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The unravelling of the human rights response to HIV and AIDS and why it happened: an activists' perspective

Over the last 30 years, many aspects of the HIV response have been 'exceptional'. One of the most remarkable has been the extent to which in theory, policy and (to some degree) practice, the respect for and promotion of human rights have been placed at the heart of the response. As such, the fact that activists have sometimes been accused of promoting 'AIDS exceptionalism' must be viewed as a badge of honour rather than an insult.

My argument, however, is that despite this exceptional response over the last 15 years, inter-governmental, governmental and donor agencies are now retreating from human rights commitments – and have been doing so since 2010. The fortunes of the Joint United Nations Programme on HIV/AIDS (UNAIDS) are emblematic of this. The agency was once a critical ally for activists within the global policy arena; an organisation that stood firmly behind civil society demands for justice and equality in the HIV response. Now UNAIDS is choosing a short-sighted and non-confrontational approach, in part because it has not been able to strategise about how to withstand the backlash against rights led by governments in an era of diminishing resources.

> This essay provides a short history of the rise and fall of the human rights approach. It suggests that the fall might yet be arrested, but only if drastic action is taken by civil society organisations to reclaim the political space created by intense, confrontational and insistent activism.

In the beginning

From the outset it is important to be clear that the public authorities responsible for responding to the HIV epidemic never willingly embraced human rights activists. In fact, the first generation living with HIV[1] in North America faced stark human rights violations. They were denied both basic human empathy and science. Yet they refused to die quietly in the privacy and anonymity of their homes. Instead, for the first time in history, 'patients' demanded their rights, and did so in a manner that fundamentally challenged public health systems and public policy processes. How this came about has been well documented; for instance, by Randy Shilts in his iconic book, *And the band played on*, and more recently in the beautifully told documentary *How to survive a plague*.

However, HIV was unusual for another reason. At first it was a disease that affected people who lived in a developed country. These were people who were used to having their rights to health (if not their sexual orientation) respected.[2] So when these rights were violated because of prejudice and fear about a new disease, they became outraged and they began to organise.

The basis of their mobilisation derived from the fact that they lived in a political environment in which they had a reasonable expectation that their demands would be met. As they began talking about these demands as 'rights', the idea that people with HIV had legal as well as moral claims to treatment, privacy and non-discrimination took root. Quickly this idea became a powerful and legitimising mobiliser.

> It is seldom emphasised in telling the story about AIDS that the first generation of AIDS activists were ordinary people taking control of their own lives and bodies.

They were not seasoned activists well versed in the language of advocacy. They were articulate about their health needs because they needed to be, not because they had professional degrees in public health or human rights law.

It was only when their voices began to be heard by some of the clan of professional health advocates and doctors who were impressed by their anger (and were sometimes the targets of their rage) that an important transition began to occur among public health practitioners.

These early AIDS activists forced the professional health experts to rationalise their claims into a language of 'rights' and thus began developing a new public health theory: one that has since become known as the 'human rights approach' to HIV.

1. Over the duration of the epidemic, language has been one of the battlegrounds where people with HIV have asserted their dignity and rights, refusing to be 'patients' or 'sufferers' or 'victims'. The emphasis has always been on living with HIV/AIDS, although even here language has changed. Today, the accepted terminology is 'people living with HIV'.
See: www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/JC2118_terminology-guidelines_en.pdf
2. This statement should not be read as diminishing the history of structural discrimination against gay people in the United States. The argument is that even within a deeply homophobic environment, American citizens lived, as they do now, within a framework that recognises that they are rights bearers. This fundamentally shaped the ability of gay men and their allies to raise questions about their rights to medicine, the fruits of scientific enquiry, and so on.

The first person to do this in a systematic manner was the late Dr Jonathan Mann, an epidemiologist who had been involved with HIV almost since its discovery.[3] In an interview in 1988 Mann said:

> *I would say that there's always been a human rights dimension to malaria and diarrheal disease and immunization and small pox. But it was never really understood, it was never really seen … and yet with AIDS we see perfectly clearly that if we don't protect the rights of those infected we endanger us all, that the rights of everyone are protected by ensuring that the rights of some are protected.* [4]

Today, Mann is credited with being one of the architects of the human rights approach to HIV. The significance of his contribution lies partly in the fact that he took the urgency and activism he saw on the streets and tried to import it into the often rigid and stagnating institutions that existed to address global health. Mann worked to ensure that this anger was heard within the World Health Organization (WHO) where he was employed at the time. Promoting human rights was a fundamental objective of the Global Programme on AIDS that Mann was instrumental in forming in 1986, and from which he resigned in 1990 in disagreement with the former WHO director-general Hiroshi Nakajima.

Following in Mann's footsteps, other important early exponents of the human rights approach included Australian legal scholar Michael Kirby, who built on Mann's intellectual and practical work to advance the notion of the 'AIDS paradox' and later became a member of the Australian judiciary.[5] Sofia Gruskin, then a Harvard law professor, was another, as were academics Daniel Tarantola and Larry Gostin.[6]

> What each of these influential early thinkers and actors had in common was a conviction that human rights were inextricably linked to law and legal action.

Self-evident as it now may sound, this idea was incredibly powerful in the early years precisely because violations of the human rights of people living with HIV were endemic in most government responses to the virus. Mandatory HIV testing of what were then called 'high-risk groups', travel restrictions and even quarantine were commonplace. This led to the creation of legal clinics, pioneered by organisations like the Terrence Higgins Trust in the UK, the Canadian HIV/AIDS Legal Network and later the AIDS Law Project in South Africa. These institutions provided tangible services related to the rights of people living with HIV.

The human rights approach to HIV can therefore be said to have originated in developed countries because they were the earliest locus of the epidemic. Initially, the approach transferred to Africa and other parts of the developing world only tentatively and intermittently. It seemed as if the idea could only ignite in a given

3. Ligon-Borden, B.L. (2003), 'Dr. Jonathan Mann: champion for human rights in the fight against AIDS', *Seminars in Pediatric Infectious Diseases,* 14 (4): 314–22. According to Wikipedia, "Mann proposed a three-pronged approach to the fundamental issue of the relationship between health and human rights. First, health is a human rights issue. Secondly (and conversely), human rights are a health issue. Human rights violations result in adverse health effects. Thirdly, linkages exist between health and human rights (a hypothesis to be rigorously tested). Literature substantiates the effects of the first two points, but Mann and colleagues proceeded to call for the validation of the third point and challenged the world to practice it." Available at: http://en.wikipedia.org/wiki/Jonathan_Mann_(WHO_official)

4. *Jonathan Mann: the legacy of a human rights advocate* (2009). [Film] Directed by Staffan Hildebrand for UNAIDS. Available at: www.youtube.com/watch?v=kNp5bB10MSc

5. Kirby, M. (1993), 'AIDS and the law', *South African Journal on Human Rights* 1(9).

6. *See* Mann, J. and Tarantola, D. (eds) (1992), *AIDS in the world*, Harvard University Press, especially 'Chapter 13: AIDS and human rights', in which it is stated that "The heated, intense dialogue between public health and human rights has been one of the most unanticipated outcomes of the first decade of the AIDS pandemic". Following in the wake of Mann and Tarantola (1992) came seminal publications such as Godwin J. et al. (eds) (1991), *Australian HIV/AIDS legal guide*, Federation Press; Gostin, L. and Lazzarini, Z. (1997), *Human rights and public health in the AIDS epidemic*, Oxford University Press.

context once enough people had become affected. When the human rights approach did finally land solidly in Africa it met with a powerful set of exponents.

One of the first people to take up the human rights approach in a developing country was Edwin Cameron. Cameron is a South African human rights lawyer, who now serves as a justice on the South African constitutional court. His early work was devoted to using the law to tackle apartheid. However, in the late 1980s and early 1990s, after he himself had been diagnosed with HIV in 1986, he began to turn to the challenges of a rapidly growing HIV epidemic in South Africa, and how the law could confront the wave of stigma and discrimination that accompanied it.

At first Cameron was better known for his practical commitment to tackling HIV and discrimination than for his writings advocating respect for and promotion of the human rights of people living with HIV. Long before Cameron disclosed his HIV status publicly in 1999, he had founded the AIDS Consortium in 1992 and then the AIDS Law Project in 1993. Both these organisations helped to change the HIV and human rights landscape in South Africa. Since becoming a judge, Cameron has gone on to write extensively on HIV, human rights, the law and social justice.[7]

Cameron, Kirby, Mann, the Terrence Higgins Trust, the AIDS Law Project, and the others groups they inspired, engaged the state, policymakers and the courts in ways that contributed to an incremental acceptance of human rights. They were advocates for an approach to HIV that took a long time to be accepted, as was evident in the conflict that led to Mann's departure from the Global Programme on AIDS.

In the face of continued institutional resistance among states that refused to address AIDS from a human rights perspective, the publication of the United Nations (UN) *Guidelines on HIV and human rights* in 1998 was an important turning point that increased momentum around the human rights approach at a global level. The Guidelines were important because they offered support and recognition for the efforts of activists at a national level. They also provided the first set of global standards on HIV and human rights, insisting that no matter the country, a set of rights must be respected for people living with and affected by HIV.

The Guidelines were co-sponsored by UNAIDS and the UN High Commission on Human Rights (UNCHR).[8] They had been drawn up at an international consultation in 1996, which again reflected the crossover of activists into public health academia and vice versa. The Guidelines encapsulated the main components of the human rights approach by advocating for the need for community involvement in policymaking, non-discrimination, preventing the misuse of criminal law, and elaborating on the right of access to treatment and the need to advance gender equality.

In their foreword to the Guidelines, Peter Piot (then executive director of UNAIDS) and Louise Arbour (then UN High Commissioner on Human Rights) "urged governments, non-governmental organisations, the UN system and regional bodies to benefit from and build upon these Guidelines, and to continue to find ways to operationalize their commitment to protect human rights in the response to HIV."[9]

In 2003, reflecting a growing acceptance of the human rights approach to AIDS, UNAIDS created a Reference Group on HIV and Human Rights. This was intended

7. Cameron, E. (2005), *Witness to AIDS*, Tafelberg; Cameron, E. (2014), *Justice: a personal account*, Tafelberg.
8. Coincidentally, this was the year Mann died tragically in an airplane crash.
9. UNAIDS (2006), *International guidelines on HIV/AIDS and human rights. Consolidated version.* Available at: http://data.unaids.org/publications/irc-pub07/jc1252-internguidelines_en.pdf

to help the organisation entrench the human rights approach by examining and advising on a wide range of topics, including developing human rights and legal guidelines and methods to support countries in designing national AIDS strategies, policies and legislation. The Reference Group was also mandated to help develop a strategic approach to integrating HIV/AIDS-related issues into UN human rights treaty bodies, charter-based bodies and other human rights mechanisms.[10]

> During this period, the focus of the human rights approach was largely on protecting civil and political rights – on people's rights to non-discrimination, equality and privacy – and on protecting people with a higher vulnerability to HIV, such as prisoners, sex workers and men who have sex with men.

The emphasis was on elaborating voluntary guidelines, law reform and genteel advocacy. In those countries where the rule of law was respected, when governments violated rights, employers or health authorities, the courts were frequently used to enforce rights. This contributed further to intertwining the human rights response with legal strategies – and the confusion of one with the other. Indeed, one of the exceptional features of the AIDS response is the extent to which the law has become formally involved in protecting and promoting the human rights of people affected by the epidemic. In most other matters related to public health, moral advocacy or persuasion is used far more frequently than the law and the courts.

Enter activists from the left

One of the reasons why the courts have been used so frequently and to such good effect is that activists recognised early on that employing the language of human rights without a strong focus on enforcement would have limited effect. While the late 1990s witnessed a widespread recognition that the human rights approach to AIDS was non-negotiable, the game-changer was to be the rise of a *global* activist movement that reset the agenda for AIDS. This placed human rights at the centre of people's demands for treatment and insisted that governments do the same. A transnational movement on AIDS was something new, but it was not accidental or divorced from the movement I have described so far.

This movement came about because by the mid-1990s the campaigns and protests of North American activist groups such as the AIDS Coalition to Unleash Power (ACT UP) had been highly successful in speeding up research that had led to a new class of medicines that could treat HIV infection. After announcement of the evidence for the effectiveness of highly active antiretroviral therapy (HAART) at the International AIDS Conference in Vancouver in 1996, the clamour began for equal access to treatment for people with HIV everywhere.

In the late 1990s, ACT UP and Gay Men's Health Crisis began to work with activists in South Africa and other parts of the world to share their experiences and methods of organising. However, a full story of the global activist response to HIV, unlike its North American chapter, is yet to be told. Beyond the fragmentary narratives[11] focusing on individuals or single organisations, there is a need for a thorough examination of the transition from a North American-led movement for rights to a global movement led

10. UNAIDS Reference Group on HIV and Human Rights, Public Report of the First Meeting, January 2003. The records of the meetings of this reference group available at: Public report of the first meeting (2003).
11. *See,* for example, Mbali, M. (2013), *South African AIDS activism and global health politics*, Palgrave Macmillan.

by the countries and people most affected by HIV. This essay does not attempt to offer this, but it does include some notes from the South Africa chapter.

People living with HIV such as Zackie Achmat and Gugu Dlamini[12] inspired the second generation of human rights and HIV activists. These activists continued to use demonstration, denunciation and the law to make their claims. The turning point came with the 13th International AIDS Conference in 2000. Holding the conference in Durban, South Africa, brought activists and scientists from the North to the frontline of the Southern epidemic, allowing established activism to fuse with a growing movement. The loudest demand in Durban was for the human right of access to antiretroviral treatment; a demand made to governments, the UN and pharmaceutical companies during the global march for access to treatment held on the first day of the conference.[13]

At its peak, between late 2001 and 2005, the AIDS activist movement was so effective that, tantalisingly, it suggested a possible change to the paradigm of public health responses to disease in general. In the words of Paul Farmer:

> *One of the ironies of our global era is that while public health has increasingly sacrificed equity for efficiency, the poor have become well enough informed to reject separate standards of care. In our professional journals these subaltern voices have been well nigh blotted out. But snatches of their rebuke have been heard recently with regard to access to anti-retroviral therapy for HIV disease.*[14]

During these years, the right to health began to appear more frequently in national constitutions, and a UN Special Rapporteur on the right to the highest attainable standard of physical and mental health was established in 2002. In addition, as the HIV epidemic took an increasing toll on developing countries, both HIV prevention and treatment became more obviously connected with the realisation of social and economic rights. In those heady days it seemed possible that achieving good health might become inextricably linked with respect for human rights, democracy and equality.[15]

This movement remained on the rise throughout much of the decade, and out of its campaigns emerged a steady stream of victories for human rights, each imperfect and incomplete but significant nonetheless.

These can be summarised as follows: growing governmental recognition of civil society as a rights holder and partner in the response to AIDS; rapidly accelerated expansion of access to antiretroviral treatment driven by the assertion that it was a part of the right to health; and curtailing and redirecting the power of multinational pharmaceutical companies, limiting their 'rights' and vesting them with greater responsibilities.

12. Gugu Dlamini never lived to see the fruits of her labour. She was an early AIDS activist in South Africa who was killed by a mob after disclosing her HIV status at a World AIDS Day event in 1997.
13. See TAC and Health GAP, *Global manifesto to save 34 million lives*. [Online] Available at: www.tac.org.za/Documents/Statements/memo.htm Its opening paragraphs read: "The Treatment Action Campaign and Health Global Access Project Coalition (Health GAP) have mobilized the largest coalition of concerned citizens ever assembled to insist on the right to health care and access to life-sustaining medicines. Our march today demanding access to treatment is the most broad-based in the twenty-year history of the HIV epidemic. We bring before you thousands of people from many different countries and perspectives. On our march today are thousands of people living with HIV and AIDS, our friends and families, as well as trade unionists, representatives of political parties, and a wide range of non-governmental organizations. We represent organizations and movements in over 34 countries, many of which cannot be physically present with us today. We are all united with a single purpose, to ensure that everyone – including people with HIV and AIDS – has access to their fundamental right to health."
14. Farmer, P. and Gastineau, N. (2002), 'Rethinking health and human rights: time for a paradigm shift', *Journal of Law, Medicine and Ethics* 30(4): 655–6.
15. It was a coincidence, but an important one, that during this period global political developments also led to a growing recognition of human rights, including the right to health, and their expression in a wide range of international conventions. This, in turn, coincided with growing political recognition that health is socially determined and often directly connected to macro-economic policy. *See:* Hogerzil, H.V., Samson, M., Casonovas, J.V., Rahmani-Ocora, L. (2006), 'Is access to essential medicines as part of the fulfillment of the right to health enforceable through the courts?' *Lancet* 368(9532): 305–11; Backman, G. et al. (2008), 'Health systems and the right to health: an assessment of 194 countries', *Lancet* 372(9655): 2047–85.

Governmental recognition of civil society as a rights holder and partner in the response to AIDS

In 2001, the first UN General Assembly Special Session (UNGASS) on AIDS took place in New York, leading to a Declaration of Commitment on HIV/AIDS being adopted 'without reservation' by 189 countries.[16] Activists from North and South gathered around this meeting to monitor and cajole governments: a practice that became routine at all subsequent UN meetings on AIDS. Several important victories for the human rights approach were reflected in the principles of this Declaration, which were then cemented into the UN system.

The victories included recognising human rights in general;[17] recognising the rights of marginalised and stigmatised groups in particular; and recognising civil society as a stakeholder whose full "involvement and participation in the design, planning, implementation and evaluation of programmes" was now said to be "crucial".[18] A further key victory was the setting of targets and timeframes, along with the acknowledgment that there should be transparency, public accountability and ongoing reporting on progress towards these targets.

> None of these gains would have been possible without civil society activism.

This was able to sustain the momentum around the 2001 Declaration for nearly a decade, contributing an important voice to further meetings of UNGASS and further Declarations in 2006, 2008 and 2011, each of which extended the gains made in the first Declaration.[19]

Rapidly accelerated expansion of access to antiretroviral treatment as a right

The clarion call of the 2000s was for access to treatment. In 2003, activists both inside and outside of WHO had pressured the agency to commit to a target of providing treatment to three million people by 2005 (the '3 by 5' initiative). Later, this transformed into a campaign for universal access to treatment by 2010 – a demand that was also reflected in the G8's Gleneagles communiqué of July 2005, promising the "aim of as close as possible to universal access ... by 2010".

Activist pressure was also influential in a well-intentioned but badly coordinated decision to establish a new architecture for funding the costs of responding to HIV, based on the principles of social solidarity and universal access. In 2002, the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund) was established. This was followed in 2003 by the creation of the President's Emergency Fund for AIDS Relief (PEPFAR) by President George Bush. Then in 2010 the Medicines Patent Pool was formed by UNITAID, with money from an airline levy in Europe. The intention was to seek and pool voluntary licenses so as to make medicines for HIV and tuberculosis more affordable.[20]

16. Available at: www.unaids.org/en/aboutunaids/unitednationsdeclarationsandgoals/2001declarationofcommitmentonhivaids/
17. Paragraph 16 of the UNGASS 2001 Declaration of Commitment on HIV/AIDS.
18. Paragraph 33 of the UNGASS 2001 Declaration of Commitment on HIV/AIDS.
19. Available at: www.unaids.org/en/media/unaids/contentassets/dataimport/pub/report/2006/20060615_hlm_politicaldeclaration_ares60262_en.pdf (*see* paras. 11 and 12).
20. Medicines Patent Pool. [Online] Available at: www.medicinespatentpool.org

The result was an unprecedented expansion in the number of people on antiretroviral treatment, and an attempt to rectify the inequality of treatment access between developed and developing countries. The significance for global health more generally was that it became arguably the first time in history where narrowing the gap between treatment access in North and South became a global political priority rather than just another manifestation of 'unacceptable' (but accepted) health inequality.

All this meant that, whereas at the time of the Durban AIDS conference in 2000 there were almost no people on treatment in developing countries, by the end of 2012 UNAIDS claimed that 9.7 million people were on treatment in low- and middle-income countries. This has led to a huge decline in AIDS-related mortality and (in some parts of the world) rates of new infection.[21]

Curtailing and redirecting the power of multinational pharmaceutical companies, limiting their 'rights' and vesting them with greater responsibilities

In the late 1990s, the world's most powerful private pharmaceutical companies overplayed their hand. In 1997, buoyed by the Agreement on Trade Related Aspects of Intellectual Property (TRIPS) confirmed by the World Trade Organization (WTO) in 1995, they instituted litigation in South Africa to try to stop the government's lawful attempt to amend its Medicines Act in order to facilitate access to cheaper medicines. What they had not factored into their strategy was that this would both enrage and provide a much-needed focus for the emerging global activist movement around AIDS.

In late 2000 and into 2001, an unprecedented global mobilisation of civil society was directed against this attempt to block the new South African law. The catalyst for this was the Treatment Action Campaign (TAC)'s application to be admitted to the case as an amicus curiae (friend of the court) in order to represent the rights of people living with HIV who needed treatment. In April 2001, after the judge ruled that TAC would be admitted, the pharmaceutical companies withdrew their case.[22]

> The victory gave momentum to a tidal wave that swept over developing countries asserting that access to affordable medicines is a human right.

In its wake, a meeting of the WTO ministerial council in November 2001 came under sufficient public pressure as to issue a Ministerial Declaration on the TRIPS agreement and public health, making it clear that states retained the power to grant compulsory licenses to make medicines affordable. According to the Ministerial Declaration, national governments retain sovereignty under TRIPS to "determine what constitutes a national emergency or other circumstances of extreme urgency, it being understood that public health crises, including HIV/AIDS, tuberculosis and malaria and other epidemics, can represent a national emergency or other circumstances of extreme urgency."[23]

Throughout the decade, under pressure from activists, pharmaceutical companies continued to reduce their prices – prices they once defended as "immovable" and "as low as possible". Antiretroviral treatments therefore became increasingly affordable. At the beginning of the decade a first-line regimen of antiretrovirals in

21. *See*: www.unaids.org/en/resources/presscentre/pressreleaseandstatementarchive/2013/november/20131120report/
22. Heywood, M. (2002), 'Debunking "Conglomo-talk": a case study of the amicus curiae as an instrument for advocacy, investigation and mobilisation', *Law, Democracy and Development*, **5** (2), 133-162. Available at: Debunking Conglomo
23. Loff, B. and Heywood, M. (2002), 'Patents on drugs: manufacturing scarcity or improving health', *Journal of Law, Medicine and Ethics* 30(4): 621–31.

South Africa had cost nearly R5,000 a month. By 2010, the same regimen cost less that R500. Today, the cost is under R100.

If we are to sustain these achievements and replicate them in other areas of health, there are lessons to be learnt from the AIDS movement. One of them is the way in which AIDS activists pioneered what they termed 'treatment literacy'. Ordinary AIDS activists were taught the science behind the medicines they needed, as well as the law insofar as it related to their rights and the campaigns that were waged. This empowered the activists for their engagements with governments and pharmaceutical companies.

It also meant that interactions between now scientifically literate activists and HIV clinicians and researchers took place on more equal terms, allowing a real dialogue between the people needing healthcare and the people researching healthcare. This was mutually beneficial. For activists, research became relevant; for researchers, activism helped the release of funds for their work. This contributed to a rapid stream of innovation in medicine and clinical trial design. One outcome was a greater level of innovation in AIDS treatment and prevention in 10 years than in tuberculosis treatment and other neglected but high-burden diseases in 100 years.[24]

This kind of alliance is strongly relevant for those involved in campaigns to reduce other causes of mortality and morbidity across the globe.

Mistakes made by human rights activists

Between 2000 and 2010, activists drove major changes in the global response to AIDS. However, with hindsight it is clear that these activists were also short sighted.

> We became enamoured with our own success, leading us to believe that we had a power and ability to lift the response to HIV to ever-greater heights – a power that, in fact, we lacked.

In many ways, the AIDS movement lacked a political strategy and analysis with which to understand both its strengths and weaknesses.

Three problems in particular were at play.

First, as described above, activism stimulated a major injection of funds into the AIDS response. Formal and informal recognition of the catalytic role of civil society meant that non-governmental organisations (NGOs), community-based organisations and social movements like TAC were showered with unforeseen riches by developed country governments, the Global Fund and PEPFAR. This was possible because of a period of economic expansion in developed countries until the 2008 financial crisis. TAC, for example, grew its budget from less than $100,000 per annum in 2001 to over $5 million in 2009.[25]

However, two under-theorised problems lay ahead, both of which could have been anticipated had NGOs and social movements been paying more attention. One

24. According to TAC, who monitor research on tuberculosis, "The most common TB diagnostic test is over 100 years old, and the only available TB vaccine was introduced in 1921 and offers limited protection to adolescents and adults. Most alarmingly, research over the last 40 years has produced only two new drugs to treat TB. This pales in comparison with the speed of research to tackle two closely related diseases: HIV and hepatitis C. Advances in drug discovery have transformed hepatitis C, once a chronic condition, into a curable infection, and the U.S. Food and Drug Administration has approved 36 drugs or combinations of drugs to treat HIV since 1987." Available at: www.treatmentactiongroup.org/tbrd2014/usg

25. See Heywood, M. (2013), 'The Treatment Action Campaign in South Africa: lessons for and learnings from the labour movement'. Unpublished paper for the Global Labour University.

problem was that the onset of the financial crisis would lead donors to become much tighter with their monies and seek to justify this on the grounds that AIDS was coming under control; that AIDS 'exceptionalism' was no longer justified; and that new global challenges, such as climate change, required their funds.

The other problem was that donors began to resent the pushiness of civil society activists, who were pursuing human rights agendas and demands that inevitably become political and at odds with the conservative policies of donor governments. The civil society agenda for transformation fell well outside the scope of traditional development aid. Campaigning for human rights also led to inevitable clashes with politicians and sometimes accusations by developing states that by funding NGOs, donors were interfering in domestic politics. Indeed, in the bilateral engagements that occur between developed country donors and the governments to whom they provide aid, one imagines there to be little enthusiasm for funding human rights organisations that expose and embarrass these governments.[26]

Second, the leadership of Peter Piot had engendered a certain amount of trust among activists in the integrity of UNAIDS . Piot gave aerial cover to activists. He listened to and understood their demands, and genuinely offered them a role in formulating policy within UNAIDS. Then in 2008 Piot stepped down and was replaced by Michel Sidibé, the first African to head the feisty agency. Sidibé initially committed himself to working with civil society. But as his tenure has progressed, he has switched attention to heads of state and governments of developing countries.

Sidibé has sought to change the rhetoric of UNAIDS; to make it 'relevant' to the changed global political and economic environment in which there is less money for AIDS. However, he has often achieved this by remaining silent on the growing intolerance for human rights and vocal civil society actors among many states. In this way he has allowed civil society to be pushed back to the margins of his agency's agenda at a moment when states and donors are doing the exact same thing.

Third, respect for human rights in the context of HIV has always been described as the 'human rights approach' to AIDS. This suggests that there can be other approaches; that there can be a non-human rights approach. But because HIV transmission is so closely tied to gender inequality, social inequality and the criminalisation and marginalisation of groups such as people who use drugs, sex workers and men who have sex with men, the only way to contain HIV is through the respect, promotion and fulfilment of human rights.[27]

> Unfortunately, UNAIDS has been supplanting the human rights approach with an investment approach in recent years. [28]

Interestingly, the new framework's three tenets of "equity, evidence and efficiency", supported by the "four fundamental principles" of "country ownership; community engagement; shared responsibility and global solidarity" that are "grounded in the local epidemiological context", noticeably underplay the language of human rights. In this paradigm, human rights features as a critical enabler rather than a basic programme activity. Even if unintended,

26. TAC, for example, was variously accused of being a front for pharmaceutical companies as well as an "agent of imperialism". Laws that propose to restrict foreign funding of NGOs have been introduced in countries such as Zimbabwe, Kenya and Egypt.
27. Between 2006 and 2012 I was the chairperson of the UNAIDS Reference Group on HIV and Human Rights. Unfortunately, one thing that struck me throughout my tenure was how little the UNAIDS senior management team understood of human rights and how poorly they paid attention to the recommendations of the Reference Group.
28. *See*: Schwartländer, B. et al. (2011), 'Towards an improved investment approach for an effective response to HIV/AIDS', *Lancet* 377(9782): 2031–41.

its relegation has consequences, as was evident in a pre-World AIDS Day statement for 2013. Here, UNAIDS noted:

> *Investments focused on reaching key populations have not kept pace. Funding for HIV prevention services for men who have sex with men is especially limited in East Asia, the Middle East and North Africa, and across sub-Saharan Africa. Investments lag in a number of countries where HIV prevalence among people who inject drugs is high. Ten countries in which HIV prevalence among people who inject drugs exceeds 10%, allocate less than 5% of HIV spending to harm reduction programmes. Notwithstanding, sex workers' are at disproportionate risk of acquiring HIV, prevention programmes for sex workers account for a meagre share of HIV prevention funding globally.*[29] *[emphasis added]*

In a similar vein, because of the backlash against human rights among donors and governments, there seems to be a concerted attempt to re-insert the language of public health into the AIDS response, taking us back to a time before Jonathan Mann and others fought to ensure that technical agencies were able to take on human rights as a fundamental aspect of their efforts.

> Today, UNAIDS, WHO and other technical agencies seem inclined to downplay the centrality of human rights and independent civil society in order to avoid resistance from conservative government agendas.

The resurgence of the public health approach must be recognised for what it is; a retreat in the face of overwhelming resistance to respecting and promoting the rights of all people living with HIV.

Of course, UNAIDS will not admit to this and lip service continues to be paid to human rights. However, the shallowness of its commitment is best judged by the small budget and low staffing levels assigned to UNAIDS' human rights department.

Furthermore, while UNAIDS continues to catalogue the areas in which there is insufficient progress in using the human rights approach, it has not itself called for action in the way it would have a decade ago. For activists who remain invested in 'ending AIDS', the question we face today is what we are going to do about it.

Taking stock

These mistakes have left the human rights response in a critical condition. We are forced once more into protecting rights rather than promoting and fulfilling them. As such, civil society activists must begin an honest, self-critical and objective analysis of where the human rights response is today and what we have really achieved on key issues.

I would argue that the only irreversible achievement has been the expansion of access to treatment, which in the last ten years has grown from less than two million people on treatment to approximately ten million by late 2013. This is hugely significant and entirely vindicates the human rights response. Millions of lives have been saved.

29. UNAIDS (20 November 2013), *Ahead of World AIDS Day 2013 UNAIDS reports sustained progress in the AIDS response*. Press release. Available at: www.unaids.org/en/resources/presscentre/pressreleaseandstatementarchive/2013/november/20131120report/

However, from the earliest days of the epidemic, human rights activists have always drawn attention to the social and political determinants of risk of HIV infection – determinants that lie in human rights omissions and violations.

On these issues, the scorecard is less satisfactory. As the world reviews the response to HIV at the end of the Millennium Development Goals, there are four crucial areas in which there must be significant civil society action if a human rights approach is to be revived.

1. Gender: there is little evidence that the human rights approach to AIDS has succeeded in bringing about greater equality of women and girls.
Despite some improvements, women and girls still face profound inequality in our world – an inequality that continues to contribute to their higher vulnerability to HIV.[30] Although the focus on the Millennium Development Goals seems to have contributed to significant declines in maternal and infant mortality, the life of the girl child who survives infancy is likely to be an unequal one, marred by unnecessary tragedies in many parts of the world.

2. In terms of sexual orientation and gender identity, there is little evidence that the human rights approach to AIDS has led to greater recognition in practice of lesbian, gay, bisexual, transgender and intersex (LGBTI) communities.
For a period during the 2000s it appeared as if the response to AIDS was beginning to push back the boundaries of homophobia. Battles for recognition of the rights of the LGBTI community were reflected in every new declaration. Over time, in some of the less human rights-friendly countries of the world, members of the LGBTI community were able to come out, engage governments and the health system, and begin to imagine how to live normal lives. Unfortunately, this window proved to be just that – a window that could be closed again.

One error made by activists was not to insist that new legislation was passed or old legislation repealed, ensuring real legal equality and the protection of the law.

The work of normative change related to homophobia requires a long-term approach and significant resources. As such, the lack of funding for human rights education and promotion, even in the best years of AIDS funding, has meant that the underlying prejudices that have always fed discrimination against people living with HIV remain firmly in place on the African continent, as elsewhere. In recent years, we have seen legal attacks on members of gay communities in Malawi, Zambia, Zimbabwe, Nigeria and Uganda.[31] Even in South Africa, with its excellent legal framework that includes strong and explicit constitutional protections for homosexuals, hate crimes have left gay activists and LGBTI community members dead. Jason Wessenaar whose murder on 18 December 2012 remains unsolved, is one example, as are the unsolved cases of Noxolo Nogwaza, Patricia Mashigo and Duduzile Zozo – lesbians who dared to walk the streets in their communities.

3. There is little evidence that the human rights approach to AIDS has brought protection of the law to human rights defenders or people with HIV in many countries.
In many countries, particularly where the rule of law and democracy is not respected, such as China and Russia, activists continue to be harassed and sometimes

30. See UN Women, *Progress towards meeting the MDGs for women and girls*. [Online]
Available at: www.unwomen.org/en/news/in-focus/mdg-momentum
31. According to AIDS-Free World, "Homosexual acts are illegal in at least 77 countries, including 7 where they are punishable by death. There are *36 African countries* with anti-gay laws." *See:* www.aidsfreeworld.org/Our-Issues/Homophobia/Homophobic-quotes.aspx

imprisoned. In China, for example, HIV-positive activist Tian Xi was imprisoned for nearly a year in 2012 because he refused to keep silent on the Chinese blood transfusion scandal,[32] demanding alongside others compensation for infection with HIV.

4. There is little evidence that the human rights approach to AIDS has succeeded in ensuring budgeting for institutions, organisations or legal frameworks that protect human rights in the AIDS response, and particularly for civil society activism. Although human rights has been supposed to occupy an equal position alongside HIV prevention and treatment, when it comes to funding it has remained the poor relation – and this undermines the whole project.

This problem is manifest in South Africa: probably one of the most rights-conscious countries in the world. Promoting human rights and improving access to justice is one of the four key strategic pillars of the National Strategic Plan on HIV, STIs and TB (2012–2016). Moreover, ensuring access to health services by key populations is central to the plan. Yet according to SECTION27, "human rights and access to justice … is costed at less than 0.1% of the total cost" of the plan.[33] Furthermore, in the third year of the plan's implementation, human rights programmes have still not been fully costed let alone budgeted for.

> The massive underfunding of human rights has now become a worldwide phenomenon.

This means that although activism has functioned until recently as the engine of the 'exceptional' response to AIDS, the world's major activist organisations are now struggling to find funding in a disinterested donor market. They are also facing growing threats to the human rights of women, people who use drugs, prisoners, sex workers, homosexuals and human rights defenders, many of whom are living with HIV.

Conclusion

The response to HIV has reached a watershed. Instead of progress in recognising human rights, there is now a backlash and a push back against the ground that was gained by the human rights approach during the 2000s. Unfortunately, resistance is difficult because civil society has fragmented again. We have lost our unifying agenda (treatment) and we are running out of steam. At the same time, UNAIDS that once offered leadership is now part of the problem, not just because it ignores human rights violations but also because it frequently tries to deal with incidents of oppression via backroom deals rather than squarely confronting unacceptable governmental conduct.

In this context, it is hard to imagine that the exceptional response to HIV, and all it has achieved, can be sustained without a revival of those prickly, non-conformist movements of people living with HIV and their allies. Without them, the response to HIV is likely to be diluted to the point where once again it takes its place alongside other neglected diseases. This would force us to agree on what is an 'acceptable' level of mortality: say, several million deaths a year of AIDS. The question activists should ask is whether we do accept this and, if not, how do we forestall it?

For those who cannot accept it, there can only be three strategies. The first is to link HIV and AIDS to other struggles and a broader world vision based on social

32. *See*: Asia Catalyst (4 March 2012), *China's blood disaster: the way forward*. [Online]
Available at: http://asiacatalyst.org/blog/2012/03/china-compensate-hiv-blood-disaster-victims.html
33. Hassim, A. (2011), 'The cost of rights: is there a legal right to transparent and efficient budgeting?' *SECTION27 Review*, April 2010–December 2011.

justice. In particular, now would be the time to link the demand for a sustained rights-based response to HIV to calls for a new rights-based order globally. Many activists are calling for a dedicated Framework Convention on Global Health, and this might begin to move the agenda forward again.[34]

The second strategy is to find resources from within our own movements, both nationally and internationally, to fund social justice activism, breaking our dependence on donor governments. The reliance on donor funding has been both a blessing and a curse. While it has provided the resources to tackle important issues, it has also made civil society organisations vulnerable to the accusation that they are imposing foreign ideas and agendas on to local populations. No matter how absurd these claims, they have been damaging in the war of ideas in which human rights are a critical concept. There are a number of interesting alternatives emerging now, including raising independent domestic resources for difficult activism from Africa's new wealthy billionaires and from membership associations.

The third and most important strategy is to revive the spirit of Jonathan Mann and countless other activists: to disentangle ourselves from governments and UN bureaucracies, and refuse to conform to norms and behaviours that perpetuate inequality.

> The AIDS response has come full circle. From the aggressive, confrontational strategies of the early years, to the bureaucratic niceties that followed the gains, we now stand at a crucial moment.

If we do not once again issue a call to arms, if the terrain of activism is not clearly marked out once again, the HIV response as we have known it may perish. Then millions of people who might otherwise have avoided infection will be at risk.

The challenge is ours to take up or ignore.

34. *See*: www.jalihealth.org/documents/manifesto.pdf

International HIV/AIDS Alliance
Together to end AIDS

BIOGRAPHY

Mark Heywood

Partly inspired by his love for punk rock and reggae, especially Bob Marley, Mark has fought for human rights since he was a teenager. He has been outspoken on political struggles, not only in South Africa, but also China. Mark joined the AIDS Law Project in 1994, and in 2010 oversaw its transition to SECTION27, and was one of the founders of the Treatment Action Campaign. Mark has written extensively on HIV, human rights and the law.

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