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Health for all

Time to consider the uncounted in the race to meet global goals

Why are we failing to end HIV?

By Sara L.M. Davis

As the International AIDS Conference holds its first virtual meeting, it's time to consider the politics that create gaps in data for the fight against HIV, writes Sara L.M. Davis

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This year was supposed to be a celebration – the year we reached the milestones set by the UN General Assembly to end HIV by 2030. But as the International AIDS Conference, the world's largest meeting of HIV scientists, officials and activists, convenes online, it is clear that the world is far off track. Why?

Many will argue that COVID-19 is to blame, and the new pandemic has certainly been devastating for the HIV response. But I argue in a new book, *The Uncounted: Politics of Data in Global Health,* that one important reason we are failing to end HIV is that the goal is itself flawed. The mirage of "ending AIDS", combined with insufficient funds to achieve the goal everywhere, drove donors to concentrate their efforts in a small number of countries while neglecting many others, and neglecting how stigma, discrimination and criminalization would undermine the response.

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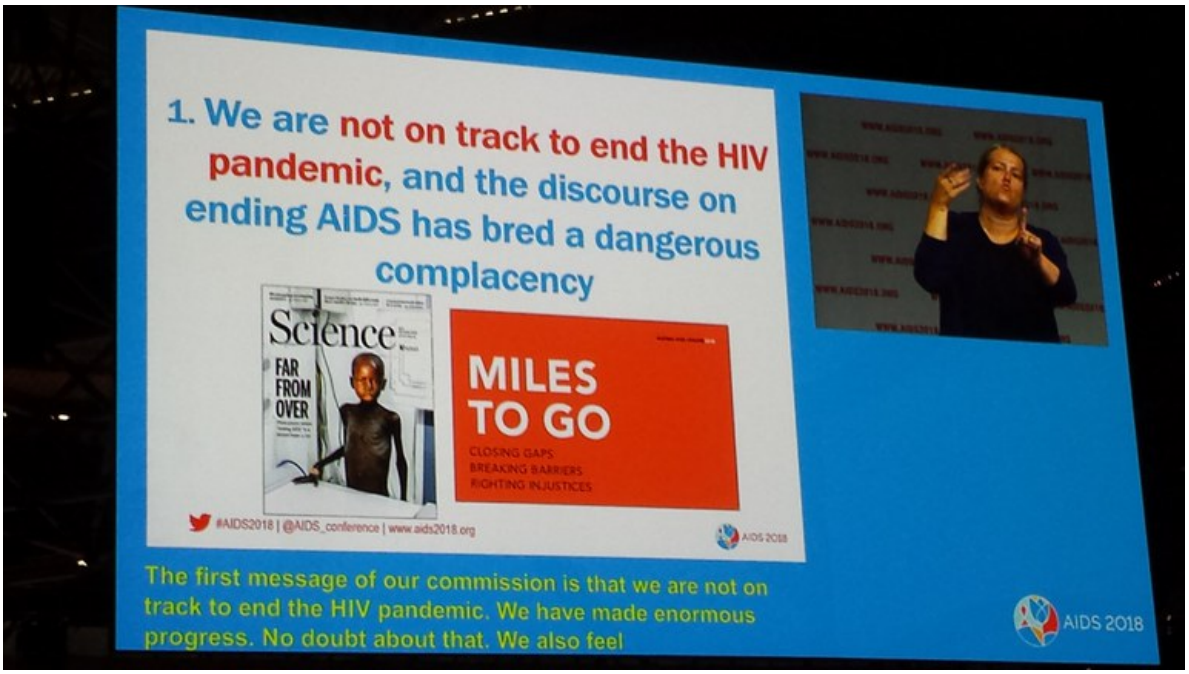

Presentation by Peter Piot at the World Aids Conference 2018. Photo: MMS

Ambitious global goals vs. flatlining funds

In approving the Sustainable Development Goals (SDGs) in 2016, the UN General Assembly committed to "end the AIDS epidemic" by 2030 (GA resolution 70/1, 16). The central set of testing and treatment targets UNAIDS set for 2020 are known as “90-90-90”:

- 90% of all people living with HIV are tested and know their HIV status
- 90% of all people with diagnosed HIV infection receive sustained antiretroviral therapy, and
- 90% of all people receiving antiretroviral therapy have viral suppression UNAIDS 2017).

People diagnosed with HIV infection who sustain antiretroviral therapy for long enough can live healthy lives, and reduce their viral load (the amount of HIV in the bloodstream) to the point where the virus is undetectable and cannot be passed on to others. In 2015, UNAIDS’ infectious disease models of this approach showed convincingly that a global scale-up of antiretroviral treatment to the 90-90-90 targets could trigger a phase change in countries where prevalence was high, such as South Africa or Uganda.

And just as important, I argue, the idea of “ending AIDS” had a strong appeal to donor countries who wanted an exit strategy. The US, UK, European countries, and Japan, among others, have been bankrolling the global HIV response for decades. By "ending AIDS" through one last massive push, they could also end, or at least reduce, that financial obligation.

Protest against the fact that in 2020 the next International AIDS Conference is to be held in San Francisco. Photo: MMS

To meet these targets, the models demanded a massive scale-up at a moment when global HIV financing was at its peak. Development assistance for HIV had risen globally in the early 2000s, dipped after the 2008 global economic downturn; and begun to rebound in 2013-14. However, just as the ambitious global targets were approved by UN member states, a tectonic political shift hit the two leading donor countries: UK citizens voted to leave the European Union, and the U.S. elected Donald Trump president. Growing xenophobia and preoccupation with internal politics resulted in cuts to development assistance for health. In 2018, it dropped by 3.3% (IHME 2019: 14). In 2019, President Trump proposed sweeping cuts of 29 percent to the Global Fund. These were resisted by Congress, which approved an increase instead, but the threat remains real (Friends of the Global Fight 2019). From 2010 to 2018, HIV funding from other donors declined by more than $1 billion (Kates et al. 2019).

The Fast Track approach promised that one day there could be an end to donor fatigue. But to reach that day, donors would need to husband their shrinking resources, clearly demonstrate to the public that the investment was delivering progress towards the end of AIDS, and make every dollar (or Euro) count. This created pressure on donors to engage in rationing. My book shows some of the heated debates that took place over which countries should be eligible for aid, for instance from the Global Fund. Donor countries prioritized the larger countries with high HIV prevalence where they believed they could bring HIV under control, especially in Sub-Saharan Africa. Priority-setting became a numbers game.

The dominance of cost-effectiveness

This logic, grounded in principles of cost-effectiveness, was reinforced by new research that began to show that at the sub-national level, targeting services in hospitals and clinics where they were needed most could deliver greater impact than would addressing HIV uniformly across the general population. Using epidemiological data to produce heat maps that showed where the epidemic was concentrated, national health planners could better position services in HIV "hot spots", services "tailored to the needs and contexts of specific populations" (Piot et al. 2015). Aid-recipient countries were encouraged to use cost-effectiveness software to develop "investment cases" that showed how they would use existing data to target services, achieving maximum impact with limited funds.

From the global level to the most granular local level, donors began to shift their priorities to align with the logic of cost-effectiveness: divesting from smaller middle-income countries where HIV was concentrated among key populations, to concentrate funds in larger lower-income countries where HIV was widespread; and targeting funds at the hotspots where transmission rates were highest. The thinking, logical on its face, was that middle-income countries that lost external aid would similarly follow cost-effectiveness principles in their own responses: when the donors pulled out, national governments would step up and finance the HIV response themselves, targeting their funds in hotspots to reach key populations (sex workers, men who have sex with men, transgender people, people who use drugs).

> *This global strategy of scale-up and targeting to end HIV was justified by mathematical models that predicted success. But the assumptions used to shape these models did not consider, or quantify, on-the-ground realities -- stigma, discrimination, gender inequality, health sector corruption – that would make actually accessing treatment so difficult in practice; they left out the things that Seaver (2015) calls "the unquantified remainder that haunts math".*

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Human rights organizations are worried! # AIDS2018. Photo: MMS

These realities include the fact that in most countries, regardless of national income level, key populations are criminalized, hidden, and vulnerable to abuse, arrest and discrimination. This should have been evident at the outset: at the very high-level meeting where UN member states voted for the Fast Track approach, some member states blackballed key populations-led groups from even participating (Holpuch 2016). As a result, in many countries, there is little or no accurate data on key populations, creating a "data paradox": "Decision-makers deny that most affected populations exist...so no research gets done on these populations; the lack of data feeds the denial; and so on" (Baral und Greenall, 2013).

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The cost of political negation is becoming clear. In 2019, UNAIDS reported that while rates of HIV were declining globally, over half of new infections were among key populations and their partners (UNAIDS 2019, 11).

Where to in the next strategy?

UNAIDS shows no sign of abandoning the flawed 90-90-90 targets. Experts I spoke with said that they felt that the 90-90-90 targets were good ones, and that it was countries that failed, often due to lack of political will. But if we are committed to decolonizing global health, it is time to rethink the power imbalances through which strategies are written and targets are set by technical experts in the global North; targets which drive donors to ration aid among countries, while the most marginalized populations are left to fall between the cracks.

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The next UNAIDS and Global Fund strategies should, as the Global Network of People Living with HIV (GNP+ 2019) has argued, "put the last mile first": Prioritize funding for the most remote and hard to reach groups, and for hidden key populations, adolescent girls, and young women, who are most at risk and have the most difficulty accessing the formal health sector.

They should also promote data sovereignty. Too often researchers have extracted data for the benefit of international agencies, with little clear benefit to local groups. Like-minded donors, including Switzerland, should push for support for community mobilization to reach those populations -- including establishing longer-term, smaller pots of funding to support the engagement of civil society groups at every level of the global HIV response: from community-based organizations that have the trust of key populations and can gather their health data, to their representatives on national and global health decision-making processes.

As we face the unfolding crisis of a second global pandemic, it is finally time to set aside the mirage of an "end to AIDS" in favor of goals that we can all work towards: a sustainable response with those most marginalized at the center.

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