**The HIV Act – better late than never**

*By Vivek Divan*

The emergence and spread of HIV/AIDS was a tragic but unique event in the annals of human health. It was tragic quite obviously 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). It was unique because with great sadness, loss and helplessness in the face of it, the epidemic also unleashed a brand of patient activism hitherto unseen. It was this activism, which made policymakers, 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 seen as the most effective approach to encourage people toward health-seeking behaviour to protect themselves and those they had sex with, or shared drugs with. 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 like sex workers, transgender people, drug users, men who have sex 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 nefarious and 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).

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. The journey of the making of the law itself has been unique, and it reflects fully the principles 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 unison, 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 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 2-year long process of research on legislative efforts elsewhere, and consultation with hundreds of stakeholders in India, before the draft law was submitted to the National AIDS Control Organisation, Ministry of Health in 2005.

***Anti-discrimination extends to the private sector***

The law that has been recently passed – the *Human Immunodeficiency Virus & Acquired Immune Deficiency Syndrome (Prevention & Control) Act, 2017* (“HIV Act”) – does indeed bear much resemblance to that draft of 2005. 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 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 & 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). For the first time in Indian law, the HIV Act extends the protection of non-discrimination against private actors too, inasmuch as the discrimination occurs against people living with HIV and their kin due to HIV status in the contexts of employment, healthcare, education, mobility, accommodation, insurance coverage, use of public services/ facilities, custodial settings, and in standing for public office. 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. 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 the Section 3 is a substantial 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. People vulnerable to HIV – sex workers, transgender people, people who use drugs, men who have sex men – have been excluded from its protective ambit. The logic of this earlier version was that such highly disenfranchised, disliked 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, the India’s new *Mental Healthcare Act* guarantees non-discrimination on the grounds of sexual orientation, 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 marginalizations only reinforces the alienation that disenfranchised people feel towards mainstream services and opportunities, invisiblizing 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.

***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 Medical Council of India’s Code of Ethics Regulations 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. 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.

While upholding 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. 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.

Section 9 of the HIV Act provides an extensive 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. 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 counseled 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 counseling. 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.

Closely linked to the issue of confidentiality and partner notification is the often ill-informed debate that swirls around the criminalization of HIV transmission. Those in favour of criminalization 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 realize 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. As the Global Commission on HIV and the Law pointed out in its seminal 2013 report, ‘Risks, Rights & 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.*” It is this very approach that the HIV Act has taken, in recognition of Section 270 of the *Indian Penal Code*, which penalizes a person who maliciously spreads a life threatening disease. 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 counseling, 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.

In these times of concerns around state surveillance linked to the Aadhar scheme, 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. 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.

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. 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. 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. Section 22 allows an exemption from criminal liability for people accessing and organisations providing such services. 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. In the 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, anti-retroviral therapy “as far as possible”, whereas the draft Bill that was submitted to NACO required free of cost provision of anti-retroviral 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. 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 anti-retroviral therapy can cause drug resistance and severe health complications. Moreover, treatment-as-prevention research has conclusively shown that the consistent use of anti-retroviral 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. Yet, it is somewhat reassuring to note the Health Minister being quoted in Parliament as stating that “*government is committed to (treating every patient) and no one will be left out.*”

***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 (Section 21), and state governments are expected to appoint and vest powers and obligations under the law with ombudspersons (Chapter 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 (Chapter 12), and civil liability instead of the futile criminalisation of violators (Chapter 13) are also given a fillip in the law.

Indeed, the HIV Act is a positive, progressive social legislation 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. Furthermore, 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.

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