

COMMENTS

HIV/AIDS legislation: an opportunity for health care reform

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The litany of woes related to HIV/AIDS continues unabated in India. An orphanage in Gujarat's Kutch district removed two boys after they tested HIV-positive. The head of the orphanage claimed that the young boys posed a risk to the other children in the orphanage. The boys have lost their mother to AIDS, their father suffers from mental illness and no one else in their family is willing to look after them. A six-year-old boy in West Bengal was struck off the rolls of his school when it was found that his father was HIV-positive. A woman in a village in Bihar's Dharbanga district was shunned and left alone to handle the cremation of her deceased husband who was HIV-positive. Her neighbours believed that they could contract the virus by entering her house. A woman was denied a ticket to fight the assembly elections for the Congress party when local leaders opposed her candidature due to her HIV-positive status.

These are a few instances that occurred only last year, and which got reported. Such events have occurred with an alarming frequency in the last few years despite government policies that espouse a humane response to HIV/AIDS and massive financial investment in generating awareness and information to debunk myths and fears.

The role of law

Why do the rights of the individuals described above need to be protected? Primarily because HIV/AIDS has thrown up such vast inequities, violent abuse and widespread stigma that human rights have been trampled on in a manner rarely witnessed in the public health sphere. However, these rights also need to be protected to address public health imperatives: by using law as an instrument of social change and protecting the rights of those infected and most vulnerable to HIV/AIDS, an environment can be created whereby stigma, violence and inequity will be lessened. This will bring the problem into the open and make it easier to control. This is the widely accepted and established "rights-based approach", which promotes several inter-related rights, including informed consent to testing, the guarantee of confidentiality, non-discrimination, and access to services including travel, insurance and treatment.

This, then, necessitates the creation of a legal environment that protects the rights of individuals affected by HIV/AIDS through the enunciation of a statutory law that guarantees such

protection. There are several reasons why a specific statute is required to govern the HIV/AIDS scenario.

The vagaries of common law: The various legal issues that arise in the context of HIV/AIDS are mostly governed by common law whereby the absence of a statute allows for the personal predilections of individual judges to decide on cases of HIV/AIDS. This lends itself to extreme inconsistency and does not promote a strong, reliable legal system.

To address discrimination: The violation of rights is rooted in the stigma and fear that the epidemic has caused. These violations are widespread and gross. They affect access to various services and sectors including health care, employment and insurance for people infected by or at risk of contracting HIV/AIDS.

Although the Constitution of India guarantees equality, it is available only in the public sector. There is an abject lack of legal control over discriminatory practices in the private sector, be it in health care, employment or insurance. This is another reason why there is an urgent need for legislation on HIV/AIDS, which incorporates anti-discrimination measures in the private sector and protects persons infected, affected and vulnerable to HIV/AIDS.

The insufficiency of policies: Although India does have the National AIDS Prevention and Control Policy, this policy does not have the status of law and is not binding or enforceable in court. The presence of a nationally applicable statute would lend consistency, clarity and predictability in order for courts to effectively pass judgement in HIV/AIDS cases.

The need for safe havens in the absence of law reform: HIV/AIDS has been seen to have its most destructive impact on those persons who have been historically shorn of their legal rights and citizenship. Legislation on HIV/AIDS is also required to provide rights to these marginalised populations (sex workers, men who have sex with men, drug users) so that measures can be taken for them and society at large to resist the spread of the epidemic. This will require simultaneous law reform that removes provisions that prejudice these populations and empowers them to protect themselves and others from HIV/AIDS. Till such law reform occurs it is necessary to protect interventions with these populations (condom distribution, information on safer sex, needle exchange, etc.) that would otherwise be seen as aiding criminal activity and

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therefore illegal.

Admittedly, legal and policy issues may not be central to an attempt to control the epidemic, but there can be no doubt that they are vital ingredients in creating an enabling environment that would prevent the spread of HIV/AIDS.

The HIV/AIDS Bill

The rights-based approach forms the basis of the HIV/AIDS Bill (1). This health legislation is the outcome of a consultative process involving the experiences of the vast community of persons working on HIV in India at every turn, including persons living with HIV/AIDS, vulnerable communities, health care workers, NGOs, workers and employers, women's and children's groups, representatives of the AIDS bureaucracy within government, and lawyers. It embodies principles of human rights and seeks to establish a humane and egalitarian legal regime to support prevention, treatment, care and support efforts vis-à-vis the epidemic in India.

The Bill touches upon the most critical legal aspects of HIV/AIDS: discrimination, the right to a safe working environment (particularly in the context of health care delivery), informed consent, confidentiality, free and wide access to information and treatment, the creation of "safe havens" within which vulnerable (and criminalised) populations can get access to life-saving health services and innovative grievance redress mechanisms. All these issues were informed by the inputs of participants in the consultative process. The draft law gained perspective due to their comprehensive feedback.

For example, the consultation highlighted an issue of importance related to children—older orphaned siblings are unable to gain access to bank accounts or property entitlements due to their minority status, which creates serious hurdles in their getting care, treatment and other services. The Bill, accordingly, recognises the guardianship of older siblings for purposes such as admission to schools, operating bank accounts, etc. It also recognises the right of children and young persons to access health care services and information in their own right. This is particularly important for children living on the streets or living on their own. It also provides for protection of inheritance and property rights and recognises community-based alternatives to institutionalisation for vulnerable and affected children.

Some provisions in the Bill reflect changes in law that are apparently unrelated to HIV — the compulsory registration of marriages, the provision of maintenance, the right of residence for women and the establishment of sexual assault crisis centres, for example. These provisions arise from an

understanding, which was enhanced through the consultative process, that women face increased neglect, discrimination and a vicious cycle of violence that not only leaves them vulnerable to HIV but that intensifies if they are HIV-positive.

The Bill fundamentally recognises the intricate link between discrimination, HIV testing and confidentiality and accordingly makes ethical principles of medical practice legally binding. This framework is qualified with exceptions. For instance, while recognising the right of HIV-positive persons to confidentiality, which allows them to determine when they can reveal their status, the Bill also provides for a strict partner notification protocol in exceptional cases, when a sexual/ needle-sharing partner is at substantial risk of infection.

At the heart of the legislation is the understanding that HIV/AIDS can have immeasurable adverse impacts on a life, a family, and a community. Therefore it is first and foremost an anti-discrimination legislation. The Bill prohibits discrimination based on a person's HIV status or even their association with HIV. It extends the guarantee of equality enshrined in the Constitution to all sectors, including the private sector.

Change is on the cards

A three-year process of intensive research and extensive consultation will hopefully soon culminate in the introduction of the HIV/AIDS Bill 2006 in Parliament. Presently, the union health ministry has sent the Bill for feedback from the state and union territory governments and responses are awaited (2). The health minister recently announced that the Bill would be introduced in the 2007 Budget Session of Parliament.

The presence of HIV/AIDS has led to the unravelling of many sad accounts of inhumanity that reflect the small-mindedness of human nature and attitudes. But this distress has also given us an opportunity to reconsider and correct the ills. Among the many shortcomings that must be rectified, of vital importance is our health system, its insufficiency, and the inequity it perpetuates. We hope the HIV/AIDS Bill is also seen as a precursor to greater health reform across the board and that it presses the state to deliver on its promise to invest seriously in this sector.

The authors were part of the core team that drafted the HIV/AIDS Bill and carried out civil society consultations and interactions with the government regarding the proposed law.

References

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