“This is the story of how Uganda went from the darling of the AIDS world, to its pariah…”

“. . . it is clear that AIDS activists were short sighted. We became enamoured with our own success . . . ”

“The question of how to get more people onto and to stay on treatment has become central to reversing the AIDS epidemic.”

AIDS Today: Tell no lies and claim no easy victories

Powerful voices that matter NOW:

Sisonke Msimang, South Africa
Mark Heywood, South Africa
Monica Leonardo, Guatemala
Anya Sarang, Russia
Asia Russell, Uganda/USA
Pauline Londeix, France
Martin Choo, Malaysia
Robin Gorna, UK
Frank Mugisha, Uganda
About the International HIV/AIDS Alliance

We are an innovative alliance of nationally based, independent, civil society organisations united by our vision of a world without AIDS.

We are committed to joint action, working with communities through local, national and global action on HIV, health and human rights.

Our actions are guided by our values: the lives of all human beings are of equal value, and everyone has the right to access the HIV information and services they need for a healthy life.

Acknowledgements

This report is the first edition of what is intended to be a biennial publication that presents the state of the civil society response to AIDS. The report is intended as the basis for reflection for community leaders, activists, programme managers, advocates, donors, policy makers and government officials.

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Executive Summary

Sisonke Msimang,

LEAD AUTHOR

This project started as a standard exercise in NGO-ese. We wanted to look at the state of civil society organisations at the end of the era of the Millennium Development Goals. We would write chapters and case studies, and present them in yearly instalments coordinated by the International HIV/AIDS Alliance (the Alliance). Backed by ‘evidence’, we hoped that they might influence policymakers and budget holders.

As the activists whose words are contained in this collection of essays and insights began to write, it became clear that this approach would not work. In each piece there was a palpable sense that activists were looking for a chance to challenge the new language of ‘success’ and ‘unprecedented scientific breakthroughs’ that have become the new AIDS orthodoxy. They wanted space to count the losses and mourn the dearth of rights in too many contexts.

In reaching out to a group of thoughtful, tough and astute activists, we had inadvertently tapped into a raging counter-narrative that seemed to have had no formal outlet until now.

The ‘chapters’ have therefore evolved into essays. We accept that the words in this collection are meditations on winning and losing: a Rorschach test marking the mood of the moment.

Taken together, they represent a wail against complacency, a battle cry in defence of human rights in an era of jargon and statistics.

As the editor tasked with making meaning out of this critical moment – the end of one development paradigm and the beginning of another – I have resisted the temptation to pull together a neat, chronological story about how the war against AIDS has been won. As the brave authors in this collection insist, the war against AIDS has not been won. To proclaim that it has is to ignore Amilcar Cabral’s famous edict that activists are to “Tell no lies…Claim no easy victories…”¹.

Before the Alliance approached me about doing this work, I had been having my own misgivings about the state of the AIDS response.

In recent years, I have watched with growing disquiet as the Joint United Nations Programme on HIV/AIDS (UNAIDS) – the plucky agency that over the last 15 years has successfully harangued, cajoled and charmed donors and governments into supporting better-coordinated, more strategic responses to AIDS – has published its global state of the epidemic report year after year.

Increasingly, the report has taken on the voice of a cheerleader, applauding country efforts, commending progress and being the bearer of good news.

The press around last year’s report was so effusive that it inspired a premature editorial in the Economist that asked, “How was the AIDS epidemic reversed?” Needless to say, for those of us who have fought AIDS and its devastating consequences for the last few decades, the influential magazine was asking the wrong question. In fact, the question was so wrong that I began to wonder about the politics of good news. So I started to talk with friends and comrades about whether the strategy of good cheer wasn’t backfiring on the AIDS movement that had been such a powerful lobby for change.

The consensus is that at a time when wealthy nations are under pressure to demonstrate frugality and success to their citizens, many international agencies know there is no longer an appetite for development failures. Funders are looking for a way to untangle themselves gracefully from commitments made to fighting AIDS a decade ago when there was a strong and vital AIDS movement. It was easier to pledge support when the virus had captured the imaginations of the citizens of rich countries, and when the activists who championed the cause were accorded hero status. For the policymakers tasked with pulling back, good news and other signs of progress would allow them to leave without looking fickle.

This puts organisations like the World Bank, UNAIDS, the World Health Organisation and the Global Fund to Fight AIDS, TB and Malaria in a difficult position. These agencies have been the bureaucratic face of the fight against AIDS. They interface directly with donors and understand the pressure that funders are under to reduce budgets and long-term commitments, especially as the deadline of the end of the Millennium Development Goals approaches.

Yet they also work with vocal civil society organisations that argue that there have never been enough resources, and point out that progress is subject to more and better funding and political will. They are also aware that prices for the next generation of AIDS drugs are soaring, and that many people are failing to adhere to treatments because the community follow-up systems are overstretched and under-capacitated.

And so the truth, as many people see it, is that the end of AIDS is at once a heady promise and a fanciful invention of spin and hyperbole.

It is a dangerous myth that perpetuates the idea that there is simply a bit of unfinished business to handle and then the era of AIDS will be behind us. The narrative leads inexorably to donors and governments committing less money in the long term, and it results in non-governmental organisations (NGOs) and communities having diminished power to make arguments addressing the structural drivers of inequality and injustice that have always shaped the contours of the AIDS epidemic.

These drivers, determinants, or whatever you wish to call them, remain firmly in place 30 years into a heroic, albeit terribly incomplete, response to the epidemic.

In almost a dozen countries across sub-Saharan Africa, people are reporting having more sexual partners, and in a number of places they report using
condoms less frequently. In North Africa, Eastern Europe and Central Asia, infection rates are actually on the incline: going in the wrong direction.

Inventing the end of AIDS when we are so far from reaching our goal is a grave and dangerous error. Promoting the headline message that we may soon be able to put the devastation behind us may make it easier for donors to justify providing short-term bursts of funding. But in the end, it will not provide people living with AIDS, and those who continue to be vulnerable to new infections, the leverage, space and time that is needed to truly ‘end’ AIDS.

The authors of the searing essays in this collection agree on one thing: maintaining vigilance is the only strategy that has ever worked in the fight against AIDS. Anything less will signal certain defeat in the long term.

The truth is that at a time when AIDS fatigue is considered to be acceptable by some people in international NGOs, large bureaucracies and United Nations agencies; there are still 35 million people who are living with HIV in their bodies. There are daily assaults on the rights and dignity of people who are women, girls, gay, transgendered, sex workers, prisoners, or who use drugs.

As I point out in my essay about women’s rights in the context of AIDS, we continue to live with an epidemic that infects higher numbers of women in sub-Saharan Africa, and which is fuelled by the continued inability of women to exercise their fundamental right to choose if, where, when and under what conditions they will have sex.

The temptation in a collection like this is to tell a story of hope and redemption that uplifts and makes the heart soar.

For many years that was the only AIDS story that could be told. The recipe was well known. Take a group of tenacious and desperate activists, add the grit and courage of some awesome doctors, blend in the wisdom of political leaders who finally see the light and, hey presto, the fight is won. There were ‘goodies’ and ‘baddies’: yet somehow, year after year, despite the burnout and exhaustion, and the seemingly insurmountable challenges, despite the daunting deaths and the gut-wrenching episodes of illness, things just kept getting better for the AIDS response.

As Mark Heywood points out in his brilliant exposition of the AIDS movement in the developing South, “We became enamoured with our own success, leading us to believe we had a power and ability to lift the response to HIV to ever-greater heights – a power that, in fact, we lacked.”

Heywood’s point is that activists may have won important battles, but they often lost sight of the big picture. This meant that they retreated when they should have continued keeping up the pressure. Many activists incorrectly thought that the new fight would need to be taken to the boardrooms. While the ability to do this is crucial, sipping lattes and sharing PowerPoints will take us only so far. Activists who only speak the language of donors and international institutions are no longer activists: they have become something else.
And this is the rough and messy truth: that activists who have forgotten how to fight are part of the problem. They are part of why there hasn’t been sufficient strategic pushback against narrow, science-driven programmes and diminished funding in recent years.

To buttress this point, Asia Russell points out that for various reasons activist groups haven’t always been able to think strategically about their actions. So they were caught napping in the immediate aftermath of the 2008 financial crisis when “donors and governments that had lost a number of battles with activists began to push back”. They pushed back by using concepts such as ‘country ownership’, ‘efficiency’ and ‘sustainability’, even as it has resulted in the breaking of promises that funded life-long programmes, and in reduced ambition and potential for scale-up for people who need it most.

The AIDS movement is still reeling from these pushbacks.

Many activists believed, as Cabral seductively suggested, “...that the people are not fighting for ideas, for the things in anyone’s head. They are fighting to win material benefits, to live better and in peace, to see their lives go forward, to guarantee the future of their children.” Russell’s essay is a reminder that Cabral may have been wrong; that activists must fight both for ideas and for material benefits. Without winning the war of ideas, the material benefits soon dwindle.

Pauline Londeix takes this point forward with an example of an arena in which activists won because ideas translated into material benefits. She remembers the jubilation of activists as the Doha Declaration conceded that public health concerns trump trade concerns. There were immediate tangible benefits for people living with HIV. Yet over time, Londeix notes, the drug companies fought back, and many activists have not engaged in the seemingly complex but important debates related to drug pricing. As Londeix argues, if activists continue to stay away from this arena, universal access to AIDS drugs simply will not be possible and the increase in drug prices that we are currently witnessing will continue unchecked.

And yet there have also been poignant triumphs. In Argentina, Monica Leonardo tells the remarkable tale of how “in an era of dwindling funds and diminishing trust in the value of good, old-fashioned activism, transgender people and their allies demonstrated that with a little bit of money, a lot of creativity and a firm knowledge of human rights and legal strategies, even the most marginalised groups can fight stigma, violence and soaring HIV rates – and win.” Her delightful David and Goliath tale reminds us of the centrality of dignity as an organising principle for activism and AIDS programming.

Dignity is a core theme in Martin Choo’s essay on the new shift towards a medicalised approach to AIDS. Choo suggests that, “At their best, in the process of addressing immediate needs, community systems also embody and pass on a strong sense of worthiness.” And Anja Sarang’s description of the work of the Andrey Rylkov Foundation illustrates how the fight for better and more comprehensive treatment for drug users is also a fight for the rights and dignity of all.

This idea is echoed in Robin Gorna’s essay on the AIDS architecture and what it might look like in the post-Millennium Development Goals era. She writes, “
we need to guide us forward is a return to the basics. We need to go back to the principles that have always guided the fight against AIDS: the respect for human rights, the insistence on participatory processes, engaging all sectors, and the commitment to the leadership and meaningful involvement of people living with HIV. It is these principles that must define what happens next.”

Frank Mugisha agrees about going back to basics. For him, the task ahead is “to ensure the fight is strategic, all-encompassing and fought…on a terrain that makes ordinary people allies of a human rights approach, rather than its enemies.”

It is precisely this clarity that is needed at this moment. When we raise our heads to look above the muck and the guts, seeking to survey the bigger picture, it is clear that the damage to the movement since 2010 is significant. It is also clear that, as in the past, if we focus too much of our energy on the money and the resources lost rather than on the strategy and the tactics needed to build better, stronger and more forceful movements, we risk putting the cart before the horse.

The stories in this collection from Latin America, Africa, Europe, America and Asia teach us that movements only succeed when they are tough, smart and light on their feet, and when they remain committed to speaking truth to power.

Yet while these voices are powerful, they are also incomplete. We struggled to secure essays from India and China, where the world’s most complex epidemics are emerging. We also tried to get responses from Ukraine and South Sudan, where broader conflicts are at play that compromise the ability of activists to do much more than respond to the day-to-day challenges imposed by conflict.

Each of the essays in this collection reminds us that we have not seen the end of AIDS.

They also serve as a stark warning that the fight about the next development framework is not about whether there is an AIDS goal or simply a set of indicators. If we allow the technical wars to define our activism, we are reducing our ambitions and playing a game that we can never win. If there is a lesson to be learnt from the big wins and the concomitant decimation of the AIDS activist movement in the last few years perhaps it is this: timidity does not work.

As all of our authors point out so fiercely, the wins were never simply about goodwill and good intentions. The battles were always hard fought and hard won on the basis of a clear understanding of power and politics.

We hope that you use these essays in your work as an activist. We hope you share the ones that speak to you, that you will write to us and tell us where our essays got it wrong. Let us know too where they describe the loneliness, desolation and joy that you have felt. Above all, we hope that you continue to resist and fight, and insist on dignity and human rights as non-negotiables. In the process, may you tell no lies and may you continue to claim no easy victories.

To read more about Sisonke Msimang, go to page 44
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 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. 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.

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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.*

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

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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)


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.

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). 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.”

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
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 narratives11 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

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11. See, for example, Mbai, 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\textsuperscript{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.\textsuperscript{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:

\begin{quote}
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.\textsuperscript{14}
\end{quote}

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.\textsuperscript{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.

\textsuperscript{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.

\textsuperscript{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.”


\textsuperscript{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., Casornvass, 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; Blackman, 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

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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.
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...
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.

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.

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

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,
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.\(^{29}\)

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.
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

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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

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justice. In particular, now would be the time to link the demand for a sustained
effects-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.  

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.jalhealth.org/documents/manifesto.pdf

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.
In 2012 Argentina passed a law that put in place some of the most liberal rules on changing gender in the world. It is now legal in Argentina for a person to alter their gender designation on official documents without getting a psychiatric evaluation or without first having gender reassignment surgery. Furthermore, transgender people in Argentina are now entitled to free hormone therapy and gender reassignment surgery if they want it.

Most incredibly in a country known for its machismo, where the lives of transgender women and men have been characterised by violence and exploitation for decades, the legislation sailed through the senate totally unopposed. Not only was the law almost certain of victory by the time it was drafted, its adoption was also virtually guaranteed.

This insight explores how this happened. It tells the story of how the lesbian, gay, bisexual and transgender (LGBT) community in Argentina won the most progressive law in the world.

In an era of dwindling funds and diminishing trust in the value of good, old-fashioned activism, transgender people and their allies demonstrated that with a little bit of money, a lot of creativity and a firm knowledge of human rights and legal strategies, even the most marginalised groups can fight stigma, violence and soaring HIV rates — and win.
In the beginning

The beginnings of this human rights victory can be traced back to 2006, when five organisations joined together to “create a new national articulation of different lesbian, gay, bisexual and transgender issues”. The movement was called La Federación Argentina de Lesbianas, Gays, Bisexuales y Trans (FALGBT) (the Argentine Federation of Lesbians, Gays, Bisexuals and Trans), and their work represents one of the most forceful and important examples of transgender activism anywhere in the world. FALGBT’s achievements, led by a powerful and determined group of transgender activists, are a testament to what an oppressed minority can do when it is strategic, well organised and invested in both normative and legal change.

Alongside allies in the human rights community and the Argentinian state, FALGBT was central to winning the right for Argentinians to decide on their gender identity without interference from the state. The organisation achieved this in the same way as other organisations in the AIDS response have fought for justice during the last two decades: through persistence, strategy, ingenuity and the application of international human rights law to a national context.

A tale of activism

Before the passage of the law, transgender people encountered severe discrimination and violence in Argentina, with transgender women in particular being killed by the police with impunity.

The statistics tell the tale more starkly: the average life expectancy in Argentina is 70 years; for transgender women it is just 30 years.

The indicators related to poverty are equally bleak. Marcela Romero, activist and member of ATTT (Asociación de Travestis Transexuales y Transgéneros de Argentina/the Association of Transvestites, Transsexuals and Transgender Argentina), has noted that in 2010, before the passage of the Gender Identity Law, 99% of transgender women in Argentina were unemployed or involved in sex work. Their lack of identity papers – crucial for opening bank accounts, paying taxes and registering at educational and medical facilities – played a major part in this. A systematic denial of their rights to education, healthcare and housing has also contributed to the rights violations that continue today.

In 1976, Jorge Rafael Videla came to power in a coup d’état that deposed Isabel Peron. For five years, Videla continued to preside over a repressive and bloody military dictatorship. He and his Generals instituted a National Reorganization Process, also known as the Dirty War, that systematically violated the human rights of all those who opposed them. Those who had “subversive ideas” or who were accused of committing “crimes against morality” were harassed, tortured and killed. Between 9,000 and 30,000 people were forcibly disappeared during the Dirty War, mainly through a network of detention centres around the country.
Minorities were particularly targeted, including the LGBT population. The University of Buenos Aires has identified 110 transgender people who died in unconfirmed circumstances. The junta’s Cóndor and de Moralidad commando units tortured and murdered an estimated 400 people presumed to be homosexuals. Transgender women were considered especially “immoral”.

The dictatorship ended in 1983, when Raul Alfonsin’s civilian government took control of the country again. The situation then improved dramatically for many groups of people. Human rights work began to flourish, and new organisations sprang up to address the crimes that had taken place under the dictatorship. However, for transgender people the environment of abuse and repression remained firmly in place. The new civilian administration was not about to round up transgender people and lock them away, but neither was it prepared to defend their rights. A deep vein of anti-transgender sentiment ran through the Argentine population.

Over the years, many new organisations sprang up to address issues related to gender and sexuality. New HIV associations emerged, as did lesbian and gay organisations pushing for rights and greater access to services for their communities. However, it wasn’t until 2003 that a small and brave group of transgender women organised in Buenos Aires to form ATTT.

ATTT worked hard to raise awareness of the situation of transgender people, starting from almost nothing. When the advocacy organisation was founded, there were no clear statistics related to HIV infection among transgender people. Five years later, ATTT had convinced authorities to include transgender people in HIV studies. The results of the first national sero-prevalence survey were frightening. They indicated that HIV prevalence among transgender sex workers was 35%. By way of comparison, the national rate at the time was 1.5%. There could be no denying it: the HIV needs of the transgender community were significant and were driven by high levels of stigma, humiliation and discrimination. A strong human rights approach was needed to address this.

Although it had a clear mandate and much to do, ATTT found it difficult to operate because of high levels of transphobia among the general population, as well as among some sections of the LGBT community. The visibility of transgender people – the result, sometimes, of an obvious dissonance between their biological and true gender identities – openly challenges established gender norms. This meant that ATTT members often encountered hostility while conducting their day-to-day activities. It was hard for them to move around without harassment, and difficult to access senior decision-makers let alone their gatekeepers. Nevertheless, over time ATTT found an ally in the Argentinian LGBT community. A strategy evolved whereby many of the objectives of the transgender movement were advocated for under the broader umbrella of the more ‘accepted’ gay rights agenda.

The power of collective organising

By the time ATTT was created, LGBT collectives had already been working actively to end institutional discrimination based on sexual orientation and gender...
identity, mainly in partnership with the people who went on to form ATTT. In Buenos Aires, advocacy relating to gender identity included a long and ultimately successful fight for gay people to enter into civil unions, accomplished in 2003.8

Capturing the momentum created by this success, FALGBT was launched in 2006. As word spread, more groups joined, including LGBT religious groups, regional organisations, identity-specific organisations, LGBT factions of political parties and academic institutions. FALGBT developed a set of national priorities that focused on fighting for equal rights, education and the end of discriminatory laws, including marriage equality and introduction of a gender identity law.9

However, despite FALGBT’s progress, homophobia remained alive and kicking. By 2008, 10 of the 23 provinces in the country still used the Fault and Misdemeanour Code to penalise and criminalise sexual minorities – in practice, to arrest and detain transgender women sex workers.10

Homophobia against the LGBT community, and the transgender community in particular, provided Néstor Kirchner’s government with an opportunity to build alliances that demonstrated its own commitment to human rights issues. President Cristina Fernández continued along this path, embracing LGBT people as one among a number of historically excluded minority groups in Argentina.

Taking advantage of the new openness within government, FALGBT began to work actively and strategically with the media. At the same time as the organisation took on the legal cases of a number of individuals in order to force the justice system to take the rights of LGBT people seriously, it also made sure that the media was kept informed of developments. FALGBT was successful in this dual approach: a sophisticated litigation strategy combined with winning the hearts and minds of the public by using media channels wisely.

To build long-term, normative change, FALGBT began to invite famous people to endorse gay rights.

The strategy increased visibility of and support for the LGBT community among the general population, and proved crucial for persuading politicians whose support was not guaranteed despite important backing from the president.

One of these celebrities was an Argentinian transgender vedette,11 Florencia de la V. FALGBT worked closely with Florencia as the public face (and first beneficiary) of activism to secure transgender people’s rights to gender identity. FALGBT used strategic litigation to test her case, allowing Florencia to put a name to an issue. This helped the public to understand the implications of not allowing an individual’s legal documents to match their gender identity. Once they could relate the need for legislation to a tangible (and attractive) face, it made it easier to push for a seemingly radical law in a conservative country.

When Florencia won her FALGBT-supported case, she became the first transgender woman to receive a new identity card and birth certificate without

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8. INADI (2007), Mapa de la discriminación en Argentina, Buenos Aires: INADI.
9. FALGBT, Objetivos. [Online] Available at: www.falgbt.org/objetivos
10. INADI (2007), Mapa de la discriminación en Argentina, Buenos Aires: INADI.
11. Vedette is a Spanish term used in some Latin American countries to describe female singers and entertainers skilled in singing, dancing and acting. Although the Spanish term is derived from the French vedette (starlet), its meaning is equivalent to the French meneuse de revue (showgirl). Florencia is a famous transgender vedette who has crossed over into mainstream Argentine popular culture.
the need to consult doctors. Her new identity as Florencia Trinidad was a triumphant moment in the fight for a gender identity law.\(^{12}\) The culmination of many years of strategic dialogue, it made it easier to take the next step: the drafting of a new law recognising gender identity as a right.

**Triumph: the Argentinia Gender Identity Law (2012)**

The Argentinia Gender Identity Law (2012) is unique because it recognises the right to gender identity. It states unequivocally that:

> all persons have the right (a) to the recognition of their gender identity; (b) to the free development of their person according to their gender identity; (c) to be treated according to their gender identity and, particularly, (d) to be identified in that way in the documents proving their identity in terms of the first name/s, image and sex recorded there.\(^{13}\)

What this means, practically, is that people can change their identity (within the female–male binary) to one that better reflects their own perception without approval by a third party. With the enactment of the new law, changing a person’s official documents has become a simple legal administrative procedure rather than a test of their mental health or biological status.

Simply put, the law allows transgender individuals to own a legal document that states their real name and reflects their real appearance.

This helps them to apply for jobs, attend schools, access housing and get a pension. It allows them to imagine a life with greater opportunity, because their documents match their lived identity.

In the case of transgender women who are also sex workers, having a document that reflects their identity can also help reduce police harassment and arbitrary arrest.\(^{14}\) Furthermore, because transgender women who change their identity are now legally considered to be women, if they are subjected to incarceration they are now sent to a women’s rather than men’s detention facility. The implications of this are highly significant.

> Transgender women who serve time in men’s prison facilities are often raped, tortured and physically abused.\(^{15}\)

The law represents an important step towards guaranteeing the right to dignity and freedom from violence for transgender people in Argentina.

Another crucial aspect of the law is that it stipulates that a person, “will be able to access total and partial surgical interventions and/or comprehensive hormonal treatments to adjust their bodies, including their genitalia, to their self-perceived gender identity.” The law makes it mandatory for all public health officials and health insurance plans to include these procedures in their compulsory medical plans.\(^{16}\)

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14. Del Mauro, M. from El Frente Nacional por la Ley de Identidad de Género and Universidad de Córdoba (2013). Interview with Martin Del Mauro conducted via Skype on 10 December 2013. [Recording in possession of author]
15. See, for example, International HIV/Aids Alliance and Redlactrans (2012), The night is another country: violence and impunity against transgender women human rights defenders, Buenos Aires, Argentina.
The legislation also makes gender reassignment surgeries available for those who want them, but importantly does not make surgeries a precondition for the state to recognise gender identity. The law makes it clear that the health system should aid those who want to go through partial or complete gender reassignment without any additional compensation, but that they are under no obligation to do so.

**A human rights win**

The power of the law is that it recognises that personal identity is different from physical appearance.

This fundamental right for human beings to define themselves is at the core of the transgender movement globally. It is no coincidence that the law was developed in an inclusive manner that brought together a wide range of voices affected by the problems that legislation sought to solve. It is also no coincidence that the law manages to address interconnected violations that lead to deeply unequal access to health and other social services.

In Argentina, transgender activists have demonstrated that, at their best, civil society organisations fighting AIDS, even in an era of reduced funding, are able to think strategically, mobilise popular support, and insist that a human rights approach is non-negotiable.

Much needs to be done to ensure compliance with the law. But thanks to the various fronts on which ATTT and FALGBT have fought – public feeling, political lobbying, and community education and mobilisation among transgender people (in particular sex workers) – the road ahead is not as steep as in circumstances where these factors are missing.

In decades to come, the story of the Argentinian movement to protect and promote the human rights of transgender people is likely to serve as a model for how to continue to keep rights at the centre of the fight to end AIDS.

**BIOGRAPHY**

**Monica Leonardo**

Monica is a lawyer and human rights defender, and author of several publications on transitional justice, judicial independence, and gender-based violence. She works as a consultant for a variety of international non-governmental and legal associations, and is a university lecturer on alternative dispute resolution.
Introduction

In the early days AIDS was a male disease. Long-distance truck drivers, miners, and other migrant workers got it in the cities; gay men contracted it before they knew how it was spread; and people who use drugs found it in their blood after they had shared needles. It seemed that the risks that men took were putting them in danger, and so masculinity seemed to be the driving force behind HIV vulnerability. Today, more than 20 years into the epidemic, women account for 52% of people living with HIV worldwide. In sub-Saharan Africa, women constitute 57% of those living with the virus. Most dramatically, 76% of young people aged 15–24 living with HIV are women.1

How this happened has been the subject of many papers and workshops. In this essay I am interested in how we reverse it.

My starting point is that I am an African woman who is deeply committed to a genuine vision of social justice.

Thus, I am mindful that there is a long and unfortunate history of some women seeking to speak on behalf of all women. Those of us with platforms have an obligation not to flatten the experiences of women whose struggles are different from ours in ways that are significant.

This essay speaks about some universal gender norms that operate across most societies in similar ways. It does not propose that these norms affect different women in the same ways. The essay also does not name or list

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specific sub-groups of women. I do not speak about sex workers, among whom infection rates and levels of violence are unacceptably high. I do not make a case for the particular marginalisation of women with physical and mental disabilities, for whom services related to the prevention and treatment of HIV and AIDS are almost non-existent. Nor do I address the specific challenges of lesbians, who face hate crimes – including murder – on an unprecedented scale.

Instead, I recount my experiences and I assess the state of play at a macro level, firm in the belief that despite the ways in which oppressions are layered and complex, there remain fundamental questions of women’s oppression that affect all women and therefore inform a shared political project among women. Using this commonality as a basis, this essay hopes to provide a clarion call for us all to go back to politics: to the basic questions of power and difference that must trouble us, and that must force us to better, more thoughtful action.

In the late 1990s it became clear that AIDS was becoming feminised. This signaled the beginning of an era of hand wringing. I remember well having conversations with women within ‘institutions that matter’. Many had begun to lobby their colleagues to take the issue seriously. They won some victories – agreements to conduct mapping exercises and focus group discussions – and some small budgets here and there. Meanwhile, in communities across the world, women simply got to work, dealing with the effects of the epidemic on their lives. Many died in the process.

In 2003, I was asked to work with a task force that the then United Nations secretary general, Kofi Annan, had established. It had a long and unwieldy title, but the Secretary General’s Task Force on Women and Girls in Southern Africa presented an important opportunity to ensure that the experiences of women and girls were part of a global policy discussion. Until then, African women had been spoken about but their voices had been missing from the discussion. Media headlines screamed about the growing rates of infection among Africa’s women, declaring, “AIDS has a woman’s face”. But until the establishment of the task force, no one in the bureaucracies of the international system seemed to have noticed that the faces of women living with and affected by AIDS also had voices, and that they might be worth listening to if the epidemic was to be tackled in any meaningful way.

As part of a small team, I set about recruiting task force members who were from the region. Many of them were seasoned human rights activists, who had seen processes like this come and go, and were skeptical about what difference it would make. Nevertheless, each of them committed their time and energy, overcoming their skepticism in the hope that what they thought about the epidemic that was affecting their bodies, families and communities so profoundly might influence the AIDS response in the region.

They had a powerful ally on their side. The newly appointed Special Envoy on AIDS in Africa was a man named Stephen Lewis. He was a talented and astute politician from Canada, who had a long history in the United Nations system (but had managed to stay sane despite this). Most importantly, he had a remarkable ability to connect with many different kinds of audiences and a visible passion for women’s rights.

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Lewis served as the task force convener on behalf of the secretary general, and I was lucky enough to work with him, coordinating workshops in each of the nine countries covered by the group and helping to write up the final report with our findings. We travelled across southern Africa, consulting with women and girls, talking to community leaders and researchers, and trying to understand why women were so disproportionately affected by the virus.

In conversation after conversation, women told us that AIDS felt like it was simply one assault too many.

They listed the many responsibilities they had and the many burdens they carried for their communities. They confided their hopes and aspirations, and made us laugh as often as they made us cry. We were awed not simply by what they were enduring but by the ways in which they were strategising and responding, and we were struck by how little external or government support they were getting.

They were a feisty, humble, sophisticated, rural, urban mélange, with a clear message. Despite the great ideological, political and social diversity of the opinions we polled, the message was frightfully clear. On the back of poverty and poor education, and lack of inheritance and other legal rights, they felt that caring for the sick and the dying, and for children whose parents had died or were dying, and worrying about their own health and that of their daughters and sons, was pushing them to breaking point.

Middle-class women told us that their savings were depleted; poor women explained that their community networks were shrinking; urban women found themselves isolated; and rural women talked about being increasingly stigmatised. Everywhere we went, we were told that collectively there was no more bandwidth for AIDS. And yet we could also see that women had no choice but to deal with what was simply the latest in a long line of catastrophes.

It struck me then that for women, the ‘solution’ to AIDS wasn’t going to come in the form of donor-funded projects, nor would it come in a syringe, and it certainly wouldn’t come from a report like ours. I realised that in the end the only thing that would save African women who, just like me, could not escape the fallout of AIDS, would be our tenacity and our determination.

There would be no end to AIDS without an end to the other inequalities that made women’s lives difficult. And there would be no end to either if we were not prepared to mount a serious and sustained assault on our governments, and on the global industrial complex that propped up so many of our leaders. I felt too young to be cynical, but much too old to be naïve.

Many things have changed in the last ten years. Pregnant women living with HIV now have life-saving medicines to prevent HIV vertical transmission. Treatment access figures are up significantly, and among young people in southern Africa, HIV incidence figures are on the decrease.

Despite this, a look back provides much food for thought. Today, peak prevalence of HIV infection is observed among women aged 20–24 years, but the magnitude of that risk has grown eight- to tenfold over 15 years. In the last two decades, there has been an exponential increase in HIV infection...
among this group.³ The prevalence of HIV among young women has increased in southern Africa, even as the resources available to the women’s rights organisations that will have to address this crisis have decreased.⁴

There is no cause for surprise in this regard. Nothing has been done in the last decade to fundamentally change the underlying power imbalances women told us about in 2003. Instead, the AIDS response has chronically underinvested in the issues that matter the most to women, and the revolution I thought was necessary back then has become more urgent.

Taking AIDS out of the picture: a new approach

In the early days of fighting AIDS, there was a strong focus on women’s biological vulnerability to HIV infection. Indeed, the history of western medical science and gender is replete with examples of how reproductive biology is associated with the idea that women are the ‘weaker sex’. Women have been treated historically as though their health is only a matter of biology. When it comes to sexual and reproductive health, an excessive focus on ‘biological vulnerability to infection’ has prevented clinicians from acting quickly enough to recognise other more important factors that have driven disease in women.

Rudolf Virchow was the father of cellular pathology and is known as the creator of the idea of social medicine. He was an outspoken advocate for public health, whose writings and teachings made trenchant recommendations about ways to improve people’s health by improving their economic and social conditions. In the late 1800s, he is said to have observed, “diseases have two causes: one pathological and the other one political.”⁵

The political ‘cause’ of disease in the case of women and AIDS is clearly gender discrimination.

When I began my journey as an AIDS activist in the mid-1990s, an HIV-positive activist friend of mine used to joke about her doctor’s emphasis on her reproductive tract. She found it amusing that he was so concerned about the extent to which her reproductive tract made her more susceptible to infection with HIV and other sexually transmitted infections, while he had never asked her questions about the conduct of her partner. My friend, like many other activists, was beginning to ask if the size and shape of our tracts were good enough reasons why so many women were becoming infected. Common sense and community experience told us that the idea that our skyrocketing infection rates were in large part due to our biological make-up was absurd. It was our relationships with men – some of them violent and abusive – that were putting us at risk.

In response, in different parts of the world, women living with HIV and affected by the virus began to change the narrative. In the early 1990s, women began to ask specific questions about the AIDS response as it was unfolding in their countries. Why were national AIDS programmes gender blind? How could prevention messages aimed at ‘everybody’ so blatantly ignore the needs of women?⁶

⁴ Research by the Association of Women’s Rights in Development (AWID) has provided evidence of the trend of donor disinvestment in the last decade. This visual summarised the situation well: www01.awid.org/map/map_02_world_financials.html
⁵ Rudolf Virchow, Emerging Infectious Diseases 14(9): 1480-1
⁶ See Mandisa Motal’s book South African AIDS activism and global health (2013) where she discusses the work of activists like Promise Mthembu and Prudence Mabele.
These questions gathered momentum, and by the end of the 1990s many women activists had begun to realise that asking questions without providing concrete and prescriptive answers would only lead to frustration. As a result, by the early 2000s many women’s organisations had begun to put forward clear suggestions for the precise ways in which AIDS programmes should address women’s short- and long-term needs. Organisations like the International Center for Research on Women (ICRW) developed toolkits and manuals; groups like the International Community of Women living with AIDS (ICW) and their regional hubs convened round tables and held meetings with researchers and officials. These groups got international agencies to adopt their suggestions and turn them into guidelines so that donor-funded programmes on the ground would be more responsive to the needs of women.

By the late 2000s, they realised that they were very, very busy but that the lives of women were not being transformed. Worse yet, as they were pushing for better AIDS responses, their own budgets were being slashed by development agencies that no longer had much money for women’s rights issues. Many of them were called to meetings with funders who, in announcing that they were being dropped as grantees, told them in no uncertain terms that the women’s movement was not as vibrant as it once had been.

Today, many women’s rights activists recognise that a more radical approach is needed; one that moves away from the technical development and programme solutions that donors and governments like to see, towards more explicitly political approaches related to transparency, accountability and direct participation in decision-making.7

While technical issues are important in public health, the women’s movement must be increasingly invested in tackling the underlying questions of democracy, governance and human rights that determine how resource allocations are (or are not) made to women.

There is a new impetus to foreground the questions of economic inequality and injustice that manifest themselves in HIV infection. Having tried to address women’s rights using AIDS as an entry point, many of us now wonder whether we shouldn’t use women’s rights as an entry point to AIDS. It is time to completely rethink our approach.

The most effective ways to prevent new infections among women and girls do not, and should not, lie in the domain of AIDS programming.

Instead, women’s rights activists and their allies in the environmental, human rights and transparency and accountability communities, must focus on putting more money, power and sexual choices in women’s hands.

In order to do this, we will first need to understand where we have come from and how the AIDS response thus far has let women down.

In the beginning there were the ABCs

In the early days, as AIDS programmes were beginning to scale up, they focused largely on preventing HIV. There was no treatment available, and so the key strategy was to ensure that everybody knew what AIDS was, how it was contracted and how it could

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7. For an excellent discussion on this see Sonia Correa, Rosalind Petchesky, and Richard Parker’s seminal book on sexuality, Sexuality, health and human rights (2008), where they argue in their introduction (p.3) that “sexuality cannot be understood in isolation from the social, political, and economic structures within which it is embedded – or without reference to cultural and ideological discourses that give it meaning.”
be prevented. In country after country, the evidence told us that there were three proven ways to avoid HIV infection: abstinence, faithfulness and using condoms. Collectively, these strategies for prevention were called the ABCs: abstain, be faithful and condomise.

Around the margins of national efforts to communicate about AIDS, some activists began to raise questions about the large numbers of people who were already living with HIV, for whom human rights and dignity remained central concerns. As national AIDS councils emerged to coordinate the AIDS response, they took on board these questions too. But something was amiss. By the late 1990s, there were billboards and signs everywhere in urban Africa urging people to test for the virus. In rural communities, people wore T-shirts bearing the logos of the non-governmental organisations that suddenly seemed to have a lot of money to fight AIDS. By and large, the messages targeted an imaginary public that was all male.

So women’s groups began to ask questions, arguing strongly that the prevention options placed before women through the ABCs were not viable or realistic. There were no programmes that helped women and girls to figure out what to do when neither abstinence, faithfulness, nor condom use was an option.

Abstain

The message related to abstinence was hard for many girls to take on board. Fourteen million girls are forced into child marriages each year. For these girls and their families, abstinence-only programmes had no value. In addition, for girls who weren’t married off at a young age, but who were living in extremely violent contexts like conflict and post-conflict societies, abstinence wasn’t a viable option either. For these young women, national messages that focused on their behaviour rather than on their circumstances were often deeply stigmatising and unhelpful.

Be faithful

Many women’s groups also critiqued the message related to faithfulness. In the context of polygamous relationships, or where male sexual partners chose to have other partners, women’s faithfulness did not protect them. Again, the message had been designed with men in mind and so missed the mark among a cohort of women who were desperate for information and strategies to protect themselves.

Condomise

The message of condom use was also inadequate. In many cultures, ‘good’ women are expected to be ignorant about sex and passive in sexual interactions. In these contexts, it was unlikely that women would be able to have genuine and respectful conversations about condom use with their partners. Some women could, of course. But for the majority, the powerful messages they had grown up with about what women and men are supposed to know about sex and sexuality negatively affected their abilities to take condom advice.8

These gendered critiques by academics and activists were prevalent in the early 2000s. But for some reason, from my perspective as an activist they did not seem to change how AIDS programmes were run and managed. Policymakers, 8. Alan Guttmacher Institute (2003), The ABC approach to HIV prevention: a policy analysis. A selection of articles on A, B and C from the Guttmacher Report on Public Policy. Available at: www.guttmacher.org/pubs/compilations/agionabc.pdf
governments and donors claimed not to know how to integrate these concerns into existing programmes. Despite the existence of the United Nations Decade for Women, the various world conferences on women, and the wide range of experts, researchers and activists on women’s rights and health that existed globally, they argued that they did not have the internal technical capacity to begin to develop and shape new responses.9

By the mid-2000s, the women’s rights movement had decided to bypass donor and government lethargy. They used their resources in creative ways to pilot projects addressing gender-based violence, girls’ education, and micro-finance initiatives. These were rolled out in different parts of the world. Most of the projects centred on the structural causes of gender inequality and how these affected HIV vulnerability and risk.

For the most part, women’s organisations supported women to access treatment, but they did not make this their primary focus of advocacy. They focused on the issues that had always been on the top of their agendas but had been made more urgent by the AIDS epidemic: property rights, girl’s education and gender-based violence. Many women’s rights groups correctly saw the increased availability of funds presented by the AIDS response as an opportunity to use resources for broad-based women’s empowerment.

**AIDS as an entry point to women’s rights**

After the Global Fund to fight AIDS, TB and Malaria (Global Fund) was established, activists from southern Africa made the case that the Fund needed to support the kinds of longer-term strategies that would address the social determinants of health. By 2006, the Global Fund board – on which a number of activists sat – had signalled its approval of a strategy that would do exactly this.

The Global Fund Framework document10 stated that the “Global Fund will support proposals that include public health interventions that address social and gender inequalities as well as behaviour practices that fuel the spread of the three diseases.” For activists in southern Africa, there was finally hope for the kind of financial resources that might make a serious impact on structural gender imbalances.

A group of women’s rights and AIDS activists from southern Africa convened in 2007 to strategise about how to access Global Fund resources in advance of a new funding round. At the time I was working for an organisation that described itself as an activist funder. With resources from the Open Society Foundation, but staffed by activists from across the region, and governed by an entirely southern African board, OSISA represented an interesting hybrid organisation that had legitimacy in both the donor world and within civil society networks. This was largely because it was prepared to support and push for difficult and complex issues.

OSISA convened a series of national and regional meetings to assess the interest of activists in going through the long and complicated process of participating in the drafting of country proposals. We looked at the quality and content of proposals that had been approved in recent years. We then figured out a

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9. This is not unique to donors in the AIDS sector. An Overseas Development Institute report on gender and peace-building notes that “Donors show a lack of understanding about gender issues across the different sectors. The issues are left to the ‘gender experts’, with the result that gender-responsive approaches often remain peripheral to mainstream donor engagement in peace-building and state-building efforts.” See Domingo, P. et al. (2013), Assessment of the evidence of links between gender equality, peacebuilding and statebuilding, Overseas Development Institute. Available at: www.odi.org/sites/odi.org.uk/files/odi-assets/publications-opinion-files/8767.pdf

plan, country by country, for getting women to agree on what would go into country proposals. We based our prioritisation on the size and scope of country epidemics, as well as the needs articulated by women’s networks on the ground.

OSISA provided resources for in-country planning meetings, and was on hand with consultants to help to do the maths, including the painstakingly detailed work of costing the proposals once activists had put them together. The group also talked through how, in each country, we would ensure that someone we knew and trusted was on the drafting committee that would submit overall country proposals.

The technical work was intensive and exhausting, but by late 2008 we had a good process and had thought through all the details. Our activists had learned the rules that guided the conduct of people on Global Fund Country Coordinating Mechanisms, and they had all managed to secure seats on these bodies. They knew the timeframes for proposal submission, and were on top of what it would involve to get each of our key concerns – violence against women, property and inheritance rights, girls education – on to the agenda in places like Swaziland, Zambia and Malawi.

What we hadn’t adequately thought through was how threatening it would be to national programme and policy heads for women living with HIV to be so well organised, technically competent and forceful in their demands. In Zambia the strategy worked beautifully, but in Swaziland we were reminded that resistance to women’s rights is often swift and devastating.

The section in the proposal that requested resources for women’s rights work was excised from the document after the final Country Coordinating Mechanism meeting but before it was sent to Geneva. We had spent months developing the wording and building consensus among women’s groups about how the resources would be divided up if the grant proposal were successful. It was a devastating blow. It underscored that the problem of gender equality could not simply be dealt with technically and administratively.

The Swaziland example illustrates that decision-makers are often wilfully and personally opposed to women’s rights. The idea that gender equality is not mainstreamed into development because technical people simply do not know how to do it is naive and dangerous. In other words, it is no coincidence that where there is a national epidemic of AIDS no government has scaled up HIV prevention programmes for women.

Twenty years into the crisis, despite all we know about its effects on women, we still have not moved beyond small, piecemeal approaches to addressing women’s needs. Even the newly popular programmes that work with men and boys to address gender equality remain small and unsystematic. Why? Because there is political resistance to women’s rights. Therefore it stands to reason that this resistance must be fought politically, not technically.

However, we all know that a political fight cannot be waged without a few key demands. The rallying cry now must be for women to have money, to have power and to be able to enjoy sex on our own terms.
Money (including access to credit and finance, economic opportunities, land and other assets)

Research over the last decade indicates that there is a strong relationship between women’s participation in the labour force and reductions in poverty. In other words, lifting women out of poverty has a disproportionate impact on overall country indicators of economic well-being. Furthermore, women’s access to property strengthens their ability to earn better incomes and to leverage credit, and often translates into more bargaining power at home.11

As the Global Coalition on Women and AIDS noted as far back as 2006, “women who have secure access to, control of and ownership of land and other assets are better able to avoid relationships that threaten them with HIV and to manage the impact of AIDS.”12

There is widespread recognition of these links, and acceptance across the world that women’s empowerment is a critical priority for the coming decade. Focusing on changing the economic circumstances for women will have clear structural benefits on women’s vulnerabilities to HIV infection, but it is also important in its own right.

Concerted and strategic partnerships between activists involved in land and economic empowerment, and those working on HIV, are crucial if a new political agenda about putting money into women’s hands is to be crafted. The question is whether we can make this a political issue, with consequences for how we vote and who we put into power in global institutions.

Power

Naila Kabeer tells us, “There is no single linear model of change by which a ‘cause’ can be identified for women’s disempowerment and altered to create the desired ‘effect’. It’s an important point. There are multiple causes for gender inequality and they are connected to one another in complicated ways.

There is no one string that will unravel the ball and solve the ‘gender question’.

Yet there is no doubt that political power is a game-changer for women’s rights and, by extension, for reducing the impact of AIDS on women and girls.14

At present, the statistics demonstrate that women have shockingly low access to and control of public processes. A recent VSO report indicates that only 13 heads of state are women, and fewer than one in four cabinet ministers around the world are women. At local level the situation is not much better. Only 20% of local elected councillorships are women. Our major cities – some as important as small countries – are run by men. Of the world’s 195 capital cities, only 10 are led by women. Worse yet, based on an extrapolation of current trends, it will be the year 2134 before men and women achieve parity in political responsibility.15


The argument is often made that putting women in power won’t necessarily address this. Yet the very notion that anyone can ‘put’ women into power requires examination. Where women participate in politics and are elected into positions of power, there is strong evidence “they are more likely to work on the problems they themselves faced.” VSO continues, “Studies have found that women are more concerned with a supply of clean water than who has to fetch it, but that they also prioritise the health of children and education – especially where women in politics have been denied access to education themselves. As importantly, the policies that women put on the agenda when they lead reduce levels of poverty for their communities, not only for women.”

What does this mean for those of us engaged in the AIDS response? Actually, it means a lot. It means that the budgets, policies and programmes that the international community is promoting stand very little chance of being taken up until we reach political parity. It also means that promoting women’s leadership is yet another structural approach to ending AIDS, and that better and more effective efforts must be made to invest in women’s political leadership at all levels. The case for AIDS has been strongly made for economic empowerment, but the rhetorical shift must now happen with respect to political empowerment. The numbers are far too stark and we simply cannot wait another century.

**Sex on our own terms**

Too many of women’s sexual encounters are framed by fear and passivity. Women around the world are often afraid to express their sexual needs and desires. The notion that ‘good’ women don’t talk about, let alone enjoy, sex presents a major obstacle to gender equality. Heterosexual constructs of manhood, on the other hand, encourage men to talk excessively about sex and in ways that are often harmful and oppressive to women. No wonder, then, that so many women are afraid to ask questions and voice their concerns in relation to sexual and reproductive health and rights issues.

What this means is that there is insufficient scope for preventing sexually transmitted infections and many other conditions that affect women’s sexual and reproductive health. It also means that too many women believe that it is necessary to stay within the narrowly defined lines of what it means to be a ‘good’ woman. Around the world and across cultures, the consequences for women who raise questions and challenge the way things are done are often severe. A stark example of this is Uganda’s Anti-Pornography Law 2014. The law seeks to curb “public indecency”, and has encouraged a number of vigilante attacks on women seen to be transgressing moral codes by wearing miniskirts. According to an anonymous taxi driver interviewed by a Kampala news outlet, “We shall not allow women to pass on the road with skimpy dresses. Undressing them in public is the only way to stop them.”

Until women can be assured that they will not be subject to violence in their homes or on the streets simply for being who they are or wish to be, we shall not win against AIDS.

Violence and the fear of violence fundamentally structure relationships between men and women. There are multiple ways in which violence and AIDS intersect and there is extensive research articulating these connections.

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16. Ibid.
The most straightforward way is through rape. We also know that sexual abuse in childhood is associated with risk-taking behaviour later in life. Girls who were abused have an elevated lifetime risk of contracting HIV because they often act out their traumas in ways that heighten their risk. They are more likely to have substance abuse problems and engage in risky sex than their peers who have not been abused. We also know that violence and the fear of violence can prevent a woman, even in a consensual relationship, from insisting on condom use or refusing unwanted sex. This fear extends to issues like testing. A woman who is afraid of her partner is more likely to avoid testing for HIV than one who is not. This affects her chances of accessing treatment and prevention of mother-to-child transmission programmes.18

Despite the overwhelming evidence that violence is a significant driver of HIV transmission in the African context, I have yet to find a single country in which government has scaled up a pilot gender-based violence programme using their own resources.

A series of reviews by the World Bank demonstrates that while laws and policies are important in addressing gender-based violence, they are not enough to end impunity. Programmes to halt violence do not work unless they are properly funded, using well-trained personnel. The World Bank notes that there is seldom “collaboration between law enforcement, legal aid, health care organisations, public health programs, educational institutions and agencies devoted to social services and economic development—for the purposes of both prevention and ensuring an integrated response to survivors.”19

Yet again this is a technical approach. Gender-based violence programmes will not get off the ground unless there is long-term, normative change. Despite all of the laws and wonderful policies that have been drawn up across the world, women continue to be blamed when they are raped or assaulted, and violations against them continue to be viewed as less serious than violations against men and boys. And because women’s larger contributions to society are not valued, gender-based violence programmes continue to be seen as marginal rather than central to economic growth and development.

Political will won’t happen on its own

Ida Susser, a long-time activist and academic, has written extensively over the years about the ways in which women, especially in southern Africa, have survived AIDS. She puts the issue most succinctly when she says, “Gay men in the US have fought to have their sexuality viewed with dignity and consideration and to take control of their own future, nevertheless, still, poor gay men have fared least well. Since it has been poor women, women of colour and women of Africa who have been the most dramatically affected by HIV/AIDS, and since such women may have even less access to power than those stigmatized for sexual orientation, their sexuality has not been afforded the same consideration and dignity.”20

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While there is no sense in creating a hierarchy of oppression,

there is also no denying that part of the world’s failure to address the extremely high burden of AIDS among women, especially African women, has to do with the fact that these women are mostly black and poor.

This fact will not change any time soon, and so activists who care about health and women’s rights have three options.

The first is to ignore the international community and instead create better and more robust women’s movements that demand money, power and sexual choices everywhere that women live. The second is to mobilise better and more effectively among global activists, ensuring that struggles for social justice are connected and that it is these fights, rather than technical papers, that drive our activism.

The third and most compelling option is for us to do both at the same time. Virchow may have been writing over 150 years ago, but his words ring true today. Diseases do have two causes. The era of pushing to better understand the pathological causes of AIDS has yielded many positive results. But for all the progress we have made on pathology, we have made only tentative inroads on the political front. The next era in the fight against AIDS must focus on changing the structures that underlie injustice. Without this, in another 150 years we will still be citing Virchow and praising his prescience. Our goal must be to prove him wrong so that the only cause for disease is indeed embedded in our biology rather than in our sociology.
Introduction

The AIDS movement currently finds itself in the throes of an unconscionable paradox. Global funding for HIV has stagnated at the very time when we are experiencing transformative developments in science that hold the potential to reverse the epidemic.

Several donors have now substantially decreased their funding to AIDS programmes, with limited or no political consequences in their home countries but with devastating impact in countries where most people are living with HIV and AIDS. These cuts have taken place against the backdrop of unprecedented developments in the science of HIV treatment, care and prevention.

We can begin to end AIDS, but countries must focus harder on the interventions we know to work. These include earlier access to HIV treatment for clinical and prevention benefit; prevention of vertical transmission to newborns; voluntary medical male circumcision; harm reduction; targeted behavioural interventions; and broader access to condoms.

So why is funding for AIDS programmes on the wane?

As austerity measures have swept across Europe, the European Union has held fast to its requirement that member states produce balanced budgets. Consequently, a number of development budgets have been significantly
reduced and HIV funds have been flatlined since 2008. In the United States (US), funding cuts have dogged the bilateral AIDS programme, threatening major gains in expansion of treatment coverage. Governments typically beg political sentiment as the reason for their cuts. Yet recent surveys of Americans show that while general foreign aid expansion is not supported, foreign aid to tackle diseases generates greater support.

These decisions by developed countries to diminish or flat fund HIV investments have triggered some criticism and protest among a small number of activists. But the power of civil society to help reverse these trends is not yet strong enough. Meanwhile, the stakes could not be higher. These funding decisions have literally life and death consequences for communities most affected by HIV in places where resources are needed the most.

This essay looks at what might have happened in the last few years if civil society capacity for highly effective campaigning – including the confrontational tactics sometimes required to carry the message directly to distracted and antagonistic decision-makers – had actually been put to use in key countries. Would funding levels have been pushed up to ensure that the scientific advancements had a chance to work at scale? Would the political commitment of donor governments to truly ending the AIDS response be different today if activists had been able to anticipate and mobilise to counteract the current crisis?

These questions are critical for civil society groups as they face a post-Millennium Development Goal funding landscape that could further shrink the pot of resources.

They are also vital for the growing number of foundations and non-profit actors that exist outside the traditional donor world, who are investigating possible high-impact investments. And leveraging state resources better, especially in high-burden middle-income countries such as South Africa, India and Brazil, requires that civil society groups be supported, nurtured and strengthened through sufficient funding.

First we won in the streets: confrontational tactics in the 1990s

Starting in 1999, with activism by a new social movement populated by HIV, health, human rights and social justice activists in the global South and North, AIDS advocacy began to generate victories the world had thought were impossible. Treatment activists pushed for bigger budgets, compelling the world’s richest nations to spend billions in additional funding to provide lifetime HIV treatment and prevention to millions around the world. They also provoked the development of new and lasting global health initiatives, including the President’s Emergency Plan for AIDS Relief (PEPFAR), the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund) and UNITAID.

Because of their advocacy, AIDS programmes saw a decade of substantial annual funding increases in donor and domestic budgets. Throughout the early 2000s, civil society’s advocacy was consequential in determining the levels of funding committed by donor governments, as well as through national health and disease programmes.

While rich countries had resources, they also had multiple priorities. They were patently disinterested in funding treatment programmes for poor people in developing countries who were suffering from a largely sexually transmitted infection. Many governments
were even less supportive of financing programmes aimed at men who have sex with men, people who inject drugs, prisoners, migrants and other populations vulnerable to HIV infection. Significant coordinated pressure from activists around the world was needed to ensure that funding was made available to avoid needless deaths.

Long-term financial commitments were made in the early years of the new millennium because activists fought hard-won political battles for these resources. The cases of the Treatment Action Campaign in South Africa, who forced a belligerent government to accede to their demands and in the process forced donor agencies to begin to resource advocacy and activism, is but one example. The Indian Lawyers Collective, and their sterling work on bringing down the cost of drugs by using legal strategies and exploiting the loopholes in TRIPS, is another. At the global level, alongside others, activist groups from rich countries fought for better and bolder funding for activist groups from the board of the Global Fund. In lesser-known but still important battles, activists insisted that programmes promoting condom use, targeting young people and working on gender equality were supported financially as part a broad understanding of what it would take to ‘end’ AIDS.

In essence, activists throughout the 1990s made sure that the price of donor inaction was simply too high to ignore.

But funding programmes about issues that mattered was not the only terrain of battle.

One of the most effective strategies of activists in the 1990s and 2000s was the strong focus on scientific enquiry. Early activism in the 1980s focused on the importance of people living with AIDS understanding the virus and the effects it had on their bodies. In the 1990s activists built on this, insisting that research money and resources be allocated to ‘finding a cure’. The global vaccine movement was lobbied; drug companies were persuaded to dedicate research and development funds; and global foundations began to make large grants aimed at science. A decade into the new millennium, these investments began to pay off.

**Then we won in the lab: AIDS activism leads to scientific breakthroughs**

In 2011, a randomised controlled clinical trial showed that when HIV-positive people had earlier access to HIV treatment, they were 96% less likely to transmit HIV to a negative sex partner. The compelling preventive benefit associated with viral suppression, along with the clinical impact of earlier treatment, was further affirmed in cost-effectiveness studies, with models in South Africa showing that earlier treatment initiation could be cost-saving in as few as five years.

In 2013, after a protracted process, the World Health Organization (WHO) released updated HIV treatment guidelines recommending a change in clinical eligibility to CD4 <500 from CD4 <350, based on the clinical as well as preventive benefit of treatment, along with initiation regardless of CD4 count for serodiscordant couples, children under five years old, pregnant women, and people co-infected with tuberculosis. WHO also recommended incorporating routine viral load monitoring into treatment programmes to increase the clinical and preventive impact of antiretroviral treatment.

At the 2012 International AIDS Conference in Washington, leading HIV researchers told the media that the evidence on treatment as prevention was decisive, and that implications for policy decisions should be “as decisive as the scientific evidence”.
The modeling data argue that countries equipped to scale up aggressively now are much more likely to get ahead of new infections, while countries that continue scale up at the same or a slower pace will remain on an unsustainable pathway, constantly playing catch up, with some falling behind.

The gains won in the streets in the 1990s, and followed up by wins in the labs in the 2000s, were both dramatic and important. But they cannot be converted into a lasting reversal of the epidemic without money. Despite important reductions in incidence among most of the highest burden countries, many countries, particularly in Eastern Europe and Central Asia, are facing rising rates of new infection alongside extremely low treatment coverage among sex workers, people who use drugs, men who have sex with men, and transgender women. These marginalised, excluded and criminalised populations require precisely the human rights- and evidence-based approaches to prevention and treatment that governments have too often refused to adopt, and they need the resources to roll those programmes out.

The game-changing benefits of earlier initiation with improved regimens have been proven. But countries have been largely unable to implement these guidelines due to flatlined or shrinking budgets. In December 2013, for example, Zimbabwe and Uganda adopted the new guidelines in their national programmes, widening their treatment gap substantially. To match the commitments made by these governments, an infusion of resources was needed to bridge the widening treatment and prevention gaps. Furthermore, crucial resources were required to support advocacy for treatment as prevention among key policymakers.

Two years later, relatively little has changed despite the science. Tragically, HIV programme managers in many high-burden countries are debating whether to expand medical male circumcision programmes or to expand adult and paediatric treatment or to expand programmes to eliminate vertical transmission or to scale up prevention and treatment for key populations such as sex workers or men who have sex with men. They are rationing services at a time when the evidence in favour of aggressive scale up on all fronts could not be more compelling.

The risk civil society faces on entering the third decade of the AIDS crisis is that we miss the opportunity to surge forward with bold scale up of proven interventions in the highest-burden communities and actually end the AIDS epidemic. The financial downturn, combined with lack of political will among many donors and insufficient investment in the kinds of nimble and fast-moving civil society advocacy needed to challenge the received wisdom that budget expansion could not be possible in a time of austerity, have created a perfect storm.

Then they pushed back: investment talk not matched by action

In the aftermath of the gains of the 1990s and 2000s, donors and governments that had lost a number of battles with activists began to push back in a more forceful and concerted manner. For many years, activists had urged institutional actors to focus on scaling up investments for populations most at risk of HIV infection and facing chronic gaps in treatment coverage, and to address the structural drivers of the AIDS epidemic. They pushed for interventions focused on the most difficult issues, and insisted on ambition and boldness in planning. These were precisely the types of approaches that countries with the resources to invest had stubbornly resisted.

Beginning in 2008, the assault on human rights, AIDS funding increases and, indeed, AIDS activism began to take more focused shape. One manifestation
of this is that those who continue to push for bigger budgets and bolder programmes to enrol greater numbers of people are accused of not understanding the economic constraints that donors now face.

Yet it is clear that the global recession was not the sole, or even the primary, reason for the shrinking of AIDS budgets that began in 2008. While it may be appealing to believe that fiscal externalities are to blame, the decline in funding has deeper political roots. A powerful, well-organised and strategic civil society is needed precisely because, thus far, the diagnosis of the funding problem has been superficial. Without activist intervention at the level of analysis, the solutions for the funding crisis we now face will not be forthcoming, and a range of interventions and people will continue to be sidelined.

One of the most interesting and pernicious ways in which donors have pushed back against activists’ gains is at the level of rhetoric.

A compelling example of rhetorical gamesmanship (and there are many) is evident in the language of ‘investing’ that has characterised AIDS policy discussions since 2010.

International agencies, led by the Joint United Nations Programme on HIV/AIDS (UNAIDS), have argued forcefully since 2010 for donors and implementing countries to consider a response to HIV modeled on a strategic investment framework. The value proposition in this investment approach is that increased and sustained impact can be achieved as a result of additional funding for key prevention and treatment interventions. The idea is that big investments now pay off far into the future. If an increase in funding commitments for high-impact intervention is allocated now, the need for continual funding – the perpetual financing cycle that donors fear – is thus diminished.

By 2008, the analysis generated by technical agencies through modeling, clinical trial outcomes and operational findings from HIV programmes in high-burden countries was aligning to indicate strongly that a surge in high-impact prevention and treatment would mean the world had a fighting chance at ‘bending the curves’ of the epidemic – the curves of new infections, of disease progression and mortality, and, ultimately, of costs. Coincidentally, this new information was emerging precisely when the financial crisis began to be felt.

One might be forgiven for thinking that the donor response to the evidence outlined above would be to make strong arguments for further funding. The idea of protecting existing gains and bending the epidemic’s curves even further would make rational sense. Instead, donor resistance to genuinely investing in ambitious AIDS programmes ratcheted up. Around 2009, in order to justify odious funding decisions, donors began tactically deploying a range of concepts that civil society organisations were not always ready to challenge.

In principle, donors accepted the findings. Yet they did nothing to act. Knowledge of the facts did not trigger the intellectually honest (albeit sometimes ruthless) response that is second nature in the world of investors: when a compelling value proposition is made, investors mobilise the additional capital needed in order to make long-term profits. The donor governments responsible for funding the AIDS response failed to heed sound advice.

But donors were not the only problem. In the countries most affected by the epidemic, national governments stubbornly – and some would say hypocritically – did not (and still have not) change course to push bolder agendas and urge
donors to act. In fact, in some cases, additional barriers to scale up have been promoted by the governments of poor countries.

These barriers include the passage of draconian new laws that further criminalise not only sex between lesbian, gay, bisexual and transgender people (LGBT) but also public health and advocacy efforts to reach LGBT communities with prevention, treatment and other life-saving services. Such efforts, for example, under Uganda’s new Anti-Homosexuality Act, could be considered “promoting” homosexuality or “aiding and abetting” homosexuality, punishable by seven years’ imprisonment, hefty fines and de-registration of organisations found guilty.

The refusal to base programmes on evidence in some countries has been compounded by donor stasis. The intensified resistance by donors to committing funding for middle-income countries, and sluggish or non-existent increases in funding for evidence-based HIV interventions by middle-income country governments themselves, are creating a perfect storm for increases in incidence in countries that have a real chance of putting the epidemic behind them.

Were we too slow to react? Rhetorical traps and distractions

As indicated above, donor and government insistence on using the language of investment (even as they divested) was not the only arena of rhetorical battle. The terms ‘efficiency’ and ‘country ownership’ began to surface more frequently. So too did the idea that it was time to make ‘a shift from emergency to sustainability’. Devoid of political context, these are each highly desirable features of any HIV programme, whether in the developing or developed world.

Yet after the financial crisis hit, these concepts were too often used by politicians as excuses not to fund AIDS programmes, even in the face of facts that indicated that substantial increases in short-to-medium investments would have long-term benefits. Often, this language was introduced to reinforce refusals by funders to keep funding promises or to soften the ground for announcements of budget cuts in the near future.

Why? In many respects, policymakers and donors saw AIDS programmes as soft targets. The success of activists in raising the issues and insisting on larger budgets made it seem to some in donor countries as if there were more funding available to fight AIDS than was actually needed. Those involved in AIDS activism, as well as donor agencies themselves, understood that this had never been the case. Despite this fact, the combination of new language designed to promote ‘efficiency’ and new tactics to promote a perception that there was a large amount of money supporting programmes (often at the expense of other diseases and development problems) caught some civil society organisations by surprise.

In many cases, whether at national, regional or global level, civil society groups were not adequately prepared or supported to react quickly and interrogate this new approach, critiquing it directly and rapidly. For example, civil society did not – as it should have – reject ‘country ownership’ as a concept that was being used disingenuously as a justification for stopping a funding relationship with a country, whether or not the government had agreed to take on those programmes, or was administratively or fiscally ready to fully take them on in the timeframes proposed by donor nations.

We also did not push back hard enough on the idea of ‘efficiency’ when this was used as an excuse to focus on relatively minor administrative challenges in order to scale back pre-existing budget commitments to global institutions such as the Global Fund.
Addressing this language was often further complicated when actual cases of corruption and inefficiency arose in programmes funded by the Global Fund, PEPFAR or other bilateral donors. Underpinned by a political agenda that was driven by reducing funding for AIDS rather than ending AIDS, the idea of ‘shifting from emergency to sustainability’ did not result in a set of benign actions aimed at responsibly taking on new programme areas and increasing the capacity of health systems to roll out to broader populations. Instead, ‘shifting from emergency to sustainability’ resulted in a cascade of actions aimed at de-prioritising the HIV response and undermining innovative, high-impact financing approaches such as those created by the Global Fund.

The work and findings of the Global Fund’s High Level Independent Review Panel provide an important example. The High Level Panel was established when high-profile corruption cases triggered a wave of distorting media coverage targeting the Global Fund in 2011. It was specifically set up after harsh donor criticism resulted in the withholding of several Global Fund contributions, and so it was ostensibly meant to review the Global Fund’s fiduciary controls and oversight. It should have looked at a narrow set of governance and audit questions, but its members leveraged the environment of crisis and extended its work far beyond that mandate. Ultimately, they developed a strong set of arguments promoting the idea that the three diseases were no longer ‘emergencies’, and that it was time to abandon core tenets of the Global Fund’s approach, such as allowing countries themselves to request funding based on what they actually needed rather than on what donors agreed to provide.

These conclusions should have been roundly criticised or rejected by civil society when they were published. As a sector, civil society did not have the capacity – the time, funding or human resources – to anticipate and curtail the way the conclusions of the High Level Panel would be framed and manipulated.

In short, civil society was outflanked.

The audacity of hope: confronting the new Obama administration

Early in the Obama administration there were troubling signals that a bold commitment to HIV treatment scale up would not be a priority for the US president. The constraints brought on by the financial depression that was beginning to grip the US were only part of the story. Initially, President Obama’s chief advisors in global health cast aspersions on the cost-effectiveness of HIV treatment – their concerns were technical and political rather than solely financial. It is also true that the president’s budget officials balked at the out-year budget obligations created by the US investment in HIV treatment. So on two fronts – funding and technical analysis – the new administration seemed less than keen to keep the commitments that the president’s predecessor had made.

There began to be clear signs that the questions being raised by administration officials about PEPFAR in Washington were playing themselves out at the implementing country level. PEPFAR seemed to be retreating from treatment expansion. For example, in Mozambique civil society partners began to report increases in technical support provision and other ‘soft’ investments at the expense of service delivery rollouts. In Uganda, a US government directive was issued in September 2009 that implementing partners were not to expand treatment coverage to more people unless a patient died or was lost to follow up.
In Washington, these developments were interpreted by some as the inevitable outcome of an administration that lacked the evangelical zeal for HIV treatment scale up that had been touted by President Bush. In response, some organisations began proactively and tactically reframing their efforts in order to adapt to the new environment. If resources to fight HIV might be diverted to other health issues, they would need to learn the new language and take on new agendas.

Maternal and child health were a priority topic for Obama’s team, as well as a legitimate cross-cutting issue. HIV infection is the leading killer of women of reproductive age around the world and thus is a crucial plank in the AIDS response. Likewise, chronic underinvestment in the leading causes of preventable maternal death undermine the impact of the AIDS response, particular in high-burden sub-Saharan African countries. Some organisations that were supported by US government funding sought to fit their AIDS activities into this new frame for cynical and pragmatic rather than programmatic reasons. It was clear to many in AIDS activist circles that maternal and child health were being raised by the new administration largely as an either/or proposition rather than as part of a vision of expanded ambition and service delivery. There were no increases in funding anticipated to accompany the new interest in maternal and child health, nor were there any clear, measurable targets that pushed over and above existing (and largely inherited) PEPFAR targets.

A core group of advocates in Washington and in implementing countries, including South Africa, Uganda and Kenya, decided to fight the shrinking political and financial space that was on display within the new administration. We were aware that it would require a multi-pronged strategy to transform this potential backlash into a commitment by the administration to champion the scale up of high-impact treatment and prevention interventions.

We chose to use tactics that had been successful since the start of the global social movement to win treatment scale up, and had continued to be deployed throughout the period of the financial downturn.

Smart, strategic and high impact activism incorporating a range of tactics, from massive grassroots mobilisation to detailed, evidence-based policy analysis.

Between February and July 2010, the Obama administration was confronted by US criticism (led but by no means solely driven by Health GAP) as well as by pressure from around the world in response to its retreat from funding the fight against global AIDS. We were aware that the International AIDS Conference, which was to be held in Vienna, Austria, presented an important media opportunity to either shame the administration or demonstrate its success.

By the time of the Vienna conference, we had won several important near-term victories. For example, in June 2010 Ambassador Eric Goosby, the coordinator of PEPFAR, announced that Uganda would end its treatment waiting lists and create 36,000 new HIV treatment slots for clinically eligible Ugandans. This followed months of treatment caps, which we documented widely in international media and were also documented by civil society organisations in various countries.
In July protesters marched in the thousands through the International AIDS Conference venue, demanding that President Obama deliver on his pledge to fight global AIDS. They also challenged the rest of the world’s leaders to keep their promises to existing AIDS programmes by not hiding behind fiscal austerity.

The attention generated by the Vienna protests served as a wake-up call for senior officials in the US administration. They began taking the consequences of waiting lists for treatment in PEPFAR-funded programmes more seriously. They also started to focus on expanding the pace of scale up even in the absence of budget increases. In other words, within a relatively short space of time, external political pressure had resulted in increased internal pressure to expand PEPFAR. This happened even before there was a financial commitment to back it up.

A year later, by the tenth anniversary of the United Nations General Assembly Special Session on HIV/AIDS, in July 2011, the collective grouping had managed to secure a new global commitment to reaching 15 million people on treatment by 2015. Less than six months later, by World AIDS Day on 1 December of that same year, President Obama announced that he was committing his administration to beginning to end the AIDS epidemic through intensifying scale up of priority interventions, including doubling the number of people being directly supported on treatment with US funding through PEPFAR.

This target was reached, with PEPFAR now investing in treatment for 6.7 million people. However, PEPFAR funding levels remain $700 million below the funding levels invested at the programme’s funding peak in 2010–2011. Many of us are now focused on fighting to reverse funding cuts from recent years in order to ensure that the positive trend in treatment scale up is continued.

This example raises a number of important questions about what might have happened if there had been enough funding for full-scale civil society advocacy campaigns led by strategic coalitions of activists in rich and poor countries. Had there been sufficient capacity in place so that the effort to challenge the Obama administration was taken on by more than a handful of groups and individuals, might the impact have been more far reaching? Had a broader range of civil society groups understood earlier on that the rhetorical shifts in ‘ownership’ and ‘efficiency’ were the beginning of a sustained assault on HIV programme ambition, scale and scope, would the cuts have been as deep?

A time for game-changing advocacy to match the game-changing evidence

When activists are at their most effective, they are fearlessly and intelligently confronting the realities of the present day while fighting to win tangible changes that transform those realities – disregarding the comfort and lure of received wisdom.

At their best, activists are agitating for ‘unreasonable’ but winnable demands.

Since the start of the financial crisis in 2008, civil society organisations fighting for access to sufficient financing to end the AIDS epidemic have had to demonstrate skill in reacting quickly while defining a bold agenda for change. We haven’t always risen to the challenge. In large part, this has been because underinvestment in civil society capacity for high-impact advocacy has left many organisations unprepared to fight back against arguments about fiscal austerity, let alone against ideological uses of otherwise welcome concepts such as ‘country ownership’, ‘efficiency’ and ‘sustainability’.
In addition, few of us were fully prepared to leverage emerging findings from science. Although we had fought for the research, once it bore fruit we weren’t ready to make the political arguments that would ensure that the HIV treatment we had so vociferously demanded in the 1990s would have wide and effective use in clinical and prevention settings.

The professionalisation of civil society advocacy also contributed to the ways in which we were caught flat-footed. Many organisations are unwilling to challenge policymakers with ambitious demands because they rely on them for budgets to implement programmes, as well as for the goodwill necessary to operate in sometimes complex national environments. This is the case for activists in both rich and poor countries.

Another factor was that with the rapid scale up of HIV programmes in the early 2000s, many activists who had previously used confrontational tactics began focusing more on service delivery; for example, through running treatment programmes. Others had been absorbed by global agencies, plucked out of the contexts in which they were most effective and deployed to pursue the institutional mandates of the very agencies that were now coopting the language of ‘ownership and sustainability’. With the new battle seeming to be about getting the systems to work, or getting global institutions to work better, activist civil society was discovered to be extremely lean when the funding and political crisis of 2008 hit.

The road ahead, however, will be even more difficult for civil society than the road since the start of the financial crisis. Even more crucial scientific advances that have the potential to further revolutionise the standard of care are in the pipeline. These include improved antiretroviral regimens that are more effective in fighting HIV; important new medications to treat hepatitis C; improved and less expensive viral load monitoring at the point of care; and improved tools to diagnose drug-resistant tuberculosis.

Just as treatment activists insisted on learning the science of HIV in order to push for better treatment and to foster political agency among those living with the virus, so the next generation of civil society actors must enter the third decade of the response to HIV with a commitment to agitating for rapid uptake of this new science in the highest-burden communities.

Rather than accepting the argument that poor countries and marginalised groups must be the last in line to benefit from scientific innovation because of issues of ‘sustainability and ownership’, activists must raise issues of justice and equity. And, as we now know, they must do so quickly and authoritively in order to influence the terms of these debates and the funding decisions that flow from them.

Civil society must also expand emerging models of grassroots and community-based ‘demand creation’ campaigns for new technologies and new programme approaches. Without insisting that the technological dividends of two decades of AIDS activism are unaffordable, civil society doesn’t stand a fighting chance of changing the conversation from one of further, more acute rationing to one of truly winning the expanded programme coverage needed to save lives, halt new infections and end the AIDS crisis.

**Where will the money come from?**

Even if activists win the political arguments, many wonder where the new money will come from. While civil society activism will have some effect, there is also a
need to ensure that the mechanisms are in place to sustain giving. In a sense, civil society groups need to push for funding mechanisms that are more resilient to political and ‘economic crises’, such as that experienced in 2008.

Three promising sources of large and sustained funding need intellectual and practical debate by activists globally. They represent the best hope for ensuring that never again can resources be used as an excuse to scale back HIV programmes at precisely the moment when they need to be expanded.

First, a ‘Robin Hood tax’ to end AIDS seeks to levy a very minor tax on financial transactions such as trade in derivatives, stocks, bonds and foreign currency exchange. The proceeds from this tax would then be invested in critical community priorities, such as fighting HIV, tuberculosis and malaria. The tax would work well alongside increased political pressure on developed and developing countries to expand their AIDS funding.

Second, non-voluntary replenishment by countries is sorely needed in the response to infectious diseases such as HIV, or preventable conditions such as maternal mortality, where annual funding needs are relatively easy to predict. For example, the model of the World Bank’s replenishment has been successful, despite the financial crisis, in large part because of its non-voluntary nature. The European Development Fund is also increasing its commitments, even to countries that have had concerns about governance issues, during this period of budget reductions in part because their funding must be spent. This demonstrates that the necessary funding can be mobilised to shore up for the lean years.

Third, and perhaps most importantly, no new approaches to mobilising sufficient levels of funding will take shape without substantially increased and predictable funding to civil society to engage in high-impact national, regional and global campaigning to drive up demand creation and government funding to control and ultimately end the pandemic.

Conclusion

Two years after a powerful rallying call to ‘end AIDS’ emerged at the International AIDS Conference in Washington in 2012, the concept risks being little more than self-serving rhetoric unless donors and governments fund the scale up of evidence-based, high-impact interventions required to defeat the epidemic, at the scale required, with the speed required, and over the long term.

In the last two years, the need for a more honest conversation about how to invest in what works has become acute, even as funding has flatlined or diminished. At the same time, activists have also faced the stark reality of virtually non-existent investment in the strategic, bold, authentic civil society advocacy that is required to push back at funding cuts and to chart new pathways to genuinely end AIDS.

As the funding cuts began in 2008, only a skeleton crew of activist organisations was equipped to respond with both elite ‘insider’ strategies and grassroots ‘outsider’ strategies. Only a few organisations and coalitions had the capacity to advocate and negotiate directly with decision-makers in the spaces in which common ground has been forged in recent years, while also ensuring that, if necessary, those same decision-makers could be confronted with the criticism, public pressure and even shame warranted by the high-stakes consequences of their policies.
A stark lesson of this period of flat-funding the AIDS response is that even a minor increase in investment in civil society campaigning, especially aimed at strategic coalitions of activists based in countries with epidemics and their allies in the global North, can force decision-makers to reverse course and even openly champion a political agenda for scaling up the AIDS response and acting on new evidence.

As activists prepare to face the post-Millennium Development Goal world, they are acutely aware that paper commitments to targets mean nothing if they are not backed by budgets. Scaling up, which is what the agreed AIDS targets require, in the face of flat funding will be next to impossible. Priority areas for programme expansion – for key populations, non-health facility-based community support services, strengthening grassroots civil society advocacy, and implementing ever-evolving and improving treatment guidelines – will not be possible with static budgets.

While the prize of reversing AIDS may be closer than ever, the stakes have never been so high.

The costs of inaction far outweigh the costs of genuinely investing in ending AIDS.

Asia Russell

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Introduction

In recent years, activists have poured significant energy into pushing for resources for institutions like the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund). Yet there has not been nearly as much sustained effort to keep drug prices low. In part, this is because many activists have taken their focus off the macro issues related to access to essential medicines and have focused instead on short-term solutions.

Given the emergency situations that many people in low- and middle-income countries have encountered, the temptation to focus on quick wins has been strong. However, it has come at a cost. After first-line generic antiretroviral (ARV) drugs became cheaply available on the market, a sense developed among the wider AIDS movement that the battle had been won.

Yet among activists who work on access to medicines issues on a daily basis, it is obvious that the battle has not yet been won.

Certainly a lot has been achieved. In the last decade, the price of front-line ARVs has been considerably reduced, and the efforts of the HIV activist community were instrumental in this regard. Between June 2000 and 2011, front-line ARV
prices decreased from $10,439 per patient per year (PPY) to $347/PPY. To solidify these gains, in June 2011, the high-level meeting of the United Nations General Assembly Political Declaration1 stated that trade barriers and intellectual property should not stand in the way of HIV treatment access. The high-level meeting was unequivocal: where trade barriers exist they should be removed.

The Declaration was the product of intense negotiations, during which civil society groups pushed hard around essential medicines and drug pricing, and won. The Declaration referenced another crucial statement, the Doha Declaration2, which had been issued in 2001 as the outcome of the World Trade Organization (WTO) ministerial conference on the Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS) and public health. The Doha Declaration stated that public health concerns trump trade concerns.3

It emphasised that there was room for flexibility within the WTO’s TRIPS agreement,4 and that these flexibilities should be used in the case of medicines.

Specifically, the Doha Declaration states, “Each member has the right to determine what constitutes a national emergency or other circumstances of extreme urgency, it being understood that public health crises, including those relating to HIV/AIDS, tuberculosis, malaria and other epidemics, can represent a national emergency or other circumstances of extreme urgency.”5

Three years after the high-level meeting and 13 years after the Doha Declaration, trade barriers to drug access have not decreased. On the contrary, they have been dangerously strengthened, particularly by a combination of bilateral agreements, restrictive patent laws in certain countries, and a lack of competition in some areas of the production of medicines and medical products. Today, the gains that many activists took for granted after 2001 are under serious threat.

In part, this is because drug companies have played a clever game. Using mechanisms like ‘voluntary licensing’, ‘tiered pricing’ and ‘standard prices’, they have signed deals that appear to be generous. Yet for the countries and generic companies that have entered into these deals, the rewards have been fleeting. Big pharmaceutical companies, like Gilead, Bayer and Novartis, have used their deep pockets and legal muscle to try to dissuade civil society groups and generic manufacturers in middle-income countries from opposing the renewal of dubious patents or the granting of new patents on old medicines. They have also worked hard to spin media stories that portray them as responsive to the public health crises that grip low- and middle-income countries.

The sad truth is quite the opposite. As Doctors without Borders research has found, between 2001 and 2011, only 3.8% of drugs approved for global use were designed to treat diseases where “treatment options are inadequate or don’t exist”.6

While drug companies certainly deserve their share of criticism, they have simply behaved according to the logics of profit making: trying to expand their monopolies

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and fighting against the competition with generics. Activists, on the other hand, have been rather less consistent in championing the access to medicines issue. Through a combination of strategic blunders, complacency and a focus on other issues that also require attention and activism, many AIDS activists have been diverted from focusing on the primary actions necessary to keeping drug prices low.

However, in the absence of strong and sustained activism, it is unlikely that essential medicines will become available in the quantities and at the prices needed to ensure universal access.

If activists do not quickly confront this crisis, there is no guarantee that the millions of people who have been placed on treatment will be able to stay on treatment and move on to second- or third-line regimens when they need them.

This insight tells the story of how we have arrived at this difficult and dangerous situation.

Technical words and important definitions

One of the biggest challenges to advocacy on essential medicines is that some activists see it as a complicated sector, replete with medical, economic and legal terminology. Often, those advocating for AIDS funding for large-scale programmes have not been able to see what is really at stake in drug pricing activism because of the jargon. As a result, essential medicines activists have had to work hard to demystify the language. This essay provides a step-by-step analysis of the big issues in essential medicines, while also making a real effort to use accessible language. Why? Because leaving these issues to the so-called experts would be a strategic mistake.

Knowledge is an important weapon for empowerment and more activists must become involved.

TRIPS

What prevents anyone from producing and distributing medicine to people who need it? In short, it is TRIPS, which was signed by WTO member countries in 1994 and has been in force since 1995. According to WTO, “TRIPS attempts to strike a balance between the long term social objective of providing incentives for future inventions and creation, and the short term objective of allowing people to use existing inventions and creations.” The TRIPS agreement obliges each WTO country member to grant at least a 20-year patent on all new medicines.

However, TRIPS gives the leverage to countries to define what can be patented or not. For instance, the Indian Patent Law is known to have quite restrictive patentability criteria (something that activists have embraced), while in other countries, the process of reviewing patent applications is very weak, which means that eventually most patent application will be granted. In other words, TRIPS protects the owners of patents, but also provides a list of circumstances under which patent rights can be minimised or circumvented in the public interest. These are known as TRIPS flexibilities.

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7. Trade-Related Aspects of Intellectual Property Rights, in force since 1995, is to date the most comprehensive multilateral agreement on intellectual property.
Compulsory licenses

One such flexibility is compulsory licensing, which occurs when a government allows someone else to produce the patented product or process without the consent of the patent owner. In recent years, a number of drug companies have tried to avoid situations where countries invoke compulsory licensing. When other companies can produce drugs, this dramatically affects the prices they can charge. It can also threaten to break their monopolies.

Patent opposition and patent law reforms

Another key flexibility of the TRIPS agreement is the possibility of countries opposing patents. In other words, countries may refuse to grant a patent, including for lack of novelty, and they may also revoke a patent. It is important to remember that each country has the right to define in its patent law what is novel and what can be patented. These are referred to as patentability criteria.

Voluntary licenses

Contrary to a common belief, voluntary licenses are not a flexibility of the TRIPS agreement but a strategy of the pharmaceutical industry, primarily designed to avoid the use of TRIPS flexibilities and to preserve their monopolies. To address this, many large pharmaceuticals that own patents have begun to grant licenses to other manufacturers in exchange for royalty payments. This is called voluntary licensing. When voluntary licenses are offered to many manufacturers across different countries, drug prices can go down, but this is rare. Most of the time, voluntary licenses are offered in highly restrictive ways. Rather than open up access, they block competition and extend the original company’s control over a given market. Often, voluntary licenses are offered as a pre-emptive move, where drug companies think they might lose a case in court, or when they anticipate that a patent application will be rejected, a patent revoked, or a compulsory license issued.

In this scenario it is easy to see why companies would prefer this route. Companies that give voluntary licenses often dictate where the active pharmaceutical ingredient must be purchased, as well as the countries to which the drugs can be exported. As Médecins Sans Frontières notes, these arrangements “do not lead to the unhindered competition that allows patients to benefit from the lowest prices possible, nor do they increase access in all countries where the medicines are needed.” If a company chooses to offer a license in Vietnam, while there is a bigger epidemic in China, it leaves very few options for people living with AIDS in China. It is also important to note that voluntary licenses are generally not accessible in middle-income countries, even though the largest epidemics exist in places like South Africa, China, India and Brazil. This fact makes voluntary licenses strategy even less relevant for diseases such as hepatitis C, concentrated in middle-income countries.

Tiered or differentiated pricing

Tiered or differentiated pricing is the concept of selling medical products in developing countries at prices that are lower than in rich countries. Tiered pricing involves segmenting markets in these countries. Companies often negotiate two different prices with the health authorities: one for the public sector and another for the private market. The globally accepted way of separating markets has been to

rely on the World Bank’s categorisation of low-, middle- and high-income countries, and in the case of AIDS, to match this with an assessment of the HIV prevalence in a given country. Tiered pricing often goes hand in hand with voluntary licensing.

In essence, drug companies have seen tiered pricing as a way to preserve their profits while responding to the perception that they are callous and indifferent to the plight of people in poorer parts of the world.

Pharmaceutical companies use the price they charge on the United States or French markets, for example, as a reference point to try to show that they are offering a ‘discount’ to the country, although countries such as France and the United States still do not have any transparent process for the negotiation of drug prices. The price of the drug is, in reality, not linked to the real cost of research and development, and the production cost of the product. Rather, it is largely based on a formula that maximises profits for the originating company.

Adopting different prices in different markets is supposed to make products more affordable in low- and middle-income countries. Tiered pricing does not imply that a price is fair or affordable. As Moon et al.⁹ point out, it just “means that different prices are charged to different segments of the market for the same product.”

How does it all add up?

When compared to the cost of generic drugs, those provided through voluntary licensing agreements are significantly more expensive. A review of over 7,000 developing-country purchase transactions between 2002 and 2007¹⁰ found that the tiered prices for 15 out of 18 ARV drugs were 23–498% higher than the generic price. In an important update, the authors note that as of mid-2011, of the three products for which tiered prices were lower than generic prices, two products now have lower-cost generics available. The short story is that differentiated pricing works to bring prices lower than they otherwise might be, but it is still is not nearly so effective as the production of generics.

Given this definitional and practical landscape, it is not difficult to see why the rapid increase in voluntary licenses in recent years is a worrying step backwards. It is driven by short-term needs rather than by the longer-term objective of increasing supply in order to meet growing demand. Most worrying, international non-governmental organisations (NGOs) have been at the forefront of celebrating and benefiting from voluntary licenses. When the option of using the TRIPS flexibilities is available, there are critical questions to be raised about why important players in the global AIDS movement have not stood firmly against the new practices that seek to strengthen patent regimes and inevitably drive up prices.

In addition, it is important to keep in mind that the strategies of tiered pricing and voluntary licensing are based only on the interests of the pharmaceutical industry. Governments at the national levels, and public interest organisations at the global level, including United Nations agencies, must begin to discuss more rules for better regulating patentability, licenses and pricing issues to prevent abuses from the private sector and guarantee public health needs.


10. Waning, B; Kaplan, W; King, A; Lawrence, D; Laufsens, H; Fox, M (2009) Global strategies to reduce the price of antiretroviral medicines: evidence from transactional databases. Available at: http://www.scielo.org/scielo.php?pid=0042-96862009000700013&script=sci_arttext
Is the ‘pharmacy to the third world’ in danger?

India is known as the developing country pharmacy. Certainly, it has played a crucial role in the development of the generic drug industry. It is estimated that more than 90% of the global supply of ARVs comes from India. The country was able to turn a lack of patent restrictions until 2005, plus a significant population and sizeable technological capacity, into an asset. In 2005, to comply with the TRIPS agreement, India had to amend its patent law. In order to prevent the granting of abusive patents, and to ensure that only new inventions were awarded with patents, activists pushed for India to include safeguards in its national law, including a clause called ‘section 3(d)’.

Even in the past few years, India’s patent office has made a number of important decisions that have upheld the TRIPS flexibilities. For instance, in April 2013, Novartis lost its legal battle to patent the anti-cancer drug Gleevec/Glivec in front of the Indian Supreme court. The court found that the drug was not ‘new’ in terms of Indian patent law’s section 3(d).

Sadly, the rules of the game have changed since 2005, and India must now abide by TRIPS agreements as defined largely by the companies who stand to benefit most rather than by the country’s own assessment. It is now compelled to grant 20-year exclusivity to drugs that are considered to be the ‘inventions’ of big pharmaceutical players. For instance, a drug like raltegravir (a third-line drug used against HIV) can be considered a real novelty. It would be difficult to oppose, as it is the first drug to be marketed in its own therapeutic class (integrase inhibitor). Fortunately, this is not the case for all new HIV drugs. But it does underscore the strategic error made by AIDS activists who thought that the question of drug treatment costs had been resolved.

The work of Initiative for Medicines Access Knowledge (I-Mak)\textsuperscript{11} demonstrates how dramatically out of step this is with reality.

In 2013, I-MAK conducted an analysis of 11 drugs considered to be new inventions that were in the pipeline and would soon require patents.\textsuperscript{12} Eight of these were simple modifications of existing compounds, so should not have constituted ‘real’ inventions. This means that the patents related to these eight drugs can be contested, and that access to each of these medications can be granted for use through TRIPS flexibilities.

The issue of competition and supply of generic forms of new ARV drugs has to be taken very seriously. Without strong and healthy competition from generics, TRIPS flexibilities will be more difficult to use because they are dependent on a generic alternative being available to supply to countries. For instance, there is currently no generic drug of raltegravir available. Because Merck has a strong patent that has been granted across a number of countries, and very deep pockets, there are no generic producers prepared to risk producing a generic only to be sued by Merck either in India or elsewhere.

\textsuperscript{12} The drugs assessed were tenofovir alafenamide fumarate, Darunavir, CMX157, rilpivirine, dolutegravir, elvitegravir, raltegravir, cobicistat, Complera, etravirine and Stribild.
What’s a fair price for a life-saving medicine?

There has been much confusion related to drug prices and the costs of production. The cost of a drug includes raw materials, labour, capital and a company’s investment in research and development. The price refers to the amount that buyers have to pay for goods or services. The price is an artificial construction, which may or may not be linked to the production cost. The difference between both is the marginal profit.

Too often, activist organisations have justified the differentiated pricing logic on the basis that there are costs associated with research and development or on the basis of the socio-economic status of the country. Many have supported the World Bank country classification, which differentiates low-, middle- and high-income countries. Yet this is a questionable way of arriving at drug prices.

Having standardised prices in poor and wealthy countries does not take into account the huge and growing income disparities within and between countries.

Even in countries that are considered to be wealthy, some people living with HIV cannot afford medication because they are personally poor.

Their country may be wealthy, but they may not have access to social security and therefore to health services. Furthermore, where voluntary licenses are offered in some places and not in others, there continue to be outstandingly large differences between drug prices, and therefore in treatment access and sustainability.

For example, for a treatment regime comprised of tenofovir + emtricitabine or lamivudine + efavirenz, the Russian Federation pays on average US$3,959 PPY, while neighbouring Kazakhstan pays half of that – an average of US$1,933 PPY. Thailand, on the other hand, pays around US$523 PPY. The Argentinian department of health pays around US$1,872 PPY for tenofovir. However, in the Argentinian private sector, the cost of the same drug is US$5,425 PPY. Interestingly, pharmacologists estimate that the average cost of producing tenofovir is less than US$400 PPY.

How can we explain such differences between the cost of production and the prices that are charged per patient?

Third-line treatments are not available in a generic form and their price is far higher. For example, in Morocco, the cost of the third-line raltegravir, darunavir and etravirine represents 13% of the total ARVs budget allocated by the department of health and the Global Fund. However, this treatment regime is used by only 0.2% of people living with HIV on treatment (only 11 people!). In other words, the purchase of second- and third-line medication for the 14% of people on treatment who need them represents more than a third of the total ARVs budget in Morocco. The amount required to give a single person a third-line treatment for a year is equivalent to the amount required to put 85 people on first-line treatment for a year.

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These price discrepancies prove the artificial nature of ARVs pricing and act as barriers to drug access. Is the fact that Morocco and Argentina are considered to be middle-income countries a good reason to justify such prices when we know that the profits of firms are still very high? In Russia and Kazakhstan, pharmaceutical companies can charge such high prices because there is no competition from generic manufacturers.

**Key debates**

Many members of the AIDS community endorse the idea that it is acceptable for middle-income countries to pay higher prices for drugs than low-income countries, and that high-income countries should pay even more. Many advocates in our movement have considered this to be a legitimate argument. However, this debate has been oblivious to one fundamental fact: apart from the elite and members of the highest socio-economic classes, few people in middle-income countries can afford the price of these medicines on the private market. In a context of increasing inequality, does it make sense to hew so closely to broad categories of drug pricing? Can we accept that in most middle-income countries, health budgets are spent on medicine purchase only, even if this is detrimental to prevention and other support programmes? In countries that cannot afford the newest HIV treatments, can we accept that old treatments such as stavudine are still prescribed, even if no longer recommended by the World Health Organization? The bottom line is that the World Bank gross domestic product (GDP) formula for determining drug prices is irrelevant and out of step with principles of health equity.

One consequence of the gradual endorsement of this differentiated pricing strategy aligned to the World Bank categories can be seen in repeated attempts from the Global Fund and the United Nations system to promote voluntary licensing and tiered pricing as a solution to enable access to treatment.

The furore over the latest Global Fund initiative, The Blue Ribbon Task Force, confirms this. Although the content of the project is still opaque, the idea is that middle-income countries receiving support from the Global Fund will pay more for HIV medicines in accordance with their ranking at the World Bank. If adopted, this initiative risks deeply undermining the work undertaken by activists and governments to ensure access to medicines in their countries.

Taking a strong stand against this practice, the HIV activist community sent a letter signed by more than 200 associations to Mark Dybul, Global Fund CEO, in May 2014. This demanded that the institutions renounce the Global Fund’s attempt to introduce tiered pricing into its procurement of drugs, based on the fact that differentiated pricing does not enable access to treatment in middle-income countries.

**Is voluntary licensing really improving access?**

Unfortunately, the strong reaction of HIV organisations against differentiated pricing strategies has not yet been matched by a similar mobilisation against the voluntary licensing mechanism, which is still largely misunderstood. Voluntary licenses are not TRIPS flexibilities. On the contrary, they are adopted by drug companies precisely to avoid TRIPs flexibilities, and at the same time to strengthen patent protections and maximise profits.

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16. See the great analysis provided by Suerie Moon (1 December 2013), Is the Global Fund heading backwards on access to medicines? [Online] Available at: http://blogs.plos.org/speakingofmedicine/2013/12/01/is-the-global-fund-heading-backwards-on-access-to-medicines/
Instead of opposing them, agencies such as the Joint United Nations Programme on HIV/AIDS (UNAIDS) and large international NGOs have celebrated the signing of voluntary licenses between pharmaceutical companies and generic companies in the past three years. They have gone so far as to consider these agreements as part of a “major turning point” in drug pricing. However, these licenses exclude most middle-income countries at a time when they are also losing the resources allocated by the Global Fund, either because HIV prevalence is not high enough or because they are considered too wealthy.

In essence, then, middle-income countries with complex epidemics are caught in the middle of changing global AIDS rules and drug company manoeuvres.

The divide and rule strategy

Little by little, the HIV activist community has become fractured. There are those who consider that voluntary licenses applied to low-income countries provide an important first step in lowering drug prices. Others are of the view that endorsing voluntary licenses is a strategic mistake because it does not change the structural factors at play in determining drug prices.

The reactions to the licensing agreement between Gilead and the Medicines Patent Pool about tenofovir in July 2011 illustrate this divide. In 2006, Gilead granted a voluntary license to Indian generics manufacturers for 96 countries. In 2011, the company extended the agreement so that it would cover an additional 20 countries.18 The media covered the 2011 agreement as a turning point in the history of treatment access and announced a “new era in the response to HIV”.19

Gilead was portrayed as a generous and humane pharmaceutical company. However, the real story was that Gilead insisted on voluntary licenses in this large group of countries because the Indian Patent Office was about to reject the tenofovir patent’s application due to its lack of novelty. China’s and Brazil’s patent offices did the same in the years that followed.

As a result, Gilead was pushed to sign the voluntary license agreements with Indian generic manufacturers in 2006, and by using voluntary licensing Gilead was able to receive royalties even though the legitimacy of the patent was contested. By 2011, the company had learned how to use the PR machine, and sadly a number of agencies, as well as the media, played along with the company.

Two years later, Gilead started marketing sofosbuvir (Sovaldi), the most promising hepatitis C treatment and the backbone of the most promising future therapies against the disease. The same groups that had praised Gilead as a “humane” company were now compelled to acknowledge the fact that Gilead may actually be the greediest firm ever.

It is still not known what the real impact of this voluntary license has been. During a meeting on hepatitis C treatment in February 2014,20 Gilead representatives argued that as far as they knew, the voluntary licensing agreements negotiated within

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the Medicines Patent Pool framework have not yet had any impact on access to treatment. This is worrying considering how much investment has been made into the Medicines Patent Pool, which was created to increase access to quality, appropriate, affordable medicines for people living with HIV in developing countries. The Medicines Patent Pool describes itself as a “public-health driven business model that facilitates the production of low-cost versions of existing medicines”. This is done primarily through voluntary licensing of key HIV medicines. So far, this model has shown its limits and its failure to address the issue of access in middle-income countries. In addition, as this model was described in the media as revolutionary for access to HIV treatments, it has diverted some governments and organisations from looking at other solutions that have proven to be more appropriate to enabling access.

We know what to do and we've won in the past

Over time, the activist community seems to have forgotten that the strategies of voluntary licenses in lower-income countries, tiered prices in middle-income countries and ‘standard’ prices in high-income countries are not concessions that have been made by well-intentioned people within the business sector. Voluntary licenses, tiered prices and standard prices are based on pure business logic. Furthermore, they are not the only, nor are they the best, way to reduce the prices of drugs in a sustainable manner.

There are proven solutions to guarantee universal access to drugs— not only to those who live in the poorest countries. These solutions focus on generic competition and TRIPS flexibilities. Within TRIPS, the Compulsory Licences mechanism is effective, as are patent oppositions and patent law reforms. Lastly, not enough countries have pursued patent law reforms to enable the full range of these options. When used, patent oppositions have shown all their power to enable generic competition, drive prices down and enable access.

This is illustrated by the case of tenofovir in India. In 2006, the main Indian generic manufacturer, Cipla, and a group of Indian and Brazilian NGOs, independently filed oppositions to Gilead’s patent applications on tenofovir. Worried that it might lose the court challenge, Gilead responded by giving licenses to 13 other generic manufacturers to make the drug for a 5% royalty. The problem was that the 13 manufacturers could only buy the active ingredient from Gilead-approved suppliers. Worse yet, while they were able to export their generic products to low-income countries, they were precluded from selling the drug to middle-income countries such as China and Brazil. Gilead’s actions effectively curbed the price reductions the generic makers could offer because of the conditions it imposed on them.

In other cases and for other drugs, for instance efavirenz in Brazil and in Thailand, local activists have learnt to push for compulsory licences. It is an important strategy in addition to opposing patents. Yet too many AIDS activists continue to push for voluntary licensing, even in instances where compulsory licenses can be invoked. It is regrettable that many HIV organisations have simply ignored compulsory licensing and/or patent opposition despite the fact that there are a number of NGOs with strong experience in this kind of strategic litigation and high-level advocacy. This is especially the case in middle-income countries, where the intellectual property barriers are a direct problem to access.
Soaring drug prices

A new frontier for activism in the coming few years will be the cost of drugs, including ARVs, in high-income countries.

Income inequalities within wealthy countries are growing, and as they do so, the idea that GDP should be the basis of drug prices is becoming less sustainable or realistic. Today, the austerity policies in place in many European countries are forcing a rethink.

Research conducted by Médecins du Monde shows that the cost of treating all people with hepatitis C in France using the prices prescribed by Gilead for its new drug patented under the name Soldavi, would be almost double the entire budget of the Paris hospital system. As a result, for the first time the French ministry of health is considering a range of options to avoid the current price of hepatitis C drugs. French advocates are even pushing for the government to issue a compulsory licence for government use in the public health system in respect of Gilead’s sofosbuvir.

It has taken far too long for this issue to top the agenda for activists, in large part because until recently it didn’t affect those in high-income countries. With the effect of the financial crisis on health budgets, they are now feeling the pinch.

Even though TRIPS flexibilities do provide an effective solution, the TRIPs-plus measures also constitute a threat that should not be overlooked. These measures are bilaterally negotiated between high- and middle- or low-income countries, and reinforce a strict intellectual property rights regime. Indeed, as Oxfam notes in an important policy paper published in 2007, “Since the enactment of the TRIPS (Trade Related Aspects of Intellectual Property Rights) Agreement in 1995, the USA has imposed progressively higher levels of intellectual property protection (TRIPS-plus rules) on developing countries, which undermines access to affordable medicines.”

It is time to take a more focused approach to bringing drug prices down, irrespective of disease.

This is only possible if health activists join forces. Thus far we have focused too much on AIDS drugs to the exclusion of many other important diseases where pricing is also a major obstacle to access. For example, the treatment for hepatitis C is unaffordable for most people with the virus despite hepatitis C being one of the leading causes of mortality among people living with HIV and AIDS. Other examples include the treatments for non-communicable diseases such as cancer, cardio-vascular or respiratory diseases, which are likely to become the leading cause of death throughout the world by 2030. Today, non-communicable diseases represent one of the most lucrative sectors for pharmaceutical companies, and the same issues of patents, intellectual property rights and low-price generic production will soon become critical in addressing each of these diseases.

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The recent comments of Marijn E Dekkers, CEO of Bayer, are an excellent illustration of the need for joint advocacy. Dekkers declared that Nexavar, a new drug that has been approved for treating kidney and liver cancer, was not developed “for the Indian market, let’s be honest. We developed this product for Western patients who can afford this product, quite honestly.”

In 2011, the United Nations organised a high-level meeting on non-communicable diseases, and in 2014 WHO published its first hepatitis C treatment guidelines. Both these initiatives could have used the support of HIV organisations and activists. It would have represented a real win-win for all health activists. That this didn’t happen is a testament to the failure of activists to be better organised and strategic in their advocacy on access to essential medicines.

The bottom line is that the issue of price and access to medicines will never be solved on a case-by-case basis because it is a systemic problem. It needs systemic remedies, which should be led by governments and international institutions to protect the principle of the right to health.

Less supply, greater demand

The issue of the sustainability of the generic pharmaceutical industry deserves serious attention from activists. Since 2005, India has been compelled to implement TRIPS. This has put sustained pressure on generic manufacturers, who are threatened with court cases by pharmaceutical companies threatening to protect their patents or, as was the case with Novartis, intimating that they will leave the country if their intellectual property claims are not “respected”. Pharmaceutical companies may not always win in the courts, but they have far more resources than generic companies. Increasingly, these court cases are deterring investment in generic companies and are serving as an incentive for the companies themselves to sign voluntary licenses.

The cumulative effect could be severe. There is a dangerous decrease in the number of generic manufacturers able to produce medicines for countries that have been excluded from voluntary licenses. These tend to be middle- and high-income countries. However, because so many generic manufacturers are based in middle-income countries, the effects of big pharma’s practices are significant. When generic companies are forced either to close or to operate on the terms of large companies, it has an impact on supply that in turn pushes prices up. Consumers lose, and drug companies invested in the patent regime win.

Thus, one of the key mistakes activists have made in the past few years has been to support voluntary licenses on the basis of extensive geographical coverage.

In the race to ensure that many countries had access to cheaper drugs, many activists overlooked the quality of that access and, more importantly, its sustainability in the long term.

Essentially, they neglected to understand the effect of voluntary licenses on the structural elements that most affect drug prices: supply and demand.
In taking stock of what could have been done differently, it must be recognised that the activist community has at times been too self-satisfied, content with past wins and unable to think strategically about the tactics the pharmaceutical industry might deploy in response to big civil society and developing country gains. Valuable time has been lost.

**We’ve reached the bottom, now it’s time to stand up**

Yet the past few years also represent a turning point. Today, the convergence of the needs of people living with HIV with those of people with hepatitis C, and with the growing number of people with non communicable diseases, will force a crucial conversation to happen. The HIV treatment community must regain its past strength. This means moving beyond advocacy for more money to be spent on AIDS programmes. This is important but wholly insufficient. Those advocating for better and increased funding, and those pushing for lower drug prices, must join forces so that the issues are tackled jointly.

The default position for activists should be to improve access to medicines using the TRIPS flexibilities and generic competition. But an even more ambitious strategy would be to overturn TRIPS entirely – to push even harder than commercial interests are prepared for us to do. This means reaching a consensus that commercial tactics such as voluntary licensing should be left to companies, and should never be endorsed by activists when we are unable to prove that they are improving access. Where we endorse short-term solutions by corporate citizens who are more beholden to their shareholders than they are to the public interest, we will undoubtedly find ourselves regretting our actions.

We have undeniably lost ground, but we also have an important opportunity to become more strategic, more ambitious, more coherent and more united in our struggles for universal treatment access and the right to health across the world.

The current debates occurring in high-income countries regarding the price of hepatitis C drugs offer us the opportunity to rethink the issue of pricing and our strategies for access, and to pursue our struggle in the hope of, one day, eradicating HIV and AIDS, and creating a fair system to enable access for all.

The author acknowledges the support provided by Christine Stegling, Othman Mellouk and Lorena Di Giano in writing this insight.
Today the world is at a tipping point in the response to AIDS. In the past five years, compelling scientific evidence has demonstrated that successful treatment has an important role to play in preventing the spread of HIV and the onset of AIDS. Viral load suppression through medication can keep individuals at high risk of infection from getting HIV, and treatment has so far been similarly effective in preventing HIV transmission in both vaginal and anal sex.

Yet alongside these tremendous gains, the realities of stigma and discrimination against people living with HIV remain stark. In my part of the world – the Asia Pacific region – even where treatment is available, there are many people who are still afraid to test for HIV. For them, scientific progress has had limited effect on their daily lives.

For too many people in the world, AIDS continues to be more than just an epidemic with physical manifestations.
In the words of Jonathan Mann, it remains a deeply challenging “epidemic of social reaction and response”.4

The test for activists in this new era of a science-driven AIDS response will be to address the unintended consequences of a biomedical approach. There are growing fears that in the race to reach more people with treatment, the biomedical approach – the ‘clinic’, as it were, that offers pills and machines, and the benefits of ‘modernity’ – might very well displace the ‘community’. There are very real questions about what happens to people living with HIV in a biomedicalised race for efficiency and delivery.

As the current Millennium Development Goal paradigm draws to a close, and given that community mobilization has been established as a critical enabler in the AIDS response,5 this essay explores the raging debate about whether the best place for HIV treatment is the community or the clinic. By looking at the life stories of people living with HIV and AIDS in the Asia Pacific region, as well as my own history as a gay positive man, I explore whether activists should continue to place our efforts in strengthening health systems for more effective service delivery, or whether we should concentrate on strengthening community systems, empowering ourselves to advocate for better environments within which HIV services can and should be delivered.

**Defining health and community systems**

When people are asked what it means to be healthy, they often say that it means feeling good. This instinctive response is in line with the World Health Organization (WHO)’s definition, that health is a “state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”.6

When we speak of health systems, most of us have an idea of what this means too. We are familiar with the roles of doctors and nurses. We accept health tests and take medications, even though we may not completely understand medical instruments or how medicines work. We are also familiar with going to pharmacies, hospitals and clinics to get our care. In all likelihood, when we think of health systems we see how these components work together to look after our health. In this vein, WHO defines health systems as the “sum total of all the organizations, institutions and resources whose primary purpose is to improve health”.7

However, it is much more difficult to define the concept of ‘community systems’. The Global Fund to Fight AIDS TB and Malaria (Global Fund), which has been instrumental in championing the concept, defines community systems as “community-led structures and mechanisms used by communities through which community members and community-based organizations and groups interact, coordinate and deliver their responses to the challenges and needs affecting their communities. Many community systems are small-scale or informal.”8

But what, really, is a community? The Global Fund admits that there is “no single or fixed definition”.9 It goes on to suggest that “communities are formed by people who are connected to each other in distinct and varied ways ... connected by living in the same area or by shared experiences, health and other challenges, living situations, culture, religion, identity or values.”10

7. World Health Organization (9 November 2005), What is a health system? Online Q&A. Available at http://www.who.int/features/qa28/en/
In essence, then, the idea of communities as places in which people are connected to one another generates an infinite number of relationships between people and institutions in as many different contexts. The social sciences have long recognised the looseness of community membership. For the purposes of academic and activist research, the organic and rich sets of relationships within communities, indeed the very ‘fuzziness’ of the notion of community, provides the basis for important analysis. But public health systems have had a less easy time accepting the vagaries of the term and the behaviours of its actors.

Thus, in the fight against AIDS, the term ‘communities’ at times reflects a public health approach: groups of people are defined as a community based by their risk behaviours. However, for activists the term reflects the political identities that are forged when people are discriminated against. It captures how they find kinship through the experience of being kept at the margins of society, through being ostracised.

While it may have been epidemiologically expedient to identify people by their HIV risk categorisation in the early days of AIDS campaigning, there are real problems with this approach. The term ‘most-at-risk populations’ can be seen as stigmatising. It labels groups of people by what they do and defines them in this sense as an imagined community. The term holds within it the moralistic residue of an era in which certain groups of people were ‘to blame’ in disproportionate ways for driving the epidemic.

The term ‘community’ also defines a sense of identification and belonging rather than simply speaking to a commonly held goal.

If health is your goal, then what do identification and belonging have to do with anything?

Surely you can achieve it alone, through your own actions, through vigilance and self-monitoring? This is, of course, a trick question, but it is an important one. Particularly where the stigma of AIDS is debilitating, the health of people living with HIV cannot be delinked from a sense of belonging. Belonging in a legal sense confers rights, but it also allows people living with HIV to feel confident and capable of claiming their rights to health and healthy sexuality, to kinship and respect.

Disparate groups of people consigned to the margins of society often define themselves as belonging to the same community precisely because they share a common experience of discrimination and vulnerability, even though in other ways they might not fit together. Being ‘put in the same box’ strengthens their voices. As the AIDS movement has shown over the last few decades, the idea of being part of a community can also turn people who previously lived on the margins of society into experts and representatives of life-worlds that people in mainstream society know little about.

Across Asia, Africa and the Middle East, at conferences and meetings, people who use drugs, sex workers, men who have sex with men, transgender people, and people living with HIV are sharing the lives of their communities. It is alternative voices like these that are helping to gain better and more comprehensive access to HIV prevention and treatment services. Today, they constitute an important community.

Yet in discussions about what happens next, about where the post-Millennium Development Goal framework takes the world, there have been few efforts to engage effectively with the people who actually use the community and health systems that currently exist.
Role delineation: who should do what for whom?

Yet there is rich experience within these groups. The circumstances in which many of these communities live are dire, filled with stigma and abuse. Over the years, many people living with HIV have come to accept that they will get poor or mediocre services at their local clinics or hospitals. Some people living with HIV simply refuse to access formal services because of the humiliation they face from some healthcare workers, or the stigma they encounter from members of the public who can guess why they are in the queue because of the way health systems are set up.

Around the world, people living with HIV who have refused to accept substandard or discriminatory services have developed powerful ways of ensuring that they get the help and support that is their right. In some places, the most effective short-term route has been to establish parallel health systems. Special clinics that cater to sex workers, men who have sex with men, or transgender people have proliferated. So too have special days or rooms set aside within existing facilities, where doctors, nurses and healthcare workers sensitive to their needs will provide HIV testing, diagnosis and treatment, and attend to their questions and concerns.

Health activists living with HIV have built up considerable community networks, knocking on doors, providing home-based care and spiritual ministry. They have carried out workshops on everything from how to use the female condom or explaining the importance of lubricants during anal sex, to talking about the science of HIV and attending the court cases of community members victimised by the police and other state officials. In some cases, they have extended this ‘community’ across borders, as the case of Maura from Papua New Guinea illustrates:

After I left Max he continued to drink heavily, his health declined rapidly and he died in 2006. His family blamed me and beat me up. I lost control of the drop-in centre and it closed. In September 2007 I developed resistance to my first-line ARVs and I was really scared that I might die. But I had contacts outside the country and I was relying heavily on them. That was something that made me feel strong inside, that I’m not doing this alone and that there is this positive community that I can fall back on. Friends helped me to receive second-line ARV medication and now the PNG [Papua New Guinea] government is working on getting second-line ARV drugs.11

Maura’s story highlights how the importance of a community stems from how it responds under duress. Although it wasn’t physically proximate to her, Maura’s community helped her to circumvent the reality of being an HIV-positive woman in a poor country. The immediate solution – to get her drugs – was of course a short-term fix. But it led to the provision of second-line drugs through the public health system, so that other women like Maura do not have to rely solely on the community response that she was able to muster.

As inspiring as stories like Maura’s may be, there has also been a backlash against the activism of this kind of community. The AIDS movement, in part because of its visibility, is often perceived as being larger and better resourced than it is. The community systems for care are criticised; seen as duplicating rather than extending.

Globally, there has been a backlash against the activists who have championed a response to AIDS with such tenacity. While it has its merits, the move towards strengthening health systems so they are better able to cater to the needs of everyone, regardless of their HIV status, can be seen as part of this backlash. With

11. Paxton, S. (2009), Diamonds: stories of women from the Asia Pacific Network of People Living with HIV, Bangkok: APN+ and UNIFEM
better health systems, the theory goes, community systems would then be used to reach key populations, to help them to come forward to receive health services. So, for example, in areas with high levels of injecting drug use, community groups would help to get people who use drugs to the clinic and into treatment. In this model, more clients are reached and the disease burden is diminished. The community system is used in an instrumental way to achieve a set of clearly defined health goals.

In the long term, then, the vision of health system strengthening advocates is that the ‘parallel’ systems and activities of community groups running actual services would become unnecessary – and indeed, some of the referral efforts might eventually become unnecessary too. However, there are real questions about whether this is a vision that people living with HIV (itself a heterogeneous group) collectively share. The question is who in this longer-term vision defines these health goals? As APN+ has noted in its studies on treatment access, the obsession with quantification might lead to a corresponding de-emphasis on concerns about quality that are often so crucial to people living with HIV. As such, if the community system is seen as subordinate to the health system, then surely the goals that communities of people living with HIV have for themselves, the vision they sketch out for their health, also become subordinate.

In my experience, even where established methods of integrated community and health systems help communities to build capacity in service delivery, they do not always help to attend to the overarching social determinants of health that drive exclusion and inequity. These are the most important challenges that community activists are required to address in the longer term.

As we move past the Millennium Development Goal era, there must be a way to go beyond the standard technical approaches to community systems towards more political, and therefore more structural, approaches to tipping the scales against AIDS. There is a real danger that we are approaching health systems as the primary focus on global health programmes, and community systems as existing to service these larger objectives. This perspective will diminish the contribution that these systems make to the way that health is understood and experienced by people living with HIV.

In part, this is not helped by the fact that community system contributions are harder to quantify. The work of legal advocacy, accompaniment and emotional support is equally difficult to quantify. So health systems get the glory, counting the number of people they treat as a measurable success. Community systems cannot point quite so easily to the number of people they directly or indirectly deliver to the doorsteps of the clinic. In a new AIDS programming landscape, where numbers rule, this is a big disadvantage for proponents of more robust and better-funded community systems.

In order to make the case for community systems, we must embrace the social response to AIDS.

The stories of people living with HIV must be told, their complexities understood and their journeys accompanied.

A personal and political journey

As I was sourcing material for this article, I came across an interview I conducted in 2009 with a person who injected drugs. At the end of the
interview, with the tape still recording, he asked, “What do you think of people like me?” My response was:

_We all have principles. You said [during the interview] you picked the wrong road [in using drugs]. I can understand that, I have also picked a wrong road in the past. I cannot say I am better or worse than you. If we share a common understanding, we can rely on one another so that we can both become better people._

As I reflect on what I said then, I realise that coming to terms with HIV has stripped away a lot of the prejudices I once had. I am not sure I could have said what I did to him if it hadn’t been for HIV. It has certainly helped me to discover a common humanity. It has made me part of a community that crosses geographic boundaries and issues like drug use or non-drug use, sexuality, gender and race.

Only those of us intimately affected by HIV can readily appreciate the social processes that structure the stigma and discrimination people living with HIV face. HIV (or any disease with moral connotations) changes us somehow. Writing of my experience with HIV in 2006, a few years after diagnosis and as I was coming to terms with treatment, I noted that:

_Treatment and the social experience of illness … become a constant process of negotiation—between my self and my body, on one hand, and the conflated effect of social interactions, on the other. When I am asked about my ‘condition’ what can I answer except by referral to such indicators as my CD4 count and my viral load? What if, as is so often the case, I feel sick but the indicators say that I am well? Such is the conundrum of illness at the juncture of the medical and the social. That is, of course, if the social is aware of my ‘condition’. Up until now, I have kept my story mostly to myself, with the exception of a few close friends and people whom I think will understand._

I can still sense the desolation I felt then.

_At the time, I had described my relationship with HIV as being like "one who watches in the darkness of night a mounting invasion it feels but cannot see"._

Looking back, I realise I have come a long way, and my well-being is testimony to the community support I have received.

As Maura’s story teaches us, it is not uncommon for people living with HIV to experience catastrophic events, when everything in their lives seems to fall apart. Community systems are important at all stages, but in moments of need they are critical. And these moments can be often and long. As APN+ has explored in its research over the years, these critical moments are experienced as ‘biographical disruptions’, traumatic moments when the stories we tell about ourselves shift so drastically that identities have to be formed anew. It is at these times that community systems help when no one else could or would.

**Context matters**

In some ways the difference between the community system and the health system is that the community system is concerned with the context in which the person’s health is lived. It is concerned with the emotional and spiritual well-being...
of the person who may or may not be sick. The health system may look at parts of the person requiring emotional and spiritual support, but these are ancillary. The physical realm is the primary concern of the medical system. Even when doctors, nurses and public health officials recognise the importance of context, they often do not have the capacity to address the contexts in which their clients are living.

The community system, on the other hand, has the ability to become that context – to take over, prop up, hold hands with, entertain, pray with, feed and clothe, even if this is only temporary. No hospital or clinic, however well equipped, can do this.

One might argue that these are still only palliative, aimed at getting someone treated. What it takes to beat AIDS is something different, something more political, something to do with inner strength, with the ability to resist and fight and challenge. At their best, in the process of addressing immediate needs, community systems also embody and pass on a strong sense of worthiness. They remind community members that they are rights holders: that they are deserving of attention and pills and roads to transport them to hospital. Communities that can foster genuine belonging are those that can address the underlying determinants of health. These communities restructure power, and in so doing help the health system to function better, aim higher and prioritise differently.18

In plotting a way forward, community activists must take stock of how we can help more people to live fulfilled lives despite their HIV status. There is no doubt that using some community resources to facilitate treatment expansion is important. However, we must not forget that we are most effective when we take the time to understand and nurture one other, creating enabling environments that will change the social determinants that prevent people from getting tested and treated. We are most effective when we demonstrate solidarity and wage battles for our rights, including our rights to life, health and love.

Conclusion

In some ways, the debate about whether to invest more vigorously in health systems or in community systems is a misguided one. Communities have been crucial in mobilising a demand for health services and delivering services to those at the fringes of society who otherwise would not be reached by conventional health systems. Yet it is also important to note that the fringes of society are as much geopolitical as they are geographical – that they are structured. Community systems play an important role in reconfiguring these transnational boundaries that make health iniquitous and stigmatising.19

Communities, especially those representing people living with HIV, play a crucial role in supporting those who are criminalised.20 Legal support to get people out of jail, time spent educating community members about their rights, efforts aimed at changing laws so that needle exchange and condom distribution programmes can function; all of these are time consuming, expensive and dramatically increase the chances of vulnerable people accessing health services to prevent or treat HIV.21

Yet there is little evidence of health systems seeking to quantify the costs of lobbying, advocacy and solidarity work. Indeed, I have yet to hear a serious conversation about community systems that asks what the costs would be to health systems and to society at large – especially for marginalised people like sex workers, young people, those who use drugs and transgender women and men – if there were no community systems at all.22

With less money to fight AIDS, and with a heavier focus on a biomedical approach, we risk many, many millions of people being unable to benefit from the scientific dividend. Why? Because the vibrant community systems that have carried the AIDS response this far – that were, in fact, crucial to the investments in science that we see today – are over stretched and under attack.23,24

Worse yet, as we approach the fourth decade of the pandemic, stigma and discrimination remain as pernicious as ever.25 Instead of establishing an oppositional relationship between traditional health systems and the community systems that provide support to people living with HIV and populations vulnerable to infection, we must accept that both are important.

There must be a radical shift towards accepting this in the new development framework.

Health systems are meaningless without community systems pushing them to be better and more effective; and community systems alone cannot meet the needs of the 35 million people living with HIV across the planet.

Both are deserving of bold, ambitious, long-term funding. With the right resources in place, and with a nuanced understanding of how community systems fight the social epidemic of stigma, we can prevent HIV transmission, we can treat AIDS, and we can tackle the social factors that are so critical to determining community health.


**BIOGRAPHY**

**Martin Choo**

Martin is a medical science and community-based researcher, APN+ representative to the board of GNP+ (2014-present). He has a strong academic background in research with key populations, and is currently running a social research project with seafarers on the east coast of Malaysia for the Centre of Excellence for Research in AIDS, University of Malaya.
Introduction

In the 1990s, Russia went through a period of unprecedented political and economic change. With the fall of communist economic and political systems, unemployment, poverty and crime began to increase. At the same time, new drug markets opened up, contributing to an increased availability and demand for drugs in the country. Health problems related to the use of drugs quickly emerged as pressing social and public health challenges.

A growing number of non-governmental organisations (NGOs) began to respond to this crisis, providing clean needles and other support to people who use drugs. However, by the early 2000s Putin’s leadership had begun to devolve into dictatorship, and political repression and state distrust of NGOs were on the rise. Shortly after Putin’s re-election as president in 2012, the situation worsened dramatically. A number of NGOs became a target of new anti-NGO laws, including the Foreign Agents Act, which imposed steep penalties on organisations involved in activities the state deemed to be ‘political’.

While NGOs in the harm reduction sector are yet to be directly affected by the Foreign Agents Act, it has created a climate of fear both for them and for social activists across the country.

From 2010, the state began to use the populist language of ‘morality’ and ‘traditional values’ in public health policy to discourage drug use, promoting a range of ideologies that were out of step with the realities of economically and socially challenged populations. At the same time it stepped up its stigmatising language against people who did not fit its vision of ‘proper behaviour’.
In the two decades since the fall of the Soviet Union, the health system failed to keep pace with the transforming circumstances of poor and marginalised Russians. Despite expanding health budgets, many activists became increasingly critical of the waste of government money, the ineffective management of health infrastructure, and the massive corruption of state officials. The situation had created a paradox: more money was allocated to health but the health of ordinary people deteriorated. This was compounded by ever decreasing opportunity for NGOs to influence their environment.

In today's Russia it is very difficult for NGOs that stand up for scientific evidence, human rights and effective policies to advance their agendas openly. Because of increasing levels of political and social repression, few organisations have managed to challenge the state on social issues. In the area of drug policy and treatment and AIDS, the Andrey Rylkov Foundation has been one of the few prepared to take up the challenge. In order to understand its efforts, it is important to first explain the terrain on which it operates.

Injecting drug use and related health problems in Russia

Nearly 5 million people use illegal drugs in Russia,1 1.7 million of whom are opiate users.2 Of the officially registered HIV cases in 2013,3 almost 60% are also people who use drugs. In some cities, HIV prevalence among people who inject drugs is as high as 74%.4 The trends in HIV prevalence and incidence show an epidemic that is on the rise,5,6 with 800,000 people officially registered as HIV positive7 and many others who simply do not know their status. In many cases, HIV treatment access is limited for people who use drugs.8 Russia also has other HIV-related health problems, such as hepatitis C virus (HCV) and tuberculosis (TB).

TB has now reached epidemic proportions in the country, including in its drug resistant forms. Russia's high TB burden is matched by one of the lowest treatment success rates for new cases in the world.

The country has the dubious distinction of the second-worst rate of TB-related mortality, and ranks third globally in total cases of multi-drug resistant TB after China and India.9

People who inject drugs are especially vulnerable to TB because they have high HIV prevalence rates. They are also incarcerated at higher rates than the general population and seldom have access to prevention and treatment services. TB remains the primary cause of death among people with HIV, and 78% of men with the dual infection of TB and HIV also inject drugs.10

An average of 74% of people who inject drugs also carry HCV. In some cities, up to 90% of people who inject drugs have HCV,11 and the total number of

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1. (4 February 2010), Interview with head of the Federal Drug Control, Rossiyskaya Gazeta, Federal issue 5101(22).
10. Andrey Rylkov Foundation (2011), Provision of effective TB treatment to drug dependent patients living with HIV, Moscow.
11. UNODC, NGO Stellit (2010), Research conducted amongst street drug users in St. Petersburg.
people who inject drugs with HCV is estimated to be over one million. While co-infection with HIV represents a clear indication of treatment need, less than 10% of all people with HIV receive treatment for HCV, while people who inject drugs simply are not provided with access to HCV treatment at all.

Despite this grave public health situation, the state provides no services to stem drug dependency and its related health and social problems.

People who use drugs are depicted by state officials as “deviant” and as criminals, and therefore undeserving of equal access to healthcare.

The Russian government refuses to adopt even the most mainstream and well-studied approaches to drug treatment, including opioid substitution treatment with methadone and buprenorphine. These are illegal in Russia due to the government’s ideological opposition to modern forms of drug treatment. Instead, antipsychotic drugs that were used against Soviet dissidents are part of the standard regimen for treating drug dependency in state facilities. This approach to drug treatment is both heavily outdated and does not conform to international standards.

A uniquely Russian approach

Back in the mid-1990s when the first needle and syringe programmes appeared with the support of international organisations, many Russian activists as well as donors believed that once there was sufficient ‘proof of concept’ the state would step in, take over and expand the distribution of clean and safe needles. Instead, today’s programmes continue to be implemented in an atmosphere of political hostility.

As post-Soviet Russia’s drug and HIV crisis deepened during the early 2000s, resources started to become available from international agencies, and new NGOs sprang up to attend to the growing need. These organisations played a crucial role in delivering prevention services to people who use drugs, as well as sex workers, men who have sex with men and young people. Many of them also advocated for better access to state-funded services and HIV prevention. Several networks were formed, including the Russian Harm Reduction Network that became a strong force in mobilising resources to support harm reduction initiatives in the country.

Around the time when these broader social upheavals and crackdowns were occurring, government opposition to harm reduction began to harden. Before 2010, activists had worked in the hope that the small but highly effective pilot harm reduction interventions they were running would be picked up by the government. With this in mind, a lot of money and effort were spent on conventional advocacy approaches. Many round tables with government representatives were held. Innumerable study tours and site visits were undertaken. Millions of pages of newsletters, bulletins, research studies and best-practice manuals were produced. None of these activities made any difference.
The government simply refused to respond to the scientific evidence in support of needle and syringe programmes and methadone substitution therapy.

Few organisations were able to actively resist the state’s stubborn stance. After 2010, civil society groups quickly understood that the only way to survive without incessant harassment was to avoid active advocacy work and exclude phrases like ‘harm reduction’ and ‘opioid substitution treatment’ from their literature. Even the Russian Harm Reduction Network decided to change its name to ESVERO in response to the new environment.

Many activists believed that the only way forward was to cooperate with the government. This was, of course, the common sense thing to do in a repressive environment. The examples of what would happen to those who opposed the state were only too evident in the daily headlines.

The Andrey Rylkov Foundation fights back

However, one organisation decided to go against the grain. The Andrey Rylkov Foundation for Health and Social Justice (ARF) started as an initiative aimed at protecting the health and human rights of people who use drugs. It was officially registered as an NGO in 2009, the same year that the Russian minister of health declared to the State Security Council (in the presence of the president and the prime minister) that the distribution of sterile needles and syringes “stimulates social tolerance of drug addicts, and violates the Criminal Code of the Russian Federation.”

This marked a decisive shift in policy against harm reduction. Until then, the ministry of health had simply ignored or withheld financial support from harm reduction programmes. Now an era began of active ideological opposition to people who use drugs by officials who should have been responsible for protecting and promoting their rights, and for their care, treatment and support.

For ARF volunteers, this policy reversal meant that the time for passive advocacy and negotiations with the government was ended. They were no longer under any illusion that building an evidence base would make any difference.

So the NGO began to strategise about how it would need to look, think and act if it were to tackle AIDS and injecting drug use head on in the new Russia.

ARF emerged from this as a small but flexible administrative platform that saw its role as fundraising for and supporting community initiatives and activists. The NGO had only two people working for it full time, as well as a part-time accountant, and no physical infrastructure. Without an office, it was able to cut down on administrative fees.

This approach allowed ARF to build dynamic, horizontal projects that were conceptualised, led and managed by community activists. It created a more decentralised approach that would allow for flexibility as needed. These strategies were designed to minimise risks stemming from any crackdowns by the increasingly heavy-handed authorities.

Then ARF decided that ten years has been time enough waiting for the city authorities to approve harm reduction services in Moscow, provide clean syringes and condoms, and information and counselling to people who use drugs on the streets. Unlike other local authorities in Russia who could be flexible, Moscow had always been aggressively and openly opposed to needle and syringe programmes, to the point where many donors and NGOs actually believed that harm reduction was illegal in Moscow, whereas in fact there was no such law.

As a result, no NGO had ever had the audacity to start providing needles to people who use drugs. Instead, they had resigned themselves to quiet advocacy, trying to convince city health officials of the benefit of such programmes, despite their cynical opposition.

However, ARF believed that in order to serve the community it needed to engage in real action. So a small group of volunteers started to work on the streets of Moscow, giving their time for free and receiving small donations of syringes, condoms and brochures from other organisations.

When ARF applied for funds from the Global Fund to Fight AIDS, Tuberculosis and Malaria, Russia’s principal recipient refused to allocate them on the basis that there was insufficient cooperation with the city authorities. Instead, it supported another NGO that had better liaison with the city health officials but refused to hand out needles and syringes to people who use drugs. So for six months, ARF’s initiative continued to run without funding until the United Nations Office on Drugs and Crime started to support ARF’s Moscow needle and syringe programme, acknowledging that it was based on sound evidence and met international public health standards.

In 2011 ARF was vindicated when it received the prestigious Crystal of Hope Award for its courageous action in fighting HIV. The cash prize funded the initiative for a further two years, and today its work continues to grow. Former participants in the programme, other people who use drugs, and activists continue to volunteer, and the organisation still operates without an office or other facilities. However, it has established an excellent communication infrastructure that allows it to coordinate and manage cases with the many different providers of vital services for people who use drugs in and around the Moscow area.

ARF’s activities have not gone unnoticed by the state. In 2012 the NGO’s website was shut down for providing “drug propaganda”, and the head of the Federal Drug Control Service has publically accused them of smuggling of methadone into Russia. ARF answered these absurd charges by turning to the law. It chose to fight for the right to distribute and provide information rather than be intimidated by the repression or ignore it.

ARF sued the Federal Drug Control Service that had ordered it to close down the website. Unsurprisingly, it lost the case in the Russian justice system. The NGO then decided to take the case to the European Court of Human Rights. It also reported the closure of the website on grounds that it believes are untrue and unfair to the United Nations Special Rapporteurs on the right to health, Cultural Rights, Freedom of Opinion and Expression and Human Rights Defenders. These actions have meant that ARF has received significant attention from a number of organisations, including Human Rights Watch and Article 19, which have spoken out against state harassment.
Beyond needle and syringe programmes: fighting the law with the law

Besides direct service provision, ARF engages in other key strategies to advance its mission. It monitors cases where the human rights of people who use drugs have been violated; it creates bold campaigns aimed at the general public; and it conducts strategic litigation. The NGO’s strategies are always imaginative, which is why they have been successful.

As with all efforts that are devised and managed by the people who are most affected, ARF’s activists refuse to play by the normal rules. The NGO’s work relies heavily on the voluntary support of activists from the drug-using community, and ARF’s spokespeople talk openly about their drug dependency, HIV status and battles with TB. While ARF’s work is intended primarily to provide practical help to people who use drugs, it also builds their capacity to engage in self-advocacy and service provision.

All of this is reflected in the excellent media coverage ARF receives both locally and from the international press. ARF volunteers are articulate and compelling experts who have themselves lived through the challenges they are working with. As a result, they have been in demand from, among others, the BBC, Voice of America, Financial Times, Independent, Associated Press, The Lancet, Scientific American and New York Times.

In 2013 ARF added a legal and human rights dimension to its work by starting a street lawyers project. This uses paralegals (outreach workers and case managers) to provide legal education and basic legal aid to people who use drugs who are victimised by police and other law enforcement officials, who are discriminated against in medical facilities, and who are forced to encounter barriers while trying to fulfil their right to health and dignity. When these cases fail in the Russian courts, ARF pushes them further. The project has taken more than a dozen cases to national and international courts, claiming violations of the rights of people who use drugs to health, protection from torture and inhumane treatment, information and the benefits of scientific progress.

Activism is necessarily political in the new Russia

ARF is an important example of how the fight for better and more comprehensive treatment for key populations can also be a fight for the rights and dignity of all people living in a society.

Its approach, moving beyond ‘paper advocacy’, has been powerful and successful precisely because it is brave and straightforward.

Above all, ARF has managed to tackle its work with courage and strategic insight because it has also organised itself differently to other NGOs. What it does and


23. Andrey Rylkov Foundation (2012), Appeal lodged with UNESCO on Russia’s violation of the right to enjoy the benefits of scientific progress. Available at: http://en.rylkov-fond.org/blog/ost/nost/art-appeal-unesco-scientific-progress/
how it does it has been devised in direct response to the political repression it encounters. AFR is less administratively vulnerable to its hostile environment because it is lean. It has adopted flexible situational planning rather than long-term strategic planning. It also has a highly mobile, almost instantaneous and horizontal decision-making process. This means that volunteers on the ground make decisions about their work, and the NGO doesn’t rely on approvals by boards and committees that have little interface with its everyday work.

But perhaps most impressively, embedded in ARF’s very DNA is a rejection of the notion that good advocacy requires government approval and collaboration.

In other contexts, working with the state is an absolute requirement. Yet in today’s Russia, the instinct to continue to please the state has led many NGOs to paralysis.

ARF’s refusal to seek government approval has meant that it doesn’t get bogged down in their fake promises. It isn’t lured by the possibility of cooperation from a state that has demonstrated that it is disinterested in partnering with people who use drugs. It is able to be uncompromising because it isn’t subject to the kinds of ideological blackmail that can occur when NGOs strike deals with certain parts of the state even as they are opposed to other parts.

Much of the litigation that the group has pursued in recent years is at the level of regional and human rights courts. The danger is that the Kremlin can ignore it if it so chooses. Despite this, ARF’s legal strategies have been successful in establishing a strong voice for the rights of people who use drugs and for effective HIV responses in a context where the state has abrogated its responsibilities.

A new set of development goals and targets will be worked out in September 2014, and ARF’s work will continue. Regardless of the post-Millennium Development Goal environment, it is likely that Russia will continue to avoid its international treaty obligations and deny its citizens access to essential public health services. In this worsening political climate, with growing state pressure on NGOs and diminishing amounts of foreign assistance, there is much to learn from the way that ARF has fought back.

The NGO stands as a proud example of how direct, confrontational activism is often the only way for the most vulnerable communities to access their rights. In this kind of charged political environment, ARF’s work offers lessons for how to exist outside the framework of technical public health responses. In Russia, activism is by necessity political.
People who use drugs defend their rights

In October 2011, Irina Teplinskaya conducted an interview in which she took the rare step of revealing her identity as a woman who uses drugs. The interview was published in a large Russian newspaper called Moskovskiy Komsomolets. Her story was then picked up and broadcast widely on radio and television. Teplinskaya filed a complaint to the United Nations Special Rapporteur on the right to health, and in 2012 she also filed a case in the Russian courts on her inability to access opiate substitution therapy (OST). The case is now under review with the European Court of Human Rights.

Ivan Anoshkin, Alexey Kurmanaevskiy and Dmitry Polushkin became involved with ARF through the Working Group on OST Advocacy. Their complaints about the absence of OST in Russia are currently under review by the European Court of Human Rights.

Maxim Malyshev, an ARF outreach coordinator and blogger, started an advocacy and litigation process in 2011 in order to protect his right to receive free diagnostics for HCV, and won the case against the Tver Oblast administration. The case protected the rights of all people to receive free diagnostics as part of treatment.

Other brave activists currently fighting in the courts include Oksana Shpagina, who has been fighting for access to OST for pregnant women. Tatyana Kochetkova and Natalya Vershinina from Togliatti, Larisa Solovieva from Kaliningrad, and Ludmila Vins and Ivan Zhavoronkov from Ekaterinburg are now committed case managers, whose skills continue to grow and whose work supports treatment access for people who use drugs.

BIOGRAPHY

Anya Sarang

Anya’s work over the past 11 years has focused on developing and supporting the emerging harm reduction movement in Russia. She has lobbied for access to health; protection of human rights; as well as dignity for people who use drugs and humane drug policies. She is President of the Andrey Rylkov Foundation for Health and Social Justice in Moscow.
"The key to our success is our own collective effort. The time for rhetorical arguments and victim blaming has passed. Now is the time for action. What we know about this disease already is enough to enable us to put in place comprehensive and appropriate intervention strategies.

“All sectors of our community must become engaged in this battle and resources available from the government must be distributed to our communities …. We need to set up a structure at national, regional and local level which goes beyond health workers and the government.”

Nelson Mandela¹

In the 1980s, the institutions and approaches that have come to be known as ‘coordinating mechanisms’ and ‘multi-sectoral approaches’ were in their infancy. By the time Nelson Mandela took to the stage in 1992 and made the statement above, brave and brilliant activists had already begun to create the systems and institutions that form the bedrock of the current AIDS response – what we now refer to as the AIDS architecture.

Civil society was, as so often is the case, ahead of government-led responses. It would be another four years before the Joint United Nations Programme on

¹ Speech by Nelson Mandela to the National Conference on AIDS, 1992.
HIV/AIDS (UNAIDS) was launched to coordinate the United Nations (UN) response, and a full decade before the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund) was created in 2002. These global and regional developments in the architecture were matched by parallel developments at country and local levels. They represented the first steps towards creating a global institutional framework for coordinating and responding to AIDS.

Looking back on my own history, at my work in community-led and bureaucratic institutions, as well as in the scientific world,

I wonder whether those structures forged in the early days of uncertainty and fear still serve their purpose.

If they do not, what is needed now to guide us forward into the equally uncertain post-2015 landscape? This essay charts that territory, looking backwards in order to understand where we might want to go next.

The story goes that Nelson Mandela, like so many political leaders, only became engaged in the AIDS struggle after leaving high office. Yet his prescient words were spoken more than two decades ago. In October 1992, Mandela – soon to become South Africa’s first democratically elected president – was invited to address ‘South Africa United Against AIDS’, the National Conference on AIDS organised by the National AIDS Convention of South Africa (NACOSA). NACOSA had been tasked with bringing together actors from a range of sectors to develop a cohesive response to the crisis.

The lengthy and ambitious AIDS plan that emerged from that meeting described intervention strategies that were already known to work. It also enshrined key principles, notably the protection of human rights and the importance of involving government departments and stakeholders from all sectors. This was described as moving “beyond health workers and the government”.

The notion of moving beyond the health system and with multiple actors became a benchmark for future AIDS policy. The approach Mandela outlined in his 1992 address can be traced forward to the present day. It was certainly the hallmark of AIDS organising in South Africa when I had the privilege to live and work there 15 years later.

Back in 1992 I was getting ready to leave Amsterdam, having worked for the 8th International AIDS Conference chaired by the human rights and public health visionary Jonathan Mann.2 By that time I had been an AIDS activist for what seemed like an age – six long years, starting in 1986 as a volunteer with the Terrence Higgins Trust (THT). The partner and friends of Terry Higgins had created the UK’s national AIDS non-governmental organisation (NGO) after his death in 1982 to humanise and personalise the issue, and to build stronger responses.

2. See Mark Heywood’s essay also in this report, where he describes Jonathan Mann’s work on AIDS and human rights. After his battle with Nakajima, Mann left the World Health Organization to head up a new health and human rights department at Harvard University. He led the 1992 International AIDS Conference in Amsterdam, switching venues from Boston in protest at the inhumane policies preventing people living with HIV from entering the United States. Mann wrote the foreword to my book, Vamps, virgins and victims: how can women fight AIDS?” (1996).
The foundations

In my early days as an AIDS activist in the UK, the idea that a political leader, let alone a head of state, would be interested in a structure to coordinate responses to AIDS was pure fantasy.

Getting any politician to even speak about AIDS in a humane way, let alone champion an effective response, took massive lobbying.³

Stigma and discrimination were not the subjects of thoughtful academic papers but of newspaper articles screaming about “gay plagues” and “AIDS carriers”.

If architecture implies buildings and solid structures, then in those days there was none. Instead, there were creative, homebuilt spaces that served a purpose but were unlikely to survive stormy weather. Small groups of friends and comrades gathered to form organisations that would care for people with HIV. They directed people to clinics and other services they needed. They defended their legal rights, developed HIV prevention campaigns, and promoted information and awareness to combat the raging discrimination and hatred that blighted people’s lives.

THT brought together a courageous and energetic group of volunteers (and a tiny staff team) who were living with HIV or were in other ways profoundly affected by what was emerging. On reflection, one of the intriguing features was that the architecture of what we now call a multi-sectoral response was inbuilt into the structure of THT. The organisation brought together people working on all the aspects of the epidemic: health, legal services, social care and welfare, spiritual responses and health promotion. In doing so, THT became a model for other groups in the UK and Europe, and went on to inspire many others, including The AIDS Service Organisation (TASO) in Uganda.⁴

In those days THT was structured around a medical group (passionate, usually gay, doctors trying to make sense of their clinical experience and the early literature); a legal service (pro bono lawyers tackling horrendous human rights abuses – people routinely evicted from their homes, kicked out of jobs and schools, and deported from countries with unfriendly entry requirements); social welfare services (advisers giving information on how to access state benefits, and volunteers providing direct social support through the Buddy service and peer support groups); an interfaith group (priests, rabbis, Buddhist leaders and lay people providing spiritual support and rebuffing some of the worst excesses of hatred); and a health education group (volunteers who analysed emerging information and experiences elsewhere, designed edgy and direct information resources and other campaigns to promote safer sex and distribute condoms and lubrication, and made sure that the heavily used Helpline was stocked with up-to-date advice and knowledge).

Those early activists were building linkages because of a shared need to support people living with AIDS.

They learnt to speak to each other because of their passion, because they were good at their jobs, and because they knew that they needed each other in order to be effective – not because there was a coordination mechanism that forced them to do so.

³. See Fowler, N. (2014), AIDS: don’t die of prejudice for a political insider’s account of those early days.
While there has been much to be proud of in the UK response, government-led architecture and coordination remains uninspiring. There is an excellent (perhaps the world’s oldest) All Party Parliamentary Group on AIDS, but that only brings together elected members of parliament (interestingly, their meetings are usually overrun by “observers” from civil society, perhaps to make up for the lack of a formal coordination structure). STOPAIDS does an exceptional job coordinating the multitude of UK-based civil society groups working on AIDS, and has done well to nimbly shift focus and approach as the epidemic has evolved. Yet the UK has never had a real national AIDS council or commission (NAC). Advisory structures have been created (and renamed) from time to time, but these are mostly add-ons to the department of health rather than free-standing multi-sectoral advisory bodies led by senior politicians and officials.

In 2003 I shifted gear from activist to bureaucrat and went to work for the UK Department for International Development (DFID). One of the early tasks for my new global AIDS policy team (itself established on good multi-sectoral lines) was to create the UK’s first ever ‘whole of government’ AIDS strategy. Through that, we convened a cross-Whitehall working group on AIDS. I only remember it meeting two or three times, and never at a political level; most other departments sending very junior officials. Even in 2005 when the (then) prime minister Tony Blair declared AIDS to be one of his priorities, in the context of a big push on Africa and development for the G8 and European Union presidencies, there was no bringing together of different government ministers, civil society representatives and people with HIV to forge a way ahead. That was all done at my lowly level. We consulted widely with civil society, but despite using formal meetings and fancy conference rooms this was nothing like the structures and approaches used in the countries on which DFID focuses its attention and resources. And it is the architecture in those countries – the ones that respond to the highest ongoing burdens of HIV – that are the main focus of this essay.

**The building blocks**

### National AIDS councils or commissions and other multi-sectoral bodies

As ever, Mandela was ahead of his time. Not only did he call for action a decade before the UN saw fit to talk in any meaningful way about AIDS, he also called for this action to be overseen by a version of the multi-sectoral NAC governance structures we are now so familiar with.

This bringing together of diversity is a hallmark of post-apartheid leadership in South Africa, and also of global AIDS organising.

While this wasn’t invented in or for Africa (Australia, for example, established a similar and highly effective partnership model of organising in the late 1980s), it certainly took root quickly on the continent.

The World Bank deserves some credit for placing a multi-sectoral response at the heart of the AIDS architecture. In 1999 the Multi-Country AIDS Program in Africa (MAP) was launched as the first major global response to HIV and AIDS. The World Bank MAP envisaged three phases, the first of which (2000–

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5. DFID (July 2004), Taking action: The UK’s strategy for tackling HIV and AIDS in the developing world.
6. As part of his ‘big push’, Blair committed the UK to using Britain’s G8 and EU presidencies to address the problems of AIDS in Africa and the UK to achieving the United Nations target of providing 0.7% of GDP in development aid. See Blair, T. (27 January 2005), Special Address by Tony Blair, Prime Minister of the United Kingdom at the World Economic Forum in Davos.

See also, de Waal, A. (October 2004), ‘British government policy on AIDS: analysis for African civil society’, GAIN Briefing Note.
The architecture of AIDS - Robin Gorna © aidsalliance.org/AIDSToday

2006) was defined as an “emergency response”\(^7\) that “required countries to set up multi-sectoral commissions to oversee national HIV programmes under presidential or prime ministerial leadership, with representation of key stakeholders from all sectors, including people living with HIV.”\(^8\)

One of the four criteria for countries wishing to access funding was the “existence of a high-level HIV/AIDS coordinating body, with broad representation of key stakeholders from all sectors, including people living with HIV/AIDS”. MAP emphasised the social and behavioural dimensions of AIDS, and the importance of creating an enabling environment as well as strengthening health systems. By April 2010, MAP had dispersed over $2 billion, including funding over 50,000 NGO-, faith-, and community-based sub-projects, many at grassroots level. MAP encouraged partnerships, consortiums and networks of special interest, and the World Bank is proud of the role it played establishing civil society engagement as a crucial part of a national response.\(^9\) Criteria for MAP funding included government commitment to channeling funds to communities and civil society, and using NGOs and community-based organisations as implementation agencies.

Two years after MAP was created, the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) gave a massive political push to the global response, and at the same time set a roadmap for action by adopting the 2001 Declaration of Commitment on HIV/AIDS.\(^10\) Among the many directions in that landmark document was the encouragement to create national AIDS coordinating entities.

There was broad acceptance that the epidemic would not be overcome without a multi-sectoral response on NACs, including the full participation of people living with HIV, community-based organisations and even the private sector.

UNGASS gave birth to the Global Fund. It was the most significant funding arrangement yet, and of course it inadvertently and dramatically reshaped the architecture further. Building on previous discussions by African Union heads of state and declarations of G8 meetings, the Global Fund was established at breakneck speed. A secretariat was in place and grants began to flow a year after UNGASS, in 2002.

The founding principles of the Global Fund stress that it is a mechanism that shares power between donors and implementers, emphasising inclusivity and country ownership. The Global Fund’s early documents noted that it would “work with a country coordination and partnership mechanism that should include broad representation from governments, nongovernmental organizations, civil society, multilateral and bilateral agencies and the private sector. The mechanism should be the highest national level responsible for national multi-partner and multi-sectoral development planning. It should preferably be an already existing body. If no appropriate coordinating body exists, a new mechanism will need to be established. Where public-private partnerships do not exist, the Global Fund may

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8. HLSP (2008), Understanding the politics of national HIV policies: the roles of institutions, interests and ideas, p.3. See also World Bank Africa Region (1999), Intensifying action against HIV/AIDS in Africa: responding to a development crisis.
support alternative partnerships among nongovernmental organizations and the private sector.” [Emphasis added]1

The following year, funding for AIDS increased further with United States President George W Bush signing the legislation that founded the President’s Emergency Plan for AIDS Relief (PEPFAR), the largest programme on health ever created by a donor government. In the first five years (2003–2008) PEPFAR pledged $15 billion to AIDS programmes, and contributions have continued to grow with remarkable effect. By September 2013, PEPFAR claimed to have direct responsibility for 6.7 million people on antiretroviral (ARV) treatment – rising to over 9 million if United States contributions to the Global Fund were also counted.12

PEPFAR (mercifully!) did not require any new structures to be created, but consistently reinforced the importance of investing in programmes designed and driven by community organisations, not all of them indigenous to the countries concerned. In recent years, there has been a stronger push on country ownership, with funds being transferred to stewardship by national governments.

This vision of a multi-sectoral response was far reaching, with many powerful, effective and also unintended consequences. The emphasis on multi-sectoralism has been vital in forcing the point that HIV is more than a health issue. The beauty of the multi-sectoral response is that when health ministries behave in perverse or destructive ways, other ministries have a space to assert their role.

A shining example of this is South Africa’s department for social development. The ministry responsible for the fallout of the AIDS epidemic quietly steamed ahead during an era in which President Mbeki and his minister of health, ‘Manto’ Tshabalala Msimang, first denied and then obstructed the AIDS response. The department for social development financed an extensive programme of grassroots organisations, and working closely with the ministry of education and local government health structures, sought to provide quality support to orphaned children and vulnerable families throughout the country. Meanwhile, the national leadership in health provided misleading information and sought to drive a perverse, denialist agenda.13

The positioning of NACs at the highest political level has led to great leadership and focus in many countries. Yet in others it has strangled the response with protocol and forelock tugging, and with too much energy devoted to moving high-level people around rooms and meetings, distracting from the impactful work at community level.

**Tackling duplication – the Three Ones**

There has also been a frustrating amount of duplication and proliferation of structures.
Many countries seemed to miss the emphasis in the Global Fund’s founding documents that the already existing body should be used to manage and coordinate Global Fund processes at country level. And so with breathtaking consistency, country after country set up new structures called Country Coordinating Mechanisms (CCMs) while Global Fund proposals were being drafted. Many key individuals would find themselves shuttling between NAC and CCM meetings, both of which were supposed to be chaired by a “senior government official”. Of course, good reasons were given for the duplication. The Global Fund was also concerned with two other diseases (TB and malaria) and involved with a single donor that appeared to have quite stringent (and constantly increasing) requirements, whereas NAC had been conceptualised to deal with a whole national response.

Soon after I started at DFID there were anxious discussions about the additional burden placed on their systems by too many partners, too much duplication, and insufficient coordination of partners. Chasing different funding requirements was causing them to lose focus on their priority needs and spend far too much time and resources attempting to meet donors’ requirements. In part, these were the same old stories that underpinned concerns about aid effectiveness principles prior to the AIDS epidemic. Somehow, though, the growing AIDS response and its institutional mechanisms seemed to be making things far harder.

Working with UNAIDS and the United States government (and with creative energy from Norway’s AIDS ambassador, Sigrun Mogedal), DFID’s secretary of state Hilary Benn called a meeting in 2004 that established the Three Ones principles. The intention was to support country governments to take greater control of their responses, with the idea that each country should have One AIDS council, One AIDS strategy, and One monitoring and evaluation system. The Three Ones certainly focused attention on the need to minimise bureaucracy and let countries get on with the real work. Sadly, ten years on there are few countries that have found a way to align their NACs and CCMs, and there continue to be huge duplications, bitter turf wars and inconsistent approaches to tackling the epidemic. I have often thought that the Three Ones should have been renamed ‘At least Three Ones’ given the continuing commitment to multiple frameworks, strategies and coordinating mechanisms.

Sitting at the table

Powerful advocacy and unified civil society activism forced political leaders to take AIDS seriously and to include civil society, especially people openly living with HIV, at the heart of the national response.

The first bold steps to establish international institutions to respond to AIDS were led by civil society.

Initially, the idea of civil society involvement in directing the response was formalised through the principle of the Greater Involvement of People living with HIV/AIDS (GIPA). The GIPA principle was adopted by 42 nations attending an international summit in Paris in 1994, and emphasises that those most affected by AIDS should have leadership roles in all aspects of responses.


People living with HIV were to be not only involved in the AIDS response as a cautionary tale – as the tellers of stories and as tokens. Instead, the GIPA principle affirmed their role as experts, as people who could and would need to analyse problems, promote information and develop proposals for changes.

It is now normative for a seat to be reserved for people living with HIV at decision-making tables – at global level as much as national. In telling his story of leading UNAIDS through its founding years, Peter Piot recalls how one of the radical acts in creating the governing structure, the Programme Coordinating Board, was to ensure that civil society had a seat so that the voices of people living with HIV could be heard. The Global Fund board has always had representation from implementers, and since 2004 the Communities Delegation has given a voice to people living with HIV and those personally affected by TB and malaria.

But sitting at the table is not enough; it is how that access is used that counts. The phrase ‘GIPA’ has morphed into ‘MIPA’, stressing that the meaningful engagement of people living with HIV should be a priority in the response to AIDS.

In the mid-1990s it was decided that the International AIDS Conferences should have two chairs: a community co-chair to sit alongside the scientific conference chair. The AIDS conference is another part of the architecture that deserve some reflection. Most health issues have regular conventions for scientists to explore the latest developments and for doctors to update themselves and meet with colleagues to form new research collaborations. All of this happens at AIDS conferences, but from the outset they have been more radical gatherings, reflecting how different the AIDS response has been to the response to other less politically mobilised diseases. From the very beginning, people living with HIV were present at these conferences, forcing dialogue with scientists and clinicians, and demanding that research be designed that would rapidly discover treatments that would change their lives.

The conferences also became the sites of loud demonstrations, often with angry exchanges with policymakers and global leaders.

Activists would turn up in their numbers to make sure that scientific discovery translated into real life programmes that would save lives.

I was asked to co-chair the 1998 International AIDS Conference. It was a huge honour, particularly because it was at a critical moment. Highly active antiretroviral treatment (HAART) had just been discovered, and had been the central focus and announcement of the previous conference in Vancouver in 1996. The 1998 Geneva conference focused on ‘Bridging the Gap’, and was all about access. In what seemed like a crazy dream, many at the conference were pushing to ensure that the benefits of this life-saving treatment would extend beyond those who lived in the global North.

At that time I was head of THT’s health promotion department, and the International Community of Women living with HIV (ICW), the Global Network of People living with HIV (GNP+) and the International Council of AIDS Service Organizations (ICASO) nominated me to the role of community co-chair. So far, so democratic. The real trick would be to consult with representatives of the three networks ahead of meetings as to what they wanted me to say. I recall the responses I got each time I approached them to ask what we wanted to put

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on the agenda: “You must demand that we are at the table!” Each time, I would answer, “But we are at the table. Now what do you want?”

Activism slips away from the table

The International AIDS Conferences, the UN specialist meetings, and the regional conferences and seminars that seemed to be hosted almost perpetually began to earn the AIDS sector a bad reputation for wasting resources and enforcing a vertical or exceptional approach. Despite this, they have been important sites of struggle and they have served as a handy barometer for the shifts and changes happening within the sector.

The experience of activists not quite knowing what to do once they got a seat at the table in the 1998 International AIDS Conference in some ways foreshadowed things to come. A decade or so later, as medical breakthroughs again began to change the landscape, governments and clinicians began to take centre stage; some would say that they have taken over the AIDS response. Civil society groups shifted from being the engine of change to being left behind.

There is a deep irony in the fact that the community groups and activists who drove the AIDS movement have now become junior players. Perhaps it was inevitable that civil society groups would exercise less influence given the amount of time and energy that many put into fighting for space and for significant structural changes.

There is a story here, though, about fighting for what we need and then not quite knowing how to use it, or at least not using it as well as we could once our demands have been met.

During my time in South Africa I had the privilege to participate in the transition of leadership of the health ministry from Dr ‘Manto’ Tshabalala-Msimang to Barbara Hogan and then to the current health minister, Dr Aaron Motsoaledi. My colleagues at DFID and I were able to support new health minister Hogan to unravel some of the policies and structures that had constrained an effective response to AIDS.

All this time, DFID continued to invest in activism, increasing funds for the Treatment Action Campaign (TAC) to sustain and evolve their work. This was a substantial challenge for TAC:17 the ‘enemy’ was gone and government now believed that HIV caused AIDS and that ARVs were indeed a good thing. How then to put the right programmes in place? What would TAC’s role be in this changed environment? Would the activist group continue to focus on the flaws in the system or would it become part of making the system work? Would it hold government to account for its new promises? The emerging answer was a little bit of both.

The story of TAC is often told as one of a heroic fight against state denialism. That is a story that deserves mass praise.

But TAC can also tell another remarkable story: that of civil society adapting and responding to changes in the epidemic and the policy and political landscape.

17. See: Mark Heywood’s essay in this report for other observations on the TAC evolution.
Under the remarkable leadership of Vuyiseka Dubula, who joined the organisation when she was in her early 20s as a volunteer and then rose to become the secretary general, TAC recovered its footing. It is an extraordinary organisation, created by and thriving on the energy of opposition and constructive engagement. It managed to reinvent itself in the political context that descended when Barbara Hogan took over in 2008, but it was not an easy journey to make the changes that were necessary.

The whole structure and base of TAC was founded around activists and local communities who were effective at pointing out inaction and injustice, and demanding change. How then to use that energy and spirit to make the right things happen? At times TAC drifted into new areas. For example, it became involved in activism related to xenophobic violence, education and other matters that were in some ways linked to the AIDS response and where rights abuses were happening, although they were not TAC’s ‘core business’. This did not always find favour with donors, and there were internal squabbles about direction that led to a period where the organisation lurched from strength to near closure.

TAC was struggling to find the right people and the right style to respond to the changed context. Now that it had got what it had been fighting for, it was unclear about what to do with its energy and activism. The necessary adaptations took time, but drew on the same values and principles that had guided the organisation during the darkest days of the AIDS response, finding again the core strength and capacity of TAC’s extensive networks.

As TAC discovered its new direction, the leadership immersed itself in developing a new strategic plan that articulated real and pressing needs. The organisation decided that it would use its local chapters to hold local and provincial authorities, as well as national government, to account by following the money, watching the systems, and monitoring whether the national strategic plan is delivered as designed. This is still work in progress, given its often mundane and bureaucratic nature, but there is no doubt that after a difficult moment TAC turned an important corner.

**A monument to AIDS**

A decade after the revolution of HAART, national and global responses to AIDS had entered a stable delivery phase. The crisis of constant death and raging discrimination, the massive inequities that led to HAART only being available in the rich global North, the lunge for effective but untested interventions; these were becoming a thing of the past. Politicians were seeing the importance of responding to AIDS and real money was moving through the newly created systems. The new mantra was ‘scaling up’.

In 2005 the UK had the presidency of both the G8 and the European Union. The government proposed the wild dream of “Universal Access to HIV Treatment, Prevention, Care and Support … for all those who need it by 2010”. Astonishingly, the Group of 8 agreed, and the Gleneagles Communiqué contained important new commitments that embraced the ideal of fully funded AIDS treatment for all those who needed it. Less than a year later, the same pledge found its way into the 2006 United Nations Political Declaration on HIV/AIDS.

18. The exact commitment was stated as: “With the aim of an AIDS-free generation in Africa… develop and implement a package for HIV prevention, treatment and care, with the aim of as close as possible to universal access to treatment for all those who need it by 2010 … We will work to meet the financing needs for HIV/AIDS”. G8 Summit (2005), Gleneagles Communiqué. Africa: a historic opportunity, para. 18(6).

19. The United Nations Political Declaration on HIV/AIDS was agreed to by member states at the high-level meeting on AIDS held in New York, 31 May-2 June 2006.
which made a commitment to “the goal of universal access to comprehensive prevention programmes, treatment, care and support by 2010”\(^{20,21}\).

By this point the response to AIDS was at its height. Activists had made their case and the response was being built. As he came to the end of his term as executive director of UNAIDS, Peter Piot did something that in many ways was symbolic of the state of the larger AIDS response. Until that time, the staff of the agency had been scattered across old offices in distant parts of the World Health Organization (WHO) site and at the World Council of Churches. Piot spent his last few years as director of UNAIDS working on building a new home for his team. The shiny, glass and steel building sits directly across the car park from the main WHO building. It sent a strong symbolic message: the AIDS movement was here to stay. It was not a forgotten, embarrassing stepchild to be hidden away in temporary, rickety buildings. It deserved stability and beauty.

Donations flooded in from art collectors and influential friends of UNAIDS. Piot had created a beautiful working environment that could not be more starkly different to the rather sterile 1960s offices that WHO continued to occupy.

The AIDS movement had grown up, but it was not without its detractors. The physical move away from the WHO building was understood metaphorically in two different ways. Some viewed it as an affirmation that the ‘real’ health agency no longer had to worry about AIDS. Finally, HIV could be separated from the mundane, day-to-day work of strengthening health systems. Others suggested that it represented another example of AIDS exceptionalism. The little virus and the activists who fought it had generated so much money and attention that the global AIDS CEO could build what was referred to as a cathedral, a ‘monument to AIDS’.

The complaints about AIDS exceptionalism were not new, but they grew ever more urgent as more resources were devoted to the upstart issue that was suddenly seen as hogging the spotlight.

The list of concerns is a long one. First, there was the suggestion that the AIDS community didn’t play nicely with TB and malaria. In response, UNAIDS created space in the new building for the Stop TB Partnership and Roll Back Malaria. Then there was the concern that AIDS funds were distracting health ministries from devoting attention to the harder task of building health systems. In response, the Global Fund created a stream of funding specifically aimed at health systems strengthening. Then it was argued that Millennium Development Goal 6 was diverting attention from Millennium Development Goals 4 and 5. In other words, the AIDS goals were likely to be met, but maternal and child health was struggling and therefore needed more and better support. In response, donor agencies and the Global Fund began to support funding that would address maternal and child health. Others in the health arena were suggesting that AIDS had had enough attention and needed to share the focus and the resources, and the new UNAIDS building was a symbol of this. This is not to say that the project should not have taken place, but it is clear that the new building did nothing to quell these jealousies and resentments.

Strikingly, at the start of 2009, a year after Michel Sidibe took over from Peter Piot as the new executive director of UNAIDS, actual cracks started to appear in the new building.
Much of the beautiful art was taken down, and for several months the elegant slate surrounds outside the building were dug up. The enormous, striking sculptures created by Mary Fisher – a remarkable woman who came out about her HIV status at the United States Republican convention in 1992 – had to be put in storage.

The architecture of AIDS, it seemed, had not been reinforced; the ornaments that adorned it were proving too heavy for it to bear.

Empty seats at crowded tables

At country level, the parallels can also be richly drawn. In early 2013 I went back to South Africa to study whether the Global Fund’s resources were being used to support programmes that would meet the needs of women and girls. Interviewing health officials in one of South Africa’s provinces I was told, “They [women living with HIV] no longer have a cause to fight at the moment – they don’t even come to the meetings any more, they were always there and they had a complaint. Now we’re waiting for them to have a cause again.”

This was a striking finding. Many AIDS activist organisations were now led by powerful women, including women openly living with HIV. This was especially important because women in South Africa – across all age groups, but especially younger women and girls – acquire HIV at far higher rates than men. There is a paradox that exists in South Africa whereby women are the strength and backbone of society yet also on the receiving end of shocking levels of violence and abuse.

I probed further. So why were women no longer interested in being at the table? In part, I suspected (and the government officials hypothesised) it was because their needs had changed. Treatment was available, services were in place, a good strategic plan was being delivered and people were living longer. The activists who had demanded a seat at a table no longer had time to sit in meetings representing others’ needs, which were anyhow less pressing. They had jobs to go to, lives to live. Why focus on a single health condition that would rarely be their daily priority?

But there is also something else at play. As funding systems have developed, communities are losing out. The research I was conducting in South Africa was part of a wider study carried out across several countries. While public health officials complained about the tapering of commitment and participation by women living with HIV, the research also demonstrated that few resources were being directed to supporting networks of women living with HIV. Without the funds for organising, how could women possibly have shown up consistently and represented one another’s demands at policy tables?

It isn’t just women and their networks and organisations whose commitment seems to be on the wane. Several countries report lengthy gaps between CCM or NAC meetings. The urgency has dropped, and when there is no imminent funding application to make then the groups that sit on these AIDS bodies would rather focus on other priorities. In India, for example, no one currently occupies the CCM seat for people living with HIV. Following fraud allegations, the representative from the organisation involved recused himself. Replacing him should not have been difficult as there are at least three national networks of people living with HIV in

India. Yet despite the fact that they have met repeatedly, they cannot agree on a successor. The one person they can all support is a veteran activist who does not want to be ‘recycled’ into the role. There was a time, five years ago even, when such a situation would have been unfathomable. The fight for cheaper drugs, scaled up programmes and treatment access was so critical that any empty NAC seat would have been quickly filled by activists keen to have – yes – a seat at the table.

One of the unintended consequences of having a seat at the table is complacency. The example above is extreme: complacency more often leads to taking meetings and processes for granted rather than a complete withdrawal and lack of participation. Yet there is another consequence of sitting at the table: the risk of co-option. This is usually a subtle shift and takes place because civil society groups that are now on the inside begin to understand how systems and processes work. Having been let in, they understand the value of not always being the angry activist making demands. On the one hand, this can be seen as demonstrating strategic maturity. On the other hand, it can be easy for activists representing their communities in the AIDS architecture to become ineffective because they no longer recognise when they need to speak the aggressive and confrontational language that propelled change in the first place. Getting the balance right between sloppy activism, being co-opted and smart engagement with government-led structures is a delicate art, and not enough energy, time or money is being invested in supporting civil society groups to develop and sustain this capacity.

A central problem is that as countries have moved to scale up and sustain financing away from the ‘emergency response’, there has been a parallel migration of funding away from civil society towards health systems. Some argue that this is as it should be: after all, it is health systems that bear the ultimate responsibility for meeting the health needs of people living with AIDS. Activists themselves acknowledge this. The point is not that community and advocacy groups should have as many resources available to them as the state, but that there must be a political commitment to recognising the importance of community contributions, and with that recognition should come appropriate and proportionate levels of funding, controlled by the community itself.

Even where the needs of community and civil society groups are blatant, where the response mechanisms that are needed are obvious, and where the resources are available, still the money often does not seem to get directed to where it is most needed.

In 2011 the Robert Carr civil society Networks Fund was created to deal with the erosion of funds for the global civil society architecture. The fund was created to respond to the problem of donor fatigue and the funding crisis that has hit the sector as a consequence of the perception of exceptionalism, yet has still not been able to secure enough resources to sustain core funding to key population networks. Despite the massive growth in resources available to support the AIDS response and the strong commitment to civil society by many funders, the civil society activism that created the AIDS movement and its architecture is grossly underfunded.
Dismantling the architecture?

The new UNAIDS building was a testament to a movement that had grown up, joined the mainstream and, in many ways, had become institutionalised. In the process, the movement had shifted from combative outsider politics to engagement with the mundane realities of implementing programmes. This has created new challenges. In some instances it has led to greater complacency. But it has also brought with it a new and more complex set of demands that have been felt acutely by people living with HIV and their organisations. These groups have been especially hard hit by funding cuts and burn out. In many countries, this has led to a situation in which community-led networks, including groups of people living with HIV, no longer play a meaningful or effective role in shaping the AIDS conversations that matter the most today.

Many activists are grappling with the question of what institutional arrangements can be put in place to move forward with effective, ambitious action to tackle AIDS. How do we position AIDS to ensure that the response has the right level of attention, resources and governance when there has been such a significant erosion in the role and importance of national AIDS architecture? Should we be taking an approach of mergers and acquisitions, or should we be hiving off separate entities?

Linked to these questions are a set of concerns about the jealousy and resentment that are the impetus of so many of the rollbacks in the progress of the AIDS response. As the new sustainable development framework is launched, there are many other deserving causes that are looking hungrily at the resources and attention the AIDS sector has amassed.

Addressing the perception that AIDS exceptionalism resulted in unfair resource allocations must be a top priority for activists today.

There are many government and donor actors who wish to see the AIDS architecture rolled up into a broader health response over the next decade or so. Some countries are now contemplating moving to establish national health councils that would deal with all health issues within the framework of social determinants of health. In India, the National AIDS Control Organisation – long heralded as a powerful, independent multi-sectoral body driving a strong and effective response – is now being brought inside the health department as a directorate reporting within the bureaucracy. In the process, not only is there a risk of the issue getting lost, it also sends a strong signal about focus. AIDS is locked back in the ‘health box’ and no longer expected to focus on education, the private sector and, critically, the human rights dynamics that are fundamental to addressing the needs of sex workers, hijras and many other highly affected communities that can only be met through human-rights centred services.

What is unclear is whether bundling up AIDS with other health issues would build on AIDS successes, and whether greater integration would meet people’s needs in a more rounded way or dilute real action by losing a firm focus. Given the multi-dimensional nature of AIDS, and the fact that activists have always insisted that it is not simply a ‘health’ issue, I fear the latter.

There is a sense among many that the era of AIDS has passed.
And while AIDS cannot stay at the top of the charts forever, it is striking that it can so easily be forgotten, particularly when the battle is so far from over.

It is remarkable how quickly the epidemic has moved out of the headlines despite emerging epidemics in the Middle East and North Africa, rapidly growing epidemics in Eastern Europe and Central Asia, and increasing incidence in countries like Russia and Uganda, where the world had proclaimed success for so long, and which now face alarming new restrictive laws and upsurges in homophobic and transphobic violence.

**Conclusion**

Despite the resentment and the progress, I am a firm believer that AIDS is exceptional. Realpolitik tells us that the era of exceptionalism is past. Determinedly fighting for a stand-alone response to AIDS simply will not work in most contexts. Yet a stand-alone, fully resourced and ambitious response is worth fighting for in many countries, especially those that continue to face hyper-epidemics such as the southern African countries, where more than 25% of the adult population continue to live with HIV.

As we move forward into our fourth decade of AIDS, it is time to review the institutional arrangements and make sure that they don’t simply reflect a boilerplate that is the same across countries. The principles of inclusion, justice and equity that led to the creation of THT,25 TASO,26 TAC27 and so many others, are the ideals that allowed for full participation in AIDS decision-making and a complex, rounded response, and must guide the future of the AIDS response.

If we continue with the architectural metaphor, perhaps the best analogy is La Sagrada Familia, the gloriously complex and somewhat unruly cathedral in Barcelona, Spain. Building began on the church in 1882, and Gaudí worked on it until his death in 1926. Since that time, different architects have continued to build on his original idea. It is now estimated that the cathedral will be completed in the first third of the 21st century, but many claim that a large part of its beauty is the fact that it is constantly evolving – a living testament to creativity and ingenuity.

Gaudí said of it: “The expiatory church of La Sagrada Familia is made by the people and is mirrored in them. It is a work that is in the hands of God and the will of the people.”

It is both within and outside of its setting, communicating with the environment that surrounds it.

The ‘living cathedral’ approach to the future of AIDS architecture appeals to me.

This is one that builds on the brilliant aspects and core foundations of what we have constructed: the centrality of people living with HIV, the reach to all sectors, a laser focus on human rights, grounded in a public health paradigm, recognising the breadth and depth of impact of this virus, and with the nimbleness and flexibility to evolve and adapt. It means rejecting the idea of a grand development plan or simple

25. See: www.tht.org.uk/
26. See: www.tasouganda.org/
27. See: www.tac.org.za/
structure as the panacea to all problems. Instead it is time for new, organic, structures to emerge.

Allowing for an organic response to emerge means tackling the simplification of a response that would merely cluster all health issues together. This is the solution that has been proposed by some, yet poses a real risk of losing the focus on human rights and the broader impact. Once again I would argue that we must look back in order to move forward. In the late 1970s WHO’s Alma Ata Declaration made the radical statement that:

**Health, which is a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity, is a fundamental human right and that the attainment of the highest possible level of health is a most important world-wide social goal whose realization requires the action of many other social and economic sectors in addition to the health sector.**

The beauty of the Alma Ata Declaration, and its successor in Ottawa nearly a decade later, is that it reminds us that health is a “resource for everyday life, not the objective of living … a positive concept emphasizing social and personal resources, as well as physical capacities” rather than a simple clinical or biomedical matter.

A more nuanced appreciation of health, and recalling the meaning of public health, reminds us of the bedrock on which the AIDS movement was built: a comprehensive understanding that unites the social, psychological, community, human rights and biomedical dimensions of what health is and how we maximise it collectively.

Jonathan Mann pressed for a response that linked health and human rights, seeing AIDS as an important pathfinder that would shift the dynamic forever. His vision remains an important guide. If there is a rush to dismantle the current AIDS architecture or force NACs and others into unholy alliances, the energy and fight for justice and rights will inevitably re surge. Resources will need to be fought for and won again or the epidemic will rebound. This does not mean that we must stick with the current structures at global and national level. In some contexts, the separatism and complexity of the structures no longer serve and must be addressed. But we must resist the urge to declare victory and close down structures or merge without paying attention to the unique impacts in each context.

I have the radio on as I write this and a news item comes on. It is a moving interview with a feisty 60-year-old woman describing her life with dementia: “Don’t call us victims,” she barks. And the interviewer reflects on how terrible it is that people suffer the silence and stigma, the reductionism of scientists promoting medicine and cures without reflecting on what daily life is like for real people. The power of the AIDS movement is palpable. We should be proud that we have transformed how people living with other health conditions conceptualise themselves and are able to fight for their rights and their visibility.

If the institutions and people responsible for turning the curve of the AIDS story can channel this impulse – the instinct for survival, the tenacity and grit and anger of people who refuse to be victims – then the form that the response takes will matter.

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29. See: www.who.int/healthpromotion/conferences/previous/ottawa/en/
very little, and we can resist the urge to find a ‘cookie cutter’ response that works everywhere. The present anxiety about restructuring bureaucracies is exacerbated by funding cuts that limit inclusion and do not let funds flow to the programmes that matter most, and by policies and silence that fuel a general sense that AIDS is ‘over’ and no longer matters.

Those of us who have been part of the AIDS response for decades know that now, more than ever, AIDS does matter.

AIDS matters because of the lessons it can teach the world (which will disappear if they are not built into new structures), and it continues to matter for the 35 million people globally who live with it each day.

It also matters greatly for the millions more who are vulnerable to infection and lack the personal skills, community spirit, resources and political support to attain a state of complete physical, mental and social well-being.

It is in this context of inequity and inadequate responses that we return to the need for the right structures, and remind ourselves of the wisdom of Nelson Mandela. As I noted at the beginning, more than two decades ago, Mandela urged South Africans to face the emerging challenge of AIDS, to work together and “set up a structure … which goes beyond health workers and the government.” Just as important was his warning that “The key to our success is our own collective effort. The time for rhetorical arguments and victim blaming has passed.”

With such wise counsel we are inspired to search for new ways of responding to the new challenges of AIDS. We must stand by those original principles of always bringing the right people to the right tables, and being sure that they have the skills and support to represent their communities, and supporting them to articulate the real needs. Country by country, the structures should evolve and (if we get it right) they will differ, but the values and direction must be retained. Our work is too important for rhetoric and competition between diseases, issues and people to get in the way. Finding creative links and connections is a right and proper thing. The AIDS movement needs to be big enough to share our gains and our insights, but not at the expense of continuing to do the right thing and of righting the wrongs where we have stopped doing what works (or indeed never started to do enough of what we knew was needed).

What we need to guide us forward is a return to the basics. We need to go back to the principles that have always guided the fight against AIDS: the respect for human rights, the insistence on participatory processes, engaging all sectors, and the commitment to the leadership and meaningful involvement of people living with HIV.

It is these principles that must define what happens next. If we fold structures deeper into a health context, then let this be based on the multi-faceted approach of public health, articulated in WHO’s Alma Ata and Ottawa Declarations, and driven by the people seeking to achieve it, not just strengthening a clinical system led and owned by doctors.
Squabbles about whether this or that body should lead will not take us forward and will not be worthy of the millions who have already lost their lives to this plague, the millions who live valiantly with HIV, and the millions more who deserve to avoid HIV in their lives. After all is said and done, it is these values and principles that must structure what the new cathedrals look like.

Biography

Robin Gorna

Robin has over 25 years experience in the global response to AIDS, having held leadership positions in government, international organisations and at community level. She is currently Executive director of AIDS Strategy, Advocacy and Policy (ASAP), an organisation she established in 2010 which brings together consultants—especially people openly living with HIV. Robin set up the first multi-sectoral team on global AIDS policy at the UK Department for International Development (DfID).
Dr. Frank Mugisha
Executive Director, Sexual Minorities Uganda (SMUG)

UGANDA

‘Smoking out the gays’:¹ How legislating for hatred has distracted Ugandans and reversed hard-won gains in the fight against AIDS

Introduction

This is a story about how Uganda went from being a darling of the AIDS world to a pariah. It is also the story of an AIDS movement that has failed to keep pace with an autocratic state more interested in maintaining power than the needs of the people it serves.

For activists around the world who are looking to regain lost ground in battles over human rights, this serves as a cautionary tale.

It teaches us that without deeply rooted social mobilisation, populist assaults against the most vulnerable populations will always succeed. The inverse is also true. With determination and resourcefulness, even the most serious violations of human rights can be brought to account.

In the late 1980s and throughout the 1990s, Uganda garnered accolades for its efforts in fighting AIDS. Community-based organisations, government officials, faith-based groups, youth associations; all rallied to fight the epidemic.

President Museveni himself was crucial to the success of Uganda’s AIDS response. He demonstrated critical leadership at a time when most African presidents were denying that AIDS was even a problem. That early fervour has now faded, and Museveni now represents the problem rather than the solution.

Today, 7.2% of Ugandans are living with HIV and the country now has the fourth highest HIV incidence in Africa. This is especially worrying given the dramatic progress the country had registered until the mid-2000s. Although 90% of Ugandans understand that ‘faithfulness’ is crucial as a prevention method, 25% of married men admit to having multiple sexual partners. Furthermore, 75% of Ugandans know about the importance of condoms in sexual health, but less than 8% of married men who are having sex outside of their marriages use condoms. There has also been a consistent decline in the percentage of people using condoms during the last sexual intercourse over the past decade. People aged 20–24 reporting condom use during last sexual intercourse fell from 56% in 2005 to 25.2% in 2011. Among those aged 15–29 the decline was less dramatic but still worrying – from 52.7% to 30.2%.

An additional concern is that among key populations such as men who have sex with men (MSM), sex workers, long-distance truck drivers, uniformed personnel and prisoners, little is being done to prevent HIV using evidence-based approaches. Instead, these groups (especially MSM) have been criminalised and taunted; subjected to humiliating public attacks both in the media and at community level.

Museveni and his ruling party, the National Patriotic Front (NPF), have turned on the country’s gay population, using them as a political scapegoat. This assault comes at a time when the data show significantly higher rates of HIV infection in MSM than the general population, and, importantly, strong overlaps between MSM and women who have sex with men.

How Uganda conquered AIDS then lost the plot

The early years of the fight against AIDS were self-funded and self-motivated. Ugandans were pushed to address AIDS because from the early 1980s onwards they had witnessed so many people dying. The movement to combat the virus did not need to be engineered and funded by donor agencies. A young and energetic new president, Yoweri Museveni, provided the public face of the fight against AIDS.

His leadership was invaluable. In December 1988 he gave a speech in which he declared AIDS a “national emergency”. In doing so, he provided the intellectual underpinnings for how AIDS would be fought in the two decades that followed. The notion that AIDS was an emergency, and therefore warranted an urgent, well-funded response, has its roots in Museveni’s embrace of the challenge that confronted his ailing nation. Thousands of Ugandan doctors, family members, teachers and community leaders heeded his call and followed his lead, mobilising to bring down the numbers dramatically.

Activists like Noerine Kaleeba, one of the founders of The Aids Support Organization (TASO) who has worked tirelessly to talk about stigma against
people living with HIV and AIDS, played a crucial role in this turnaround. So too did doctors like Dr Elly Katabira, who provided critical care at Mulaago hospital and pioneered outpatient services and home-based care that was focused on dispelling fear and ending stigma. Using community approaches, mass media and innovative research, the country worked in a coordinated fashion to address an epidemic that many had believed could never be defeated.

Soon external money began to pour in to take the fight to the next level. Many donors set up offices in the country, and new large-scale programmes began their operations. Yet somehow external funding did not accelerate the progress the country had already achieved. Instead, a widening gap developed between what people across Ugandan society know about AIDS and what they practice.

**The facts about gay-identified people in Uganda**

The exact or reliably estimated numbers of LGBT in Uganda vary greatly - many live in the capital city of Kampala. The 2009 survey of sexuality and AIDS in Uganda indicated that 78% of MSM in Kampala have ever had sex with a woman; 44% have lived with a female sex partner; 16% are currently living with a female sex partner; and almost a third (29%) have fathered children. The study authors note that “MSM in Kampala are at substantially higher risk for HIV than the general adult male population.” The estimated adult male HIV prevalence in Kampala at the time of the survey was 4.5%, and the findings confirmed that the HIV infection rate in MSM was close to 14%.

The experiences of MSM in Uganda are similar to those of MSM in other African contexts. In the previous decade, a number of studies sought to better understand HIV incidence and prevalence in MSM communities. The findings from these, ranging from Botswana to Kenya and Uganda to Cameroon, indicate that unprotected anal sex is widespread. Knowledge and access to appropriate risk prevention measures are inadequate, and MSM in some contexts engage in transactional sex. Additionally, as Smith et al. point out, “stigma, violence, detention, and lack of safe social and health resources are widely reported” by MSM.

Faced with the reality of higher HIV infection rates and poorer access to services, including treatment, than the general population, it would be scientifically prudent for the Ugandan government to embark on a range of programmes designed to ensure that MSM can access the prevention, care and treatment support they need.

Instead, the government has chosen a different path. Since 2009, led by David Bahati and financed by a section of the United States evangelical movement led by Scott Lively, the Ugandan government has opted to turn away from science. Through legislation, as well as in increasingly violent anti-gay rhetoric, they have conducted a dangerous crusade aimed at victimising LGBTI and driving homosexuality underground.
The Anti-Homosexuality Act (2014)

The legal elements of this crusade took shape in the Anti-Homosexuality Act, which President Museveni signed into law in February 2014. The passage of the act was marked by much controversy. Indeed, by the time that the president had signed the bill, a global campaign to stop him was in full swing. Museveni defied and mocked his critics, making it possible through the new law for the state to imprison people for life if they are found engaging in homosexual acts.

In addition, the law makes the “promotion” and “recognition” of homosexual relations illegal. This specifically includes government entities or non-governmental organisations (NGOs) inside or outside of Uganda. Many activists are certain that this clause exists to ensure that gay-identified people do not access critical services like healthcare. While the version of the act that was ultimately passed did not include the death penalty clause (originally it was dubbed the ‘Kill the Gays’ bill because it threatened death to homosexuals), it remains an extremely dangerous law.

The Anti-Homosexuality Act fuels homophobic violence and puts the lives of gay-identified people at significant risk. Already there have been numerous reports of communities attacking LGBTI because they are emboldened by the law. In driving LGBTI people further underground, it makes it harder for them to safely access services, including for HIV prevention and treatment. The 2009 study found that men reporting a lifetime history of homophobic abuse are at increased risk of becoming HIV infected.

There are other concerns too. Uganda had taken significant strides towards becoming less conservative in terms of sexual attitudes. The president himself drove an agenda to talk openly about sex in order to address a problem that was killing so many. Yet the approach to the Anti-Homosexuality Act re-imposes rigid norms and uses the state to enforce them. Moralising promoted by the evangelical Christian movement has resulted in a reluctance to seek commodities and services for fear of judgment. Judgment is literally killing Ugandans across the social and economic spectrum, and turning this around is the key to their healthy future.

An overall assault on democracy

Museveni’s political longevity, and his increasingly brutal methods of holding on to power, are crucial to understanding the current AIDS response in Uganda.

As most Ugandan human rights activists will tell you, the decision to jeopardise the nation’s health has everything to do with power and nothing to do with medical science.

Today, even the most basic rights – freedom of assembly, expression and association – are under threat in Uganda. Indeed, many people in Ugandan society are scared to speak up in defence of anybody, least of all those in the LGBTI community. The Public Order and Management Act, signed into law in 2013, has changed the landscape fundamentally for NGOs. According to the Act, public meetings are prohibited between 7pm and 7am, and no public
meetings at all are allowed at and around democratic institutions, including parliament and the courts. Furthermore, the interior minister has broad powers to designate “gazetted” areas where assemblies are prohibited. The new law also gives the police and other law enforcement agencies broad powers to use force to disperse meetings.7

This has significant implications for all civic groups and for those who promote human rights in Uganda. It means, first and foremost, that Uganda is virtually a police state. This is a point that democracy and governance monitors have made repeatedly in the past decade. The violent intimidation of opposition politicians (whose numbers are also limited by the extension of the presidential term) and the growing use of the state as an extensive patronage network have long worried many observers.

The ballooning size and multiplying powers of the state are just one illustration of how patronage networks extend across the country today. In 1990, Uganda had 33 districts covering its territory. Today, there are 112 districts. There are also 70 cabinet ministers and 114 ministerial and presidential advisers, 375 members of parliament (70% of them representative of the ruling NPF) and 134 commissions and quasi-state bodies. Each of these owes significant, if not primary, allegiance to the president of the country or the ruling party. This vast and influential group who are beholden to Museveni has played a major role in creating an environment in which human rights and democracy are severely curtailed in Uganda.

The criminalisation of gay-identified people themselves, as well as of their sexual behaviour, must be confronted on both human rights and public health grounds. Yet without an environment in which human rights defenders can operate, successful legal or social challenges are unlikely. In other contexts, angry citizens might march for change. In Uganda a permit is now required before this can happen. In other contexts, human rights groups might meet to strategise with LGBTI organisations about a fight-back strategy. In Uganda this is illegal because they are obliged to turn them in if they know their sexual orientation.

The Christian right targets Uganda

Over the last decade the Christian evangelical movement has played an increasingly prominent role in Ugandan life. The growth in conservative congregations is now beginning to have an impact on the behaviour and attitudes of ordinary Ugandans. The size, infrastructure and capacity of the evangelical movement have yet to be quantified, but there is no doubt that it has a distinctly American flavour. Large camps are held annually in Kampala whose sole focus is on getting young people to commit to abstinence, and conferences are held with American churches in the southern states where evangelicalism is most strongly rooted. Additionally, increasing numbers of educational and health institutions are run by evangelical groups that promote their faith among those seeking services.

No foreigners have been more systematic and consistent in spreading the ideologies of conservative evangelical Christianity than Scott Lively (who is being sued on my behalf by the United States Center for Constitutional Rights for fermenting anti-gay discrimination).

Lively introduced the narrative of the ‘international gay agenda’ to Uganda. His central thesis is that male homosexual behaviour targets children, and he makes wild claims about a gay conspiracy to ruin families and nations. He has even gone so far as to intimate that gay people were behind the genocide in Rwanda. This latter assertion is in line with claims in his book, *The Pink Swastika*, that homosexuality caused Nazism.

A prominent United States human rights organisation, the Southern Poverty Law Center, has put Lively and three organisations with whom he is affiliated on a watch list of organisations that promote hate speech.

Much of that hate speech is targeted at gay people both in the United States and Uganda. Lively has inspired a movement that has many Ugandan backers. There is no question that the brand of conservatism that he extolls has captured the imaginations of many senior officials in the country. The key drivers of the anti-homosexuality movement in Uganda include Stephen Langa and Martin Ssempa, both of whom have significant congregations.

Lively and the religious groups with whom he works in Kampala have unfettered access to parliament. His parliamentary addresses are never open to comment or official responses from the members of the LGBTI community whom he attacks (even if they were, the fear of arrest and harassment would be a disincentive for participation). He is also provided with unprecedented media access. For example, during one trip to Uganda in 2013, Lively’s remarks were broadcast continually for five hours on state television.

With the Anti-Homosexuality Act serving as a lightning rod, it has become clear that some individuals in communities have zealously taken up the call to shame LGBTI people, turning in scores of homosexuals. The media has published lists and churches have banned people from attending services for being “suspected homosexuals”. The Anti-Homosexuality Act has demonstrated that Ugandan society is deeply homophobic. Indeed, the most painful thing for many activists to accept was that the law was widely supported across society.

**The sins of the AIDS movement**

While the evangelical movement has taken up much of the time and attention of key NGOs involved in the AIDS response, the AIDS movement itself has some serious questions to answer about its own conduct. As far back as 2008, Milly Katana, a prominent AIDS activist in Uganda, remarked that one of the largest and best-known NGOs in the AIDS response had “lost the crowd”. She argued that it was “riding on the back of its history … Of course it’s the biggest – outsiders trust it, value it, they give them more money and they are expanding services, which is great. But to me that doesn’t mean that they are leaders.” Her comment could be applied to the sector as a whole. With resources on the table and success in hand, many organisations became complacent and began to take a more bureaucratic approach to the AIDS response.

There were two consequences of their complacency. First, it meant that as evidence began to emerge of new behaviours that could drive incidence back up again, the NGO sector was insufficiently organised and proactive to read...
the signs and push government to mobilise accordingly. Second, many AIDS organisations lost touch with the communities that had originally driven the AIDS response. While they may have continued to provide services to them, a more bureaucratic approach meant they were less likely to pick up on trends and the ways in which conservatism was being understood and lived.

Unlike in other countries where the AIDS response had initially entailed confrontations with governments that had to be convinced through political and social pressure to tackle the epidemic, in Uganda there had been no major anti-government struggle. Because government, and Museveni in particular, had always been on the same side as activists, there was no history within the AIDS movement of combative or confrontational activism.

Corruption

One of the most discouraging but important issues that faces AIDS and human rights activists in Uganda today is the issue of corruption and the abuse of AIDS resources. Uganda has been rocked by a number of scandals implicating senior officials and NGO actors. In 2006, the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund) cancelled a $200 million grant because of abuse by high-ranking officials, and their relatives and friends. Employees of the newly established Project Management Unit disbursed monies to NGOs that only existed on paper, and Global Fund money ended up in coffers that were used to fund Museveni’s (successful) campaign to end term limits so that he could continue in office for a third term.9 Some of those involved in the scandal were jailed, but for the most senior and well connected there were no repercussions.

While corruption presents the sharp end of the stick, there have also been basic management problems at the Uganda AIDS Commission (UAC) for a number of years. Many of those who work in the AIDS sector in Uganda believe that corruption and cronyism are endemic not only in the UAC but also in the ministry of health. Yet few AIDS NGOs are prepared to take this on systematically. For example, many activists are concerned that counterfeit antiretrovirals are available on the market, and that drugs are siphoned off from the public sector to be sold on the black market. These issues are evidence of a broader institutional malaise that has crippled the Ugandan AIDS response for at least half a decade. Yet there has been little traction in addressing these issues in part because of weak capacity within the AIDS response.

Lack of independence

Many of us believe that the UAC must become independent of the president if it is to carry out its mandate effectively. We also believe that it is not yet capable of monitoring and evaluating the work of AIDS service organisations. A strong call from grassroots organisations is that the UAC should build its capacity to conduct activities outside of Kampala. Many suggest that there is a crucial role it should be playing in the fight against corruption, and in the management and roll out of programmes on the ground. Without being independent and itself above reproach, and without having the technical and staff capacity to conduct visits or establish a physical presence in rural areas, it is unlikely that much will change.

2004r/#ixzz30XtuhifC
Insufficient strategy and tactics in advocacy

There are fierce and important battles to be fought against the Anti-Homosexuality Act and against the impulse to push the abstinence-only messages of the conservative Christian movement. Although these conflicts are crucial, if NGOs responding to AIDS do not actively mobilise, if they are not better prepared to take on these political entanglements, then they will be outwitted and outpaced by those who wish to evade evidence in favour of morality-based programming.

Mapping the future: proactively taking on the conservative agenda

It is clear that for Ugandan activists and public health officials working to end AIDS, the real battle for the next five years will be against the forces within society that have promoted an especially virulent form of conservatism. Struggles to fight the growing homophobic violence in Uganda matter because gay rights are human rights. They also matter because they signal the beginning of a larger assault on the rights of other groups regarded by the Christian conservatives as entry points for their efforts to cement their particular brand of “family values”. Many women’s rights organisations are concerned about the rise of misogynistic language. They are also worried about the Anti-Pornography Act, passed earlier in 2014, which is already curtailing women’s rights.

A news report from a Ugandan daily\(^{10}\) notes that “women have been forbidden from wearing clothes like miniskirts and cleavage-revealing blouses (“tops”) that excite sexual cravings in public, unless for educational and medical purposes or during sports or cultural events.” It seems likely that the scapegoating, blaming, moral crusading and victimising will continue against an ever-widening group of people. The prospects do not look good for an AIDS response that is respectful of women’s rights; one that recognises women and girls as autonomous beings who have rights to condoms and family planning, and to choose when and under what conditions to have sex.

Taking Lively to court

The fight against conservatism is precisely why Sexual Minorities Uganda (SMUG) decided to pursue action against pastor Scott Lively. The case serves as an opportunity to proactively deconstruct the conservative religious ideology that has imprinted itself so strongly on the consciousness of Ugandans. The idea Lively promotes is that homosexuality is itself foreign to Uganda, and that it was brought to our shores through an international ‘gay agenda’.

Therefore by his logic, the only means of fighting the gay agenda is through a patriotic defence of the Ugandan family and its Christian values. SMUG’s view is that the role of Lively and others who are exogenous to Africa in fermenting hatred requires exposure. Ugandans must begin to ask more rigorous questions about the morality of the evangelical movement itself.

Returning to basics

In the years to come, civil society groups in Uganda will need to go back to basics.

The fierce competition for resources within the LGBTI, AIDS and human rights sectors has led to a fragmented response, when what is needed is a united voice. The strong preference for the services of professionalised NGOs by donors rather than community-based grassroots organisations is leaving many NGOs open to the criticism that they are doing the bidding of their donor ‘masters’ rather than what is best for their constituencies. It also means that the AIDS response is much less connected to community issues and concerns than it was in the past.

Outside the development world that many NGOs have become accustomed to inhabiting, a priority for activists in the next five years will be to focus on changing the hearts and minds of ordinary Ugandans. This will only happen if those at the forefront of the fight are able to think creatively about expanding their grassroots base. In the current context it is hard to imagine this. Yet without a massive engagement with the churches, schools and community structures that currently support homophobia, it will be impossible to tackle.

The biggest lesson Uganda teaches us is that complacency and politics make a particularly virulent combination. HIV is on the rise once again in Uganda because success bred complacency among the general population, and it bred arrogance and corruption among NGO and government leaders. Now that sexual behaviour has become criminalised among the LGBTI population, and the time has come for activists to confront the state, they find that the tools that should be at their disposal have been destroyed. The freedoms that allow people to challenge power and win have been whittled away.

Those fighting for an AIDS response that meets the needs of all Ugandans will not find success until they join forces with those who are defending the rights of ordinary people to voice their concerns and participate in a fully functioning democracy. It is not too late for Ugandans to challenge the crusading, moralising forces of conservatism. AIDS activists have years of experience around the world in doing this. For Uganda’s civil society groups, the task that lies ahead is to ensure that this fight is strategic, all encompassing and fought in a language and on a terrain that makes
BIography

Frank Mugisha

Frank is one of the most prominent advocates for LGBTI rights in Uganda. Winner of numerous awards, he is recognised nationally and internationally for his activism for full legal and social equality in Uganda. He is founder of Icebreakers Uganda (IBU), an organisation created as a support network for LGBTI Ugandans who are out or in the process of coming out to family and friends; and is currently Executive Director of Sexual Minorities Uganda (SMUG).
“In reaching out to a group of thoughtful, tough and astute activists, we have inadvertently tapped into a raging counter-narrative that seemed to have had no formal outlet until now.

Taken together [these essays] represent a wail against complacency, a battle cry in defence of human rights in an era of jargon and statistics.”

Sisonke Msimang,
Lead Author