

SOCIO-LEGAL DIMENSIONS OF AIDS: PROPOSALS FOR AN AIDS ACT

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PRELUDE

Being a sure killer disease, Acquired Immuno Deficiency Syndrome (AIDS) is perceived as a serious threat to humanity. Since the detection of the first known AIDS case in U.S.A. in 1981, a phenomenal rise in the number of AIDS victims has been reported worldwide. According to the W.H.O. there are estimated 15 million people all over the world who are infected by AIDS. Of these more than one third are suspected to be children. More than one million of these victims are likely to be in India. By the end of this century, India is projected to be acquiring 25% of the world's total AIDS' victims. Whether these projections are accurate or not, India has to be ready to meet this serious threat. The strategy to check the menace of this virus is the dire need of the day in any serious endeavour to save the humanity for the twenty first century. An effort has been made here to identify the socio-legal approach to tackle the menace of AIDS.

SOURCE OF AIDS AND ITS VICTIMS

The researchers and experts in medicine have identified three established sources of spread of AIDS, namely -

1. Transmission of infected blood directly into the blood stream through intravenous, intramuscular injections. This blood to blood transmission of HIV may be caused by the use of unsterilised needles or their repeated use or when blood products are to be transfused to the recipient;
2. The contact of infected blood or semen or secretions with the mucous membranes in the vagina or rectum. In common parlance it is known as infection through unprotected sex. Strict adherence to monogamous sexual relations and use of unbroken condoms is recommended as a good preventive measure for protected sex;
3. The infection can be transmitted by an infected woman to her fetus during pregnancy or possibly during delivery. The infants acquiring the virus through perinatal transmission have been referred to as 'Special Children' in this paper. These special children need to be recognised as sufferers for no fault of theirs.

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TWO APPROACHES TOWARDS AIDS VICTIMS

One school of thought to check the spread of AIDS has propagated the mandatory testing of all persons with a view to isolate such persons who are found HIV positive. It also emphasizes the stigmatization of the victim. The focus of this approach here is not to check the spread of AIDS, but the exclusion of the victim from all others. The second school of thought emphasizes the integration of persons found HIV positive with others without stigmatisation by preserving their confidentiality. It also insists for no compulsory testing and non-discriminatory provisions for the victims. For this school, the focus of approach is to provide a humane medical care for the HIV person and not his exclusion from all others. These two approaches can be characterised as 'Isolationist' and 'Integrationist'.

The Isolationist approach was given a trial in Romania and Cuba where it is reported to have failed.¹ The entire population was required to be tested for HIV. Those found positive were to be compulsarily isolated. The failure of the experiment was not only because of the expenditure involved in it and the problems relating to the feasibility of conducting proper and efficient tests on every one but also that many persons chose to go to other areas or underground for fear of being isolated as in case of solitary confinement.

In the Indian context, Goa was the first State to amend its Public Health Act in 1987 whereby a new clause VII was added to the existing Section 53(1). Under the new clause, it was mandatory (as the term used is 'shall') for the authorities to isolate the person who had tested HIV positive. Clause VIII further provided that the material, equipment provided to the HIV positive will not be used by any other person thus presuming that AIDS is a contagious disease, which is medically wrong. This is further affirmed by clauses X and XII which provide for destroying the linen and mattresses used by the HIV patient; and the restriction that those handling the patient shall ensure that they do not come in contact with the patient. When Mr. Dominic D'Souza had challenged these provisions in the Court, through an amendment in 1989, the word 'shall' in clause VII was replaced by the word 'may'. On these very lines the AIDS Prevention Bill, 1989, was introduced in the Rajya Sabha in August, 1989. Section 4² of the Bill required every registered medical practitioner to inform the local designated health authority about the seropositivity of a person. Section 5³ of the Bill empowered the health authority to direct the victim to submit to compulsory testing and to remove himself forthwith to a hospital or other place so as to check the further spread of the virus. Section 9⁴ of the Bill empowered the surveillance Centre of a State to conduct tests compulsarily on the general public or selected group of persons to determine and monitor the spread of the virus. Those testing positive could be required to disclose the source from where they possibly got the virus.

The 1989 Bill (which fortunately was withdrawn because of the serious protest by several social organisations) heavily relied upon this Isolationist theory. It was more in the form of a handle to preach moral devoid of compassion and common sense. A medical problem was sought to be solved through a forced reform in one's outlook in life. The Bill had totally overlooked the scientific facts about AIDS.

Two significant cases (out of the numerous) relating to AIDS victims are those of Dominic D'Souza⁵ of Mapusa, Goa and Swapan Ganguly of Calcutta. These cases

establish it beyond any doubt that the policy of isolation can only aggravate the misery of the alleged or genuine victim. Both the victims were blood donors. In D'Souza's case, he was taken in custody by the police. He was put to compulsory testing. Subsequently, he was put to solitary confinement. With the intervention of the Court, he was sent out from the solitary confinement to a T.B. Hospital but his movements were restricted in a limited area. Swapan Ganguly, on the other hand, was wrongly suspected to be carrying the virus. The scandal hungry media persons were quick to publish his name and picture in the newspapers and magazines. As a result of this publicity, the boys in the neighbourhood threatened his parents, wife and son to leave the area within seven days before anybody else was infected. Despite his repeatedly testing negative, he was kept in solitary confinement. The justification for his confinement ultimately was given, in the not so unexpected bureaucratic idiom, as the 'law and order situation'. Ganguly's case shows the emotional distress, unrooting of family and damage to one's reputation which can be caused in the absence of confidentiality being maintained about the victim.

The integrationist approach on the other hand emphasises the adoption of persuasive and educative methods as differentiated from coercive methods. It opposes mandatory testing, isolation of the victim, discrimination in employment, treatment and services. It lays special emphasis on education about AIDS and positive behaviour towards the victims. It discourages stigmatisation by putting checks on making the identity of the victim unnecessarily public.

The World Health Organisation and the majority of member Nations at the U.N. have opted for this integrationist approach. In India too we need an AIDS Act based on integrating the victim as a part of a concerted health policy and a constructive movement to check the spread of the virus.

To achieve the above, it is proposed that the following measures need to be adopted immediately:

SPREAD OF EDUCATION ON AIDS

Instead of fanning panic of AIDS, the population needs to be enlightened about the causes of the virus and the preventive steps needed to check the same. The misgivings about AIDS must be rebutted effectively. Simultaneously the high risks on account of AIDS need to be highlighted. The media has a very important role to play in it. The newspapers, for example Indian Express through its campaign 'Express Social', have been contributing in this direction. Such campaigns need to be supported and strengthened. The massive programme of the National Service Scheme through its project Universities Talk AIDS (U.T.A.) is a welcome step. The medically established findings such as the fact that one cannot get AIDS by living with the patient, sharing toilet, swimming, sharing clothes, utensils, shaking hands, eating or drinking with him, sitting or playing with him or by his sneezing or coughing or mosquito bite need to be highlighted so as to persuade the fellow human beings to treat the victim as one amongst themselves. The message should be that AIDS victims are human too and that we have to fight AIDS and not AIDS victims.

SPECIAL CARE OF SPECIAL CHILDREN

The infants who are infected during pregnancy, are the victims of another's fault or ignorance. They need to be treated as a special class by themselves as they have to suffer for no fault of their own. Constant support will have to come from the welfare state and the society at large for these special children. Their bringing up and education deserve a more sensitive care than ordinary children in a family. Special children must get special attention from all concerned in the society.

NO COERCIVE TESTING AND CONFIDENTIALITY OF THE VICTIM

The population will have to be persuaded through educative methods that it is not only in an individual's own interest but also of the society at large that potential victims know as to whether they are infected by the virus or not. The identity of the victim must remain a secret between him and his physician. With the consent of the victim, the information may be permitted to be shared with the selective few like spouse, a close friend or a relative in the best interest of the victim. This will save the victim from stigmatisation and encourage people to go in for voluntary testing.

APPROACH OF THE MEDICAL/PARA-MEDICAL PERSONNEL

Another crucial factor to check AIDS is going to be the behaviour of the physician and his staff towards the victim. The Victim will need to be treated more humanely. Unfortunately the medical profession has been found most wanting in this direction. Mr. Dominic D'Souza on the attitude of the medical staff in hospital wrote thus:

The treatment I received from the medical personnel at the sanatorium could be compared to that meted out to lepers of old. They were most unsympathetic. Every day a doctor would come, supposedly to check me, but would stand outside the room and ask how I felt, leaving with a sigh of relief when I said I was well and not sick. Pills of Liv-52 and vitamins B-Complex were sent in my meals.⁶

Similar attitude of the paramedical staff was plainly noticed at the P.G.I.M.E.R., Chandigarh where the nursing staff refused to enter the isolated room of an AIDS victim alleging that they could be infected.⁷ The tormenting experience of AIDS victims at the hands of the medical staff is clearly in violation of professional ethics and patient care. If the professional himself cannot practise what he is telling others to do, the fate of victim can be imagined well. The Medical Council of India must put it as a part of the ethics of the profession that the AIDS victims are not to be treated as a danger to the society but as a part of the society.

ENCOURAGE BLOOD DONATION

Blood donation as a movement is already afoot in the country. The welfare state must give it further boost. The remarkable contribution of the Blood Bank Society, Chandigarh is an indicator. Inspiring people to become blood donors will facilitate the detection of AIDS cases and no coercion is practised in this process to ascertain its existence in a person. The blood bank must inform the donor if he is found HIV positive and do the necessary counselling.

AN AIDS ACT REQUIRED

Unlike the Goa Health Act or the AIDS Prevention Bill, 1989, a comprehensive legislation in the form of an AIDS Act is the need of the hour. The proposed Act, *inter alia*, must ensure -

1. That the object of the Act is to check the spread of AIDS with the victim as the focus. It should emphasize the dignity and rights of the AIDS victim, to educate the people about the epidemic and save the humanity.
2. That the phenomena of AIDS and its causes, i.e., how it is transmitted and how it can be avoided must be specified in the Act.
3. That there will be no compulsory testing. It will be with the consent of the person only. However, compulsory testing may be done on groups like sex workers in red light areas and their potential visitors by setting up AIDS surveillance (NOT POLICE) Clinics.
4. That isolation and chaining etc of the victim are prohibited.
5. That secrecy about the identity of the victim shall be maintained.
6. That there shall be no discrimination in matters like employment, education, travel or other public benefits on the ground of an individual's HIV status.
7. That the Medical Council of India (as the apex professional body) shall regulate the proper service to the victim at the hands of his physician and his staff.
8. That breaching of confidentiality will be punishable.
9. That there will be mandatory screening of HIV in manufacture of blood or blood related products.
10. That the State shall ensure the spread of awareness through education on AIDS.

The above suggested measures may not provide any short cut to check the menace of AIDS but it is hoped that these may contribute significantly in that direction if they are implemented sincerely.

NOTES

* Paper submitted for International Conference – AIDS: LAW AND HUMANITY, New Delhi.

1. The Layers Collective, May 1992, p.5.

2. Section 4 of the Bill read: "Registered medical practitioner to give information:

Every registered medical practitioner who, in the course of his practice becomes cognizant of the existence of any case of HIV infection in a person, a person suffering from AIDS or a drug addict in any private or public dwelling, hospital, nursing home or any other place, shall give information of such person in such form and manner as may be prescribed and with the least practicable delay to the designated health authority within whose local limits he is practising."

3. Section 5 of the Bill read: "Power of designated health authority to call for information, etc.:

On the receipt of information under Section 4 or from any other source, the designated health authority shall have the power to direct the person referred to in Section 4 -

(a) to furnish such information as that authority may require from him for initiating action under section 7 and section 9;

(b) to submit himself for test;

(c) to remove himself forthwith to a hospital or other place for special care and medical treatment where the authority considers it necessary so as to do in the interests of such person and also to prevent the spread of HIV infection."

4. Section 7 of the Bill provided : "Steps to be taken by designated health authority:

The designated health authority shall, on receipt of information under Section 4 or from any other source, take steps to provide for -

(a) Counselling by qualified and specially trained person, and also take such other precautionary steps to prevent the spread of HIV infection as it may deem necessary."

Section 9 of the Bill read: "Surveillance centres to conduct survey and to report cases of HIV infection to designated health authority:

(1) Every surveillance centre shall conduct clinical or laboratory tests or shall cause such tests to be conducted for the purposes of detecting, determining or monitoring the rate of HIV infection or for identifying the persons so infected amongst the general public or selected groups of persons;

(2) Where a person has been detected to be having HIV infection or as suffering from AIDS, the designated health authority may require the surveillance centre

to take steps to trace the sources from which such person has acquired HIV infection and the sources through which he might have transmitted the infection to others.

5. Dominic D'Souza died this year after setting up an organisation known as 'Positive People' in Goa.
6. The paper titled 'State and Societal Reaction' by Dominic D'Souza presented by him at the Conference on "AIDS: Impact And Intervention", Bangalore, January 9-10, 1992.
7. The Indian Express, June 30, 1994.