

Executive Summary

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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.

1. Cabral, A. (1965). *Tell No Lies, Claim No Easy Victories*.

Available at: <http://newwritings.wordpress.com/2009/02/11/cabral-tell-no-lies-claim-no-easy-victories/> (accessed 01.08.14)

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."² 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 Declaration³ 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, "What

2. Cabral, A. *Revolution in Guinea*, stage 1, London, 1974, pp70-72

3. The Doha Declaration on the TRIPS Agreement and Public Health was adopted by the WTO Ministerial Conference of 2001 in Doha on November 14, 2001

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.





BIOGRAPHY

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Sisonke Msimang is lead author of ***AIDS today***. Currently Senior Programme Specialist at Sonke Gender Justice, she is a Southern African writer and activist with expertise in race, gender, democracy, HIV and politics. Sisonke's work has a particular focus on the role of civil society actors in addressing global development challenges.



Extract from '*AIDS Today: Tell no lies and claim no easy victories*' [2014 edition] published by the International HIV/AIDS Alliance (International Secretariat).

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