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The architecture of AIDS: building a movement, sustaining a response

“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.

4. Kalibala, S. and Kaleeba, S. [Personal communication] See also Grebe, E. (2012), *Civil society leadership in the struggle for AIDS treatment in South Africa and Uganda*, University of Cape Town.





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.⁵ 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,⁶ 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 (2000–2006) was defined

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*.





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 at 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 support

7. World Bank, *Multi-Country AIDS Program for Africa (MAP)*. [Online]

Available at: <http://web.worldbank.org/WBSITE/EXTERNAL/COUNTRIES/AFRICAEXT/EXTAFRHEANUTPOP/EXTAFRRREGTOPHIVAIDS/0,,contentMDK:20415735~menuPK:1001234~pagePK:34004173~piPK:34003707~theSitePK:717148,00.html>

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*.

9. World Bank, *Multi-Country AIDS Program in Africa (MAP): achievements and highlights*. [Online]

Available at: <http://web.worldbank.org/WBSITE/EXTERNAL/COUNTRIES/AFRICAEXT/EXTAFRHEANUTPOP/EXTAFRRREGTOPHIVAIDS/0,,contentMDK:20415735~menuPK:1001234~pagePK:34004173~piPK:34003707~theSitePK:717148,00.html#Highlights>

10. United Nations (27 June 2001), United Nations General Assembly Special Session (UNGASS) *Declaration of Commitment on HIV/AIDS: “Global crisis — global action”*. See para. 29. Available at: www.un.org/ga/aids/docs/aress262.pdf





alternative partnerships among nongovernmental organizations and the private sector.” *[Emphasis added]*¹¹

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.

11 . Global Fund to Fight AIDS, Tuberculosis and Malaria (2001), *The Framework Document*.

12. U.S. President’s Emergency Plan for AIDS Relief, *Shared responsibility-strengthening results for an AIDS-free generation: 2013 PEPFAR results*. [Online] Available at: www.pepfar.gov/documents/organization/218406.pdf

13. See, for example, the presentation delivered to the Parliamentary Select Committee on Social Services by Dr Connie Kganakga, Chief Director for HIV and AIDS, 19 September 2006), *Progress report on the HIV/AIDS programme of the department of social development*.

Available at: www.pmg.org.za/docs/2006/060919hiv.pdf; Multi-Sectoral HIV and AIDS Support Programme (MSP), *MSP impact*. [Online] Available at: www.mspsouthafrica.org/aboutus/mspimpact/; UNAIDS-Lancet Commission Working Group 2, *Can the experience of the AIDS response serve as a transformative force in global health and development?* (forthcoming)





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.¹⁴ 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 1994,¹⁵ and emphasises that those most affected by AIDS should have leadership roles in all aspects of responses. People living with HIV were to be

14. UNAIDS (25 April 2004), "Three Ones" key principles. "Coordination of National Responses to HIV/AIDS": Guiding principles for national authorities and their partners.

15. A brief summary of GIPA is available at: www.aidsalliance.org/TechnicalThemeDetails.aspx?Id=34 [Retrieved: January 2014]





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 recalls¹⁶ 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 on the agenda: "You must demand

16. Piot, P. (2012), *No time to lose: a life in pursuit of deadly viruses*, W.W. Norton.



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".¹⁸ 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,¹⁹ which made a commitment to

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(d). Available at: http://data.unaids.org/topics/universalaccess/postg8_gleneagles_africa_en.pdf

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.





“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.

20. United Nations (31 May–2 June 2006), *United Nations General Assembly Political Declaration on HIV/AIDS*, para. 49. Available at: www.un.org/ga/aidsmeeting2006/declaration.htm

21. I have written elsewhere about how moving it was to arrive in South Africa and see TAC banners proclaiming exactly the words we had drafted for the G8 and UN – and to see that they were mobilizing action on the ground. See Gorna, R. (9 April 2013), *Once upon a time in Gleneagles.....* [Online] Available at: www.huffingtonpost.co.uk/robin-gorna/once-upon-atime-in-gleneagles_b_3043160.html





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."²²

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

22. Western Cape Health Department [Interview] Unpublished interview undertaken as part of a review of the implementation of the Global Fund's Gender Equality Strategy for UN Women and the Global Fund.





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.²³ 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 Fund²⁴ 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.

23. Yuvaraj, A. 10 June 2014 [Personal communication].

24. See www.robertcarrfund.org/ A team from ASAP [the consultancy established by Robin Gorna] was responsible for the consultations and design of this fund.





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 Família, 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 Família 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:

[H]ealth, which is a state of complete physical, mental and social wellbeing, 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.²⁸

The beauty of the Alma Ata Declaration, and its successor in Ottawa²⁹ 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”³⁰ 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 resurge. 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

28. See: www.who.int/publications/almaata_declaration_en.pdf

29. See: www.who.int/healthpromotion/conferences/previous/ottawa/en/

30. World Health Organization (21 November 1986), *The Ottawa Charter for Health Promotion*.





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).



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