurable. A third reason, perhaps the strongest, is the element of stigma and discrimination attached to this condition.

This element of stigma and discrimination has given rise to a number of strategies and policies, such as where we talk of informed consent, confidentiality, counselling – both pre-test counselling and post-test counselling. Until about twenty years ago, there was a lot of stigma attached to diseases such as tuberculosis as well. People suffering from tuberculosis used to be kept in sanitariums, away from the general population, and people feared being in close vicinity to TB patients, because it was a highly infectious disease, and there was a kind of social stigma about it. Tuberculosis has now become totally curable and today there is no stigma or discrimination attached to it.

Human rights are very important in tackling the stigma and discrimination. It is not a simple issue, rather it is a complex interplay of different competing human rights. There are the rights of the positive person, the rights of fellow people, and the rights of society as a whole. It becomes a question of how one human right outweighs another. This is where the judiciary's role is so important, in deciding what is prudent, and which human right outweighs another when they are in competition.

The right to confidentiality is a very important right for HIV positive people. It does have certain exceptions, however, such as if there is a judicial demand in the administration of justice, or for the personal benefit of that person in the course of his medical treatment.

NACO's current policy comes out of the three Cs – informed consent, confidentiality, and counselling without discrimination. For the purpose of voluntary and confidential testing and counselling, treatment centres have come up all over the country. These centres are very important, providing not only facilities for HIV/AIDS testing, but a whole gamut of activities such as trained counsellors for pre- and post-test counselling, prevention services, treatment, care and support services.

Should partner notification operate as an exception to the right of confidentiality? Partner notification is a concept where if an HIV positive person is in an intimate relationship with another party who is identifiable to the positive person's physician or counsellor, and there is an imminent and significant risk of transmission, should the positive person's partner be informed?

Many corporations are now requiring mandatory pre-recruitment testing. The employers want to have physically and mentally fit employees. Many insurance schemes stipulate that the employer should not employ people who are HIV positive. Employers say it is simply an issue of medical fitness; the prospective employee is subjected to other tests, urine, blood, sugar etc. If the prospective employee is suffering from any other chronic ailments, the employer may choose not to take him. Generally in these situations, the Three Cs set out above are not properly followed.

As a police officer, I should describe the situation in the uniformed forces. Uniformed forces personnel require vigorous training and strenuous exercise as they are working in remote, difficult areas of the country. You must have high mobility and living conditions can be very difficult. Physical fitness standards, including endurance, adaptability to a situation and alertness, must be high. With these kinds of job requirements, the health standards we currently follow in our recruitment are that eyesight has to be good and there should not be conditions such as knock-knee, flat foot, varicose veins, chronic illnesses, or physical defects, and there should be good mental and bodily health. We check blood pressure, weight and do routine blood, urine, stool examinations. If anyone is found defective in some way, he is not taken.

With this in mind, if somebody is living with HIV or any other condition, it bears a high cost. Sick leave will rise – this is the view of police bureaucracy –suppose the person gets injured and bleeds, there is a risk to comrades because nobody knows that to handle him, bandage him and, inadvertently, they may suffer. The positive person can offer no assistance to other injured persons, because there is a risk of exposure to the injured person. The positive person cannot offer a blood transfusion which may be needed in the field because facilities for testing blood are not available in the field.

So there is a view amongst the uniformed forces that there has to be pre-recruitment mandatory testing – this is not my view. All over the world there is a rising trend of mandatory testing pre-recruitment to military forces, police forces, and even UN peacekeepers are mandatorily tested for HIV prior to deployment abroad.

Closer to home, in Andhra Pradesh, a rule in the Police Manual required pre-recruitment testing. This rule was challenged in the Andhra Pradesh High Court, which upheld the challenge. The state government has brought the case to the Supreme Court, where it is currently under consideration.

Mr. Suresh Mohammed, National Aids Control Organisation (NACO)

Provider-initiated Testing

Counselling and testing services in India started in 1997 and from a few model centres in Mumbai, Chennai and Delhi, we now have 4,000 counselling and testing centres throughout the country. An integrated counselling and testing centres is a place where a person is tested for HIV of his own free will, as advised by medical provider. Traditionally in India, counselling and testing services have been client-centred and client-initiated.

There has been a yearly growth in counselling and testing services in India. The counselling and testing centres act as a feeder to all other HIV treatment and care services in this country. Unless and until a person is diagnosed as HIV positive, we cannot put that person on ART, we cannot provide that person with care and support services, so testing and counselling is a crucial component of the HIV/AIDS programme. The growth has been steady, save for the last two years where we see a very steep rise in the counselling and testing services in India. In 2006, we have counselled and tested about 4 million people, through those 4,000 counselling and testing centres.

What is the rationale for this new concept called provider-initiated counselling and testing? Despite the large number of people who have been counselled and tested, only 13% of HIV positive people know they are HIV positive. This trend is repeated around the world – the majority of HIV positive people in any country do not know their status. Client-focused testing and counselling have not given the results we expected. If more people became aware of their HIV status, we would be able to link them with treatment and care services, giving very clear health benefits to those people. From a public health point of view, a person who knows he or she is HIV positive can prevent him or herself from transmitting the virus to others.

So what is provider-initiated counselling and testing? It might be appropriate when a client goes to a physician, perhaps with a sexually transmitted disease, or a reproductory tract infection, or a pregnant woman comes in to an anti-natal clinic. These groups of people who are referred by healthcare providers are the types of people who would be given the provider-initiated counselling and testing, This means the clients would be given pre-test information, or group counselling and then offered testing.

So if I went to an integrated counselling and testing centre, I would be given information about the benefits of HIV testing, but I would be clearly told that I could refuse testing. If I opt in for HIV testing, I would then be tested. If I opt out, I can say I do not want to be tested and that is the end of it. It changes the balance from the client having to actively opt in to the client having to actively opt out.

Other clients who come to the centre, for example having seen an advertisement, and deciding to go for counselling and testing, have to actively opt in and say they want to be tested. Someone who is referred by a medical practitioner however, would have to actively opt out. This is provider-initiated counselling and testing. There is post-test counselling available for all the clients.

Pre-test information is a crucial part of provider-initiated counselling and testing. The clients are provided with information about HIV testing, about HIV, what the benefits are of being tested, and what services are available if the test is positive. The client is then offered testing, at which point they can opt out. They are clearly told that they have a right to refuse testing, if they so wish.

So informed consent is obtained before the test, although it is not necessarily obtained in writing. Verbal communication is adequate for these purposes of obtaining informed consent. Post-test counselling for negative test results includes an explanation of the test results and reinforcement of the prevention message. For positive test results, there is a protocol for the post-test counselling. Clients are informed of the test results, counselled, given time to think about them, and provided with any necessary follow-up services.

Today, only 65,000 people are availing themselves of free ART available from the government. Why is this when we have 5.2 million people affected? It is because the majority of people affected do not know their HIV positive status. Provider-initiated testing and counselling aims to link these positive people to treatment and care services.

Provider-initiated counselling and testing will help identify the HIV status of people living with HIV, who are not aware they are HIV positive. It will lead to clear benefits in terms of health outcomes for an HIV positive person. It will enhance the rights of positive people to access ART, which currently only 65,000 people in this country are doing, out of 5.2 million. It is applicable only where a client is referred by his or her healthcare would fail to further the genuine government interest of reducing HIV transmission. Furtherance of this interest of the government is achievable through less coercive policies which are more effective in the long run.

Background of National HIV/AIDS Policy and the Way Mandatory Testing Conflicts with It.

To formulate a strategy for the prevention and control of HIV/AIDS in India, the Ministry of Health & Family Welfare launched a National AIDS Control Programme in 1987[27]. A number of guidelines were issued on various subjects like blood safety and HIV testing. These guidelines are in conformity with the WHO and the Joint United Nations programme with HIV/AIDS (UNAIDS) guidelines on HIV/AIDS[28].

The fundamental principles on which the policy is based are as follows: a) voluntary testing, b) pre and post test counselling, c) confidentiality, and d) information dissemination about the infections.

Voluntary Testing

The guidelines maintain that testing should be voluntary[29]. There are a number of reasons why public health experts encourage voluntary testing for HIV. First, voluntary testing can contribute to early testing of the infection which can, once diagnosed, be treated immediately[30]. Medical evidence suggests that early testing can lead to early treatment[31] and a better quality of life[32]. Secondly, HIV testing can contribute to the overall surveillance of the pandemic. This information can assist public health officials by enabling them to focus on centres most in need of education, care and treatment[33].

Mandatory testing may allow governments to identify more HIV-positive people and focus more attention on diagnosis in high-risk groups[34]. However, even assuming that a

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[27] National AIDS Control Organisation., online, http://www.nacoonline.org/about.htm

[28] In the first six months of the implementation of the statute, the Illinois government lost $77,250 in marriage license fees. Tax revenues and job opportunities also declined because business that specialised in marriage related services such as tuxedo rentals, catering and floral arrangements, suffered a 25percent decrease in income. With fewer weddings taking place, fewer people travelled to Illinois attend wedding and, therefore, restaurants, hotels and tourist related-industries were undoubtedly also deprived of some revenue.

[29] NACO, NACO Guidelines, Guidelines on HIV testing, 2002 3 at 2 online, http://www.nacoonline.org/guidelines/guideline_10.pdf [30] Supra note 23 at 86

[31] The advent of combination therapy in 1996 (also known as Highly Active Antiretroviral Therapy or HAART) radically altered the natural history of HIV infection. HAART has resulted in a decrease in the incidence of AIDS, opportunistic infections, and AIDS related mortality by 60-80percent. The number of deaths attributed to AIDS in the United States decreased from 50,876 in 1995 to 16,371 in 2002 according to a review of data from death certificates by the U.S. Centers for Disease Control. It is important to note that many of the deaths reported in these studies occurred in patients who had already developed clinical AIDS before they had access to HAART. The weight of the clinical and scientific evidence suggests that clinical AIDS can be averted altogether in HIV-infected individuals if they are followed closely enough. HAART treatment makes the difference between sickness that will quickly lead to death, and a healthy and productive person. In a study in Taiwan it was shown that providing HAART to all HIV positive citizens corresponded with a 53percent decrease in the rate of new HIV infections. (Chi-Tai Fang," Decreased HIV Transmission after a Policy of Providing Free Access to Highly Active Antiretroviral Therapy in Taiwan" 2004,) The World Bank had estimated in 1992 that Brazil's prevalence rate would be 1.2percent in 2000, but because of this aggressive treatment programme in combination with broad prevention efforts the prevalence rate was in fact 0.6percent.) World Health Organization "The World Health Report 2004: Changing History" (2004) at 23). [32] Ibid at 87. [33] Ibid. [34] UNAIDS/WHO, Policy Statement on HIV Testing. 2004, online, http://www.who.int/hiv/topics/vct/en/

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Since the very beginning of the HIV/AIDS pandemic, there have been continuous efforts at mandatory testing of the individuals for the presence of HIV/AIDS[23]. An intrusive policy like mandatory testing is usually justified by arguing that it is imperative for protection of public health[24]. However, it is pertinent to note that mandatory testing is an unsound public health policy and arise out of fear, prejudice and frustration[25]. Balancing individual autonomy with public welfare and societal need is the central concern of public health law[26]. These are mostly quick-fix solutions initiated by the government to pacify the public.

MS. DIPIKA JAIN

The Government of India is considering enacting mandatory pre-marital HIV screening statutes/policies in the states of Goa and Andhra Pradesh. This paper examines the proposed policy and analyses whether it is a rational, effective and feasible public health policy response to the HIV/AIDS pandemic.

However, mandatory testing is an irrational and ineffective public health policy. I argue that such an intrusive policy

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23. Eisenstat, Steven," An Analysis of the Rationality of Mandatory Testing for the HIV antibody: Balancing the Government's Public Health Interest with the Individual's Privacy Interest" (1990-91) 52 U. Pitt. L.Rev at 327
24. Ibid. 25. HIV is a retrovirus composed of a protein capsule and genetic material in the form of RNA, a type of nucleic acid. HIV infection is usually acquired through sexual intercourse, exposure to contaminated blood (most commonly through poorly regulated blood banks or intravenous drug use), or mother to child transmission. Upon entering a human cell, the HIV virus uses the cell's energy, protein, and nucleic acid-synthesizing machinery to replicate itself. The host cell then dissolves, releasing thousands of copies of the replicated virus into the host's body. HIV targets CD4 T-cells, a type of white blood cell that helps to organize and coordinate the body's immune response against infections by signaling immune cells to perform their unique functions. HIV weakens the body's immune system until it can no longer resist infections. An HIV infected person dies of these infections and not the virus itself. HIV-infected patients are susceptible to many types of pneumonia, diarrhea, tumors and other illnesses that would pose no threat to uninfected individuals. These illnesses that are unique to AIDS patients are known as "AIDS defining illnesses." (UNAIDS, "Protocol for the identification of discrimination against people living with HIV" Geneva. 2000)
26. Gonen, Julianna S, "Removing Informed Consent From HIV Testing of Pregnant Women: A Return to The Maternal-Fetal Conflict" (2001) 2 Geo. J. Gender & Law at 765.

provider. It is not applicable to everybody. Provider-initiated counselling and testing is only offered where someone is referred having presented with clear symptoms and signs associated with HIV, such as sexually transmitted diseases. In all cases, it remains voluntary and confidential.

comprehensive depiction of the epidemic is possible through mandatory testing, the underlying problems driving the epidemic remain. Voluntary steps by an individual are more likely to result in necessary behavioral changes[35]. In part, behavioural changes may be brought about by cultivating an increased sense of personal responsibility, instead of cultivating a false sense of security that "the government is handling it." Mandatory HIV testing violates people's right to autonomy and bodily integrity[36]. Coercive HIV-testing is a violation of privacy and autonomy[37].

It has been repeatedly reiterated by WHO that any response to the HIV/AIDS epidemic must respect human rights and invite the voluntary cooperation of PLHAs and the general population to be effective[38].

Pre and Post Test Counselling

HIV counselling is a confidential dialogue that enables individuals to examine their knowledge and behavior in relation to their personal risk of acquiring or transmitting HIV infection[39]. This counselling helps them decide whether or not they should undergo an HIV test and also provides them with support when they receive their test results. Both pre- and post-test counselling are essential because it is important to have a clear understanding of what the test is and what its implications may be, in order to make informed choices.

Disclosure of test results without pre and post counselling can lead to adverse psychological consequences, including suicide attempts and major depressive illnesses. Testing without a patient's consent offends ethical and legal norms. Hence, mandatory testing is an unsound public health policy.

Confidentiality

Anonymous voluntary testing is another way of encouraging people to get tested[40]. Due to the fear, anxiety and stigma attached to HIV/AIDS, people are generally apprehensive about getting tested. Anonymous and voluntary testing would create a receptive environment.

The second important principle of the National HIV policy is that of protection of confidentiality. Both anonymous and confidential testing opportunities help to facilitate test seeking among the general population as well as the high risk groups. The disclosure of a person's HIV status all too often results in social ostracism including loss of employment, denial of access to medical services, and domestic violence[41]. As a consequence, very often those who most need treatment or information do not seek it out in the apprehension of a social backlash[42].

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35. Ibid.
36. Ibid.
37. Canadian HIV/AIDS Legal Network , HIV Testing Fact Sheets: Forced HIV Testing to Avoid Infection? Testing of Patients, Health-Care Workers, and Prisoners, (2000) 1.
38. World Health Organization, Statement from the Consultation on Testing and Counselling for HIV Infection, WHO Global Programme on AIDS, 1992.
39. Supra note 29.
40. Supra note 38.
41. Supra 23 at 89.
42. Ibid.

Confidentiality of an individual's HIV-status and health status is one of the most important (yet problematic) aspects of an effective response to HIV/AIDS. Assurance of confidentiality serves multiple purposes. First, full confidence is necessary for testing in order to encourage people to be tested without fear of disclosure, including disclosure of either their HIV status or of the mere fact that s/he had an HIV test[43]. This is particularly relevant in a country like India where a woman tested for HIV may face violence or reprisal from her husband regardless of the test result. Second, in regards to treatment, full confidence in a physician or counsellor is necessary in order to provide optimal diagnosis, counselling and care. Patients may be unwilling to discuss information about drug use, sexual behavior, and HIV-status without assurance of absolute confidentiality. Finally, confidentiality upholds the basic principles of human dignity and privacy[44].

Information Dissemination about the Infection.

Dissemination of accurate information on HIV/AIDS is the most effective means to let HIV positive people know about the infection and available treatment. Education and prevention programmes are the optimal public health measures because they can achieve a long-term impact by promoting individual action. Prevention and awareness campaigns are considerably more effective than affording mere diagnoses. Such programming can also lead to higher rates of voluntary testing. The general consensus of the international community is that it would be better to spend the bulk of resources proactively fighting the epidemic rather than identifying it[45].

Mandatory pre-marital testing may lead to the dissemination of inaccurate information[46]. Such information may deceive the public by suggesting that the testing is foolproof. It has been stated that no test of biological system is foolproof even under the best laboratory conditions. For instance, to detect as asymptomatic HIV positive person by using ELISA test in a population where the prevalence of infection is 1%, there are 50% chances that a person detected positive is actually positive after one ELISA test and 99% positive after two tests[47]. Hence, it is likely that one result will be falsely positive in every 100 tests. Even if the western blot test is used as a supplemental test instead of a second ELISA, the chance of detecting truly positive increases to 99.8%[48]. Moreover, HIV testing is not always accurate[49]. The HIV antibody test does not detect HIV directly but looks for antibodies for HIV. Antibodies are factors that are produced by the body to fight infections. Antibodies take time to form[50]. Accordingly, HIV test results will not be positive until enough antibodies are present in the blood for the test to find them. This time period between when a person is actually infected with HIV and when antibodies to HIV can be detected in the test is called the window period[51]. A person may test negative for HIV during the window period, a period which lasts between three weeks to six months[52].

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43. McLean, "HIV Infections and a Limit to Confidentiality", (1996) 12 Afr. Journal of Human Rights, 252 at 453.
44. Ibid.
45. Supra 23 at 89.
46. Ibid.
47. Supra note 28 at 2.
48. Ibid
49. Supra note 23 at 91.
50. Supra note 39.
51. Ibid. 52. Ibid.

Pre-marital HIV testing may also mislead people by suggesting that HIV tests are only important for people considering marriage. Thus, mandatory HIV testing significantly chips away the effectiveness of the National HIV policy. Pre-marital mandatory testing can result in decreased number of HIV tests, a delay in the early diagnosis of the disease, violation of the right to confidentiality and privacy and also dissemination of erroneous information. Accordingly, the disadvantages of mandatory testing far outweigh the advantages. There are several ethical and constitutional challenges of enacting a pre-marital mandatory HIV test policy. These will be analysed in detail in the next section.

Ethical Implications

It is abundantly clear from the above discussion that the National HIV policy upholds the ethical principles of informed consent and confidentiality. These principles will be discussed in this section.

Informed Consent

The informed consent doctrine is based on "the premise that a patient has the right to make an informed choice about medical options for diagnosis and treatment. The doctrine is rooted in a model of the physician-patient relationship in which decision making is a collaborative process rather than a one-way path.[53]" The doctrine of informed consent has five functions[54] and they are: (1) protection of a person's self-determination; (2) minimising coercion of the patient; (3) avoidance of unrealistic patient expectations; (4) enhancement of therapeutic self-scrutiny; and (5) fostering rational decision making[55]. These principles advance a person's sense of freedom wherein he/she can take a decision. This free decision making process enables a person to experiment and to discover things valuable to him or to others[56]. When a doctor informs a person about the risks and benefits of a treatment, it reconfirms an individual's status as a competent person by suggesting that he/she is capable of both making a choice and sharing in decision-making[57]. However, the participation must be free[58]. There is a definite asymmetry in health care information available to the doctor and the patient. The act of exchanging the information reduces this inequality because it enables a patient to make his own decisions, assuming he/she understands the consequences of his/her decision[59]. In this regard, the principles of autonomy focus on access to information and an individual's control of that information[60].

Thus, informed consent is intended to bring about a patient's autonomous decision-making. However, there are certain exceptions[61]. Informed consent can be waived in three situations.

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53. UNAIDS (2003), Fact sheet on Stigma and Discrimination, December 2003, online, http://siteresources.worldbank.org/INTEAPREGTOPHIVAIDS/Resources/fs_stigma_discrimination_en_pdf.pdf July2006)
54. Ibid.
55. Ibid.
56. Ibid.
57. Ibid.
58. Ibid
59. Ibid at 823.
60. Ibid.
61. Gonnen, Julianna S, "Removing Informed Consent from HIV testing of Pregnant Women: A Return to the Maternal-Fetal Conflict." (2001) 2 Geo.J.Gender & L 765 at 770.

First, there is an emergency exception, where if the patient is likely to suffer serious harm or death if treatment is not administered, consent can be waived[62]. Second, there is a waiver exception where a patient voluntary decides to waive the right to be fully informed[63]. Lastly, there is an exception based on therapeutic privilege, where the physician believes that disclosure itself may cause serious physiological or physical harm[64]. Arguably, imposition of mandatory testing without informed consent does not meet the criteria for these exceptions.

Mandatory testing seemingly means that a person's consent is no longer sought and clearly does not fit into any of the above-mentioned exceptions[65]. Mandatory HIV testing is not justifiable on principles of informed consent. If a person tests positive it can be extremely devastating for the person, while a negative test can instill a false sense of security[66]. Further, such testing implicates "principle of beneficence—that medical intervention must be done for the good of the patient"[67].

Conceptually, informed consent signifies the consenting individual comprehends the information and implications of the medical intervention in question, and has voluntarily chosen a particular course of action[68]. Usually, informed consent is required for risky medical procedures such as surgery, but the same principles underlie informed consent for HIV-testing, even though HIV-testing has no physical/medical risks attached. Rather, the relevant risks and benefits originate from the possibility of positive HIV-status.

Practically, informed consent for HIV-testing is comprised of two separate components: providing sufficient information about the test/procedure (inform) and ensuring the test is completely voluntary. Sufficient information about the test requires, at a minimum, an explanation of the medical and preventative benefits of testing, of follow-up services, of the consequences of a positive-test result, such as partner notification, and an explanation of the purposes, risks, harms, and benefits of testing/not testing[69].

A closely related issue is whether the individual must give specific, informed consent for an HIV-test, or if general consent to blood work and diagnostics is sufficient to carry out an HIV-test[70]. The prevailing consensus requires specific consent for HIV-testing, although many medical practitioners continue to resist such an approach, covertly and openly[71]. Physicians are known to test for HIV either with general "implied" consent or without any authorisation from their patients[72]. Although the true number of doctors involuntarily testing their patients for HIV is not known, reports in India indicate that as many as 95% of patients listed for surgical procedures are involuntarily tested for HIV[73].

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62. Ibid.
63. Ibid.
64. Ibid.
65. Supra note 53 at 828
66. Ibid.
67. Supra note 53 at 846.
68. Ibid.
69. UNAIDS/WHO Policy ,HIV Testing Fact Sheets: Consent to Testing at 1.(2002)
70. Ibid.
71. Ibid.
72. Ibid.
73. Ibid.

The covert testing of patients has become much easier with the development of rapid result HIV-tests, raising multiple ethical issues.

Aside from the legal and social violations of privacy, the test results bypass all of the safeguards of pre-test counselling and informed consent. Cases have arisen of doctors simply informing individuals of their positive status and abruptly ending treatment. An alternative ethical dilemma subsequently arises as to how the individual should be informed of his or her status, as both withholding the knowledge and revealing the results of an illegitimate test (possibly motivated by some discriminatory suspicion) are unethical[74]. Such ethical dilemmas can and should be avoided. To best serve the interests of the individual's human rights, privacy, autonomy and public health, informed consent should be required for all HIV-testing except in cases falling into special exceptions.

Confidentiality

Confidentiality is a concept encompassing a duty inhibiting the passing to others of knowledge about another person or entity. The duty may be either social or legally enforceable. Confidentiality may attach to information about any aspect of another person's life, past or present conduct, nature, or physical or psychological attributes[75]. D. Felman explains that the "right to confidentiality can be most persuasively described as deriving from a right to privacy, which, in turn, stems from right to human dignity and autonomy.[76]"

Without confidentiality, the critical bridges linking PLHAs and the rest of the community may become barriers, imposing silence and an unwillingness to interact for fear of discrimination and stigma. Few would willingly undergo an HIV-test or AIDS-related treatment if they believed the results could easily become public. A distrust of health and social services will drive the epidemic further underground, crippling the efficacy of public interventions. Confidentiality is especially crucial in more conservative countries such as India, where a parallel epidemic of stigma and discrimination accompanies HIV transmission.

Privacy, moreover, is a human right based on an individual's personal autonomy and freedom of choice[77]. Privacy protections allow PLHAs to decide when, where, how, why, and to whom to disclose the information[78]. The core of confidentiality is not simply the non-disclosure of knowledge, but the effects of unexpected, unwanted, and unauthorised disclosures which can have traumatic and devastating effects on infected and affected people.

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74. Supra note 59
75. Cameron, Edwin Justice, "Confidentiality in HIV-AIDS: Some Reflection on India and South Africa" (2001) 1 Oxford.U.Commw.L.J. 35 at 36.
76. Feldman, D. "Civil Liberties and Human Rights in England and Whales" (1993: Clarendon Press, Oxford) 400 at 353.
77. Ibid.
78. Canadian HIV-AIDS Law Review,A long way from there to here: human rights approaches to HIV-AIDS in a local setting, , April 2005.

Yet while confidentiality facilitates an effective response by protecting PLHAs from stigma and discrimination, and encourages open communication with their care providers, it is also clear that an absolute rule of confidentiality can have adverse effects on public health policy because of the clear risks inherent in non-disclosure[79]. Thus, the traditional view concerning confidentiality posits that while the specific burdens of stigma and discrimination that accompany HIV/AIDS heighten the need for confidentiality, the modes of transmission and nature of the infection appear to heighten the need for disclosure and public safety measures. In essence, the traditional view envisages a direct conflict between privacy and public welfare.

At first glance, this view is plausible, requiring a broad, simplistic balancing test between private and public interests. However, as indicated above, there is increasing recognition that effective public health interventions cannot succeed without privacy protections[80]. A new understanding of individual rights as a component of the public interest has consequently arisen, whereby the aggregation of private, individual interests is necessary for the achievement of the public interest. Thus, the balance of interests becomes an even finer, subtler balance between two public interests: firstly, the public interest in protecting every individual's confidentiality, which in the aggregate facilitates effective interventions and responses; secondly, the traditional public interest in disclosure, whether for partner notification, court proceedings, press publication, epidemiology or planning interventions

Mandatory HIV testing increases the chances of breach of confidentiality. In most situations, marriages in India take place under much scrutiny of the family and community. In this context, an individual's HIV status is likely to become public knowledge leading to a breach of his/her confidentiality.

A cursory analysis of HIV/AIDS statistics and epidemiology can lead to the instinctive conclusion that the guarantee of privacy rights and consent for PLHAs exacerbates the epidemic by knowingly allowing spouses, sexual partners, drug-injecting partners and other at-risk parties to be exposed to infection[81]. It might also be concluded that such protections prevent the epidemic from being known in the community, contributing to the "invisible" nature of the epidemic[82]. Though such conclusions have intuitive appeal, research and analysis of the social aspects of the epidemic - particularly the role of denial, stigma, and discrimination - show that the protection of privacy, confidentiality, and consent are pivotal to decreasing the spread of HIV/AIDS[83].

Yet, despite increasing recognition as a critical component of HIV/AIDS programming, problems of confidentiality and privacy have not been approached comprehensively, or with the same urgency as prevention, treatment and other issues. Nevertheless, laws reflecting respect for ethics and privacy are indispensable to safeguarding the basic human rights and dignity of PLHAs, as well as facilitating effective responses to the epidemic. Right to confidentiality and consent will be discussed in detail in the next subsections.

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79. Ibid.
80. Ibid.
81. UNAIDS, Opening up the HIV/AIDS Epidemic, UNAIDS Best Practice Collection, UNAIDS, 8 (2000).
82. Ibid
83. Ibid

Constitutional Implications

Mandatory pre-marital HIV testing statutes are subject to constitutional challenges on several grounds. More specifically, mandatory HIV testing amounts to a violation of both individuals' right to marry and individuals' rights to privacy.

Violation of Right to Privacy

Breach of confidentiality and informed consent jurisprudence are not yet as well-developed and distinct in India as in many foreign jurisdictions. In addition, a comprehensive legislative response to confidentiality and privacy, particularly regarding HIV/AIDS, has not yet been developed. Since the Constitution of India provides no explicit right to privacy or confidentiality, the Judiciary has been forced to resort to Article 21[84] of the Constitution of India, holding that the right to privacy is included within the right to life and liberty[85]. With regard to HIV/AIDS within judicial proceedings, the Bombay High Court, like most international jurisdictions, has held that PLHAs can litigate their claims under a pseudonym to avoid revelation of their identity[86].

The constitutional right to privacy in India, although categorised as a fundamental right, is nevertheless limited in its scope. For example, the derivation of the right to privacy from Article 21 means that the right can only be enforced against the state, not against private individuals[87]. An additional limitation on Article 21 privacy jurisdiction arises from the fact that the right to privacy has not been specifically guaranteed in the text of the constitution. As a result, the right to privacy and confidentiality are not considered to be absolute rights, but rights that must be balanced against the public good and curbed accordingly[88]. Even though the right to privacy is usually set aside, there is a growing recognition of this right by the Indian Courts. The courts weigh the State's interest in public health and safety quite heavily but perceive individual interest as nominal[89]. Nevertheless, coercive measures like mandatory testing amount to violation of the right to privacy.

Right to Confidentiality in Indian Courts

As in other jurisdictions adjudicating the confidentiality of PLHAs, Indian case law reflects a balance between the gravity of the risk posed to the public or a specific person, and the right to confidentiality. However, given the dearth of explicit privacy protections in statutes or the Constitution, the Indian judiciary, while cognisant of the right to confidentiality and right to privacy, has afforded less protection to these implied rights. In doing so, the Indian judiciary has generally afforded more weight and breadth to the

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[84] Article 21 Protection of life and personal liberty-
No person shall be deprived of his life or personal liberty except according to procedure established by law.
(Constitution of India, 1950)

[85] PUCL v. Union of India & Another (AIR 1997 SC 568)

[86] MX of Bombay Indian Inhabitant v. ZY and another, AIR1997Bom406 (1997)

[87] Kharak Singh v. State of UP, 1 SCR 332 (1964)

[88] Sharda v. Dharmpal, AIR 2003 SC 3450.

public interest than to the right to confidentiality. When faced with a conflict between the two values, the court consistently enforces the right that advances public morality or the public interest (in its traditional conception), at the cost of confidentiality[90].

The Indian cases reasonably demonstrate that the judiciary prioritises the reduction of transmission and effective responses to the epidemic. This is the strength of the decisions. The weakness resides in the characterisation of the rights of PLHAs as individual obstacles to a greater public interest.

Despite increasing recognition as a critical component of HIV/AIDS programming, problems of confidentiality and privacy have not been approached comprehensively, or with the same urgency as prevention, treatment and other issues. Nevertheless, laws reflecting respect for ethics and privacy are indispensable to safeguarding the basic human rights and dignity of PLHAs, as well as with facilitating effective responses to the epidemic.

Mandatory Testing: Other repercussions

Besides constitutional and ethical challenges, the mandatory HIV testing may result in further marginalisation of the vulnerable population. Some of these concerns are discussed.

Adverse Impact on Women

Though this policy is being supported by many legislatures and women's groups, it is an irrational policy which may have adverse consequences[91]. In a patriarchal and gender-biased society like India, women are vulnerable to the infection despite not practising high risk behaviors. Marriage itself is considered a risk. In India, sexual inequality compounds the danger by making it difficult, if not impossible, for women to enforce their choices about whom they wish to marry or with whom they wish to have sex[92]. They are often unable to negotiate safe sex. Often, women do not know that condoms should be used for preventing anything other than pregnancy, or do not have the negotiating power to demand their use. In marriages, condom use is rare because it inhibits pregnancy and is perceived as a sign of infidelity. Men, who are often the ones who bring HIV into a family, accuse women who suggest condoms as being unfaithful. Indian culture values fertility, and women want to get pregnant, which, as a source of pride, would improve their status[93]. Male dominance puts women into a position where they are unable to refuse sex for fear of violence, and unable to practise safer sex[94]. Hence, married women are increasingly becoming infected by HIV because their husbands often engage in high-risk behavior. Much of this could be changed, but only with knowledge and empowerment. Unfortunately, most married women have little knowledge or awareness of the risks they face because most of them are

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90. Lawrence Gostin, The AIDS Pandemic, (2003: The University of North Carolina Press) at 141

91. Dr. Tokugha Yepthomi v. Apollo Hospital Enterprises Ltd. & Another, AIR 1999 SC 495

92. Tandon, Tripti, "Mandatory Testing, HIV-AIDS and Marriage - Discordant bedfellows?" (2002) website: http://www.lawyerscollective.org/^hiv/^Publications/Articles/may_2002.asp

93. Ibid.

94. Hamblin, Julie and Elizabeth Reed. Women, the HIV Epidemic and Human Rights: A Tragic Imperative, (1993: UNDP Publications)

95. Ibid.

illiterate and the HIV/AIDS campaign, until very recently, only focused on high risk groups. Most young girls and women are required to be innocent of sexual knowledge and there is also a strong weight on her virginity until marriage[95]. Females' lack of sexual knowledge is looked at as a sexual honour and a form of purity, and this succeeds in preventing women and girls from accessing and seeking helpful information[96]. They fear seeking such information as it may call into question their virginity[97]. Estimates show that 39 percent of HIV-positive adults in India are women[98], and the number of young women, aged 15-24, living with HIV/AIDS is twice that of young men[99].

The fact that a large number of married women are getting infected is a cause for concern for many sectors of the civil society in India, especially the women's organisations. However, this is a narrow and restricted way of looking at the issue because it fails to take sex post-marriage into consideration[100]. Further, women will be at greater risk after marriage as an HIV negative certificate may not allow them to negotiate safe sex[101]. "It may also give the women a fake sense of security foreclosing possibilities of safer practices.[102]"

Marriage in India is considered to be a private matter. However, with the proposed legislation in place, some marriages will be driven underground[103]. This will make already socially vulnerable women even more vulnerable. Mandatory testing is analogous to an isolationist approach that can discourage people from accessing healthcare services[104]. This can be extremely counter-productive, and will drive the pandemic underground.

Further, this is an illogical measure that fails to consider infections after marriage. It fails to look at possibilities of sexual practices outside a marriage.

Lack of Access to Tests/Treatment

HIV positive test results needs to be followed by treatment, care and support. However, universal access to ARV[105] drugs continues to remain elusive to the Indian positive population. In spite of the free ARV policy of the Indian Government[106], the anti-

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[95] UNAIDS, "Gender and HIV-AIDS: Taking stock of research and programmes",(March 1999) at 9, online, http://www.unaids.org/en/in+focus/topic+areas/gender+and+hiv-aids.asp?StartRow=60 cited October 11, 2003.

[96] Ibid.

[97] Ibid.

[98] Kaiser Family Foundation, "HIV-AIDS in India," September 2005. http://www.gatesfoundation.org/nr/downloads/globalhealth/aids/aids_in_india_kff.pdf

[99] Ibid.

[100] Supra note 25

[101] Ibid.

[102] Ibid

[103] Ibid.

[104] Ibid

[105] Antiretroviral drugs are medications for the treatment of infection by retroviruses, primarily HIV. Different classes of antiretroviral drugs act at different stages of the HIV life cycle. Combination of several (typically three or four) antiretroviral drugs is known as Highly Active Anti-Retroviral Therapy (HAART).

[106] The Government of India, in response to the filing of the Voluntary Health Association of Punjab Vs. Union of India,(Access to ARV drugs petition) in 2003, announced a policy for provisioning anti-retroviral treatment to 1,00,000 people living with HIV-AIDS, free of cost, with implementation starting on April 1st, 2004. The goal of the programme as outlined in the draft NACO guidelines was essentially to place 100,000 AIDS cases on structured ART by the end of 2005 and be able to provide treatment to additional of 15-20percent of AIDS cases each year, thereafter, for a period of five years. The government, thereafter, created a new target of treating 1,00,000 by 2007 after realizing it would not meet its 2005 goal: As of November, 2006 a total of 32,000 people are on ARV drugs whereas the UNAIDS estimated there are 7, 85,000 people in India who require ART treatment as of August 2005.

retroviral treatment initiative has not achieved any desirable public health goals in light of both the estimated number of people in need as well as other competing public health needs. In 2005, UNAIDS estimated there were 7,850,00 people in India who required ARV treatment[107]. It is unequivocally stated in the 2006 UNAIDS report that India's antiretroviral coverage remains well below 10 percent[108]. Despite the policy, very few people have access to ARV drugs. The important question to ponder is whether the people with newly tested infections will have access to these drugs. It is pertinent to note that the CD-4 testing, which is needed to monitor the patient's immune system to accurately determine the correct drug therapy, is backlogged across the nation[109].

Further, a comprehensive national treatment programme must include counselling and regular follow-ups with medical professionals to educate those taking ARVs about the risk they still pose in transmitting the virus despite their decreased viral load. Such measures will ensure that the rate of new HIV infections will decrease. Research points out that testing alone cannot solve the problem; it has to be followed by proper counselling and behavioural changes[110].

Thus, the cost of initial test, the repeated confirmation tests and subsequent treatment, followed by adverse psychological impact of the tests, need to be considered before enacting such a law[111].

Rise in Corruption

In a developing country like India, it is not difficult to obtain a forged HIV negative certificate by bribing the authorities. Such law may give rise to the existing corruption thereby making the whole exercise futile and ineffective. Further, people can easily travel to other states to get married. There are twenty eight states and seven Union Territories in India. This would not only result in losses in revenue accruing from wedding preparations, but would also defeat the purpose of the state government to track the epidemic.

Further, though there is a compulsory registration of marriage requirement in India after the Supreme Court's decision in 2004, most of these laws may not be followed in the villages where people usually get married according to their culture and religion.

Marginalisation of the Vulnerable

If the government implements the policy of mandatory pre-marital HIV testing, this may then encourage the government to impose mandatory HIV testing in other arenas such as in employment, in prisons, and for sex workers. This will lead to further marginalisation. Identification of infected individuals will result in stigma, discrimination, violence and loss

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[107] UNAIDS and WHO. Progress on Global Access to HIV Antiretroviral Therapy:, A Report on '3 by 5' and Beyond", March 2006http://www.who.int/hiv/progreport2006_en.pdf

[108] WHO/UNAIDS. Treating 3 million by 2005: making it happen: the WHO Strategy. (Geneva: World Health Organization, 2003.)

[109] Voluntary Health Association of Punjab Vs. Union of India(Ongoing petition in Supreme Court of India)

[110] No author listed, "HIV: Compulsory and Falling Incidence?" (2006) Volume 367, Issue 9517,The Lanchet,1118 at 1119.

[111] Ibid.

of human rights. There can be no legitimate or successful response to HIV/AIDS without respecting individuals' human rights, fundamental freedoms and dignity.

Public health experiences in both India and worldwide demonstrate that coercion and intrusion can render any policy ineffective[112]. For instance, the Congress government in India initiated a family planning programme for a restricted population growth[113]. However, this resulted in forced vasectomies and, in some cases, sterilisation of women. Officially, men with two children or more had to voluntarily submit, but many unmarried young men are also believed to have been sterilised to meet the official targets[114]. This programme was criticised in India, and was blamed for creating a public aversion to birth control. The programme also resulted in many people succumbing to forced sterilisation and vasectomies[115].

Financially Unfeasible

This policy would be incredibly expensive to implement, and would be a drain on resources. Increased testing may lead to more diagnosis, which would result in a greater demand for care, support and treatment. India is the second most populated country after China. Every test would have to be followed by a repeated confirmatory test. Every new infection would require treatment. The government is unable to treat the existing infections. Will it have additional resources for the newly diagnosed infections? The cost of initial testing, the subsequent treatment, and the care and support will have to be taken into account before implementing such a law. Further, testing centres would have to be set up at a district level. Since, the government cannot possibly set up testing centres at every village in the state, people from these villages would have to travel to other centres to get tested. In this process, they would require compensation for loss of income and for travel allowances.

As seen in the case of Illinois, mandatory HIV testing is expensive and difficult to implement, thus diverting HIV/AIDS resources from more effective prevention measures. Whether subject to a cost-benefit analysis, or whether viewed from the perspective of protecting human rights, mandatory testing is a shallow, injudicious and ill-advised policy.

Recommendations

It is evident from the above discussion that the proposed public health policy of mandatory pre-marital HIV testing is irrational and unfounded. The government should desist from enacting such a policy. Instead, this section will suggest that the government should use its existing resources to create awareness about HIV and to educate people on the issue. The HIV/AIDS and Human Rights International Guidelines[116] advocate that

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112. Supra note 89 at 135

113. Dutta,Shantanu, "Family Planning-India's abandoned agenda"(2006).website: http://desicritics.org/2006/11/04/004844.php

114. Ibid.

115. Ibid.

116. Published by OHCHR and UNAIDS, 1998

people affected with HIV/AIDS should not be subject to criminalisation or other coercive measures on the basis of their HIV status. Applying restrictive measures to people simply on the basis of their HIV status violates their fundamental human rights[117]. The existing legislation is an impediment to high risk groups accessing healthcare, and information and legal reforms are required.

Education and Awareness

Instead of insisting on mandatory pre-marital HIV testing, policies should focus on providing education, information and generating awareness on HIV/AIDS. There is a need to create an enabling environment for young people so that they may obtain the necessary knowledge and access the relevant services that may protect them from HIV/AIDS. Education is essential for human development and dignity, as well as for the progress of society as a whole. AIDS education is not usually offered in schools, but is occasionally available for young people aged 15 and older. Nevertheless, 42 % of boys and 69 % of girls age 15 to 17 are not in school[118]. Further, two-thirds of the world's illiterate are women[119]; and a study shows that illiterate women are four times more likely to believe there is no way to prevent an HIV infection[120]. Globally, more than 80 % of young women do not have sufficient knowledge about HIV/AIDS[121]. During their last sexual encounter with a non-cohabiting partner, only 51 % of women used a condom, compared to 59 % of men[122]. Women lack the power to negotiate safe sex. This ignorance and vulnerability, especially prevalent among women, could be eliminated with targeted education. With knowledge comes empowerment, and this knowledge may eliminate some of the causes for the spread of HIV. Education could reduce poverty and economic dependence, improve health, delay marriage, and increase a woman's self-confidence and decision-making power[123]. People have limited knowledge about HIV/AIDS, and many impoverished people in India are not educated enough to understand the causes of AIDS and how it is transmitted. Thus, the government should invest resources in creating an enabling environment through educating people and spreading awareness.

Education and prevention programmes are thus a superior public health measure as compared to mandatory pre-marital HIV testing because education and prevention may have a long-term impact by promoting individual action. Prevention and awareness are considerably more effective than diagnosis. Such programming can also lead to higher rates of voluntary testing[124]. Properly conceived, the only question that remains is whether diagnosis should occur prior to education and preventative measures, or whether it should lead to them; similarly, it must be asked whether education and preventative measures should be undertaken

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117. Richard Elliot, Criminal Law, Public Health and HIV Transmission: A Policy Option Paper,2002
118. UNICEF/UNAIDS/WHO "Young People and HIV-AIDS: Opportunity in Crisis," June 2002, online, International women's health coalition fact sheet: www.iwhc.org/resources/HIVAIDSfactsheet.cfm
119. UNFPA "Gender Equality Factsheet,"2005, online, http://www.unfpa.org/swp/2005/presskit/factsheets/facts_gender.htm
120. UNAIDS, UNIFEM, and UNFPA; "Women and HIV-AIDS: Confronting the Crisis", 2004.online, http://www.unfpa.org/upload/lib_pub_file/308_filename_women_aids1.pdf
121. Ibid.
122. Ibid.
123. Ibid.
124. Ibid.

prior to possible diagnosis, or whether they should lead to diagnosis. Although all components are necessary, the general consensus is that it would be better to spend the bulk of resources proactively fighting the epidemic rather than identifying it. Combating stigma, increasing condom distribution, expanding rapid voluntary testing programmes, increasing access to syringe-exchange programmes, and improving HIV education in schools will all be effective means by which to control the spread of the infection. These initiatives will prove more effective if the legal barriers to access of safe syringes, condom distribution amongst the commercial sex workers and men having sex with men are removed.

The evaluation of whether HIV testing should be implemented requires an examination of whether the contended government interests is achievable. These interests need to be balanced against the right to privacy of those who are tested. It is abundantly clear from the above discussion that pre-marital HIV testing will not serve government's contended interest and will at the same time violate fundamental human rights.

Dr. Anjali Gandhi, Director, Sarojini Naidu Centre for Women's Studies, JMI

HIV/AIDS affects women in a different way than it does men. Women suffer a greater burden of ill health, and are further disadvantaged due to gender inequalities vis-à-vis HIV/AIDS.

Almost half of the PLHA population comprises women, and the global rate of women infected as compared to men has risen from 41% to 50 % (UNAIDS figure). In India, STD clinic data reveals an increasing number of young women below 30 years-old are infected with HIV/AIDS.

DR. ANJALI GANDHI

Biological vulnerability is one reason for the increase in infection amongst women. Women are more vulnerable to HIV/AIDS infection because of their anatomy and the way their bodies are structured. For instance, during sexual intercourse a relatively larger area of mucus membrane is exposed in a woman, compared to a man. Therefore, a larger quantity of fluid is transferred from men to women. Further, the viral content of male sexual fluids is much higher than that of female sexual fluids. Hence, the micro-tears that can occur in vaginal tissue during sexual intercourse make women more vulnerable to HIV infection. There is a one in a 1000 chance of a woman transmitting the infection to a man but a one in 500 chance of a man transmitting the virus to a woman.

Gender is a set of culturally accepted norms of behaviour that is appropriate for sexes in a given society. Most societies, including those of developed countries, are patriarchal. About seventeen tribal societies have been identified by anthropologists where there is significant gender equality and violence against women is uncommon. Patriarchy perpetuates gender inequality, and impacts adversely on women's health in many ways. Women, for instance, are generally burdened with homecare, childcare, care of the sick, etc. This may have a negative impact on a woman's health, especially when she is HIV positive.

The main reason for HIV transmission to women is marriage. According to the IIPS report, 45% of Indian women are married by the age of 18. Women in India get married in a very vulnerable position, where the men usually do not disclose their status and then go on to infect their partners, if positive. This is one of the biggest challenges in India today.

HIV and violence against women are interconnected. The lack of power to negotiate safe sex practices results in violence against women. Lack of awareness about HIV/AIDS also places them in a vulnerable position. The lack of self-perception of risk, where the woman is not aware that she may be at risk also increases her vulnerability.

Lack of access to adequate health services is another factor which results in women's ill health, and increases their susceptibility. Most existing healthcare services are either integrated with the child care programmes, or primary health services where they receive add-on services. Exclusively women's health services are generally unavailable. This is further aggravated by the fact that more often than not, if a couple is infected, it is the man who receives the healthcare benefits. The lack of access to healthcare services and unequal gender norms make access to healthcare services extremely challenging for the female population of the country.

In India, out of 27 million deliveries, approximately 56,700 children are infected with HIV. Even if a woman knows about her status, she would generally prefer to deliver the child rather than abort because child birth is a matter of prestige for a married woman.

The next issue that needs attention is that of early child marriage. Sex education is imperative. The prevention efforts should be aimed not only at school/college-going adolescents but also at people who are unable to access education. Livelihood training is very important for women, because infected women continue to live. Hence NGOs and positive network groups should work towards this.

There is a need for greater evidence-based research, both in understanding the problem and creating an interventional model. It is essential to understand what models will be successful and applicable to given situations.

Lastly, and most importantly, the issue of patriarchy must be addressed. Patriarchy, or the power of man over woman, or authority of powerful over less powerful, is the most important factor in making women vulnerable and disadvantaged in situations specifically dealing with health issues.

Recently, Dr. Coleman of New York, a renowned coronary artery heart surgeon, declared in the newspaper that he was infected with hepatitis B. His practice increased exponentially. I interviewed his patients, curious to know why they were still going to him. I was told by most of them that they were going to him because he had shown he was an ethical doctor. I am therefore of the opinion that a person in a marital relationship should similarly disclose his status if he happens to be HIV positive. It is important to be ethical.

Ms. P Kousalya, President of Positive Women's Network (PWN)

Access to treatment for HIV positive women in STD/ART clinics is a big challenge. The low social status of women in society means they are ill treated. Verbal abuse is one such problem that women constantly face in a healthcare setting such as parent to child transmission (PTCT) centres. The recent Domestic Violence Bill can be used to address this problem.

MS P KOUSALYA

Secondly, there are certain programmes which aggravate discrimination and stigma issues. For instance, there was a self help group in Tamil Nadu to help commercial sex workers, which included HIV positive women. The CSW were not comfortable with the inclusion of the HIV positive women. HIV positive women were therefore being discriminated against. Funding is also a huge challenge. Most of the funding was going for other programmes and only 36% of the funds were given to the HIV positive women's group. Hence, women have to deal with dual stigmatisation.

Property and inheritance rights are a huge challenge for most women all over the country. When an HIV positive couple invest their hard earned money to buy or develop a certain type of property, it is regarded as inherited property. Therefore, after her husband's death, the property is usually not given to the wife for the same reason.

In most families, children are regarded as property. If a child is HIV positive, he is handed over to the mother. If the child is negative however, there is a tendency for the husband's family to take the child away and separate the mother and the child. As a result, there are large numbers of destitute women and children. There are no facilities available for these destitute and homeless people. The State AIDS Control Society in Tamil Nadu has doubts about the number of people who are destitute. Namarkal district has long been identified as a high prevalence place, with a large number of destitute women and children. This led to the immediate commencement of a rehabilitation programme for these women and children. However, one programme is not enough and such programmes need to be replicated in other places as well.

Irrespective of whether a particular district or a particular area is high or low prevalence, irrespective of whether it is on the HIV map or not, this is something that needs to be addressed because rights of women, rights of widows, rights of destitute women are hardly ever addressed and this may be a perfect opportunity for them to have access to the law.

By and large, rights-based information and knowledge amongst women is negligible, and irrespective of whether they are educated women or poor and illiterate women, there is little or no knowledge about rights. Is this something that the judiciary can address, perhaps through the legal aid systems?

There are a number of questions about which we have no knowledge. For instance, can a positive mother adopt her children? Or can a single widow or a destitute woman also adopt children? This is important because there are large percentages of orphaned and vulnerable children are either out on the street or in care homes, or in care centres. The second issue is that of the property rights of these children. If adopted, can the property be managed by the legal guardian who has now adopted them, or can the children control the property even before they are 18?

Further, the livelihood options for women have to go beyond the traditional methods of tailoring and candle making. There is a need to look at some kind of serious business and income generation scheme. There are self-help groups but getting loans and insurance are issues which are a huge challenge. Is there a way to address these problems?

Dr. Bitra George, Family Health International

I would like to start with a short story of a ten year old girl called Lata (her name has been changed). She is an orphan living in Andhra Pradesh. Her parents passed away two years ago, and she has been ostracised by other members of the family. She is currently living with her 65 year-old maternal grandmother. She has dropped out of school to take care of her younger siblings. The important question for us is what will happen to her when her grandmother dies?

An "HIV infected child" means a child infected with HIV, and an "HIV affected child" is someone whose parents, either one or both, are infected with HIV/AIDS. A "child orphaned by AIDS" can be a "single orphan" or a "double orphan". A "single orphan" has only one parent and a "double orphan" has none. Children at the highest risk of being affected by HIV/AIDS are usually street children, children of sex workers etc.

50% of all new infections in India occur in people below 25 years of age. 39,000 children are infected through parent to child transmission. It is estimated that around 120,000 children are living with HIV/AIDS in India. There are approximately 2.5 million children living with HIV/AIDS globally, and around 180,000 in Asia. Further, around 15 million children are orphaned globally by HIV/AIDS and there are absolutely no figures regarding vulnerable children.

The impact of HIV on children is multi-fold. Children usually suffer from psycho-social distress, economic problems and property loss. There is also reduced access to health care and nutrition. Children without adequate adult care are discriminated against, exploited for child labour and also vulnerable to sexual abuse.

A recent UNICEF study explored the barriers in access to healthcare. The study concluded there are two major responsible factors. The first is stigma and discrimination. The second important factor is the myths about HIV transmission. The myths exist even amongst the educated population. For instance, there is always confusion whether a child infected with HIV can transmit the infection to other children. The virus dies in the open air in 30 seconds, so it is very difficult for a child to physically transmit the virus. Similar irrational fears aggravate discriminatory behavior in a variety of circumstances.

More often than not, access to healthcare services is denied to children by their own parents. For instance, sex education is not encouraged in India. Such denial will expose more children to unwanted pregnancy, unsafe abortion, STDs and HIV/AIDS. Largely, the best interests of a child are decided by the State. Most of the laws in India, including those governing fundamental rights, provide for the rights of children. India is a signatory to international conventions such as the Child Rights Convention (CRC), which outlines various rights accorded to children, including the right to health. The Millennium Development Goals to which India is a party also outline various goals to be achieved with regards to children. There are several national policies on children, for example the 1987 National Education Policy, the National Child Labour Policy, the Juvenile Justice Act, the National Charter for Children for 2003. The draft HIV Bill also has special provisions for children, women and young people.

The National AIDS Control Programme outlines special provisions regarding children. The policy provides for treatment of 40,000 children by 2011. There are numerous programmes under the Ministry of Women and Child Development, which is the nodal agency for child care.

Various agencies are putting together a draft national operational guideline, which defines programmes for infected and affected children. It is looking at medical care, psycho-social support in terms of counselling, nutritional support, educational support, social protection, economic strengthening, legal support and shelter and also alternative care, in terms of foster care, orphanages, and other facilities.

Despite good laws and policies in India, there is very little change, mainly because of ineffective implementation of these laws. Addressing stigma and discrimination is one of the most important areas that needs attention. Finally, the entire social protection services in India are insubstantial, and need to be strengthened.

Mr. Nicholas Robinson, Yale Law School, and Ms. Shruti Pandey, Human Rights Law Network

Progressive Judicial Decisions from India and around the World

These cases can be classified in three categories.

(1) One should be able to keep one's HIV status confidential

(2) One should be treated with dignity and not discriminated against if one's HIV status becomes public

(3) Restriction of movement, breach of confidentiality, discrimination, and mandatory testing not only threaten the liberties of individuals, but also jeopardise a successful public health response to HIV.

The first successful case law in India was the landmark judgment, MX of Bombay Indian Inhabitant v M/s ZY (AIR 1997 Bom 406). A public corporation was to regularise casual labourer MX. A physical exam revealed that MX was HIV positive and thereafter MX was not regularised and his contract terminated.

The Bombay High Court held that PLWHA cannot be refused a permanent post on the basis of fear that the person will not later be able to perform the duties. Further, if the HIV positive status results in impairment, a "reasonable alternative" should be provided if the employee is otherwise suitable. The Court also opined that "the State and public corporations like Respondent No 1 cannot take a ruthless and inhuman stand that they will not employ a person unless they are satisfied that the person will serve during the entire span of service from the employment till superannuation." This makes clear that discrimination on the basis of an HIV positive person's potential future incapacity is unlawful in the public sector. Similarly, in Chottulal Shambhai Salve v State of Gujurat (2001) and RR v. Superintendent of Police (2005), the Gujurat High Court and Karnataka High Court respectively held that otherwise qualified HIV positive persons could not be refused employment in the police force. In a similar case, in Mr. X v State Level Police Recruitment Board (2005) the Andhra Pradesh High Court noted that PLWHA cannot be condemned to further stigmatisation and "economic death" through employment discrimination.

There are plethora of judgments from the Indian courts that have upheld the employment rights of positive persons, thereby preventing stigmatisation and economic death of the person.

The Canadian case of Fontaine v. Canadian Pacific Ltd. (120 N.R. 152, [1991] F.C. 571 (Canada) highlights the principle of constructive dismissal. A private employer was held liable for "constructive dismissal" of HIV positive employee by allowing an inhospitable climate to develop where employee felt he had to leave.

There is a reasonable accommodation case from the United States. In Melvin Buckingham v United States of America (998 F.2d 735 (1993), the court held that otherwise qualified employees should be reasonably accommodated to enjoy the benefits of their job and receive treatment for their handicap. This may include reassigning the employee to be closer to medical treatment.

There are ample judgments stating that employers have to take efforts to reasonably accommodate those who are HIV positive. It may involve going to an office, moving somebody to an office that is closer to HIV treatment, or reassigning somebody in their job, etc.

A Columbian judgment, Yudis Luiz Mercado Herrera v Sociedad Medica Santa Marta Ltd (T-469 2004 (Columbia)), states that the private sector, like the state, has an obligation to promote the progressive improvement of the quality of life for marginalised groups.

These cases usually fall under the Disability Act in the USA, and constitutional law in Canada.

There are numerous reports of HIV positive children being discriminated against in schools or being effectively barred from schools.

For instance, in District Community School Board v Board of Education (502 N.Y.S.2d 325 (Sup. Ct. 1986), it was held that exclusion of children with HIV from schools violates both U.S. statute and the 14th amendment of the US Constitution. The court stated that the student's return to a normal classroom "poses no significant health threat to his peers" and would demonstrate to the public that the problem of children with AIDS must be dealt with on a rational basis.

This second case, Robertson v Granite Community Unit School Dist. No. 9 (S.D. Ill. 1988), involved an HIV positive child who was put into a handicapped classroom. The court ruled that the child did not qualify as handicapped.

In India, there have been no reported court cases on access to education, although a few have been reported by the media.

The next issue is that of confidentiality. In MX of Bombay Indian Inhabitant v M/s ZY (AIR 1997 Bom 406), the court held that PLWHA can litigate under a pseudonym in order to protect their identity. In another case however, Mr. X v Hospital Z (AIR 2003 SC 664), the Court recognized an HIV positive person's right to confidentiality, but allowed an exception for a hospital to inform a prospective spouse and his/her family. It further held that an HIV positive person has a right to marry, as long as they inform their prospective spouse of their HIV status.

The issue of confidentiality has been dealt in a different manner in the USA and Canada. In N.O.L. v District of Columbia (D.C. Cir. 1995), for instance, a husband claimed that a hospital should have informed him that his wife was HIV positive. The Court held that the hospital owed the husband no duty to disclose his wife's HIV status. Instead, hospital staff owed a duty to the wife to refrain from disclosing that information to anyone, including her husband, without her written consent. It is important to note that in this case, unlike most other jurisdictions, it is the person who decides and not the hospital.

Francies v Kapla 127 Cal. App. 4th 1381 (2005) is another confidentiality case where in a medical leave note to the patient's employer, the physician noted that the patient "is managing HIV disease." The Court held that the physician's acts constituted medical malpractice and violation of the Confidentiality of Medical Information Act.

In Z v Finland ([1997] ECHR 220009/93), Z's husband, X, was charged with a number of criminal offences. Z's doctor testified she was HIV positive during the trial. The decision which published her identity and her HIV status, and the court file (containing her medical record), was sealed for 10 years. The Court held that the 10 year period of confidentiality was too short. The applicant's identity and medical condition should not have been published. The Court found such publicity may "discourage persons from seeking diagnosis or treatment and thus undermine any preventive efforts by the community to contain the pandemic."

Common Cause v Union of India (Writ Petition (Civil) No. 19 of 1992) is a Supreme Court decision on the issue of blood banks, where the government was directed by the Supreme Court to regulate blood banks. The Court found the current state of blood banks were a serious threat to public health. The government was directed to enact comprehensive regulations for blood banks and set up an autonomous organization to oversee blood banks.

There are a few other cases where a person was infected in a blood transfusion or a surgery because of the negligence of the hospital and the hospital was held liable to pay damages.

In P v Union of India (2001, Kolkata High Court), a woman was awarded damages by the hospital for being infected with HIV through contaminated blood that was not acquired through the hospital blood bank as required under the Drug and Cosmetics Act. Similarly, in M/s Vijaya v Chairman & Managing Director (2002 ACJ 32), a woman received a blood transfusion from her brother during an operation at the hospital. She was infected with HIV through the operation. The hospital was found to be negligent. It should have tested the blood at time of transfusion. The patient was awarded damages.

In a French case, X v France, (9900/82 ECHR, 1991), a hemophiliac received HIV-contaminated blood in the 1980s and sought damages from the government. The Court held that the National Blood Transfusion Foundation should have been aware of the risk to those receiving blood, halted supply of contaminated blood, and properly informed the hemophiliac community of the risks. The State was ordered to pay damages.

In LX v Union of India (Delhi High Court, 2004), an under trial prisoner tested positive in prison. He was given ART treatment, and subsequently released on bail. The Court ordered the government to continue treatment at AIIMS under the government's ARV rollout programme.

Ubaque v Director, National Model Prison (Columbia Constit. Ct., T-502/94 (1994)) is a case from the Colombian Constitutional Court. The court held that HIV positive prisoners require at least the same rights as all other individuals, including in the provision of ARVs and medical treatment for HIV/AIDS. Further, in Nolley v. County of Erie (776 F. Supp. 715 (W.D.N.Y. 1991)), the US court held that placing red stickers on an inmate's possessions indicating her HIV status violated the prisoner's right to privacy.

On May 16, 2007 the Supreme Court dismissed a PIL calling on the Court to issue an order requiring pre-marital HIV testing (Source: Indian Express).

In X v Commission of the European Communities ([1995] IRLR 320 (ECHR)), X applied for work with the Commission and was invited to undergo a medical examination. He declined an HIV test. However, the medical officer ordered blood tests, and concluded X was suffering from AIDS. X's application was rejected on the grounds that he was physically unfit. The Court held that the right to respect privacy requires a person's refusal to undergo a test be respected in its entirety, although an institution may refuse to hire someone because they will not undergo a medical examination.

Glover v Eastern Nebraska Community Office of Retardation (686 F. Supp. 243 (D. Neb. 1988) is a case from the Unites States. An agency for care of the developmentally disabled required its employees to be tested for HIV. The Court found there was little risk for transmission in this setting, and mandatory testing therefore violated privacy rights unreasonably.

India Network of Positive People v T.A. Majeed is an ongoing case in the Supreme Court of India. In 1993, Majeed was given a licence by the Drug Controller to sell "Immuno QR" - an ayurvedic medicine for basic ailments. Majeed claimed "Immuno QR" cured

AIDS. The Drug Controller cancelled the licence, but the Kerala High Court stayed the cancellation. Later, the Kerala and Bombay High Courts ordered that he could not advertise "Immuno QR" as an AIDS cure. In 2007, the Supreme Court directed Majeed not to produce "Immuno QR" until final disposal of the case, and directed the Kerala High Court to expedite the case.

In other countries, more stringent drug regulation laws prevent drug providers from falsely claiming a drug can cure AIDS. Individual doctors can be held liable for malpractice if they promote quack cures for AIDS.

An ILO study found that 32% of HIV positive patients had been refused care in India in a healthcare setting notwithstanding that Article 21 of the Constitution of India has been interpreted to include the right to health

Refusal of care is a big problem in India where a lot of people report that when they go to doctors in hospitals, the doctors either overtly refuse care, or make up an excuse. Bragdon v Abbott (118 U.S. 2196 (1998), is a landmark US case where an HIV positive person was refused treatment by a private dentist at his office, although the dentist offered to treat her at a hospital. The Court held that a healthcare professional could refuse treatment only in the case of significant risk. What constituted such risk would depend on the objective medical and scientific data available and not on the professional's perception of risk.

In Pt. Parmanand Katara v Union of India (AIR 1989 SC 2039), the Supreme Court held that the state has a duty under Article 21 to preserve human life through medical assistance. In the ongoing VHAP v Union of India (Writ Petition (Civil) No. 311 of 2003), the VHAP requested a comprehensive ARV rollout. After the Supreme Court issued notices, the Central Government announced the phased roll-out of its ARV programme.

Raj Bahadur v Union of India (2003 VIAD (Delhi) 393) is another of such cases. A Delhi government employee with AIDS was entitled to treatment in a hospital under the Delhi government. The employee needed specialised care, and was referred to AIIMS, which is not a hospital under the Delhi government. The Court held that the rule should be interpreted liberally, so the necessary treatment could be given.

In a public interest litigation, Subodh Sharma v State of Assam (MANU/GH/0016/2001, the petitioners claimed there were systemic problems in HIV/AIDS programmes in Assam. The Court ordered the government to:

- Implement NACO guidelines, and monitor the implementation
- Inquire into fund irregularities, carry out regular audits
- Close illegal blood banks
- Open AIDS counselling centres

- Provide equipment, facilities, and trained personnel
- Not refuse positive persons treatment

N.N v la corporación del Seguro Social Militar (2003 05354 (Bolivia)) is a case from Bolivia. Member of the military received free AIDS treatment for two years, until it was suddenly stopped under a new social security law. The Court held that the right to health, because it related to the right to life, must be considered as a fundamental right. It logically prevails on all inferior laws. The Court ordered the military to continue providing the claimant with the medication, regardless of the social security law.

Treatment Action Campaign v RSA Ministry of Health et al. (CCT 8/02 (2002) (South Africa) is a South African case. NGOs and individuals challenged the government's decision to restrict the use of Nevirapine, a medication used to prevent the mother-to-child transmission of HIV. The Court held there is a "minimum core" of obligations that should be taken into consideration when looking at the reasonableness of a state's health plan. The restriction of Nevirapine "is not reasonable and is an unjustifiable barrier to the progressive realisation of the right to health care" as enshrined in the Constitution. The Court ordered the government to make Nevirapine available.

Mr. William Garcia Alvarez v Caja Costarricense de Seguro Social (5778-v-97, 1997 (Costa Rica)) is a case from Costa Rica. The Court ordered the Government to provide PLWHA with ARVs free of charge. The Court cited the right to life and health as enshrined in the national Constitution, and as endorsed by Costa Rica in international treaties. It held that economic restraints could not be cited as an excuse for denial of the right to health.

Hon'ble Mr. Justice Yacoob of the Constitutional Court of the Republic of South Africa

I should begin by saying that none of my comments must be understood as creating the impression that the South African judiciary's way of dealing with these issues is necessarily a better way. What I will do is describe our approach and put forward an approach which is somewhat different from other approaches that one has seen and, hopefully, will be able to raise some ideas to put into the pot. We are all human beings after all, and can only change and develop on the basis of new ideas and thoughts. No policy, no judicial approach is ever static in my view, and therefore, one needs to keep an open mind on these issues, even after one has been judging them for a while. One never knows what new approaches will come forward.


JUSTICE YACOOB

There are two aspects of HIV/AIDS sufferers with which I need to deal. The first is medical treatment. That is covered by the socio-economic rights in the South African Constitution. Those socio-economic rights, contained in Sections 26 and 27 of the South African Constitution are indeed comparable to the directive principle of state policy in the Constitution of India. The Indian judiciary, particularly before 1997, has done a great deal in expanding the notion of the directive principles of state policy, and broadening them, some say too much.

In the more recent jurisprudence of the Indian courts, particularly the Supreme Court, there is a feeling that perhaps the courts went too far prior to 1997. Leaving that aside for one moment, the difference between the two regimes is quite clear. While we in South Africa have socio-economic rights to work with, you in India have the directive of state policy to work with. In a sense, therefore, your job is more difficult.

As judges, we have to decide our cases as they come before us. As judges, we are not to prejudge issues, which can make attending colloquia quite complicated. The purpose of such colloquia is for us to begin to learn a little more about the context, and to develop certain general principles and approaches - on a tentative, prima facie basis, because the general principles and approaches cannot be said to apply to all cases we have before us.

We start on the basis that murder is wrong, and that a very heavy sentence is appropriate for murder. When however we hear argument in a particular case about the circumstances, we may deliver a lower sentence. We all start off with certain presuppositions and there nothing is wrong with that. There are certain principles which we can all accept as starting points, but a lot of it depends on which side of the bed you got out.

If you accept principle A as a starting point, you reach conclusion one; if you accept principle B as your starting point, you reach conclusion two. I will end on the basis that we in South Africa have certain starting points that I would commend as legitimate starting points, subject of course to parties' rights to make argument that those starting points are absolutely wrong.

The case of Treatment Action Campaign v Republic of South Africa Ministry of Health et al came before the Constitutional Court in 2002, at a time when I was in India. The Treatment Action Campaign ("TAC") worked towards ensuring appropriate medical treatment in relation to prevention of mother-to-child transmission of HIV/AIDS. Socio-economic rights in South Africa are contained in Sections 26 and 27 of the South African Constitution, each of which are phrased in identical terms. Section 26 is concerned with housing, which we need not worry about, and Section 27 with food, water, social security and health or healthcare. Section 27 is divided into three subsections. Subsection one says everyone is entitled to access healthcare. Subsection two says the state must take reasonable legislative and other measures within its available resources to ensure the progressive realisation of the right to healthcare, and the third subsection talks about emergency medical treatment.

Sections 26 and 27 were first discussed in the case of South Africa and others v Grootboom and others, in which the court came to the conclusion in relation to Section 26 (which reads the same as section 27) that Sections 26.1 and 2 must be read together. In other words, that access to healthcare is guaranteed by Section 27.1, but that the state obligation is defined in subsection two. The state obligation is carefully defined on the basis that it is not possible to achieve full realisation of all socio-economic rights immediately. The sections as drafted give the court some jurisdiction, though limited, to ensure the government is not left to its own devices, in relation to the development of health services, including HIV health provisioning within health services.

So Section 27.2 has been held to be justiciable and the court can determine the question of whether the state has complied with its obligation under Section 27.2; whether the State has taken reasonable legislative and other measures within its own resources to ensure compliance with the right given to citizens under Section 27.1.

The Constitutional Court held that what "reasonable legislative measure" means is that (*ad hoc*) measures are not enough. What those words really mean is measures which amount to a coordinated, well developed comprehensive programme at all levels of government, to ensure effective implementation of the right under Section 27.1. Not everything need be done immediately, but a reasonable part of the budget must be brought into the process. In relation to reasonableness, it was held that one must take particular care of vulnerable people, those who are particularly in need. That is particularly important in relation to the TAC case.

If we start on the basis that people affected by HIV/AIDS are vulnerable people who need society's care and attention and who suffer greatly, and if we start on the basis that unless this care and attention is given appropriately and properly in relation to these vulnerable people, the whole of our society will collapse, you get one conclusion. If, on the other hand, you start on the basis that gay and lesbian conduct is fundamentally immoral, sex worker conduct is fundamentally immoral, that HIV/AIDS starts from that conduct, and therefore that vulnerability does not come into the picture, you will not have any particular sympathy for first hypothesis and would reach a different conclusion.

You might also start from the hypothesis that the problem is not too great because less than one percent of the people in India suffer from HIV/AIDS at the moment and therefore it does not really matter because we will get this thing under control quickly, not by medication, but by controlling the commercial sex industry, and so on. If you start with either of these latter two hypotheses, when you look at medical treatment you come to a different conclusion. It is absolutely vital for us therefore to internalise where we are going to start.

The trouble is we quite often do it subconsciously, and subconsciously start at a particular point without knowing it. As judges, we need to constantly know, without making any subconscious assumptions, that the starting points determine the result, particularly in this kind of case. We have therefore got to question the starting point.

Our starting point in South Africa was determined by the gay and lesbian cases. Those cases dealt with whether it is right to say that homosexuality was a crime. In those cases, we came to the conclusion: a) that it was right for gay and lesbian people to get married; and b) that it was wrong for consensual homosexual conduct to be criminalised. The basis for these decisions was that the Constitution required us not to unfairly discriminate on the basis of sexual orientation. But the basis on which we came to that conclusion in our earlier gay and lesbian cases, the strong fundamental thesis of those cases, was that to regard homosexuality as a crime and to treat homosexual people badly in that way was a fundamental affront to their dignity. So that was our starting point. Our starting point was that homosexual people had their right to dignity enshrined in the Constitution and, therefore, an attack against homosexual conduct was a fundamental attack on their dignity. We started on the basis that homosexual people in society have been a vulnerable minority, that they have been the victims of serious prejudice. Although many people have thought that homosexual activity is not good, the South African Constitution does not contain such prejudices. In the circumstances, we had to look at setting aside the problem, recreating society and make it happen differently.

Look at the figures for the AIDS epidemic in India, and the first starting point may be that if, in a period of 21 years, the number of cases rose from 4 to 5.2 million, and if you continue the same regime, if we extrapolate on that figure then we can only imagine what it will be like in the next 21 years.

The Treatment Action Campaign case was decided in the context of this being a problem of huge proportions. The South African Government had to concede, firstly, that its programme to prevent mother-to-child transmission was justiciable. TAC came up with an interesting argument, on which they were not successful, which posited that Section 27 created two rights. The right under Section 27.1 was the right to medical care. In this case, that meant the right to treatment to prevent mother-to-child transmission of the HIV virus. They argued, relying on a United Nations Committee Statement, that this subsection created some sort of minimum obligation of the state. They then argued that subsection 27.2 placed an obligation on the state to provide that minimum in a reasonable fashion.

The Constitutional Court rejected this argument, having already decided in Grootboom that subsections 27.1 and 27.2 had to be read together, and that what they meant together was that the state had an obligation to provide reasonable treatment and healthcare.

The Constitutional Court then looked at whether it was reasonable that the drug for preventing mother-to-child transmission of the virus, Nevirapine, was not available at every hospital in South Africa. It was an interesting debate. For Nevirapine to work most successfully, very simply, the mother needs to take a tablet before birth and a couple of drops are given to the child after birth. The medication was available free of charge to the South African government, with the result that there were no costs involved other than dispensing the drug. Despite that, Nevirapine was available only in two pilot training centres per province. In other words, in 18 centres throughout the country, Nevirapine was not made available, even if counselling and other services were available and if it was medically indicated.

In a sense it was an easy case. We need to understand that if we did not prevent transmission, the child was likely to be born HIV positive and could die very quickly. It was quite clear from the medical evidence that Nevirapine would prevent mother-to-child transmission. The South African Government came up with the justification that in the rural areas, partly through culture and partly because mothers could not afford to feed their babies with formula, even if you used Nevirapine to prevent transmission at birth, the baby would become infected through breast feeding. The Constitutional Court held that the risk some babies would become infected through breast feeding was no reason not to provide Nevirapine at all. At least the drug would effectively prevent a child becoming HIV positive in some cases.

The Government also argued that there could be side effects because the children could develop a resistance to treatment if they receive Nevirapine. Again, the Court found it was better to have resistance developing later in some cases, than to deny the drug altogether and create the almost certain chance that the child will be HIV positive. It was very clear in this case that the Government's attitude was not reasonable.

Again, however, it is a question of starting point. If you had the starting point in this case that Government decisions cannot be questioned by the courts, you would have had a very different decision. Nevirapine would not have been given to pregnant women, and many more deaths would have occurred.

In India, it would have to be approached as a life and death matter. The Constitution of India protects people's right to life. I would suggest there is a stronger argument for extending this to reasonable healthcare facilities for people living with HIV/AIDS than there may have been for extending this to a right to adequate housing. It depends on where you start.

Even if you consider that the Constitutional Court of South Africa was wrong to say that gay and lesbian conduct is acceptable, and that gay and lesbian people are vulnerable people who have suffered considerably at the hands of society and who have been the victims of discrimination. Even if you say we were wrong on that starting point, there is a supporting argument that not everybody who suffers from HIV/AIDS is a "guilty" party.

HIV/AIDS began in India in 1986. You never know whether an infected woman picked up the virus because her husband picked it up somewhere and gave it to her, and she is an innocent party. You do not even know whether perhaps the woman picked it up somewhere, gave it to the husband and the husband was the innocent party (although statistically this is less common). You do not know whether this 19 or 20 year old was born in 1987, and her parents were HIV positive. As time goes on therefore, the moral hypothesis becomes so utterly weak that it becomes nonexistent, so I would suggest that the moral starting point is wrong for two reasons. One is because gay and lesbian people and sex workers as well are particularly vulnerable people in society. The second is because you never know how people become HIV positive and you should not assume there is any kind of moral culpability.

It would be a very interesting exercise to look at of, say, 10 million sufferers, how many are the "guilty", "immoral" people, and how many really are good people who have become victims themselves. My sense is that you will at least be able to come to the conclusion that 6 to 7 million of that 10 million are absolutely innocent, and only 3 million – even on the hypothesis the guilt thesis is correct – are actually guilty.

Looking now at the case of Hoffman v South African Airways, which is a very interesting case. It brought into play the equality provisions of the South African Constitution. Section 9.1 of the South African Constitution says that everyone is equal before the law, and entitled to equal benefits and protection of the law. Sections 9.3 and 9.4 concern discrimination. Subsection 9.3 says that the state may not discriminate on certain grounds and subsection 9.4 says that ordinary people may not discriminate on certain other grounds.

The South African jurisprudence on equality is broadly that firstly, you must decide whether there is a rational basis for the distinction. If there is not, the distinction is unfair discrimination – this is really a threshold inquiry of rationality. Is there a connection between the law or the conduct concerned, and some sort of achievable governmental purpose? It is actually a very low threshold. Once the conduct or law is found to be rational, the next part is to see whether it is unfair. If the distinction is based on one of the listed grounds, it is automatically unfair. The list of grounds is however non-exhaustive, so conduct can be unfair even if not based on one of the listed grounds. The list of grounds is quite wide-ranging. It includes sexual orientation, but not HIV/AIDS status.

In the South African Airways case, the claimant had applied for a job as a cabin attendant for South African Airways. The applicant went for an interview, and was found to be suitable. He went for a psychometric test, and was found to be suitable. He went for a health test, again found to be completely suitable. When he went for a blood test, early stage HIV/AIDS was discovered. He was then found to be not suitable, because of being HIV positive.

The airline's justification was based on safety, health and operational grounds. The safety grounds were that people need to be safe. Cabin crews need to have vaccinations against all sorts of viruses, and this is more difficult for people living with HIV/AIDS. Secondly, when HIV positive people are sick, they will not be able to serve people properly. Thirdly, for operational reasons, the airline said it could not really train people living with HIV/AIDS because they would not be able to work for a very long time, it would therefore be a waste of resources. Finally the airline said that, operationally, all other airlines had a policy of not employing positive people as cabin attendants and therefore the airline's commercial viability would be impacted if they did employ people living with HIV/AIDS. The airline was frightened that if people knew it was the only airline without a policy of not employing HIV positive people, the passengers would go to other airlines. The airline was thus relying on other people's prejudice.

If your starting point is commercial viability, that has more to do with fairness then vulnerability. In this sort of case, you would decide you cannot let a whole airline collapse because of people who are HIV positive, who are a minority in society. The High Court found in favour of South African Airlines, although the judgment suggests some guilt on the part of the judge about it.

So the matter came before the Constitutional Court of South Africa. The equality provision in the Constitution makes it quite clear that dignity is a very important principle, and the relevant one here because HIV/AIDS was not listed as one of the grounds in Section 9 of the Constitution. A secondary problem was that there was a temptation on the part of the court to decide the case on the basis of disability. Gay and lesbian people however objected to this because they felt they should not be referred to as people with disability. They said they would rather lose the case than win it on that basis.

What the Constitutional Court found was that all members of society, regardless of their position in society, whether they are gay or not, whether they are HIV positive or not etc. must be accorded equal dignity. That dignity is impaired when a person is unfairly discriminated against on the basis of his HIV status, so that was in a sense the starting point of the judgment – to say that dignity is important. Then we said the determining factor concerns the impact on the person who had been discriminated against. One needs to look at this quite carefully. In the judgment, we said that people living with HIV/AIDS constitute a minority and that society has responded to their plight with intense prejudice. The question is what can we, the judiciary, do? Do we have a duty at all if a particular group in society is responded to with intense prejudice?

People living with HIV/AIDS have been subjected to systemic disadvantage and discrimination. They have been stigmatised and marginalised. As the present case demonstrates, they have been denied employment because of their HIV positive status, without regard for their ability to perform the duties of the position from which they have been excluded. Society response to them has forced many of them not to reveal their HIV status for fear of prejudice. This in turn has deprived them of the help they would have otherwise been entitled to. People who are living with HIV/AIDS are one of the most vulnerable groups in our society, notwithstanding the availability of compelling medical evidence as to how this disease is transmitted. The prejudices and stereotypes against HIV positive people still persist.

I consider any discrimination to be an instance of stigmatisation, and an assault on dignity. The Constitutional Court made it clear in South African Airways that an employer refusing employment because of HIV positive status is further stigmatisation, and if a court were to confirm it, it would be even greater stigmatisation.

The Constitutional Court came to the conclusion that we all want to live in a society where everybody is treated as a human being, and when people like that are excluded from jobs, we suffer as a society. Our morality suffers, and we become an opportunistic society.

There is a third case, a prisons case, which applies Treatment Action Campaign and South African Airlines, in holding that medical services to people living with HIV/AIDS must also be available in prisons.

The point I simply want to make is that if our starting point had not been a particular view of fairness and the potential destruction of society, our views would have been very different. The judiciary as I understand it, has to think carefully about and investigate this HIV scare, and come up with a principled approach. We must not be the victims of starting points of which we are not truly aware.

One final concept is the meaning of independence and impartiality. Many people confuse this with objectivity. I subscribe to the thesis firstly that objectivity in judges is a nonexistent phenomenon. We are all, in the end, weak, vulnerable human beings and we come to judging doing the best we can with all our predilections, our past, everything that happens to us. We must understand that we are victims of the past, and that the subjective is inevitable; but the subjective is not necessarily bad because the inquiry is not whether it must be totally objective. The inquiry is what the correct balance is between the subjective and the objective appropriate for a particular subject. We are not judging machines, we are judging human beings and therefore an element of the subjective is inevitable and, I think, extremely important.

What we struggle for is the right balance between the subjective and the objective in the judging process, and I actually struggle with this a great deal. If I suddenly start thinking I'm objective and stop questioning myself at every stage of the judging process, I become subjective without knowing it. I will become the victim of my circumstances without knowing it. For me therefore, I can survive in this job only if the struggle is always there and the questioning is always there, asking whether my starting point right or whether I am the victim of something subconscious.

Let me end by saying that HIV/AIDS is a scourge on our society. It is quite miserable. HIV/AIDS sufferers are vulnerable people. Gay and lesbian people are vulnerable people. We sit with a huge problem in relation to which there are no easy answers, and all I can do in the end is wish all the judges in the world the courage, the strength and the openness of mind to deal with this huge problem properly and appropriately.

Answer in response to a question from the Judiciary about the South African Airways case

My thesis, and that of the Constitutional Court, was that how someone acquires the HIV virus is irrelevant. You might acquire it because you were immoral, or idiotic or behaving entirely innocently. The result is that you remain vulnerable, whether you like it or not. Does it make any difference whether I became blind because I had meningitis when I was 16 months old, or whether I became blind when I was 20 years old, having sex with someone's wife whose husband came and stabbed me in both eyes? Obviously that is a very extreme example, but does the cause of the blindness make the blind person in the end any less vulnerable? My view is that it does not.

The Court's injunction against South African Airways discriminating against someone on the basis of their HIV status was an injunction against all airlines doing that. It is inconceivable that all the airlines of South Africa will close down as a result of the court's decision. You cannot decide cases on the basis of what you do or do not suspect. If there was evidence that the airline would close down, rather than mere suspicion or allegation, we would have analysed that evidence quite carefully to look at the probability of the airline would close down. We have to decide things on the basis of evidence and on the basis of probabilities.

There was no contention that all the South African airlines would close down. It was merely a competitiveness argument that South African airlines would make less money. Understanding the European human rights jurisprudence as I do, it is much more radical than South Africa. So all European airlines will be bound by European human rights jurisprudence. I would imagine that the Indian and American people will follow suit, although the American Supreme Court might be a little more complicated in that regard. In the end, the prospect of everyone losing their jobs and all airlines in South Africa closing down and the European Commission coming to the conclusion that we were wrong is, to me, just a little bit distant.

Question

The South African Airways judgment makes very enlightening reading. One reason was that it was clear in that case the only bar on that person's employment was his HIV status. That discrimination could not be answered.

Answer

Quite right. This person's HIV status was also at a very early stage. The medical evidence was quite clear about that. So what the airline did was to say that all HIV positive people could not be employed. With appropriate medication, a person who is HIV positive can work productively for many years. We know people who are HIV positive and who have been living for 20 years with medication, without any serious problem.

Question

I understand you have to protect a person's right to confidentiality, but the problems arise in trying to balance this with a person's right to know the HIV status of his proposed partner, his right to safe procreation, his right to have a healthy child and the unborn child's right to lead a healthy life.

Answer

You need to have a double strategy. You cannot have a prevention strategy and then say everyone who does become infected must have been bad. You must regard the people living with HIV/AIDS as vulnerable and as human beings. Do you treat them as human beings and make sure the state's resources are available to them, or do you say no?

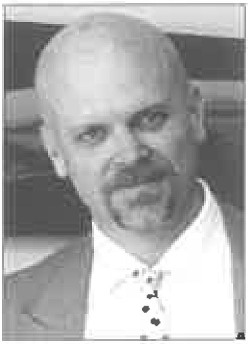
On the competing rights, I would not say in India that you will necessarily come to the same conclusions as we have done in South Africa, but it is something for the judiciary to think very carefully about.

Mr. Gary Lewis, UN Office on Drugs and Crime (UNODC) Representative for South Asia

Mr Lewis has been a serving member of the United Nations for 20 years. He is currently the representative for South Asia with the UNODC, which is one of the co-sponsors of UNAIDS. Mr Lewis spent five years in South Africa as an international civil servant from 1999-2004.

Harm Reduction Techniques and Their Use in South Asia

The use of injecting drugs poses a great threat to civil society in the context of HIV. HIV/AIDS is prevalent in South Asia, and that prevalence is being driven to a significant extent by drug use. Particularly, injecting drug use presents one of the most efficient means of transmitting HIV and other blood borne viruses. The UNODC's objective in South Asia is to assist member states in their struggle against drugs, crime and terrorism in all their manifestations. One of the UNODC's biggest challenges lies in addressing the harmful prevalence of injecting drug use and the resultant proliferation of HIV.


MR. GARY LEWIS

Many of the methods for controlling the spread of HIV through injecting drug use are controversial; however, what works may not be popular, and what is popular may not work. Heroin is the most well-known of the injecting drugs manufactured and used in South Asia, but injecting pharmaceuticals are the source of the problem in much of South Asia including India, Bangladesh, Nepal, and Pakistan. These pharmaceuticals, formulated for legitimate medical purposes, are now manufactured for illicit sale and diverted to the drug trade.

The predominant misconception that injecting drug use is a problem concentrated largely in the North-Eastern states of India obscures the correlation between such drug use and HIV. HIV is most prevalent in the south of India, at the tip where there are three states that are heavily infected. The North-East, namely those three states that are bordering Myanmar, also suffers from high HIV prevalence, driven by the presence and prevalence of injecting drugs, including heroin. However, the latest epidemiological trends indicate that injecting drug use is present in all parts of India, including the rural areas, the major metropolitan areas, and subsidiary towns.

South Asia, as South Africa did, is experiencing generalisation of the epidemic outside the geographic areas with which it is conventionally associated. Historically, highly marginalised, highly stigmatised groups such as injecting drug users, female sex workers, and men who have sex with men have driven the spread of HIV. According to the Ministry of Health, the number of injecting drug users in India ranges from 90,000 to 190,000. However, according to the Ministry of Welfare and UNODC, which ran a survey three years ago, India has 1.2 million injecting drug users. Depending on which figure is employed, calculations yield vastly different results in terms of the percentage of the injecting drug using population who are provided with treatment by the government and civil society.

Given the objective of increasing the proportion of injecting drug users provided with care and service, the statistical prevalence of injecting drug use makes a big difference. The problem is less severe in Nepal, Bangladesh, and Pakistan in terms of absolute numbers, but these countries have relatively smaller populations and, thus, may have comparable problems in terms of per capita prevalence. Injecting drug use is a significant driver of the HIV epidemic; thus, the nature of the laws made in the context of injecting drug use and the way in which those laws are implemented are integral parts of the prospective solution.

The problem of HIV necessitates consideration of drug use outside the context of law enforcement, with an eye to controlling the epidemic from a public health perspective. Nations around the globe have ratified the international drug control conventions; there are three of these, and they are essentially of a prohibitionist nature. This is probably a good thing. However, it is important to bear in mind that certain approaches are not particularly facilitative of a public health perspective on the issue of HIV prevention. Within the existing provisions of the law, space must be made for public policy approaches to the problem; many such approaches have proven to be effective in reducing the spread of HIV while not promoting drug use.

Curing drug abuse entails a three-tiered approach. First, we must try to prevent onset of drug use. However, if prevention campaigns, school-based prevention, counselling, and the like do not prevent drug use, the next step involves prevention of injecting drug use. Providing early treatment for substance abuse, which is essentially a chronic, relapsing disorder, prevents users from adopting injecting drugs. If this fails, the third step is to treat the dangerous behaviours associated with injecting drugs first, thereby making injecting drug users safe for themselves while promoting a trajectory that ultimately leads towards abstinence. In that context, harm reduction is crucial.

Harm reduction is an approach which limits the negative consequences of certain behaviours, even though the underlying habits are not necessarily eliminated. The elimination of drug use and drug abuse is something one looks at in terms of the individual in the long-term. In the short-term, however, harm reduction services must be offered without judgment and without moralising. Moving injecting drug users away from street environments, in which paid sex and other factors further perpetuate the epidemic, and into a stable environment, can avert immediate harm and provide a foundation for the eventual elimination of addiction and dependency. Such harm reduction services have proven effective.

Harm reduction is based on the individual's right to help and the realisation that drug addiction is a disease, rather than on a theory of crime control. Regardless of which statistics one adopts regarding the percentage of injecting drug users receiving coverage, a problem clearly exists. Moreover, in addition to the quantity of services being provided, the quality of those services is of great import.

Oscar Fernandez, a champion in the struggle against HIV and AIDS in India, recently launched a study in Kolkata, and also helped to launch the current policy review on South Asian law as it relates to narcotics control and HIV. The study employed harm reduction interventions, largely comprised of needle- and syringe-exchange programmes. It also employed substitution of alternative drugs that are less harmful, in terms of the means by which they are administered, and that act in a manner that stabilises the user. A third approach involved the provision of information concerning safer sex and safer methods of administering drugs.

Provision of condoms, peer outreach and support, and the like, proved to be very useful. However, problems arise when the services are provided far from the user's home, when the counsellors are not trained, when the medication is not adequately monitored, and when the services themselves are not accessible. For example, in certain districts on the Myanmar border, harm reduction services are not available.

Syringe-exchange programmes seek to deter injecting drug users from sharing injecting equipment, thereby spreading blood borne viruses. These programmes operate against a backdrop of communal solidarity among injecting drug users in a particular location; an attitude of alignment against law enforcement agencies promotes camaraderie which manifests itself, in part, through the sharing of injecting equipment. The premise of the programme is that if one provides an individual with a clean needle and syringe for every injecting episode, or for at least a reasonable number of injecting episodes, that individual will not be inclined to share needles. This has proven useful in many countries, and is starting to show promise in South Asia as well. Unfortunately, in the context of individual outreach workers distributing needles, provision of these instruments can be construed as abatement to the drug using act and is punishable in all jurisdictions.

Further, the conspicuous presence of programme personnel in a particular area exposes potential beneficiaries of the programme to law enforcement. The "drop-in centre" approach combats this by utilising a very inconspicuous building, normally on the main street in any town or village. Generally, a television, a radio, some chairs, people and maybe equipment for some of the local games are present. The "drop-in centre" approach seeks to provide a place where users can feel safe, get treatment for abscesses, sexually transmitted infections and the like, and also pick up needles and syringes for sanitary administration of injecting drugs. In practice, if law enforcement personnel are brought on board, briefed on what is happening, and informed concerning the underlying theory, syringe-exchange programmes can function effectively.

Substitution of alternate drugs can be effective for an individual who wishes to quit injecting, but does not have the strength at the moment to do so. Such individuals can be provided with an oral substitute which, if administered in a clinically sound setting and in gradually decreasing doses, can do two things. First, the user stops injecting and thereby avoids a major health risk. Second, the tapered dose weans the user from dependence on the drug and sets the course for abstinence. Two drugs are used as substitutes in South Asia: methadone, which is used in Nepal, and buprenorphine, which is used in India, among other places. Buprenorphine deters heroin use by blocking the receptors responsible for the drug's psychoactive effect, rendering the administration of heroin or other opiates ineffective. The drug provides relief from withdrawal systems, but has a low incidence of addiction, which makes it preferable to methadone. Oral substitution drugs come in tablet form, and are crushed and placed in a paper envelope. The registered drug user receives a dose sublingually on a regular basis. The individual is then directly observed by a registered nurse or doctor for ten minutes to prevent them from spitting out and selling the drug. The initial dose is normally between four and eight milligrams, and is decreased over time. It generally takes about 9 months to complete the process.

Unfortunately, several problems exist. All countries in South Asia currently prohibit possession, consumption, and supply of drugs except where medically indicated, where the drug is needed to facilitate detoxification, where the drug is necessary to prevent the disability or death of a user, or where the drug is consumed by a specific category of person. However, legal regimes vary by region; thus, treatment options are often limited, despite the fact that both methadone and buprenorphine are on the WHO's essential medicines list. For example, methadone is a medical drug in the Maldives whilst buprenorphine is illegal; the reverse is true in Bangladesh. Treatment options tend to be dictated by legal controls rather than clinical outcomes.

Finally, regulatory mechanisms including licensing are not in place in many regions. Despite these obstacles, India has benefited from a number of efforts to make oral substitution therapy available, and these have been successful in large part.

Unfortunately, our review did not extend to Afghanistan, which has recently joined the South Asian Association for Regional Cooperation (SAARC). Of the seven SAARC member countries surveyed, the extant law, based on the international drug control conventions, failed to envisage the reality of the HIV epidemic. The laws in South Asia establish penal provisions relating to abatement, criminal conspiracy, common intention, attempt, and drug trafficking. Statutory provisions establish offences for possession, distribution, and supply of drugs, for the use and consumption of drugs, and for allowing one's premises to be utilised in the perpetration of one of the aforementioned offences. These laws seek to control drug use through punitive measures, but the harm reduction services are gravely insufficient; this is admitted by everyone, including the government.

The available data point to several means of curbing the use of injecting drugs and the HIV epidemic. First, harm reduction measures should be incorporated within the rubric of medical treatment. Secondly, statutory immunity should be extended to service providers acting in good faith. A similarly useful measure, albeit one necessitating substantial legal acrobatics, would require the legislature's enactment of an overriding clause that protects officially endorsed programmes from prosecution under drug control laws. Finally, efforts must be made to treat people whose main problem in life stems from their chemical dependency. Recent medical findings have shown drug use to be a chronic disorder, and a disease much like any other. Contrary to popular opinion, drug use often cannot be overcome by simple force of will, whether that will is directed toward bettering oneself or toward compliance with statutory prohibitions.

Question

It is all very well providing medical help to those who are able to accept it. What do you do, however, with a person who is unwilling to receive this treatment and support?

Answer

This situation arises in many families, where the person affected is violent and unwilling to seek treatment. I do not think there is any one recipe for success. I use the metaphor from time to time of an individual walking along the side of a deep lake. There is a sign at the side of the lake saying do not swim, dangerous water. The person plunges in. The person swims out, ignoring all the advice and gets into difficulty. A passer-by comes. What, according to our code of moral and ethical demands ought that passer-by do? Ought the passer-by to stand at the side of the lake and say "the fool has gone in, let him drown"; or ought the passer-by say "I'm human, I must extend some form of dignity and respect to my fellow human"?

If the person does not want the help, the question becomes what the state does and what the individual does. I know what, as an individual, I would do. The question for public policy is what the state must do and I cannot answer that.

Question

This syringe-exchange programme could be seen as an abatement of crime. What statistical evidence do you have for its effectiveness? There should be some evidence, not just a feeling that it actually reduces risky behaviour. Does syringe-exchange ultimately lead to giving up the drugs, or does it facilitate that behaviour?

Answer

That response is a common, intuitive response. Were I not immersed in this problem every single day, seeing the misery of drug addiction and other forms of crime, I would no doubt be thinking the same thing. Supply creates its own demand, and if you give the supply, would you not expect demand to rise?

We do try to be evidenced-based in our work. We do not just run around saying things without the sound weight of what we believe is scientific evidence. As it turns out, counter intuitively, the demand does not rise because of what you are dealing with here. In the case of individuals who are benefiting from oral substitution therapy, their frame of reference is just getting the next hit and their circle of friends tends to be other users. They are not running around looking for people to inject drugs. Most people do not wake up in the morning and say I think I will start injecting heroin today. It is a gradual process. It is an evolution, through which the individual descends into some of the lowest abysses we can imagine.

It has been conclusively shown that the provision of safe injecting equipment has not led to an increase in injecting drug use behaviour. Similarly, the provision of oral substitutes, such as using methadone or buprenorphine, has not led to an increase in drug use. This is not only the case in countries where these programmes have been around for a long time such as Australia, Switzerland and other parts of the so-called developed world, but in India as well we have been running our own demonstration sites and pilot projects over the past year and a half, in five clinically-controlled settings. What we have found so far is that the provision of these two options, syringe-exchange and oral substitution, as part of the overall comprehensive package, has reduced drug taking and has led to health promoting behaviour. It makes the individual more functional within the family. It has reduced the crime rate.

Question

From your vast experience in this part of the world, please tell us what the major causes of people falling prey to drugs are?

Answer

This is not a small question. The reasons why predominately young people fall prey to substance abuse is common in every country in which I have lived, including my own island in the Caribbean. Those reasons come primarily from the search that we all have as human beings for recognition and some sense of dignity and worth, especially at a vulnerable and testy age of teenage-hood, where peer pressure becomes the primary factor with which kids have to contend.

For most teenagers, their long term vision is very limited. They want to be recognised for their sporting, academic or "cool" prowess. Added to that are other ancillary factors, such as the availability of drugs. Supply can create its own demand in many respects. In addition, you have depression and boredom. The kids need to feel like an adult. They need to impress their peers, a flip side of peer pressure, and many of those aspects are associated with an unsound family life.

In drug control, there are many predictive factors that do not necessarily guarantee a person is prone to substance abuse, but that if you see enough of those factors lining up, you would say there is a high risk here. One interesting dimension, which I think I can say on the basis of evidence that has mounted up over the last seven or eight years, is that there now seems to be some clinical evidence suggesting certain people are genetically disposed to become more addicted to substances than others. I do not want to put it more strongly than that. I think the major aspect is the environmental, the socio-cultural aspect in which teenage hormones rage quite ferociously, and make the kids available, susceptible and vulnerable to drug addiction.

Mr. Oscar Fernandes, MP, Minister of State for Labour and Employment

Role of Parliamentarians

When Parliament was unable to bring Members of Parliament together to fight the menace of HIV and AIDS in our country, about 4,000 students and youth from all over the country gathered in Talkatora Stadium and had a mock session of Parliament. They passed a piece of legislation and gave it to us Parliamentarians saying, if you elders cannot pass a piece of legislation, here is one, give it out straight away. This showed the youth of the country feel there is a need for legislation in the country specifically on HIV/AIDS.


MR. OSCAR FERNANDES

The greatest problem we will face when passing the legislation, and the judiciary will face when dealing with it, is that natural law decides what is good and bad, what is right and what is wrong. When it comes to this particular disease, however, a new element has to be added, an element of compassion will have to be taken into consideration.

For example, a driver drives too fast, he knocks someone down and kills them. He has to, and will, be punished. The question is, however, whether we can do something to see that the driver does not drive too fast in the first place. Can we work out a system in our country to see that the driver takes children to school properly, and brings them back safely.

When we legislate on HIV/AIDS, there is an element of compassion which comes into it. I was in the deep interior of a tribal state to which I had gone for campaigning. I was sitting at the house of a legislator, and I opened a photo album and saw a couple of pictures of the tribal people there. My attention was drawn to a particular photograph, where a very elderly woman, around 90 years old, was standing outside the house and a young girl of about 21 was sitting. I found it peculiar, and I asked them what the reason was for the elderly lady standing, whilst the young girl was sitting down. He told me, yes, what you say is a tragedy. This young girl's grandmother sent her to Delhi to study, with a great hope. Now the grandmother has to look after this girl. She has come back with AIDS and is not even able to stand, so she is sitting down. The grandmother who needs to be looked after has to take care of this child.

A similar feeling arose in me when I saw a photograph of a child crying near the dead body of the mother, and the news item said that the father of the child had died of AIDS, that the mother also had AIDS and that there was nobody for the child. The child was weeping and it was discovered that the child was also HIV positive.

You will have read the news reports about the children affected by HIV/AIDS not being admitted to school in Kerala. There was a big protest. The teacher said you cannot admit children who are HIV positive to our school. The parents protested as well. Government stood its ground and said the school had to admit the affected children. Other children started leaving the school, so there were fewer children and some of the teachers had no work and so had to go. Eventually, only the HIV/AIDS affected children remained at the school. How do you deal with this situation?

We have a warning that our number in India of people living with HIV/AIDS is increasing. We can take some comfort in the fact that we have not yet passed the danger mark, but should we not take measures to stop the spread of the disease before we do? We used to blame the truck drivers and other high risk groups, but today the disease is moving into the general population.

I speak to children and students of today, and they admit to pre-marital sex and I think the numbers are quite large. How can we protect our children from the spread of HIV and AIDS?

As Members of Parliament, we have certain responsibilities to see that the disease does not spread any further. So people ask us how much we know about HIV and AIDS. How many Members of Parliament know about the epidemic? The media has come to the conclusion that not many Members of Parliament know very much about HIV/AIDS. That is the precise reason we formed the Parliamentary Forum on HIV/AIDS, because we do not know. We need to learn, we need to be told, and then we are supposed to act. We are elected representatives – if we do not talk to our constituents about this, who will?

One afternoon, a handsome looking young man came to my house. It was about 3 o'clock, and I was still in the office. I asked him why he had not come to my office and he said, "Sir, I don't want to come to your office." I asked him why and he said, "Sir, I cannot come to your office," so I asked him what his trouble was. He told me that he was affected by HIV/AIDS. He was the son of a judge, whose parents had thrown him out. We think that the problem does not affect us, that we are insolated against it, but it affects everyone, so we must take the message to the masses. Within families, we have to talk about the issue.

I do not think we will be able to control the spread of disease by legislation alone. Awareness is essential, and that awareness can come through different mediums, different government bodies. One judgment can open the eyes of many people. I am very happy that the highest judicial officials sitting at this Colloquium can deliberate on and advise us about how to formulate the legislation.

Question

The question of disability is not defined or addressed in this draft HIV Bill. Is this something which you are able to address?

Answer

Yes, definitely. If there is something lacking, on which the judiciary with its experience can guide us, we would be happy to incorporate such points.

Question

This Bill is undoubtedly comprehensive. I do not see that the issue of discrimination in e.g. employment is dealt with however. Is this something which can be addressed?

Answer

Certainly, if there is discrimination it needs to be addressed. We have to protect both people who are already employed from being fired if they become affected by HIV/AIDS, and those who are prospective employees.

Question

What about social protection for people who have to leave their employment because they develop AIDS and are unable to perform their duties?

Answer

We have looked into whether we can provide such people with some sort of insurance cover. I have had a meeting with the Life Insurance Corporation of India about whether they can charge a reasonable premium for HIV/AIDS risk, through which we can provide coverage for such people.

Question

What about someone who was in the Army but had to leave because he had AIDS. The Army would have discharged him quite rightly and, in my view, a welfare state needs to do more than merely provide this man with insurance cover.

Answer

The first aspect of this is whether the man is able to provide services, or whether he is disabled due to suffering from AIDS. If the man is able to work, albeit not in a combat zone, he could be provided with alternative service in the Army.

Question

The Army's rules are that it will not permit any type of service for people suffering from AIDS, as opposed to people who are HIV positive. We must also think of those people who are unable to work at all because of AIDS.

Answer

I will discuss this aspect of the Bill with the Defence Ministry. They also have civilians in their service, so perhaps such people could be shifted to the civilian service. I will take that as a suggestion from this group.

Question

If you look at section 2(d) of the draft Bill, the term "children affected by HIV/AIDS" means "persons below the age of 18 years who are HIV positive, or have a parent or guardian who is HIV positive, or have lost a parent or guardian to AIDS or live in households fostering children orphaned by AIDS." Does this include a foetus?

Answer

This is something on which we will need to consult and take proper advice.

Question

Should the Bill place an emphasis on prevention rather than cure? Should the Bill provide for compensation to be provided to someone who has been infected with HIV through no fault of their own and through the fault of another person? If someone contracts the virus through a blood transfusion, there is redress available against the doctor and the hospital. But what about someone who negligently causes their sexual partner to become infected?

Answer

There is the possibility that a penal provision could be inserted into the Bill.

Question

Section 4(1) provides that:

"No person shall be subject to discrimination in any form by the State or any other person in relation to any sphere of public activity including:

(a) Denial of, or termination from, employment or occupation unless in the case of termination:

(i) a person who is otherwise qualified, in the written assessment of an independent healthcare provider qualified to make such an assessment, poses a significant risk of transmission of HIV to other persons in the workplace, or is unfit to fulfill the duties of the job..."

Is this point not redundant, given that HIV can be transmitted only through the exchange of bodily fluids? It is not contagious or infectious like other diseases which might be spread in the workplace.

Answer

I agree that this will not be used very often but for certain specific employments, where there is a risk of blood being exchanged for example, it has been retained.

Mr. Ashok Row Kavi, Humsafar Trust

First, I would like to look at why the issue of HIV/AIDS is a stand alone issue, requiring its own programme in this country. There are, for example, efforts to integrate it into the reproductive and child health programme, RCH. There are also efforts to integrate it into the national rural health mission. Many of us, however, disagree with this approach.

MR. ASHOK ROW KAVI

The reproductive and child health programme has been integrated into the public health sector in a very systematic way. The same is true of the malaria and TB programmes. They have, in many ways, been very successful in reducing child and maternal mortality. Malaria has practically been eliminated, and India's success story on TB is well known. The core of each of these programmes, is their client populations, these are cherished populations such as reproductive couples, children, mothers. You do not, for example, find health programmes for menopausal women of this country.

If you look at the HIV/AIDS programmes, after ten years of the National AIDS Control Programme, which is now going into phase three, three client populations have been identified. These are the core groups on whom we have epidemiological information showing a very high HIV prevalence. One is sex workers, both male and female. The second is intravenous drug users, and the third is MSM.

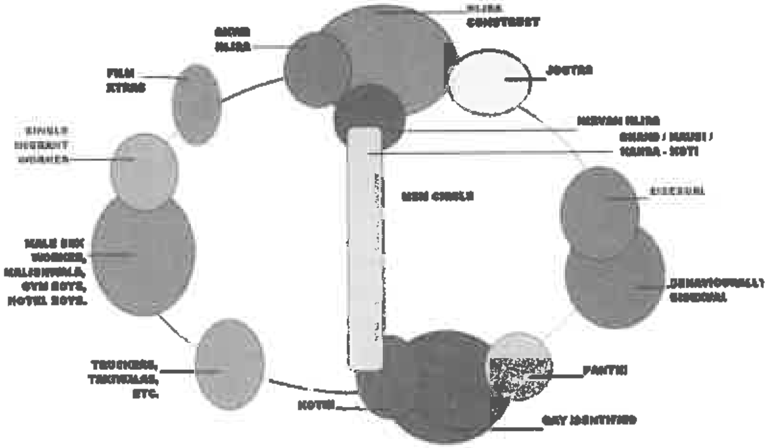
I remember being present at the International AIDS Conference in Montreal in 1989, and an official from the Indian Ministry of Health said we had no homosexuals in India. So I stood up, and said I happen to be one. The official asked who had let me out of the country. It has taken us ten years to recognise and understand that there are same sex behaviours in men, and women, in this country and that it affects a significantly large section of the population.

The official estimates of MSM in India is higher than the number of women involved in commercial sex work. Reaching out to these populations is extremely difficult, they are invisible populations. It is not easy to find commercial sex workers who are not based in a brothel. It is not easy to find IDUs and it is certainly not easy to find MSMs in this country. These populations are highly stigmatised, socially marginalised groups.

These populations do not fall into any government programme. Reaching out to them is going to be a real problem. This is why the National AIDS Control Programme is a stand alone programme and, I believe, must remain so.

I have been involved in the mobilisation of homosexuals in this country, and an activist in the gay movement. I am also the convener of the Indian Network for Sexual Minorities. Every time we went to NACO, they would say to me I was the only man shouting and fighting for homosexual rights and that they did not see them where they were working. In the whole of Goa, for example, there were supposed to be only 90 MSMs. We know that sex tourism is rampant on the beaches of Goa, so a central survey was carried out in Goa, showing that 20% of the community is men who have sex with men.

In this diagram, the large bubble in the middle represents men who have sex with men:



Prepared by:
THE HUMSAFAR TRUST

All the groups shown at the top are those whose identity is based on gender. These groups are very visible, but they are also highly marginalised, such as hijras. Even within the hijra group, there are further sub-groups. 80% of hijras are not castrated, but men who cross dress. They live in hierarchical social religious groups, with a guru and chelas under him. They live a very marginalised life, and are socially unwanted. They often end up begging on the streets. Despite the process being suppressed, boy children are dedicated in temples, just as girls are dedicated. As the tradition is being suppressed; yet there are still large numbers of men in the temples, many of them are finding themselves doing sex work in the cities. In Mumbai there are supposedly 90,000 hijras on the street. The old traditional occupations are gone, however, and most of them are now in prostitution.

At the bottom are those groups whose identity is based on behaviour. These include homosexual people, divided again into receiver and penetrator. The men who receive are quite effeminate, called kothis, which is an Indian construction of sexuality. Their lovers are called panthis. There are also the gay identified men, which is quite a western concept coming into India.

On the left of the diagram are shown the groups of men having sex with men who are vulnerable because of their work place situation, such as cleaners, masseurs, film extras in Mumbai and Kolkata. The groups on the right are behaviorally bi-sexual men. These are men who, when congregating in large numbers, do have a tendency to have sex with each other when women are not around.

This shows the reason why the only way you can reach out to these populations is through the community-based groups formed by these populations.

The National AIDS Control Organisation is working with populations who are not wanted by society. That is why it is a stand alone programme. NACO in turn has to work with more than 5,000 NGOs, which are not solely community-based. It is only by working with these groups that NACO is able to reach out to these populations.

Question

Would a rereading of section 377 help prevent the spread of HIV/AIDS?

Answer

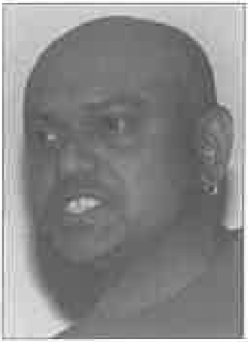
We may want to say that sex between consenting adults is not something within the state's parameter of interference. I accept that private acts are not necessarily consensual. That rereading would have to be done, however, by the judiciary or the legislature, and not by the victims of the law. All we can do is plead with the judiciary and the legislature to do it.

I refuse to believe that as a homosexual I am an unnatural human being. I am subject to all the human feelings which are shared by the rest of humanity. I do not have two horns, and I cannot accept the fact that such a large section of the population should be labelled as "unnatural." The Kinsey Report, one of the oldest sexual reports, found nearly 37% of American males were frequently or mostly having sex with their own sex. That is a huge number. In India, the statistic may be even higher, because of the lack of access to the opposite sex.

It is high time to go beyond what is natural and unnatural, and to talk about human dignity.

Mr. Rahul Singh, NAZ Foundation

Section 377 of the Indian Penal Code criminalises homosexuality activity. This section affects all sexual minorities. Not long ago, a man came into our organisation, and he was on the verge of a nervous breakdown, having been receiving "treatment" from a government hospital for his homosexuality. We approached the National Human Rights Commission about taking up his case, and they told us they could not take it up because gay rights are not human rights, as a result of Section 377.


MR. RAHUL SINGH

In Lucknow, an organisation working with MSM had its offices raided. The officials of the organisation were booked under Section 377 for aiding and abetting a crime.

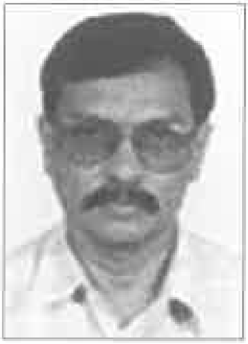
In this context, the NAZ Foundation, with the consent of all organisations in India working on gay rights, filed a case in the Delhi High Court to read down Section 377 of the India Penal Code. We did not ask for the repeal of Section 377, because it is also used in child sexual abuse cases. We simply asked that it be read so as to exclude consensual sexual activity between adults in private from the definition of criminal activity.

I ask therefore that the plight of sexual minorities in India be considered with open and progressive attitudes.

Dr. Smarajit Jana, National Aids Control Organisation

A strong commitment at the highest level is very important in the fight for prevention of HIV. We have therefore, designed a robust national programme, which is led by the Prime Minister of the country.

85% of the new infections in this country are through sexual intercourse. Sex workers are, therefore, an important constituent of the HIV prevention programme. We look particularly at female sex workers, and our target is to reach them as quickly as possible with access to services, thus creating a supportive environment, so the ability of that core group to negotiate effectively for safer sex practices is strengthened.



DR. SMARAJIT JANA

Ultimately, every sex act can be a protected sex act, preventing spread of the infection from one person to another. Women who work in the sex trade and have multiple sex partners are more vulnerable to the spread of infection, so I will focus on the issue of vulnerability and how that vulnerability can be addressed, particularly the national and international evidence of what makes programmes successful.

Global experience suggests the best programmes are those based on peer-to-peer outreach, where someone from the key population is trained to become a health educator who can reach the rest of the key population, which is largely invisible in most circumstances. With NACP II, we came up with the concept of creating an enabling environment so we could reach the key populations.

An often cited example is that of the Sonagachi Project in Kolkata. The programme was started in 1992 when there was one percent condom use. Over the period to 2005, we have data which shows there is significant increase in condom use – from hardly 1-2% to 96%. This was done through peer educators trained and oriented to do the job. They were provided with lots of support systems, including education for themselves, their children. developing micro credit and financial support to help address their day-to-day needs. Similarly, the rate of sexually transmitted infections, which had begun at around 25%, was brought down to 8.7%. The HIV rate has remained stable at 5-6%, whereas in other comparable populations, it has risen to 30-35%, or even higher.

The peer workers then expanded the programme to cover a further 26 areas, this was before they received any support from outside sources. It became apparent that the problems were not just lack of information or availability of condoms, but went much deeper than that. The social attitudes to sex and sexuality put sex workers at the mercy of unethical practices and make them unable to negotiate safe sex. There are numerous examples of the police and other administrations harassing sex workers, evicting them, and torturing them.

When President Bush sits with the president of Afghanistan, is it information, is it negotiation skills that will determine the outcome of the negotiations, or is it the power situation between the two that will determine the outcome of the negotiation? What holds true in that situation, is the same for all negotiations, including those between sex workers and their clients, sex workers and their landlords, sex workers and the police. So, the programme must seek to empower the sex workers.

In Sonagachi, they have created a self-regulatory board with committee members made up of local lawyers, social welfare representatives, medical doctors etc. The committee members and sex workers organise it, and they have been successful in controlling the entry of minors into the sex trade, as well as drastically restricting trafficking.

All of these efforts to empower people engaged in the sex trade mean they are more likely to be able negotiate for condom use by their clients, thereby preventing the transmission of the HIV virus from client to sex worker or vice versa.

This way of working with marginalised and stigmatised groups so they are seen as agents of change, rather than just recipients of services, has been used successfully in other countries such as Bangladesh, Thailand and Brazil. Similar success has been seen in Australia and New Zealand, where they have moved to a decriminalised status for commercial sex workers.

There is currently much debate in India about the changes being made to the Immoral Trafficking Prevention Act. The proposed changes have been laid before Parliament, and they are now being considered by the Parliamentarians. Parliamentarians are considering whether we can include clauses which will criminalise the clients of commercial sex workers, but not make soliciting a criminal offence. My view is this would make the commercial sex workers even more vulnerable – you are still criminalising the activity.

They will go further underground and our people and interventions will not be able to access them or their clients. This will make the situation explosive and dangerous.

Question

Prostitutes have a right to livelihood, but they do not have the right to spread HIV/AIDS. Can there be a reasonable restriction imposed on them, such as disclosure? What is legally possible, given their high risk group status?

Answer

We have found the best way of respecting commercial sex workers' right to livelihood at the same time as protecting them from spread of HIV infection is to provide them with access to free services, including voluntary counselling and testing. This means they are in contact with a treatment centre and has made good progress towards bringing down the prevalence rate, not just in West Bengal, but in states such as Tamil Nadu and Andhra Pradesh. Our approach is therefore to encourage the commercial sex workers to come in to access those services, and to get them into contact with the ART centres, and the positive networks, so they can explore different livelihood options.

Comment

An approach which might be taken vis-à-vis the criminal law is that the intention behind actions is relevant. The intention to reduce the spread of HIV/AIDS is very different from the intention to aid or abet the commercial sex industry.

Dr. Denis Broun, UNAIDS Country Coordinator, India

Patents

Patent is a French word meaning a royal privilege, which privilege was exclusivity. Originally, it was not necessarily exclusivity for an invention, it could be for a commercial route, or becoming exclusive supplier to the king.

DR. DENIS BROUN

Patent law was invented in Venice in the 16th century, and included the compulsory disclosure of inventions to the public, so the inventor might be recognised as such. At that time, it was not so much for the financial privilege of being the inventor that it was important, but it was a form of protection against being accused of witchcraft and getting burnt alive. So people had to ask for patents when they invented something, otherwise it was considered they had dark intentions for it.

We can see, therefore, that the concept has evolved a lot. When we speak of patents today, we speak of patents which reward innovative things which are possible to reproduce and which can be used industrially.

Anti-retroviral treatment started in India just three years ago. This is later than many other countries. As of today, 127 ART centres treat 70,000 people. Anti-retrovirals are also provided in private hospitals, whether for-profit or not-for-profit, and India has several large NGOs which provide treatment to patients. A quick survey, we took among pharmaceutical companies suggests, perhaps 35,000 patients are covered this way. In addition, anti-retroviral drugs are sold in pharmacies all over the country to roughly 22,000 people.

Many of these drugs are sold individually, but the official treatment guidelines from NACO are for a combination of three drugs. So you find drugs which are sold singly in the pharmacies, but they should be combined with other drugs, according to the NACO guidelines. Unfortunately, we know that there are patients in the private sector who buy only one single drug, and are not treated properly.

The Indian government covers access to first line drugs. These correspond to a combination of three products, and NACO has two such combinations. One is for people who have TB in association with HIV, and one for people that do not have TB in association with HIV. Many patients who take this product will eventually become resistant to it. It is like an antibiotic that people take for a very long time. After some time, the virus mutates and becomes resistant to some of the drugs and about 5% of patients become resistant to first line treatment. This proportion increases if people do not have access to regular treatment, if people do not comply with their prescription instructions, if people under-dose, or temporarily stop from time to time because of the treatment's side effects.

When someone becomes resistant to first line drugs, they need to be treated with second line drugs. For the time being, NACO does not cover the cost of second line drugs, only first line drugs. As of today, therefore, second line drugs are sold only in the private sector.

The difference between India and most other countries dealing with the HIV/AIDS epidemic is that many of the generic drugs are manufactured here in India. Currently there are at least ten manufacturers of anti-retrovirals, and new ones come along quite frequently. Five manufacturers are pre-qualified by the WHO and those five supply about one half of the world's generic anti-retrovirals.

In total, the WHO has pre-qualified 158 drugs of different types, combinations etc., and more than half of them are manufactured in India. The products manufactured in India are of good quality. Most of the first line drugs which have been pre-qualified by the WHO have also been approved by the Food and Drug Agency in the United States for PEPFAR procurement. PEPFAR is a US Presidential initiative in the fight against AIDS. Some second line drugs have also been qualified for procurement by PEPFAR.

First line ARV drugs are now generally off-patent because they were invented long ago and are now available as generics. There are several second line products off patent in India, which can be manufactured as generics. These second line products are not purchased by the Indian government as yet. The Indian government has announced that once one lakh people are on first line treatment, second line treatment will be made available.

Retail prices in India are higher than in most of the export markets. This is because of the structure of the market here in India. Drug companies have to add to their production price excise duties and VAT, which means the drugs when sold retail here are more expensive than when sold retail in Africa.

Most first line products are off patent, but it is not as simple as saying "one product, one patent." A product can be off patent in its originally invented form, but additional patents can be accrued. For example, Efarivenz is off patent as far as the invented product itself is concerned. The mechanism to manufacture it in crystallised form is still under patent, which patent has been granted in India. When ARV products were first developed, positive people were having to take 50-55 pills a day, because there were so many products. They have now been put together in fixed dose combinations, as happened with tuberculosis, and the method of combination was patented. So you can have products which individually are off patent, but in combination are under patent in several countries.

In the Patents Act 1970, as amended by the Patents (Amendments) Act 2005, we have a mechanism specific to India which is not found in many other countries. This is the pre-grant opposition. When a company or an inventor wants to acquire a patent, they must open a file for it and people who think the patent should not be awarded have the right to bring opposition before the patent is awarded, i.e. pre-grant opposition. In most other countries one can normally only sue once the patent has been awarded. This mechanism has been extremely useful, especially at a period when the law is still young, and has allowed very healthy debates on how to interpret many aspects of the law, without patents having been granted which would have created exclusivities disputed after the fact.

Certain groups have specialised in bringing pre-grant opposition cases, Lawyers Collective has been important in this regard. A famous case was that of Combivere. Combivere is a combination of three drugs, each of which is out of patent. The combination itself is made by Glaxo-Smith Klein and the patent application was brought to the Kolkata patent office. Lawyers Collective strongly attacked the application because the combination was already available in India through several manufacturers. Glaxo-Smith Klein withdrew their application, so ultimately there was no fight over the intellectual property rights.

Another example of pre-grant opposition is Tenofovir, one of the most important second line drugs - it has even become a first line drug in the United States. It is a good drug which is well tolerated. The drug manufacturer, has made a patent application, which is being contested on two grounds. The first is that the product was known about before 1995, so before the period for which patents can apply in India. The second ground is that the step taken by the drug manufactures to develop Tenofovir was an obvious step (which would not be protected by patent law) rather than an innovative step (which can be protected by patent law).

Recently, the Indian patent office has awarded a patent for Efarivenz. This one took some of the activists by surprise, so they are filing a post-grant opposition within one year, as is permitted by law. One of the big questions to arise is the interpretation of the legislation and its compliance with the Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS).

When a pharmaceutical company carries out clinical trials, it amasses a large amount of data. This data is supposed to be public, or was until some years ago in most countries, and formed part of the patent application. That meant when a generic manufacturer wanted to start making the drug, the clinical trials did not have to be redone. Data exclusivity means the data would remain the property of the inventor, and the generic manufacturer would have to conduct clinical trials again, delaying the arrival of generics, by a couple of years usually. Data exclusivity is not part of the Indian patent law. There is however a strong movement from companies, Indian and foreign companies, to include data exclusivity in the patent law. This is of course being disputed.

There is an important Novartis claim under Section 3(d) of the patent law. Section 3(d) is one of the most liberal aspects of the Indian patent law, it provides that when a drug is already known, modification, especially a slight or obvious modification, of that drug cannot be patented. It was on this ground that the patent for Novartis' drug, Glivec, was refused. Novartis appealed the decision, and also brought a case challenging the Indian patent law's compatibility with the TRIPS Agreement. [The Tamil Nadu High Court recently rejected Novartis' claim].

In the view of civil society, Indian patent law has some shortcomings. One is that the compulsory licence is so difficult to obtain. There is no real deadline for the grant of a compulsory license, so the whole process can run for a very long time. Rights of appeal against compulsory licences are broad and the imposition of a compulsory licence has to be considered by the Indian Cabinet – unlike countries such as Thailand where the decision to issue a compulsory licence can be taken by a ministry department.

Where do we see the future? Most probably the big intellectual property battles underway are not going to be won by the large manufacture companies, rather the generic manufactures will probably get their way. However, the next drugs to be developed for treatment will be fully protected by patent. We have two new families of drugs which will be the anti-AIDS drugs of tomorrow, and they will be completely patented.

India has never had to negotiate on patent rights, because it has the capacity to manufacture generics. Brazil had to do a lot of negotiation, and India will have to be ready to use the compulsory licence. Whatever happens, India will remain a large-scale producer of generic drugs.

Question

At the international level, have any steps been taken to prevent unreasonable pricing of drugs, irrespective of the patent processes etc?

Answer

Intellectual property rights and price negotiations are really two different issues - some countries have been able to grant patents and get low prices whereas others are granting patents and getting high prices for the same product. It depends on the country's capacity to negotiate. There are some mechanisms for worldwide negotiations, such as UNITAID which is funded by a levy on airplane tickets. Where there is a global negotiation with manufacturers in the name of poor countries, the global fund can promise manufacturers very large orders, so they can obtain very good prices. But this is not a mechanism to protect against high price. It is just a mechanism allowing access to lower prices in certain contexts, usually government tenders.

Question

Is there any instance of state exercise of sovereign power to acquire an invention? In the context of the TRIPS Agreement, is there any place in the world where this has been tried, the nationalisation of an invention?

Answer

I think the patent law of each country includes a provision that patents can be refused on grounds of national security or public health, so for a lot of reasons patents can be refused, or compulsory licenses granted. When a compulsory licence is granted, in a sense the government is buying the patent because there will always be monetary compensation for the manufacturer. Thailand, Brazil, Indonesia, Malaysia and Mozambique have all exercised their right to grant compulsory licences for HIV/AIDS drugs.

Recently, the World Bank and one of its partners have come up with a system for vaccines, where they have created a kitty of about a billion dollars. There are terms of reference for the development of a vaccine. The first company to fulfill those terms will receive the funds in the kitty, and the invention will belong to the world.

Question

Can you tell us a little bit about the recent Brazilian governments decision please?

Answer

The Brazilian government had thus far decided to negotiate with patent holders to reduce prices, but the reduction of prices they were obtaining was not satisfactory. They therefore took steps to have a compulsory license granted instead, something which is being used more and more. The Brazilians were very patient during the negotiations before arriving at the point of granting compulsory licences.

In November last year, in Thailand, there was a conscious decision to what I would call shoot first, and negotiate later. They issued a compulsory licence immediately, then went to the manufacturers and said if you want us to withdraw our compulsory license, you better negotiate. There are two strategies there, and the Brazilians are coming close to what the Thai government did. This suggests the large drug manufacturing companies were not highly motivated to negotiate.

Question

You mentioned that we manufactured the generic drugs in India, and we export them to Africa. India is a big exporter of these drugs, and yet in India, the prices are much higher than the international prices. One, why is that and, two, why is compulsory licensing so difficult in this country?

Answer

For the pricing it is clear, it is VAT and excise duty that makes the difference in price. Discussions to remove excise duty for ARV drugs are still underway. As far as compulsory licences are concerned, India never arrived at the point of compulsory licensing because generic manufacturers were manufacturing very high quality copies. If we have new products which come with very good patent protection and high prices, then the question of negotiation and compulsory licensing will come up, but it is too early as yet.

Ms. Yashashri Gurjar, Chief General Manager, Ballapur Industries

Industries need to respond to the HIV/AIDS crisis because we employ a large number of people, directly and at secondary and tertiary levels. A lot of families depend on industrial labor and HIV, as you know, is a silent killer. It has a long incubation period, may not be visible for years to come, and the cost of losing skilled man power for companies is very high. The cost of losing unskilled man power for companies is also very high, because when a person is doing even an unskilled job for a period of time, he gets better at doing it. Losing him means training someone new to perform the unskilled labour. It has also been proved that for industries, the cost of prevention, cure, where possible, and treatment is much lower than the cost of losing manpower. It is therefore in the interests of industry to look at prevention as a big issue.


MS. YASHASHRI GURJAR

In the absence of any legal provisions, it is important for industries to make their stand clear about how they are going to deal with HIV/AIDS issues, and what their perspective is on the rights of people living with HIV/AIDS.

Ballapur is the largest manufacture of paper and pulp in the country and has its locations largely in very remote areas, next to forests. We are faced with the problem of being in areas which do not have a lot of facilities available to people. We are very active on corporate social responsibility, which is the department I lead in the company.

We felt that HIV/AIDS intervention was necessary for us because we operate in remote areas. Some of our units are in the high prevalence states such as Maharashtra and Andhra Pradesh. Much of our workforce is casual and contract labour. They come without families and are therefore considered to be at a higher risk than other groups. We have more than ten thousand truck drivers going in and out of the factory in a year and, in a sense, our responsibility extends also to them.

We ran a pilot scheme in our units and found that overall awareness of HIV/AIDS as an issue was very low, so we considered it urgent to take this issue up in the workplace. The first thing we did was to institute a workplace policy. As there was no law in place, the company needed to outline what it meant when it said it would deal with the issue of HIV/AIDS. One of the key elements of the policy is that we have committed to not screening people for HIV. We will not discriminate against employees for advancement in employment due to their real or perceived HIV status. Another key component of the policy is that we will provide HIV awareness training. We have also committed to supporting voluntary testing for people.

We have committed to providing appropriate care and support to employees living with HIV/AIDS, something which distinguishes us from most other companies in the country. Any employee who has tested positive and who requires treatment, care and support, even to the extent of requiring reasonable accommodation in his job, will be provided with such by the company as a compassionate issue, and we will revisit the policy periodically.

These are the overall policy components. How did we put this policy into action? When we say there will be no screening for the purposes of HIV testing and exclusion from employment, that does not mean we are not creating awareness among the company, or that we are ignoring the issue. What we are saying is that we are going to tell our people that if they consider themselves to be high risk, they should voluntarily get themselves tested. We will not force it on them, but we do advise them it is in their own interests to know whether or not they are positive.

Our programme has now been in operation for two years. We have found so far only 100 people have been willing to get themselves voluntarily tested. We believe this is a start though, and that as long as we can remove the stigma and discrimination associated with HIV/AIDS at the workplace, more and more people will follow suit.

What we mean by saying we will not discriminate on the basis of HIV positive status is that a person's positive status will not be disclosed to anybody else, unless the person consents. We will make reasonable accommodation. We have done so in the case of two employees so far, in order for them to be able to perform their duties.

As a brief case study, we have a 32-year old employee who tested positive. His family refused to acknowledge this fact. He is presently receiving treatment for tuberculosis. We have a counsellor at each of our units to support health and HIV intervention programmes, and the employee was provided with emotional and psychological support by the relevant counsellor. The counsellor's cases are kept confidential, even from doctors if no medical treatment is required at that time. In this case, all necessary work related adjustments have been made, for example this person works only general shifts, he does not do any night shifts because he needs to take more rest to be able to recuperate from the shifts. He is already on tuberculosis treatment, so we do not put him on any nightshifts.

Through our prevention programmes, we have been able to reach out to 22,000 employees, communities, their families and truckers in the last two years. It is not just about conducting awareness programmes and moving on. It is also visiting them again and seeing that the awareness programme has caused some behavioural modification. Behavioural modification is more easily said than done, and it needs more consistent follow up work. We do all this quality programming through trained employee-volunteers.

One of the issues the company faced was building time into the work schedule to talk about HIV/AIDS with the employees. We could not expect an employee to give up his Saturday to talk about HIV/AIDS issues. His spare time and time with family is equally precious. So we have allowed for employees to take two hours out a week to do peer education.

Condom vending machines have been installed. Truckers' clinics have been set up, and provide HIV/AIDS testing. HIV/AIDS cannot just be a project. It has to be part of the entire process of the company, the way it exists and the way it functions. Every new employee who comes in is provided with awareness materials about HIV, our policy on HIV, and how we deal with HIV. This happens for all employees, whether they come in at a senior level or the most junior level. It has been institutionalised in such a way that it becomes part of the business agenda, rather than remaining merely an external project.

We have nine people living with HIV/AIDS in the company which, out of a total of 6,000 employees is not that significant a number. We work with our HIV positive people and their families to include holistic living as part of the treatment programme.

We also work with NACO on establishing anti-retroviral treatment centres. We have committed to 2 or 3 centres, the first of which is being set up in Chandrapur, Maharashtra – a high prevalence state.

One of the key things we have learnt is that you need the involvement of the top management. Without that, you cannot run these kinds of programmes. Simply having a policy in place without the meaningful support of the management is like saying there is a law but it will not be implemented. Even if the policy is signed by the chairman, the implementation of that policy is in its spirit, which has to be top-down. There are all kinds of misconceptions about why we should be responding to HIV/AIDS in the first place and spending money on these programmes, so the management has to be sensitised to these issues. Once you get their support and commitment, the rest of it flows very easily.

You also need buy-in from employees, because they themselves create the atmosphere when a follow-employee stands up and says "I am HIV positive." That atmosphere has to be developed, and that is why so far only 100 people have voluntarily been tested. We are still a long way from creating that atmosphere in the company, where people would want to disclose their status to fellow employees.

Another important factor is the participation of the unions in this whole process. If the unions are not a part of this, things like making reasonable accommodation for employees gets questioned, and can become very controversial. Getting the unions involved helps to create less stigma at the workplace, as they are working towards protecting workers' rights.

Question

How do you include the unions in your programmes?

Answer

We do it by taking them into consideration and sensitising them. The unions themselves have people whose mindset is against those people who are living with HIV. The stigma and discrimination is so prevalent. They raise questions on the issue of reasonable accommodation, such as why are accommodations being made for this man, but not for that man. It then becomes an industrial relations issue. So we have to make the unions understand that HIV/AIDS is not like any other disease. In an equal world, it would be fine to equate HIV/AIDS with cancer or any other chronic patient, but HIV, because of the inherent stigma, needs special attention.

Question

Do you feel that the Government, rather than the public sector companies, ought to be carrying out this work?

Answer

There are a lot of public sector companies who are starting to put policies in place on HIV/AIDS.

Mr. Elango Ramachandran, President of the Indian Network of Positive People (INP+)

I represent people who are living with HIV in India. I myself have been living with HIV for 19 years. I say that so that people can understand that people living with HIV can lead normal, full lives.

GIPA stands for greater involvement of people living with HIV/AIDS. This is a small introduction about GIPA. In Paris in 1994, 42 countries signed a declaration coming to the conclusion that there should be a greater involvement of people living with HIV in the planning and decision making of all HIV/AIDS programmes. GIPA is so important because there is a lot of stigma and discrimination faced by PLWHA in India and we, the people who are living with the virus, are able to much better contribute to the fight against the epidemic.

MR ELANGO
RAMACHANDRAN

I have been involved with the National AIDS Control Organisation, but some of the places given to PLWHA are very tokenistic, just to show that they know what GIPA means. GIPA should entail meaningful involvement, and it should be visible involvement. There should be involvement at all stages of the process, and we need the ability to take decisions of our own.

When talking about preventing new infections and removing stigma and discrimination, no programme will succeed unless it involves people living with HIV/AIDS. We need to be brought to the frontline, otherwise the stigma and discrimination will not reduce. GIPA is an old principle, but it is not implemented properly. If it were, stigma and discrimination would certainly decline.

One of the major problems facing people living with HIV/AIDS is access to treatment and discrimination in the healthcare sector. Before it becomes necessary for someone who is HIV positive to take anti-retroviral drugs, proper treatment for opportunistic infection needs to be available widely and freely to all people, particularly those in rural areas, living with HIV.

There are lot of under trial prisoners living with HIV who are dying badly, like animals in the hospital. They are not receiving the drugs necessary for HIV positive people. There must be some mechanism whereby people living in prison with HIV/AIDS are able to access appropriate medical treatment. They need treatment both for opportunistic infections and anti-retroviral drugs

We need to address certain issues head on. These include (i) access and rights to property; (ii) sex education in schools; (iii) access to schools for children who are HIV-positive; (iv) confidentiality for HIV positive persons; (v) insurance policies and premiums;

I am very scared about the issue of patents. Policy guidelines say that once you have started giving someone ARV treatment, it should be given for that person's lifetime. Now, after four or five years, that person may develop resistance to first line drugs. That means you then require second line drugs. These are not, however, included in the government programmes, so those people do not get treatment. There are around 3000 to 5000 people right now who need second line drugs, but the patents are held by the pharmaceutical companies, making the drugs expensive. We have filed 15 pre-grant oppositions in different parts of the country.

I think HIV-specific legislation is very important, and I am hoping that an HIV Bill is passed very soon. Then hopefully the judiciary will be at liberty to give some better decisions.

Comment

I was involved in a case where there had been negligent transfusion of blood in a hospital. We awarded compensation to the person who had become infected with HIV. There are a lot of cases like this for the judiciary. But there are other cases which the judiciary could tackle, which are not being brought before the judiciary. Hopefully more will be brought.

Hon'ble Mr. Justice Tandon, Judge of the Allahabad High Court

The provisions of the Constitution of India are not only guidelines for the masses, they are the fundamental rights of citizens of this country. Article 21, which provides that no person shall be deprived of his life or personal liberty, has been expanded from time to time by the judiciary. The protection of life afforded by the Constitution is exhaustive, and includes the right to receive medical treatment. In Copula Hingorani v. State of Bihar (2003, volume 6, SCC p1) it was emphasised that man cannot be treated like an animal. The relevant portion of the judgment says the basic needs of man have traditionally been accepted to be threefold - food, clothing and shelter.

It has further been held that this right implies a right to food, a right to water, to a decent living environment, to education and medical care, and to shelter. These are the basic human rights known to civilised society. The right to shelter, when seen as part of the right to life, should be deemed guaranteed as a fundamental right. The States of India should be deemed under an obligation to secure for citizens the right to shelter, subject of course to economic constraints. In a democratic society, one should have permanent shelter, so as to physically, mentally and intellectually equip oneself as a useful citizen and equal participant in democracy.

So the term "life" in Article 21 of the Constitution is a wide and far reaching concept. It denotes something more than mere animal existence. In State of Punjab v Mohinder Singh Chawla (AIR 1997 SCC p1226), it was established that the right to health is integral to the right to life. The Government, therefore has a constitutional obligation to provide health facilities for its citizens. If a government servant suffers an ailment requiring treatment at a specialised hospital, it is the duty of the State to bear the expenditure incurred by the government servant.

In this context, what are the factors contributing to the HIV/AIDS epidemic? HIV/AIDS is known as a life threatening disease and is associated with behaviours such as men having sex with men and injecting drug use which are stigmatised in many societies. Religious or moral beliefs lead some people to believe that HIV/AIDS is the result of moral fault in some societies. Laws, such as compulsory testing, rules and policies can increase the stigmatisation suffered by people living with HIV/AIDS. Stigma and discrimination can also arise from community level responses to HIV/AIDS. People living with HIV/AIDS also face discrimination in the workplace.

Today, HIV/AIDS threatens the welfare of people all over the world. The important things are to provide medical facilities for prevention and control of the global epidemic, as well as to create a more enabling environment leading to the increased visibility of people living with HIV/AIDS as a normal part of society. Education has an important role, together with awareness and understanding about HIV/AIDS amongst many groups of society. Combining education and awareness programmes puts us in a stronger position to prevent new infections. We should be teaching people about how to protect themselves from infection, how to use condoms, how to have safe sex, how to use clean needles and prevent transmission in a medical setting.

The Legal Services Authorities should be part of the education process, working towards eliminating stigma and discrimination. In many countries, the HIV/AIDS programmes are not reaching those most at risk of infection, such as young people, women and girls, male and female sex workers and injecting drug users. We need to work to make sure our programmes do reach those most in need of them.

It is the duty of the state to prevent the disease from spreading. With the recognition that both the preamble of the Constitution and the fundamental right to life enshrined in Article 21 emphasise the value of human dignity, the Supreme Court began to address the importance of health as a fundamental right. In the directive principles in Part IV of the Constitution, Article 47 declares that the State shall regard raising of the level of nutrition and the standard of living of its people and the improvement of public health as amongst its primary duties. In addition to Article 47, the right to health is supported by Article 38, which talks about social order to promoting the welfare of the people. Articles 39E, 41 and 48A can also play a role here.

The four things to which every citizen has a right in the context of HIV/AIDS are (1) education; (2) awareness programmes; (3) medical treatment; and (4) I believe yoga and meditation should be available to people and made a part of their lives.

Mr. Alankar Malavia, Charca

CHARCA is an abbreviation for Coordinated HIV/AIDS Response through Capacity Building and Awareness, which is a joint UN initiative in India working in nine states, for which nine UN agencies have joined hands to reduce women's vulnerability to HIV/AIDS.

I was recently in a state in which sex education has been banned. The Principal Secretary of Health said to me that it was "fashionable" these days to talk so much about HIV/AIDS, when we had also to deal with diseases such as tuberculosis and cancer. More people are dying from these diseases, so why is so much attention being focused on HIV/AIDS? I was very surprised when he told me he had never seen a positive person in his life.

I immediately connected this experience with an experience I had in a town in Andhra Pradesh. I was walking down the street, meeting with peer educators, and generally talking to the community. I asked a self-help group of Muslim women what impact HIV/AIDS had had on their community. I was able to converse quite comfortably with them in Hindi, and within about five minutes of me having asked that question, half of the women were in tears. They told me about the difficult choices they had to make between affording treatment for their husbands, their family members and affording food on the table.

So we need to look at the expenses associated with living with HIV/AIDS. For someone who has full blown AIDS, the out-of-pocket expenses amount to almost Rs. 2,000 per month. That is over and above the treatment and medicine they are provided by the government for free. Out of every five people eligible to receive ARV treatment, only five are able to do so. Of those who are able to access ARV treatment, those who are malnourished when they start the treatment are six times more likely to die than those who are not malnourished.

What are the barriers to people accessing ARV treatment? One is the stigma and discrimination associated with HIV/AIDS. This is a social factor which pushes the entire epidemic underground, and which makes people reluctant to come forward to receive treatment.

There is also the structural issue of availability of the drugs. There are patches where supply is disrupted, times when no medicines are available. There are also issues related to the attitudes of healthcare providers.

Out of pocket expenses are those payments made by the patient at the point of receiving healthcare. That is a WHO definition, which takes a cross sectional view of the point of interface between the patient and the service provider. Theoretically in this country, therefore, there are no out of pocket expenses because the ARV treatment is free. In actual fact, there is the health service user fee, the contribution to health insurance, the price of consultation of treatment, drugs etc., and opportunity cost. Under NACP there are currently 124 ART centres. Having one in your district still means travelling to the district hospital, travelling back to where you live, first getting your CD-4 count done, then accessing ARV treatment if necessary, together with counselling. This is a loss of at least two working days for the positive person. There is also the extra care and support needed by that positive person from their family, which again can be loss of wage and represent an opportunity cost.

Globally, there are 1.3 billion people who do not have access to effective or affordable healthcare. There is a term - iatrogenic poverty – which means a poverty induced by medicine. It occurs when, in order to access medicine, the entire family becomes impoverished. That is of concern in India - district hospitals are the point of delivery for all treatment services, which is challenged by the cost of travel and other associated out of pocket expenses.

Unlike, say, cancer, HIV/AIDS has great stigma attached to it. You cannot issue people living with HIV/AIDS with photo passes which declare they are HIV positive, it would be a breach of that person's right to confidentiality. This is a very difficult issue.

In this context, food security is also a crucial issue. The United Nations Committee on Economic and Social Rights defines food security in the context of the human right to food. The right to food covers both accessibility and availability of food. In the India context, accessibility means affordability. There is a nexus between HIV/AIDS and nutrition in India. HIV/AIDS is a determining factor of food security, as well as a consequence of food and nutrition insecurity. Poverty leads to food insecurity which can result in malnourishment, or risky survival activities. Engaging in commercial sex work is very often a product of poverty. This then leads to faster progression of HIV/AIDS.

Being sero-positive increases the body's energy needs and diminishes appetite. It also decreases the body's ability to digest and absorb nutrients. Nutritional status in turn can affect both the efficacy of ARV treatment and the patient's ability to adhere to the treatment regime. There has to be a policy development which takes account of this interaction between HIV/AIDS and food insecurity. The internationally-recognised right to food must be reflected in domestic policies and practices, in order to create conditions whereby people are not required to engage in high risk practices in order to access food.

Mr. Firoz Khan, Lovelife Society

I have been HIV positive for the last five years. At the time I found out I was positive, there was no counselling offered to me, nor any testing module. When I subsequently went to one of Delhi's CD-4 count machines, I was told to come back in six months to get my test done.

After I had had my test done, I came to know that the centre with the CD-4 count machine caters to only 12 people in a week for their tests. Samples were taken from people only once a week. The centre actually had the capacity to conduct 50 tests every day. The centre was running way below capacity which was causing a lot of people many problems. Without having access to CD-4 count machines, an HIV positive person is unable to know the condition of his or her body, and whether ARV treatment is required.


MR. FIROZ KHAN

It is generally not feasible for HIV positive people to avail themselves of the services of private hospitals and pay Rs. 3,000 - 4,000 each time they need to get a CD-4 count test taken. I am from Delhi, so it was less burdensome for me to regularly visit the hospitals here, but I am lucky in that sense. Some people had to come e.g. from Patna, Bihar, West Bengal, Madhya Pradesh or Rajasthan. Some had to stay in Delhi for a week - an x-ray on one day, a doctor's appointment the next etc. During this week, they had to sleep outside the hospital, on the roads or, if they could afford it, in hotels. In this way, ART centres proved to be very unfriendly institutions, particularly given the attitude of some of the doctors.

I still wonder who made the policy of conducting only 12 tests a week on a machine which can conduct 50 tests a day.

How did such a policy commence? Even today, in most of the hospitals, machines which have a capacity of conducting 25 tests do not actually conduct more than 12, leading to a waiting list of 300 or 400 clients. Only a positive person can really relate to the problems faced by a positive person at this time in their lives. The person needs to take leave from his work, his salary gets cut and by the end of the month, he might be left with only half the salary. Every positive person faces this problem, as every month at least 3-5 days are spent visiting the hospital.

On complaining to the administrative department about the policy regarding the CD-4 count machines, we were told that the policy is absolutely right as the staff are already overworked with sample collection and testing. But the fact remains the machines are capable of running 50 tests a day, and were running 12 a week. This is a policy undermining the rights of people living with HIV/AIDS and it is inhuman to make a person wait six months just for such a test.

The CD-4 count machine at Safdarjung Hospital, had a period when it was not working for 11 months. Repeated complaints about this resulted in a response only that someone would come from Nagpur to get it repaired.

Orissa has only recently had an ART centre rolled out to it. Prior to that, people had to come all the way to Delhi, which further increased the burden on the services available in Delhi.

When we spend 3-5 days in hospitals every month, our time, energy and money is spent on this. The remaining money goes in buying the medicines. We get ARV treatment free of charge, but we do not get all the required medicines. Thus on average I would say 30-40% of the money a positive person has is spent in making trips to the hospital and buying medicines. We often do not therefore have enough money to buy food and ensure shelter.

My motive is to highlight the problems faced by a positive person, and bring them to your notice.

Hon'ble Mr. Justice Rajiv Sharma, Judge of the Allahabad High Court

Human Right to Health in the Context of Human Immunodeficiency Virus/Acquired Immunodeficiecy Syndrome (HIV/AIDS) and Section 377 IPC

Human rights belong to an individual as a consequence of being human. They refer to a wide continuum of values that are universal in character and, in some sense, equally claimed for all human beings. Human rights are understood to represent individual and group demands for the shaping and sharing of respect, tolerance and forbearance in the pursuit of other values.

The origins of the concept of human rights are usually agreed to be found in the Greco-Roman natural-law doctrines of Stoicism, which held that a universal force pervades all creation and that human conduct should therefore be judged according to the law of nature and in the law of nations, in which certain universal rights were extended beyond the rights of Roman citizenship. These concepts taught more of duties than rights, however, and allowed for slavery and serfdom.

It was during the period from the Renaissance until the 17th century that the beliefs and practices of society so changed that the idea of human (or natural) rights could take hold as a general social need and reality. The writings of St. Thomas Aquinas and Hugo Grotius, as well as the Magna Carta, the Petition of Rights of 1628, the English Bill of Rights, all reflected the view that human beings are endowed with certain eternal and inalienable rights.

The modernist conception of natural law as meaning natural rights was elaborated in the 17th and 18th centuries by such writers as Rene Descartes, Gottfried Leibniz, Benedict de

Spinoza and Francis Bacon. Particularly to be noted are the writings of the English, the most important natural-law theorists of modern times, and the philosophers, including Denis Diderot, Voltaire, Montesquieu and Jean-Jacques Rousseau.

The struggle against political absolutism in the late 18th and 19th centuries further advanced the concept of human rights. Thomas Jefferson and the Marquis de Lafayette gave eloquence to the plain prose of the previous century, and freedoms were specified in a variety of historic documents such as The Declaration of the Rights of Man and of the Citizen (1789) and the Bill of Rights (1791) and the Constitution of the United States (1787).

The idea that natural law is the foundation for human rights came under attack during the late 18th century by such men as conservatives Edmund Burke and David Hume, as well as by Jeremy Bentham, a founder and leading proponent of Utilitarianism. This assault continued into the early 20th century. The idea of the rights of mankind endured in one form or another – the abolition of slavery, labour laws, population education, trade unionism, universal suffrage – and came into its own following the rise and fall of Nazi Germany.

Although the existence of human rights is no longer debated, the nature and scope of those rights remain the subject of dispute. Questioned, among other matters, are the source of human rights, the way in which they are validated, whether or not they are irrevocable and what their limits are.

By the late 20th century, it had generally come to be agreed that all human beings are entitled to some basic rights, making the birth of the international and universal recognition of human rights. In the charter establishing the United Nations, all members pledged to achieve "universal respect for, and observance of, human rights and fundamental freedoms for all without discrimination as to race, sex, language or religion," and the UN has continued to affirm its commitment to human rights, particularly in such documents as the Universal Declaration of Human Rights.

International concern for human rights has also been evident outside of the United Nations. For example, the Conference on Security and Cooperation in Europe, which met in 1950, eventually produced the Helsinki Final Act in 1973-75; the European Convention for the Protection of Human Rights and Fundamental Freedoms, which first met in 1950, eventually produced the international Covenant on Civil and Political Rights and the European Social Charter; the Ninth Pan-American Conference of 1948 adopted the American Declaration on the Rights and Duties of Man; and the Organisation of African Unity in 1981 adopted the African Charter on Human and People's Rights. In the 1980s a new approach to human-rights advocacy – the use of domestic courts to clarify and safeguard international human rights – also began to evolve.

There are also a number of private groups involved in human-rights advocacy. One of the best-known international human-rights agencies is Amnesty International, an organisation dedicated to publicising violations of human rights, especially freedoms of speech and religion and the right of political dissent.

As regards the international human right to health, the said right emerged at the international level immediately after the Second World War, most notably in the constitution of the WHO. But, like all economic, social and cultural rights (ESCR), the right to health was a victim of the Cold War. During the Cold War, ESCR were marginal and neglected. For some forty years, the international right to health received relatively little serious attention.

That changed in the 1990s. When the Berlin Wall fell, it not only liberated people, it liberated ideas. The holistic conception of human rights – that all human rights have equal status – re-emerged and was re-affirmed at the human rights world conference in Vienna during 1993. Civil society organisations – especially those in the South – insisted that the holistic neglect of ESCR should be redressed.

We should never forget that progress in the field of international human rights is invariably driven – or inspired – by national civil society organisations. The frontline of the human rights struggle does not run through the UN corridors of Geneva or New York. It runs through Lagos, Sao Paulo, Mumbai – and Ottawa – as well as smaller communities that do not show up on the world atlas.

In any event, the re-emergence of the holistic conception of human rights in the 1990s coincided with another important international development. In 1997, Kofi Anan's UN's reforms were endorsed by the General Assembly. According to these reforms, human rights are a cross-cutting issue and they are to be mainstreamed across the United Nations.

The Commission on Human Rights passed a resolution establishing a UN Special Rapporteur on the right to health. Mainly, it set out three broad objectives:

- First objective, to promote, and to encourage others to promote, the right to health as a fundamental right. The right to health is unquestionably part of international human rights law, but still many people do not grasp that it is a fundamental human right. They feel intuitively that the right to a fair trial and freedom of expression are human rights, but they do not instinctively regard the right to health as a human right.

- Second objective, to clarify the contours and content of the right to health. There is a growing national and international jurisprudence on the right to health, but still the legal content of the rights is not yet well established.

- Third objective, to identify good practices for the operationalisation of the right to health at the community, national and international levels.

In short, the right to health means there are grey areas – some of them extensive and there are good faith disputes and disagreements, just as there are in all worthwhile fields of human endeavour. But the important point is that the right to health is not just a slogan – it is not just a bumper sticker – it has normative depth and something constructive and concise to say to national and international policy-making processes.

On the protection of human rights in the context of HIV/AIDS, the report of the Secretary General provides an overview of actions taken by some of the governments and specialised agencies (the ILO, UNAIDS, the OHCHR, the UNFPA, the UN Relief and Works, Agency for Palestine Refugees in the Near East (UNRWA) and the WHO). The report also reflects information provided by the Human Rights Commission of some countries as well as NGOs. The information related to measures taken to implement the international guidelines on HIV/AIDS and Human Rights.

The summary of information provided by various UN bodies notes that HIV/AIDS is a workplace issue because it threatens the fundamental rights of workers, undermines incomes and livelihoods and reduces productivity and profitability; the role of the workplace in the struggle to limit the spread and impact of the epidemic; the ILO code of practice on HIV/AIDS and the world of work; support for the treaty bodies and special mechanisms of the Commission related to the integration of HIV/AIDS issues in their mandates; activities to combat the stigma and discrimination associated with HIV/AIDS, in particular in the context of the follow-up to the DDPA; the development of the joint UNAIDS/OHCHR International Guidelines on HIV/AIDS and Human Rights and so on.

The Commission adopted by consensus a resolution on the protection of human rights in the context of HIV/AIDS in which it has been noted that the Declaration of Commitment on HIV/AIDS affirms that the realisation and safeguarding of human rights and fundamental freedoms for all is essential to reduce vulnerability to HIV/AIDS; the enactment of legislation in some countries to promote human rights in the context of HIV/AIDS and to prohibit discrimination against affected persons and members of vulnerable groups; more than 95 percent of all people inflicted with HIV live in the developing countries, mostly in conditions of poverty, underdevelopment, conflict and inadequate measures for the prevention, treatment and care; an increasing proportion of people living with HIV/AIDS are women; welcomes the creation of and the progress made by the Global Fund to Fight AIDS, Tuberculosis and Malaria; expressed concern that the lack of full enjoyment of human rights by persons suffering from economic, social or legal disadvantage heightens their vulnerability to the risk of HIV infection and to its impact, if infected; noted the continued discrimination in law, policy and practice, in many countries, against people infected, affected or presumed to be infected by HIV; noted that stigma and discrimination on the basis of HIV or AIDS status are obstacles to an effective response to the disease.

Several million women and infants are currently infected with HIV, and within a matter of a few years, many of them will die of AIDS. The international community is increasingly concerned with the implications of HIV and AIDS in women and infants, on family life in particular and on society in general. Among the many strategies deployed to deal with the problem of HIV/AIDS in women and infants, and to minimise HIV transmission, are legal interventions. However, not all such interventions are capable of satisfactorily responding to the problems of particular relevance to women and infants. AIDS-related legal approaches relating to women and infants in the contexts of screening, occupational hygiene and licensing; breastfeeding, adopting and infant care; and abortion. There is a need for the HIV/AIDS problem in women and infants to be studied from a broad social perspective, before appropriate legislative strategies are devised. The failure to do so might result in the formulation of ill-conceived strategies which focus on narrow and low-priority issues.

Long-term and sustained improvements in women's health can only be achieved by eliminating the inequalities and disadvantages that women and girls face in education and economic opportunity. Research shows how secondary education for women is associated with high age at marriage, low fertility and mortality, good maternal care and reduced vulnerability to HIV and AIDS. It also shows how improved infrastructure and economic independence is linked to improved health. Improvements in education include making school more affordable and building secondary schools close to where girls live. Key changes include improving content, quality and relevance through curriculum reform and teacher training and other activities aimed at transforming attitudes, beliefs and gender-biased social norms. Governments also need to guarantee effective and independent property and inheritance rights to land and housing for women. Gender inequality is deeply rooted in attitudes, institutions and market forces. Consequently, political commitment at national and international levels is needed to enact these policies and allocate the necessary resources for gender equality and women's empowerment to improve female health.

It is believed that India will soon have the highest number of HIV/AIDS cases of any country. Some reports project that 37 million people will be infected within the next two decades. Sadly, few studies have examined the legal claims of those who suffer with this disease in this, the world's largest democracy. The conventional wisdom is that the Indian judiciary frequently protects the rights of the poor, the under-represented, and the ill. But findings reveal that, at least for people with HIV, the courts have not extended to this group full constitutional protection. The implications of this conclusion force us to revisit whether the courts in India best safeguard the rights of others who are disadvantaged.

India is a very traditional society. The law also remains very traditional, especially in the area of human relationships. It legally recognises only one form of biological and physical intimacy which helps in procreation. The law is not likely to change in the near future because the society is based on religious traditions where procreation is an obligation for the performance of various religious rituals. The family is a very important micro unit of India society and the institution of marriage strengthens it.

Indian society is male dominated and is very unequal, though equality is guaranteed under the constitution as a fundamental right and that no one be discriminated against on the basis of sex. Men consider themselves very sought after and it is true that they not only have a special status but also have a price, therefore, they get or can demand a considerable dowry in marriage (though recognised as a social evil).

The Indian Penal Code was formulated by the British Parliament for Indian in the 19th Century. Indian society considers that this legislation has served it well on the whole and consequently there has been very few changes after India became independent. Indian sexual morality is governed by the provisions of section 377 of IPC. It deals with unnatural offence; denies among other sexual relations those with the same sex, which fundamentally differs from rape. Consent, relevant for rape, is immaterial for unnatural offence under Section 377 of the IPC. It deals with private morality of consenting adults apart from other things. There is no decision in India where consenting adults were involved.

According to section 377 of IPC, whoever voluntarily has sex against the order of nature with any man, woman or animal shall be punished with imprisonment for life or with imprisonment for a term, which may extend to 10 years.

The Encylcopaedia Britannica says sodomy is 'noncoital carnal copulation. The term is understood in history, literature and law in several senses:

- As denoting any homosexual practices between men, in allusion to the story of Sodom in Genesis 18:19;
- As denoting anal intercourse;
- As synonymous with bestiality, zoophilia, i.e. sexual relations between human beings and animals; and
- As comprehending a number of other sexual activities, ranging from sexual intercourse with minors to mouth-genital contacts and oral intercourse between adults.

Section 377 of IPC punishes all this. The language is not so explicit. It has been worded vaguely. It punishes those who have carnal intercourse against the order of nature with any man, woman or animal. Any intercourse without consent or with a minor or with an animal or with someone incapable of giving consent is wrong and should be punished, but it is against the order of nature even if it is between consenting adults. What is the meaning of the word against the order of nature? Some answers are provided by Khannu v Emperor[125] in which it has been held that the natural object of carnal intercourse is that there should be a possibility of conception of human beings. But is it, in modern times, still true, still accepted? This was clarified in Lohia Vajant Lal v Dev Chand[126] wherein it has been held that it is a common thread that runs almost in all cultures and religions. Is there something more fundamental to it?

In Great Britain, the Wolfenden Committee was appointed to consider sodomy laws. It gave its recommendation in 1957, the same time as the 'fall of parity' on Homosexual Offences and Prostitution in Great Britain. Using the findings of psychoanalysis and social science, the report urged that public statutes avoid the attempt to legislate morality and that they concern themselves only with the sexual acts that offend public democracy or disrupt order. The committee therefore recommended that private homosexual liaisons between consenting adults be removed from the domain of criminal law. It accepted that

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[125] AIR 1925 Sind 286

[126] AIR 1968 Gujarat 252

Mill had said, 'the only purpose for which power can be rightfully exercised over any member of a civilised community, against his will, is to prevent harm to others. His own good either physical or moral, is not a sufficient warrant." The recommendations of the Wolfenden Committee were accepted and accordingly, the Sexual Offences Act 1967 was framed.

Sodomy is a crime in many countries including India and is condemned as a mark of abnormality. Some laws provide penalties as severe as life imprisonment for homosexual intercourse, even if the relations are voluntary and between legally consenting adults. So-called sodomy laws apply even to married couples not only in India, but also in other countries.

The NAZ Foundation, which works for AIDS awareness, has filed a public interest litigation in the Delhi High Court seeking the repeal of section 377 IPC which makes all types of unnatural sex including homosexuality an offence punishable by imprisonment for up to 10 years. NAZ argued that section 377 IPC is violative of Articles 14, 15, 19(1)(a) to (d) and 21 of the Constitution.

The High Court declined to interfere with the provisions because the petition was filed by an organisation and not by individuals and the matter is not of 'public interest.'

NAZ contested the verdict in the Apex Court and the Apex Court sent back the petition to the High Court, saying that it is a matter related to public interest.

Indira Jaisingh of the Lawyers Collective, which represented NAZ, said "We can't do advocacy amongst a section which is essentially criminal in the eyes of the law. How do we recommend safe sex to prevent HIV/AIDS to people who are criminals in law?"

Section 377 IPC criminalises any penetrative sex that does not lead to reproduction, thereby criminalising sexual expression by homosexuals, bisexuals and transsexuals. Even though this section does not lead often to filing of court cases against sexual minorities, it becomes a powerful weapon in the hands of police and goondas to harass, extort and torture sexual minorities in our society.

Their human rights are routinely violated by police, goondas, healthcare providers, families and other state/non-state actors and access to redressal mechanisms are hindered by their criminal status. As our laws recognise only heterosexual marriages, the right to marriage and family is denied to same-sex couples and transsexuals. This, along with various civil laws, overtly and covertly deny sexual minorities their rights to inheritance, property, insurance and other allowances.

Repealing section 377 IPC will become a precondition in demanding changes to various civil laws. Already the Law Commission of India in its 172nd report (on reviewing rape laws) and recently the Planning Commission of India have recommended the repeal of section 377 IPC.

Provisions of section 377 IPC are to preserve public order and decency to protect the citizens from what is offensive or injurious and to provide sufficient safeguards against exploitation and aggravation of others, particularly those who are specially vulnerable because they are young, weak in body or mind, inexperienced, or in a state of special physical, official or economic dependence. It is not, in my view, the function of the law to intervene in the private lives of citizens.

The importance which society and the law ought to give to individual freedom of choice and action in matters of private morality. Unless a deliberate attempt is to be made by society, acting through the agency of law, to equate the sphere of crime with that of sin, there must remain a realm of private morality which is, in brief and crude terms, not the law's business.

Controlling the HIV/AIDS pandemic will likely be the greatest challenge to the public in the 21st century. HIV is a miniscule bit of RNA, but this viral event causes a profoundly human phenomenon. Modifying intimate experiences, changing established social relationships, and challenging global inequalities are all parts of the response to HIV.

Solidarity and price may be the most effective counter to stigma. To control HIV, we must just admit that the problem belongs to all of us.

A JUDICIAL COLLOQUIUM

HIV/AIDS AND THE LAW

The book records the proceeding of the Judicial Colloquium on HIV/AIDS and the Law speaking about rights based issues and HIV specific legal problems and potential solutions. The aim of the Judicial Colloquium was to bring together senior members of the Judiciary from across India's High Courts to discuss the legal problems faced by people affected by HIV/AIDS. Key issues discussed at the colloquium were the right to confidentiality, rights of women and children, access to treatment, and issues of stigma and discrimination.

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