

‘AIDS changed everything – or has it?’

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It is not hyperbole to claim that AIDS was to global health what mobile telephones proved to banking and citizen accountability—a disrupter of unprecedented magnitude, breadth and potential.

When AIDS began to claim lives among gay communities in the 1980s, men and women who had organized under banners of queer liberation used those skills and tactics to challenge the way societies respond to disease.

Gay men, many of whom were young professionals, broke many rules of the game. They subverted the prevailing patient-provider relationship in a way that expectant mothers or those preparing to die had never dared. They self-organized prevention, care, support and eventually treatment too.

The movement mobilized in a manner which effectively weaponized what might have remained a medical issue – putting it on political agendas through well-orchestrated campaigns and direct action. In so doing, they promoted fundamentally new norms of what was acceptable and unacceptable. Marginalized in many ways, but empowered by identity politics too, the movement fast-tracked medical research and drug approval processes through activist tactics—for example, using civil disobedience and a sophisticated media campaign to shut down the US FDA and upending international scientific AIDS conferences with mass die-ins.

Thinking and acting political was the hallmark of the movement. This comment touches on four governance disrupters pioneered by the AIDS movement, a broad coalition of insiders and outsiders, as a political project for social justice.

Front runner of global health diplomacy. AIDS was the first health issue to be discussed in the UN Security Council in 2000 and in the same year the first to be the subject of UN General Assembly High-Level Meeting. The trend to leverage AIDS in international relations continues as evidenced by the prominence it has had in BRICS health summits and more recently in relations between China and Africa – but this was only possible as a result of the “politicization” of AIDS.

Enshrining inclusive governance. Taking a megaphone to the disability movement’s motto of “nothing for us without” the AIDS movement institutionalized the “GIPA principles” (Greater Involvement of People Affected by HIV) in all facets of the response—including official engagement in reporting on country progress. People living with HIV as well as “key populations” including sex workers, drug users and men who have sex with men, became the drivers of global strategies not passive recipients.

Harbinger of rights-based approaches. The movement, supported by activist lawyers, claimed a range of rights in relation to government obligations and progressive social change. This included most prominently the right to treatment which brought the movement into conflict at times with the state and at times with the private sector. The Treatment Action Campaign (TAC) of South Africa, with support of a global advocacy coalition, engaged in strategic litigation against the South Africa government to secure treatment. On the international stage, the slogan “patient rights before patent rights” reflected the mobilization around TRIPs flexibilities in intergovernmental negotiations

to facilitate access to affordable generic drugs. The language of rights was also deployed in service delivery calling, among other things, for zero discrimination – particularly for key populations.

Multisector governance. Like most diseases, a range of social determinants drive vulnerability to HIV. But it was the AIDS response that championed the idea of national commissions under the auspices of heads of state or government which ensured action and accountability across ministries. Similarly, a Joint UN Programme was established, now consisting of 11 agencies, working with a common budget, a formal division of labour and a shared governance and reporting system but also serving as a guiding institution for the cause.

If nothing else, AIDS demonstrated the art of the possible based on the power of strategic collective action and the logic of refusing the status quo. Ambitious targets as well as people-centered services, governance and accountability have proven that unparalleled progress on the structural determinants of HIV and treatment scale up are possible.

Nonetheless, that these disruptions to the global health business model become the norm is in no way assured and all indications are that lessons have not been learned. Too many global health issues remain apolitical, lack citizen engagement and operate in technocratic silos. Profits over people; technocrats over activists; suffering over solidarity prevail. The time is now for a more activist approach to global health governance in the image of the AIDS movement.

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