

Controlling the HIV Epidemic with Antiretrovirals

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I am indeed honored to deliver the Jonathan Mann Memorial Lecture before this august gathering. It is appropriate that Mann's legacy be continued through such a series of lectures. Not only was he amongst the first to fashion the international response to the HIV pandemic but, more importantly, the first to bring to the HIV response the discourse of Human Rights and make it its central and integral feature. His legacy not only needs to be remembered but also built upon. For his insights provide us critical ideas for our future work.

Now that HIV is on the wane, it becomes necessary to take look at what happened, from the early days, when it was an emergency all over the world through when it became a treatable, chronic ailment to present phase when we are thinking of eliminating it altogether, the lessons it holds for us, the HIV and the Human Rights communities.



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During the early phase of HIV, it was difficult to identify People Living With HIV (PLHIVs) because they were asymptomatic and healthy for a considerable period of time. Moreover as HIV is also a sexually transmissible disease, it could spread across boundaries of race, class, nationalities etc. Nobody was immune. Most importantly, HIV spelt a death sentence. This created a fear psychoses, stigma and prejudice. It attracted unprecedented attention across the world. More so because HIV was detected first amongst white gay men. While this reinforced prejudice, it was perhaps fortuitous that HIV was indeed detected in the US where a movement could mount a response at the time. Just imagine the situation if HIV had been detected amongst people in a developing country!

Though gay men were a marginalized community and discriminated against in the US, the gay and lesbian movement had already picked by the time HIV hit America in 1981. As death stared in their face they were able to mount a rights-based response built on community activism. In the deafening silence of the US administration that greeted Gay Men from 1981 to 1987, their demand that the US President address the AIDS crisis was significant and led to the Ryan White Care Act, a federally funded program for treatment of PLHIVs in the US. Community activism, combining both the direct experiential knowledge and the intellectual knowledge of HIV, defined the text of the movement. Experience and pain gives one the passion to climb mountains. Intellect, on the other hand, gives one the ability to keep on the right track. This unity of pain, experiential learning and passion and reason, intellect and logic was to define activism on HIV all over the world.

The classical public health response to pandemics involving communicable diseases was to test, identify and isolate those living with the disease (the isolationist response). By the late 1980s, over 80 countries, including those in Europe and North America had such isolationist legal



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responses to HIV. In my own country, India, the first law on HIV in Goa did precisely that. Because of the nature of the epidemic, it was impossible to carry out this strategy. In practice it was the marginalized communities that were targeted (the so-called high risk groups of sex workers, drug users, gay men). It was in the challenge to that law on constitutional grounds in a case relating to the first Indian HIV activist, Dominic D'Souza that I got involved in the HIV movement.

It has rightly been noted that, *“into this moral and ethical fray entered Jonathan Mann with his insistence on logical and compassionate concern for each individual that led public health authorities to perhaps their finest hour.”* Later Mann was able to identify *“the vulnerability of the people to HIV on account of the marginalization, stigmatization and being discriminated against.”* In each society, Mann wrote that, *“those people who were marginalized, stigmatized and discriminated against - before HIV/AIDS arrive - have become over time those at highest risk of HIV infection”*. Mann was clear that without rights HIV will proliferate. Mann thus *“called for respect for human dignity and social justice, insisting upon their necessity not only for economic development, but also for the protection of any population’s health”*. Mann’s colleague and my guru, Justice Michael Kirby developed the rights paradigm in what he termed the HIV paradox namely, that the *“recognition of and respect for individual human rights does not impede prevention and containment of HIV, but actually enhances it”*, reminding us that classically it has been thought of otherwise.

With his passion and sheer logic Mann was able to convince a large number of States to a compassionate and human rights based response to HIV. It is the aspect of dignity that is central to Mann’s thinking that I would like to tease out in this lecture.



What then were the elements of the rights based response to HIV? In the early days till the mid nineties, there was no treatment for HIV. Without treatment there was no incentive to know one's HIV status. Rather, to a PLHIV, an HIV positive result meant negative consequences such as loss of job, housing and being ostracized from the community or even the family. The biggest issue was how to tackle stigma and discrimination. As testing was directly linked to stigma and discrimination, the rights issues that this raised were, (a) no testing without informed consent, which emanated in the autonomy of the individual; (b) maintaining confidentiality of the person tested HIV positive, which directly related to her/his privacy, and (c) preventing discrimination, that is ensuring equality. All these human rights impinge on the dignity of the individual. They are the elements of the right to health approach, which I have elaborated elsewhere. In developing countries, this posed a huge problem, as these rights, except for discrimination by the State, were not entrenched in practice.

Thus, in India, our first challenge was to introduce this specific set of ideas of the rights discourse relating to the dignity of the affected individual, into the HIV response. We did this by advocacy within the government, the medical profession and in simultaneously attempting to build confidence in the communities of PLHIVs, sex workers, drugs users and gay and transgender groups. We even had a verdict from the Supreme Court that PLHIVs could not marry. That only gave us an impetus to further argue for the protection of rights and ultimately, overturn the verdict. In this, we were aided by the fact that most of the knowledge about HIV was within international multi-lateral organizations, the issue had not taken overt political overtones domestically and decision makers (mainly bureaucrats) were willing to listen to technical experts. This was pushed by a well-informed civil society, which resisted the



isolationist strategy and promoted the integrationist response. Our advocacy made a huge difference. Ultimately the Government in India adopted a rights discourse.

Yes, informed consent, confidentiality and non-discrimination were introduced. However there was a crucial difference in the way the marginalized groups were seen.

In India, like in many developing countries, as Mann recognized, HIV was heterosexually driven. The key question for developing countries was to understand the dynamics of this transmission. Fortunately, epidemiologists recognized that transmission amongst the heterosexual population in India was primarily conducted by male clients to sex workers, sex workers to clients and then to their wives. Instead of preventing PLHIVs from marrying, as was being advocated, epidemiologists were able to successfully argue that what was needed was a program of high rate of condom use amongst clients of sex workers. This would be more effective in cutting HIV transmission, ultimately, to married women. The government followed the strategy of empowering sex workers to negotiate condom use with clients. A legitimate question does arise why clients were not directly targeted for using condoms. Different governments followed variants of this strategy. There was the 100% condom program in Thailand. In India, we followed the bottom up approach.

We had a good example to go by in sex workers in *Sonagachi* in Kolkata that enunciated the 3 Rs to get sex workers to negotiate condom use with their clients, namely, Respect sex workers; Recognize their wisdom, ingenuity and capacity; and Rely on their knowledge and skills as professionals. It was rooted in the dignity of sex workers. The group themselves evolved a code of conduct - 'no condoms, no sex.' The results, in terms of preventing HIV transmission were



impressive. Building on this pool of collective consciousness and human solidarity, the same group of sex workers is today, confronting other social-ills like human trafficking, violence against women and also extending support to other marginalized groups in society.

This community led model led to one of the largest program of condom promotion through empowering sex workers. The results were there for all to see. A study, later published in the *Lancet*, vindicated this position. This strategy (loosely termed harm reduction) was also adopted for injecting drug users (clean needle syringe supply program) and amongst Men having Sex with Men (MSM) (condom promotion).

This period saw the government encouraging the setting up self-help groups of PLHIVs, sex workers, drug users and gay men. This was unthinkable earlier. These networks were, apart from experience sharing groups, crucial in imparting information and knowledge on HIV and advocating for their rights. Unlike all other epidemics before it, HIV was defined by the active participation of such networks, communities combined with NGOs that exemplified the unity of intellect and emotion; reason and pain and science and passion, to achieve paradigm shifts.

While it was good that the government had taken up what we considered to be the “rights based approach” on board, it is important to note that there was a crucial difference between our thinking and that of the government. To its credit, the government had, notwithstanding criminal laws, agreed to reach out to marginalized groups, i.e. sex workers, men having sex with men and injecting drug users. Over a period of time, we thought, that this would evolve into addressing the issues of sex workers holistically, including punitive laws, which impaired the rights and dignity of sex workers. This is where we were wrong.



Governments did not look at these concerns the way we did. For them, what mattered was the prevention and control of HIV. The Government adopted a utilitarian strategy of using marginalized groups only to prevent HIV transmission, a public health goal. Governments saw empowerment of sex workers limited to ensuring that they were able to negotiate condom use. Addressing issues of criminalization, violence, social and legal protection of sex workers was not their concern.

The same goes for people who inject drugs. The strategy adopted was to provide clean needle syringes. However, the others issues concerning people who use drugs, particularly decriminalization of consumption and possession of drugs for personal use, though raised were left unaddressed. Similarly, Hepatitis C, a parallel epidemic amongst injecting drug users, which is transmitted in the same way as HIV, was largely unattended to in the developing world, such that even accurate data of prevalence is not available. Thus, while HIV amongst injecting drug users was addressed, hepatitis was not. A PLHIV will not die due to “AIDS related complications” but because of Hepatitis C. That speaks volumes of the respect and dignity we accord to people who inject drugs.

Fortunately, we were able to mould the response a bit, not through the government but through the judicial route. After a very important case that we won on HIV, to prevent discrimination in employment in the Bombay High Court, gay men sought legal advice from us. We challenged the infamous section 377 of the Indian Penal Code, which criminalized same sex relations, on constitutional grounds. We got a very good decision from the Delhi High Court, which based on, amongst other grounds, that of human dignity. The Court held that the



offending section *“denies a person's dignity and criminalizes his or her core identity solely on account of his or her sexuality.”* It recalled a decision of the Canadian Supreme Court, which stated that, *“dignity requires us to acknowledge the value and worth of all individuals as members of our society. It recognizes a person as a free being who develops his or her body and mind as he or she sees fit. At the root of dignity is the autonomy of the private will and a person's freedom of choice and of action. Human dignity rests on recognition of the physical and spiritual integrity of the human being, his or her humanity, and his or her value as a person, irrespective of the utility he can provide to others.”*

If one has to make an assessment of the HIV response in developing countries one has to come to the conclusion that its strength was in its pragmatism; it was the only state program that recognized marginalized groups as such and proactively reached out to them with services. However, the weakness in the response was that despite acknowledging the nexus between disempowerment, vulnerability and disease, it did not go beyond HIV. It was not rooted in the dignity and humanity of the individual, which meant addressing all issues affecting the individual.

The irony about the success of combating HIV is, that unlike in any other response to any disease in history, affected communities were central to the HIV response, yet the same people do not matter anymore, and are increasingly falling off the table. This, I would submit, is because human dignity has not been central to the HIV response.

Today, in significant parts of the world criminalization of same sex behaviors continues, and at times with vengeance. HIV may have been contained among homosexual men with their full



participation but they may face death penalty for being who they are. Similarly, a substantial number of countries criminalize consensual sex work or activities associated with it. New Zealand has shown the way here but dogmatic attitudes refuse to look at their legal model. The same goes for possession and personal consumption of narcotic drugs and psychotropic substances. Portugal has pioneered a public health approach to drugs, but the ideologically driven war on drugs prevents its wider acceptance. Similarly, the Supreme Court of Canada allowed a supervised drug injecting facility [INSITE] to be continued. The Court found that on balance: *“the potential denial of health services and the correlative increase in the risk of death and disease to injection drug users outweigh any benefit that might be derived from maintaining an absolute prohibition on possession of illegal drugs on INSITE’s premises”*. Again criminalizing HIV transmission is a major challenge, particularly in the developed countries. The laws even penalize when there is no transmission; at times they don't take into account the culpable mental state of the PLHIV accused, or the use of condoms or now, undetectable viral load because of antiretroviral therapy, making them overbroad in their application.

Such criminal laws infringe human rights generally, including the right to health, which requires non-discriminatory treatment and equality in respect of availability, accessibility and acceptability of health facilities, goods and services, and to respect, protect and fulfill the rights of all persons, particularly the marginalized and vulnerable communities. Punitive laws disempower communities and thus impede access to such health facilities, goods and services.

Moreover, criminalization of social behaviors ultimately undermines the inherent value and dignity of individuals so targeted. This in turn diminishes their self worth and further prevents the realization of the right to health and other human rights. Therefore decriminalization of



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such conduct is absolutely necessary to address not only disempowerment but also the dignity of the individual to enable the full realization of the right to health and other human rights.

While the utilitarian model took over and relegated the dignity of the communities to the background, the advent of triple combination Anti-Retroviral Therapy (ART) in the mid nineties changed the Human Rights discourse in HIV radically, particularly on the issue of consent to testing which had dominated the debate till then.

While triple combination treatment ART became available in West, the PLHIVs in the developing countries could not access ART even in 2000. Product patent protection on medicines ensured absolute monopolies so that pharma companies could charge a monopolist price, about US 10,000 per patient annually, which denied access to life saving ART to PLHIV in developing countries. In Southern Africa and other parts of the developing world, HIV was wreaking havoc in the lives of the PLHIV, with thousands dying every day. Mann had recognized this when he stated that of all the walls dividing people in the AIDS epidemic, *"the gap between the rich and the poor is most pervasive and pernicious."* A movement sprang up against this inequality in access to drugs in the international system, led by South African activists.

During the International AIDS Conference in Durban in 2000, Justice Edwin Cameron, an openly gay and HIV positive judge, now the judge of the Constitutional Court of South Africa put it thus: *"In this I exist as a living embodiment of the iniquity of drug availability and access in Africa. My presence here embodies the injustices of AIDS in Africa because, on a continent in which 290 million Africans survive on less than one US dollar a day, I can afford monthly medication costs of about US\$400 per month. Amidst the poverty of Africa, I stand before you*



because I am able to purchase health and vigor. I am here because I can afford to pay for life itself."

The indignation at this inequality and injustice in matters concerning life and death reverberated globally. The call was for all persons, from the rich or poor countries, black or white, irrespective of gender to have their right to life respected unequivocally, through the provision of ART. The movement for treatment, another example of the coming together of pain and passion, rationality and science and was able to garner support from around the world. The message was simple then. The international community – activists, UN organizations, and Governments – were mobilized. Coupled with announcements by Indian generic pharmaceutical companies that ART would be available at USD 350 per patient annually, as opposed to price of 10,000 USD of the MNC. A paradigm shift achieved. As a result, not only PEPFAR was established but also the Global Fund on HIV, TB and Malaria and subsequently UNITAID to fund the purchase and delivery of the ARVs to the developing world.

Indian generic companies were able to do this because of the Indian patent law from 1972 to 2005 that only protected process patents but not product patents. This was consciously changed for this precise purpose. It may be noted that in 1972, India had among the highest prices for medicines in the world. Thereafter, competition flourished and by the 1990s, India had the lowest medicine prices in the world.

Over a period of time ART, has become available around the world. Though, even now there are a significant number who need ART but are not getting it, the gap has narrowed considerably and continues to narrow. Indian generic companies are crucial to delivering ARVs to the



developing world. They supply over 90% of the ARVs (all safe and good quality) at low cost to the developing countries. These are funded by PEPFAR, GFATM and UNITAID and prequalified, thus ensuring safety and quality. In India, for instance, all who need the first line treatment are getting it. Even second line ART would be available in India soon. However, third line treatment would be a problem in India and elsewhere in the developing countries.

The ART rollout in a significant number of developing countries was not possible without the assistance of the PEPFAR, the GFATM and UNITAID. These mechanisms need to be continued and strengthened if we want to tackle HIV and associated diseases of TB and Malaria, and I would argue for the right to health as a whole.

What did availability of ART mean in terms of Human Rights? Our experience in India and others around the world shows that unlike earlier, PLHIVs now prioritize right to treatment and non-discrimination over confidentiality and consent. The introduction of Provider Initiated Testing and Counseling [PITC], where a provider first tests the patient and only if s/he is found to be positive, would counseling be offered; there is no informed consent before testing] was hotly debated in intellectual circles but hardly in community fora. Despite opposition by Human Rights groups, PITC was adopted as the protocol internationally, albeit restoring 'voluntariness' in a diluted form. That was possible because initiation of treatment, considered to be the most important for PLHIV, necessitated testing, and was acceptable even if it was without informed consent.

Please appreciate that informed consent is fundamentally about the respect for the dignity of the patient, to equalize the otherwise unequal relationship in health settings between the



doctor and the patient, obliging health care providers to impart information before testing and encouraging health seeking by communities. The battle in trying to entrench informed consent in developing countries in health care settings may have been lost, but only temporarily.

The scenario in Access to Medicines is changing yet again, which will surely impact human rights. Reality is a bit more complex now.

India, being a signatory member of the WTO has signed the TRIPS agreement, which required it to introduce product patents. It did so in an unusual way. Understanding that in North America and Europe nearly three fourths new patents were being granted to new forms of known substances without any significant increase in therapeutic benefit, India changed its patent law in 2005 by amending section 3(d) which now provides that new forms of known substance will not be patented unless they show significant increase in efficacy. This was a subject matter of challenge and interpretation in the *Novartis* case, which we won. The Supreme Court of India interpreted section 3(d) in the manner that we had contended, namely that efficacy is therapeutic efficacy; physico-chemical properties (hygroscopicity, thermodynamic stability, free flow and processability) are not a matter of therapeutic efficacy and that increased bioavailability by itself would necessarily increase therapeutic efficacy. That would have to be demonstrated independently.

This would help Indian companies to deliver ARVs at affordable cost to developing countries for some time. Indian generic companies may find it increasingly difficult in the future to supply ARVs in the same manner as they have done in the last decade. First, as MNCs will increasingly seek to patent new molecules, Indian generic companies may find it difficult to oppose them.



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Second, a number of Indian companies have been bought out by International MNCs, both originating and generic. This would reduce the incentive for them to challenge patent applications. Third, the EU and the US are putting a lot of pressure on India through their Trade Representatives to change the Indian patent law to allow easier patenting, through Free Trade Agreements. Fourth, MNCs have used the Medicine Patent Pool to enter into agreements with Indian generic companies to effectively reduce competition from them. So the threat of Indian generic companies not being able to deliver affordable ARV in the next decade is quite real. Of course, there are counter strategies, some of which we in the communities are pursuing effectively. However it is anybody's guess who will win out.

What this could imply in terms of inequity on the international scale is quite ominous. In an era where the science has pegged 'Treatment as Prevention', this means that Governments may want to testing larger populations for HIV and start ART treatment immediately. This will again raise the issue of consent and confidentiality. Can testing and then treatment be carried out without informed consent? Moreover most of the developing countries will not be able to afford this strategy from their own resources. We need to persuade governments to put in their own money. But at the same time we need able to expand and run global support for funding in a significant way. Otherwise, it is likely that we may return to the days of 2000 where there was a divide between the developed and developing countries in the matter of treatment, as also prevention.

Simultaneously, in developing countries, there has been a move to integrate HIV services into wider health delivery. That is inevitable. The response to HIV was vertical. That has been criticized. However, I seriously doubt whether the HIV response could have succeeded as a mainstream program in the developing world. The success in the HIV program was based on



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reaching out to the marginalized communities, sex workers, drug users, gay men and PLHIVs themselves. It was based on the activities of these communities and NGOs and the amalgamation of community and science to achieve paradigm shifts. This response would not have been possible in mainstream health systems in developing countries in the early stages. They would not have involved these communities. They were not attuned to the issues of marginalized groups or issues of rights discourse, particularly consent, which was very important in the early days. These are grave challenges in terms of human rights. The success lay in having it as a vertical program outside the mainstream systems. This allowed us to think out of the box and involve communities. It would be now possible to do that with the mainstream health systems as pathways of the involvement of communities have been established.

What is the way forward? Or should I say, what should be our agenda?

There are opportunities staring in our face. The movement to integrate is one. Treatment as Prevention is the other. That apart, there is the post-2015 MDG agenda of Universal Health Care. These are all opportunities where the lessons in the HIV response can be taken and influence the field of health as whole. We cannot afford to be parochial any more. The HIV community is starting to think of health care as a whole. We have to influence the outcome of the debate. In this context, we should seriously consider of commitments from all states for health as a whole on a Human Rights paradigm.

I would return to Mann who *“understood ... the fundamental significance of human dignity in the debate about health and human rights.”*



Our agenda must include the following.

Firstly, respect for the dignity of life should be the defining context in the future of HIV and health response. When HIV services are mainstreamed, we would necessarily have to look the individual's health as a whole not in the parochial tunnel of one disease. The key issues like autonomy and consent would come up again and ought to become the backbone of the response based on entitlements and not give way to utilitarianism.

Secondly, the HIV response should be based on the full participation of the communities affected with NGOs and civil society, exemplified by the unity of pain, experiential learning and passion and reason, emotion and intellect. Communities have to be involved in the policy making, implementation and monitoring and evaluation.

Thirdly, we should ensure that drugs are available and accessible at affordable cost. That will require resisting efforts Free Trade Agreement, Bilateral Investments, which want increasing and easy patenting.

Fourthly, the experience of the HIV response in the context of PEPFAR GFATM and UNITAID shows that the funding must be available to purchase drugs, not only for the HIV response but for the whole health system. This is an imperative. A large number of countries simply cannot afford to fund health care. However, if we want to achieve a paradigm shift we should not only increase funding to these entities but think of increasing their coverage to the whole of health.



Despite the economic crisis, this is possible as the resources for global health can be pooled and made available.

In this globalized world, global solutions are necessary. A global convention on health is the need of the hour. Let us work for it.

I would end with Mann's sentiment. With logic one can have good health care. But it will remain only clinical and cold without passion. It is the passion that makes the difference.

Thank you.