

COMMENTS

The HIV Act – better late than never

VIVEK DIVAN

Abstract

Although over 15 years in the making, the HIV legislation has recently been passed in India. This Act is unique in many respects, and hopefully a precursor to broader health sector legislation. The process of law making in this instance included a robust consultative process with civil society and other stakeholders involved with HIV. Some of the unique aspects of the Act, as it was eventually passed, include an anti-discrimination provision to cover violations by the private sector, and concrete provisions to ensure informed consent while seeking HIV-related testing and treatment, and confidentiality of HIV status. However, the law fails to recognise the enhanced vulnerability to HIV that some people – sex workers, transgender people, men who have sex with men, and people who use drugs – face, which should have been addressed by extending anti-discrimination guarantees to these communities, thereby providing a legal tool to access health, employment, educational, and other sectors; while also serving public health imperatives to encourage marginalised people towards health-seeking behaviour without fear of stigma and mistreatment. Yet, at least the legislation does protect these criminalised communities from punishment when they access or are provided HIV-related services and commodities, which could otherwise be tantamount to a crime. Another drawback of the law is the diluted obligation of the State to provide antiretroviral treatment to those in need. The legislation also provides options to redress grievances, which are localised, less formal and intimidating, and more accessible than courts, thereby recognising that implementation and actualisation of rights is critical to the success of the law, and efforts to control HIV.

Introduction

The emergence and spread of HIV/AIDS was a tragic but unique event in the annals of human health. It was tragic because many millions perished due to the epidemic before life-sustaining treatment was made available (although the tragedy is even more acute in many ways today when millions still in need of such treatment are unable to access or afford it

for varied reasons) (1). It was unique because along with great sadness, loss, and helplessness, the epidemic also unleashed a brand of patient activism hitherto unseenⁱ. It was this activism, which made policy-makers, legislators, health bureaucrats, and practitioners realise that isolation and stigma were only going to fuel the spread of HIV, by pushing sexual and other HIV-related human behaviours and conduct “underground”. The activism of people affected by HIV also gave real meaning to the phrase, “*nothing for us without us*” – their robust participation in policy decisions and implementation of programmes led to stellar responses to control HIV in many parts of the world.

This advocacy led to the shaping of a “rights-based” inclusionary approach that empowered people, including the most vulnerable, to access health and related services, and was demonstrably seen as the most effective approach to encourage people towards health-seeking behaviour to protect themselves and those they had sex with, or shared drugs withⁱⁱ. Such an approach required multi-pronged efforts: skilful counselling services for people seeking HIV-related services; widespread messaging to provide preventive information and commodities (such as condoms, and appropriate gear for healthcare workers to protect themselves); laws and policies that empowered those affected or vulnerable to HIV (often deeply stigmatised people such as sex workers, transgender people, drug users, men who have sex with men, and people living with HIV) so that they were encouraged to access vital information and services instead of being shunned by society and criminalised by the law; and, significant investment in improving health delivery and provision of treatment when it finally arrived.

It was this “rights-based” approach that the global community adopted as the international response to HIV, after some trial and error with punitive and coercive policies and mindsets that only made an already elusive virus spread more stealthily in dangerous ways. As part of the community of nations, India too adopted this approach through a national HIV/AIDS control programme – an effort of government together with civil society and NGOs (often at odds, sometimes in unison, but always with the common aim to quell the epidemic)ⁱⁱⁱ.

Although late by several years, today India has reached a point when an important, and for the most part, epochal law has been passed to crystallise the “rights-based” approach to HIV in written statute (2). The journey of the making of the law has itself been unique, and it reflects fully the principles

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of participation and inclusiveness in its making and shaping. Those most affected by such a law – people living with HIV, those most vulnerable to the epidemic (the aforementioned deeply stigmatised), and people encountering HIV in their lives (at the workplace, in healthcare settings, etc.) were all part of extensive discussions across the country in the early 2000s when the law began to be conceived. Indeed, in the spirit of union, the making of this law emerged from a non-partisan request by Indian lawmakers in 2003, supported by all the then major political parties. And, in the spirit of a national HIV response that was multi-pronged and multi-sectoral, the request was made to the pioneering non-profit organisation Lawyers Collective HIV/AIDS Unit (LC) to devise and submit draft legislation. LC negotiated that it would submit the draft after consulting with the vibrant, active and vastly experienced civil society that had engaged with HIV in India over many years. Thus began a two-year long process of comparative law research on legislative efforts elsewhere, which led to the publication of *Legislating an epidemic: HIV/AIDS in India* (3) and consultation with hundreds of stakeholders in India, before the draft law was submitted to the National AIDS Control Organisation (NACO), Ministry of Health, in 2005^v.

Anti-discrimination extends to the private sector

The law that has been recently passed – the *Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (Prevention and Control) Act, 2017* ("HIV Act") (2) – does indeed bear resemblance to that draft of 2005^v. Precedent-setting, salutary provisions have been retained. Chief among these is Section 3, which prohibits discrimination across the board for the first time India. Until now, the right to be treated as equal in the eyes of the law (and to therefore have a claim against an act of discrimination) has been guaranteed by Articles 14, 15, and 16 – Fundamental Rights in the Indian Constitution. This protection could only be enforced against the "State" viz government entities (defined by Article 12, and clarified by judicial interpretation)^{vi}. For the first time in Indian law, the HIV Act extends the protection of non-discrimination against private actors too, inasmuch as the discrimination due to HIV status occurs against people living with HIV and their kin in the contexts of employment, healthcare, education, mobility, accommodation, insurance coverage, use of public services/facilities, custodial settings, and in standing for public office (2:Sec3). Discrimination has been a much too frequent experience for people living with HIV, and the aim of this provision is to deter it in these aspects of public activity (4). Indeed, the assurance of non-discrimination to people living with HIV can contribute in enhancing not just the individual's life but can also mitigate the stigma that surrounds HIV and AIDS, thereby contributing to a strengthened response that addresses underlying determinants of HIV vulnerability, and serves public health needs.

Although Section 3 is a significant protection for people living with HIV, one crucial aspect of this anti-discrimination provision has been left out of the original draft that was

submitted to NACO after widespread consultation^v. People vulnerable to HIV – sex workers, transgender people, people who use drugs, men who have sex with men – have been excluded from its protective ambit. The original draft prohibited discrimination on "HIV-related grounds," which included "HIV status, actual or perceived," "actual or perceived exposure to HIV," or conduct that "perpetuates ... systemic disadvantage ... against a category of persons..." This language was intended to cover people vulnerable to HIV. The logic of this earlier version was that such highly disenfranchised, stigmatised and criminalised people should be empowered to seek health-enhancing services by facilitating a conducive and enabling social environment that allowed them to access healthcare, employment, educational and other facilities and opportunities in a non-discriminatory manner. Emerging from rights-based underpinnings, such framing of the law was not only the right thing to do in achieving an equitable society, but would also have served public health goals by bringing people in from the margins to access health services, which would in turn become increasingly sensitive to their contexts and needs over time. (Indeed, India's new *Mental Healthcare Act* guarantees non-discrimination on the grounds of sexual orientation, (5) which begs the question why it was thought fit to remove the application of non-discrimination to those vulnerable to HIV, including homosexual men in the HIV Act.) Not recognising the need to address these marginalisations only reinforces the alienation that disenfranchised people feel towards mainstream services and opportunities, invisibilising their lives, and allowing HIV to fester in hidden, ignored contexts. Imagine a world in which the mandate of the law required institutions to treat sex workers with dignity and equality. Over time, insensitive hospitals would be forced to become responsive to sex workers' needs, and hostile venues would become hospitable safety nets where health concerns would be fully addressed, and HIV could be nipped in the bud. Such a scenario would have been given great impetus if the HIV Act had extended its anti-discrimination protection to those known to be historically vulnerable to HIV.

Additionally, this gap in the HIV Act creates a complicated (and possibly legally questionable) situation whereby, for example, a sex worker who is denied private healthcare services because of her occupation will have no legal standing to challenge such exclusion, whereas a sex worker who is HIV-positive will have protection under the law.

Legislating consent and confidentiality

With another first in Indian law, the HIV Act also stipulates clear standards of informed consent and confidentiality to be maintained in relation to HIV status between patients and health workers. What were hitherto standards developed through judgments and common law or in the Medical Council of India's Code of Ethics Regulations (6) have now been given legislative gravitas. Indeed, such standards can and should be adapted and applied across the health sector irrespective of the health condition that a person may have.

In recognition of the autonomy of the individual, the law lays down the principle that informed consent is a requisite for HIV testing and treatment, and that it needs to include pre- and post-test counselling services (2: Sec 5). Although the law leaves much of the methodological detail to obtain informed consent to be formulated through guidelines, it stipulates well-accepted legal principles that exempt the requirement for informed consent including when required to follow court orders, for epidemiological reasons, and in cases of blood, tissue, and organ donation (2: Sec 6).

Giving primacy to the right to privacy, the HIV Act protects the forced disclosure of HIV status by any persons (except if required by court order), and requires the maintenance of confidentiality of HIV status by knowledgeable persons who are in a fiduciary position unless informed consent for such disclosure is obtained (2: Sec 8). As is the case with other public health-related legislation certain exceptions to non-disclosure are also provided for, including in court cases and legal proceedings, in situations of shared confidentiality between healthcare workers in the best interests of the patient, in appropriate cases of partner notification as laid down in Section 9, and for statistical surveillance if the disclosure does not lead to revealing the identity of the person (2: Sec 8). Indeed, all rights come with responsibilities; in free societies the assurance of rights is the rule, while curbing them remains the exception. As the Supreme Court of India recently pointed out while upholding the paramount nature of the fundamental right to privacy, "Natural rights are not bestowed by the State. They inhere in human beings because they are human" (7). Privacy, and its cousin confidentiality are of that nature, yet they can be limited in very exceptional circumstances. This is what the HIV Act does in balancing the rule to maintain confidentiality of HIV status with the need to disclose in certain cases. Confidentiality is not only embedded in the Act as a corollary of the right to privacy, but also as a sound public health strategy. After all, if it were not assured people would shun approaching a health system, which could expose them to social opprobrium by revealing their HIV status without limits drawn by the law.

Section 9 of the HIV Act provides a detailed protocol for partner notification with built-in safeguards to ensure that a balance is maintained between a person living with HIV to retain confidentiality of status, and a partner who may be at risk of being transmitted HIV (2: Sec 9). The section allows only the person's physician or counsellor to make such disclosure to a partner after being satisfied that the partner is at significant risk of transmission, that the person is not going to inform the partner despite being counselled to do so, the person has been told of the intention to notify the partner, and that the partner is told in person after receiving counselling. An exception to partner notification is made even when it satisfies these conditions – when a healthcare provider reasonably apprehends that the person living with HIV is a woman who will be subject to violence, abandonment or other severe actions by her partner (2: Sec 9).

Closely linked to the issue of confidentiality and partner notification is the often-ill-informed debate that swirls around the criminalisation of HIV transmission. Those in favour of criminalisation argue that penal law is the only blunt instrument that will deter people living with HIV from transmitting to others (particularly women). Little do they realise that the vast majority of HIV transmission occurs unknowingly, or that it is often women who get tested first and are then blamed for transmitting to their husbands or to their children through breastfeeding (8). As the Global Commission on HIV and the Law pointed out in its seminal 2013 report, "Risks, rights and health", "*Criminalisation is justified under one condition only: where individuals maliciously and intentionally transmit or expose others with the express purpose of causing harm... existing laws – against assault, homicide and causing bodily harm, or allowing intervention where a person is spreading communicable diseases – suffice to prosecute people in those exceptional cases*" (9). It is this very approach that the HIV Act has taken, in recognition of Section 270 of the Indian Penal Code, which penalises a person who knowingly, intentionally, or maliciously spreads a life-threatening disease (10: Sec 270). Given the existence of this general law, Section 10 of the HIV Act instead stipulates the duty to prevent HIV transmission by a person who is HIV-positive, has undergone counselling, and is knowledgeable about the nature of HIV and its transmission. This duty includes taking risk reduction measures with or self-disclosure to a partner (2: Sec 10). The object of this provision is to apply a responsibility to take care of an informed HIV-positive person – of their sexual or needle-sharing partners, to mitigate the rash and malevolent behaviour envisaged by the penal code.

In these times of concerns around State surveillance linked to the Aadhaar scheme (11), the HIV Act requires all institutions keeping records of HIV-related information to adopt data protection measures in accordance with guidelines to be devised in this regard (2: Sec 11). Adequate precedent on robust data protection measures of health records exists globally, which will hopefully form the template for devising guidelines under the HIV Act^{vii}.

Linked to the issues of informed consent, confidentiality and non-discrimination, the HIV Act laudably also retains crucial provisions that provide health workers with a much-needed right to a safe working environment (2: Sec 19). Section 19 stipulates that institutions providing healthcare services and other venues which carry a significant risk of occupational exposure to HIV shall ensure universal precautions and post-exposure prophylaxis to all workers who may be occupationally exposed to HIV and train and educate them on their use and availability.

Safe havens within criminalised contexts

Another vital and commendable aspect of the law is the assurance of "safe havens". As pointed out above, many of those needing HIV-related services are the vulnerable sex worker, injecting drug user, man who has sex with men or

transgender person. All of these people and their communities live fundamentally criminalised lives in one way or another (9). Well-established efforts by organisations to provide preventive information and services – such as condoms, clean syringes, etc. – are potentially criminalised too for doing so, and workers have been arrested or constantly harassed in the past (12). Section 22 allows an exemption from criminal liability for people accessing and organisations providing such services (2: Sec 22). This, in essence, is meant to be a stopgap arrangement to deal with the inefficacious and misconceived use of criminal law against these groups. Ultimately, however, India must realise that criminalising sex work, homosexual sex, or the person using drugs provides no social value, worsens the lives of people in already marginalised circumstances, and certainly fuels an already devastating HIV epidemic among people in these contexts. Meanwhile, the HIV Act provides some safety for crucial HIV and health information and services to be accessed by and provided to people in these marginalised contexts.

The Right to Health, but not the right to medicines?

An aspect that has received some attention and criticism is contained in Section 14 of the HIV Act. This clause disappointingly qualifies the obligation of the State to provide, inter alia, antiretroviral therapy “as far as possible”, whereas the draft Bill that was submitted to NACO required free of cost provision of antiretroviral therapy premised on every person’s right to the highest attainable standard of health as per the International Covenant on Economic, Social and Cultural Rights, which India is signatory to^{viii}. The watering down of this obligation appears to be a way for the State to avoid responsibility for providing essential medication for those living with HIV. This is particularly dangerous given that the discontinuation of or the inconsistent taking of antiretroviral therapy can cause drug resistance and severe health complications (13). Moreover, treatment-as-prevention research has conclusively shown that the consistent use of antiretroviral therapy can reduce the viral load to such a negligible extent that a person living with HIV is prevented from transmitting to a sexual partner (14). Yet, it is somewhat reassuring to note the Health Minister being quoted in Parliament as stating that “[the] government is committed to (treating every patient) and no one will be left out” (15).

Addressing the bane of implementation

Finally, a law that provides substantive rights is likely to be futile in actualising those rights (and in this case, contributing to HIV control efforts) if it is not endowed with rigorous obligations and systems to ensure effective implementation. This law retains most of the enforcement mechanisms that were suggested in the original draft. Institutions of a certain size are required to set up grievance redress mechanisms with complaints officers (2: Sec 21), and state governments are expected to appoint and vest powers and obligations under the law with ombudspersons (2: Chap 10). These mechanisms are intended to be cost-effective and speedy ways in which aggrieved people can seek justice and alternative (but not replacement) options to an often archaic, expensive,

and inaccessible court system. Special procedures such as suppression of identity orders to facilitate litigation by people living with HIV to approach courts (2: Chap 12), and civil liability instead of the futile criminalisation of violators (2: Chap 13) are also given a fillip in the law.

Indeed, the HIV Act is a positive, progressive, social legislative measure that should contribute in effectively dealing with the HIV epidemic where it continues to fester – in groups of people who find themselves marginalised and vulnerable. It has come to pass after inordinate delay, and will only bear fruit if it is backed with financial and human resources that ensure its effective and humane implementation. Moreover, it is hoped that the HIV Act acts as a precursor for broader health legislation to provide rights and obligations in the context of healthcare, make health systems and personnel more accountable, and fully realise the right to health for all Indians.

Note: *The author was part of the core team that drafted the HIV Bill, and led the wide-ranging consultation process for it while managing the Lawyers Collective HIV/AIDS Unit in the 2000s.*

Notes

- i For an illustration of activism in India see <http://www.thehindu.com/news/cities/mumbai/the-shining-legacy-of-dominic-dsouza/article18449535.ece>. Activist experiences from the United States and South Africa can be found at <https://www.theatlantic.com/health/archive/2011/12/before-occupy-how-aids-activists-seized-control-of-the-fda-in-1988/249302/> and <https://quod.lib.umich.edu/p/passages/4761530.0010.011/-tac-in-the-history-of-rights-based-patient-driven-hiv-aids?rgn=main;view=fulltext>
- ii For an early description of the rights-based approach to HIV/AIDS see, Gostin, Lawrence, “A Tribute to Jonathan Mann: Health and Human Rights in the AIDS Pandemic”, 26 J.L. Med. & Ethics 256–258 (1998) available from <http://scholarship.law.georgetown.edu/cgi/viewcontent.cgi?article=1746&context=facpub>.
- iii International agreement on the HIV/AIDS response and human rights imperatives for the same were first reflected in the UNGASS Declaration of Commitment on HIV/AIDS, 2001. Available from: http://www.unaids.org/sites/default/files/sub_landing/files/aidsdeclaration_en_0.pdf. This has been succeeded periodically by the UN Political Declaration on HIV/AIDS, 2006 (http://www.unaids.org/sites/default/files/sub_landing/files/20060615_hlm_politicaldeclaration_ares60262_en_0.pdf), 2011 (http://www.unaids.org/sites/default/files/sub_landing/files/20110610_UN_A-RES-65-277_en.pdf) and 2016 (<http://www.unaids.org/en/resources/documents/2016/2016-political-declaration-HIV-AIDS>).
- iv An overview of the process is available from [http://www.lawyerscollective.org/files/ENGLISH%20\(July%202007\)%20FINAL%20COPY.pdf](http://www.lawyerscollective.org/files/ENGLISH%20(July%202007)%20FINAL%20COPY.pdf) and <http://www.lawyerscollective.org/our-initiatives/hiv-and-law>
- v The original draft that was submitted to the government in 2005 is available from <http://www.lawyerscollective.org/files/Final%20HIV%20Bill%202007.pdf>.
- vi Article 12 of the Constitution of India states, “In this part, unless the context otherwise requires, the State includes the Government and Parliament of India and the Government and the Legislature of each of the States and all local or other authorities within the territory of India or under the control of the Government of India.”
- vii See, for example, the UK’s Data Protection Act 1998, and the Access to Medical Reports Act 1988 Available from: <http://www.aidsmap.com/Access-to-medical-records/page/1505571/#item1505575>
- viii The International Covenant on Economic, Social and Cultural Rights is a foundational human rights document that the vast majority of countries are signatory too, including India. Article 12 (1) requires States

to recognise "...the right of everyone to the enjoyment of the highest attainable standard of physical and mental health." Available from: <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CESCR.aspx>

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Medical ethics in times of conflict – why silence is not an option

JOHN CHISHOLM, JULIAN SHEATHER

Abstract

In this commentary we argue that medical ethics has a key role in discussing the effects of conflicts and other violent human rights abuses. Contemporary medical ethics is an emerging academic discipline without clearly defined boundaries and we have no desire to impose them. We are seeking instead to indicate the kinds of issues that naturally and ordinarily arise within its purview. Recent history has seen a closer relationship and interdependency between medicine and the state. This has led, at times, to tension between professional obligations and state interests. Many would prefer medical ethics to step aside from sectarian politics and focus on the doctor-patient relationship and the objective and neutral medical sciences that underpin

it. However, given the role that social inequities play in health outcomes, doctors have been obliged to speak out against such inequities or even against state practices which directly contribute to poor health. For those committed to the impartial practice of medicine, and to the promotion of human wellbeing, silence during times of conflict is seldom an option.

Introduction – politicising medicine

In her foreword to the British Medical Association's (BMA) handbook on medicine and human rights, Dr Wendy Orr, a former District Surgeon in Port Elizabeth in South Africa, writes with great force about working with detainees during the apartheid regime (1). She describes how, as a young doctor, she became aware of the systematic abuse of detainees by the security forces and the silence, complicity and evasiveness of her medical colleagues. She recounts her disbelief and growing moral disorientation as she realised she was expected to declare patients "fit" for punishment, to provide medical witness to regular canings and to turn a blind eye to torture and other forms of physical abuse. Dr Orr's moving testimony is, sadly, only one example in the handbook of the many ways in which the provision of healthcare has been compromised by state pressures during times of conflict and tension. Other conflicts cited include the Balkan wars of the 1990s where health professionals were targeted and killed for treating

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