

Global AIDS Funding and the Re-Emergence of AIDS ‘Exceptionalism’

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Abstract

Recent years have seen the re-emergence of charges of AIDS exceptionalism in response to significant increases in global funding for health that have coalesced around HIV/AIDS treatment. These increases are argued to illustrate that AIDS demands an exceptional and exaggerated portion of global resources to the detriment of other health needs and the strengthening of health systems. I argue in contrast that AIDS ‘exceptionalism’ in funding represents a welcome departure from a long-standing norm that tolerates grossly insufficient domestic and global allocations to health. In this light, AIDS ‘exceptionalism’ while a political anomaly, has acted as a transformative corrective to exclusionary and inequitable HIV/AIDS policies, and may offer important strategic opportunities for increasing attention to other global health inequities and assuring realization of the right to the highest attainable standard of health. To realize this potential, civil society actors, policy-makers and international organizations should utilize the normative, strategic and operational possibilities opened up by amplified AIDS funding as the thin edge of a considerably larger global health wedge.

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Introduction

Recent years have seen the re-emergence of charges of AIDS exceptionalism in response to significant increases in global funding for health that have coalesced around HIV/AIDS treatment. These increases are argued to illustrate that AIDS demands an exceptional and exaggerated portion of global resources to the detriment of other health needs and the strengthening of health systems. These arguments have revived older critiques of ‘AIDS exceptionalism’ which condemn HIV/AIDS policy as unjustifiably different from the treatment of other infectious diseases and as potentially counter-productive. In this paper I explore a contrasting argument that rather than illustrating misplaced political priority on a single infectious disease, AIDS ‘exceptionalism’ in funding represents a welcome departure from a long-standing norm that tolerates grossly insufficient domestic and global allocations to health. In this light, AIDS ‘exceptionalism’ while a political anomaly, has acted as a transformative corrective to exclusionary and inequitable HIV/AIDS policies, and may offer important strategic opportunities for increasing attention to other global health inequities and assuring realization of the right to the highest attainable standard of health. The paper proceeds to explore this argument by outlining (1) early debates around AIDS exceptionalism, (2) the AIDS funding revolution, (3) the revival of AIDS exceptionalism, and (4) arguments in defence of exceptionalism.

(1) Early AIDS exceptionalism

In 1991, Ronald Bayer, an American public health academic, identified AIDS exceptionalism in that country as ensuing from an alliance of gay leaders, civil libertarians, physicians and public health officials who

resisted applying to HIV the “broad statutory provisions established to control the spread of sexually transmitted and other communicable diseases,” including those relating to HIV testing, reporting, partner notification and quarantine.¹ Their argument held that AIDS should be treated differently from other infectious diseases because widespread AIDS-related stigma and discrimination required health measures that protected confidentiality, privacy and autonomy.² Bayer argued however that policies that treated HIV as fundamentally different from other public health threats would be increasingly difficult to sustain: in this light Bayer prophesied that “[i]nvariably, HIV exceptionalism will be viewed as a relic of the epidemic’s first years.”³

The two decades since have proven Bayer’s prophesy to be remarkably inaccurate. In country after country globally where epidemics have erupted, so too have debates over AIDS exceptionalism. In 1998, Kevin De Cock, a Belgian doctor working for the US CDC in Kenya, argued for the ‘normalization’ of HIV/AIDS by treating it “more like other infectious diseases for which early diagnosis is essential for appropriate therapeutic and preventive measures, within the requirements of informed consent and respect for confidentiality.”⁴ In 2002, De Cock repeated this call in the *Lancet*, arguing that the AIDS exceptionalist approach was an inappropriate response to the severity of AIDS pandemics in Africa, which instead required “an overwhelming, emergency response emphasising regular HIV testing, diagnosis, prevention, treatment, and mitigation of social effects.”⁵ De Cock singled out for particular criticism, human-rights based approaches to

HIV/AIDS prevention, which opposed mandatory and routine HIV testing without informed consent. De Cock argued that through their onerous requirements, such approaches had reduced the efficacy of public health strategies for prevention and care across the continent.⁶

De Cock’s article attracted tremendous criticism by human rights advocates who argued that widespread HIV/AIDS related stigma required greater levels of privacy and consent.⁷ Nonetheless, De Cock’s position won out in global policy, provoking the adoption of routine (opt-out) HIV screening in many African health care settings and seeing De Cock himself appointed as director of WHO’s HIV/AIDS program.

While contentions about the exceptionality of HIV/AIDS have centred on its apparently unique political status, other scholars argue that almost all major public health measures have inspired political disputes over time.⁸ Scott Burris argues that even the common notion that HIV is uniquely stigmatizing was only true relative to other contemporary health conditions, since in their time, cholera, tuberculosis and syphilis were all “badges of vice and dissipation.”⁹ To this extent, Burris argued, HIV/AIDS simply illustrated that “[t]he passions that disease can inspire are what make public health as much a political art as a biomedical science.”¹⁰

(2) *AIDS and the Global Health Revolution*

Nowhere has the political nature of public and global health been more apparent than in recent dramatic shifts around HIV/AIDS and global health funding. Over the past 10-15 years, political attention to global health has experienced what is increasingly viewed as a

¹ Ronald Bayer, “Public health policy and the AIDS epidemic: An end to HIV Exceptionalism?” *New England Journal of Medicine*, 324, 1991, 1500, at 1501.

² *Ibid.*

³ *Ibid.*, at 1503.

⁴ Kevin M. De Cock and Anne M. Johnson, “From exceptionalism to normalization: A reappraisal of attitudes and practice around HIV testing,” *British Medical Journal*, 316, 1998, 290, at 290.

⁵ Kevin M. De Cock, D. Mbori-Ngacha and E. Marum, “Shadow on the continent: public health and HIV/AIDS in Africa in the 21st century,” *Lancet*, 360, 2002, 67, at 69.

⁶ *Ibid.*, at 67.

⁷ See for example, Sophia Gruskin and Bebe Loff, “Do human rights have a role in public health work?” *The Lancet*, 360, 2002, 9348, p.1880, and Joanne Csete, Rebecca Schleifer and Jonathan Cohen, “Opt-out” testing for HIV in Africa: a caution,” *The Lancet*, 363, 2004, 9407, p.493-4.

⁸ Scott Burris, “Public health, ‘AIDS exceptionalism’ and the law,” *John Marshall Law Review*, 27, no.2, 1994, 251-272, p252.

⁹ *Ibid.*

¹⁰ *Ibid.*

revolution, resulting in the creation of new institutional actors, new governance mechanisms, transformed ideas regarding the priority of health in political decision-making, and radical shifts in funding for global health.¹¹ This revolution is most dramatically apparent in relation to development assistance for health (DAH). Despite widely varying estimates, all studies suggest sharp increases in DAH since 1990, with studies illustrating a doubling, tripling and even quadrupling of DAH in this period.¹² Moreover these increases seem to have picked up considerable speed since 2001: while DAH doubled between 1990 and 2001 (from approximately USD 2.5 billion to USD 14 billion), it doubled again between 2001 and 2007 (to approximately USD 26.8 billion).¹³

HIV/AIDS has accounted for a substantial portion of this financial boon,¹⁴ and now consumes a significant amount of global health funding, growing rapidly from US\$0.2 billion (3.4 percent of DAH) in 1990 to US\$5.1 billion in 2007 (23.3 percent of DAH).¹⁵ The focus on

HIV/AIDS is similarly reflected in the creation of major new funding institutions and programs, including the establishment in 2002 of the *Global Fund to Fight HIV/AIDS, Tuberculosis and Malaria* (GFATM) and the creation of the U.S. government's 2003 *Presidential Emergency Plan for AIDS Relief* program (PEPFAR), which has made that country the leading state donor to global health. GFATM has since approved around US\$15 billion in 140 countries, while the US government increased its financial commitment to PEPFAR from US\$15 billion to US\$32 billion.¹⁶ These two programs, together with other multilateral, bilateral and philanthropic funders (such as the Gates Foundation), currently account for approximately 60 percent of AIDS funding in Sub-Saharan Africa, with over 50 percent from the PEPFAR program alone.¹⁷

These programs focus on a broad range of AIDS services across the spectrum of prevention and treatment. That treatment is a focus of these programs is itself a remarkable outcome given earlier political struggles over intractable refusals by the pharmaceutical industry, their host governments and international institutions to lower drug prices and advance access to affordable antiretroviral treatment in Sub-Saharan Africa (the vast epicentre of the global HIV/AIDS pandemic). This position is exemplified in the fact that in 1998, the official policy of WHO and UNAIDS was that given high drug costs and the need for effective prevention, treatment was not a wise use of resources in poorer countries.¹⁸ This position shadowed a broader policy consensus that cost-effectiveness demanded a brutal triage in which prevention of HIV/AIDS was funded

¹¹ See David P. Fidler, "After the revolution: Global health politics in a time of economic crisis and threatening future trends," *Global Health Governance*, 2, no.2, 2008/9,1; Jon Cohen, "The New World of Global Health," *Science* 311, 2006, 162, and Santiago Alcazar, "The Copernican Shift in Global Health," Global Health Programme Working Paper No. 3, 2008, The Graduate Institute, Geneva.

¹² See for example, World Bank, *Healthy Development: The World Bank Strategy for Health, Nutrition and Population Results* (Washington DC: World Bank, 2007); Institute for Health Metrics and Evaluation (IHME). 2010. *Financing Global Health 2010: Development assistance and country spending in economic uncertainty*. Seattle, WA: IHME; and Nirmala Ravishankar, Paul Gubbins, Rebecca J. Cooley, Katherine Leach Kernon, Catherine M Michaud, Dean T Jamison and Christopher JL Murray, "Financing of global health: tracking development assistance for health from 1990-2007," *The Lancet*, 373, 2009, 2113-24, p. 2117..

¹³ Nirmala Ravishankar, Paul Gubbins, Rebecca J. Cooley, Katherine Leach Kernon, Catherine M Michaud, Dean T Jamison and Christopher JL Murray, "Financing of global health: tracking development assistance for health from 1990-2007," *The Lancet*, 373, 2009, 2113-24, p. 2117.

¹⁴ Ibid, 1-2.

¹⁵ Ibid, p. 2118. The large variations in estimates of available funding are exemplified in comparing this amount with UNAIDS' contention that US\$15.6 billion was available from all sources for HIV in 2008. See UNAIDS and WHO, *Global Facts and Figures 09* (2009), available online:

http://data.unaids.org/pub/FactSheet/2009/20091124_fs_global_en.pdf

¹⁶ See U.S. Government Presidential Emergency Plan for AIDS, "Latest PEPFAR Program Results," on <http://www.pepfar.gov/documents/organization/141876.pdf>

¹⁷ Alan Whiteside and Julia Smith, "Exceptional epidemics: AIDS still deserves a global response," *Globalization and Health*, 5, no. 15, 2009, p.4.

¹⁸ World Health Organization and UNAIDS, *Guidance Modules on Antiretroviral Treatments: Module 9: Ethical and Societal Issues Relating to Antiretroviral Treatments*. WHO/ASD/98.1, UNAIDS/98.7, (Geneva: World Health Organization, 1998), p. 13.

instead of treatment, an ethically questionable choice in a gross pandemic that had already infected almost 28 million people in sub-Saharan Africa, and a dubious dichotomy given the preventive impact of effective antiretroviral treatment.¹⁹ The transformation of this status quo came through effective rights-based advocacy by social movements which challenged the morality of refusals to treat that in effect protected private commercial interests at the expense of public health needs in Sub-Saharan Africa.²⁰

Treatment advocacy resulted in a dramatic global reduction in the price of AIDS drugs, and saw corporations, governments and international organizations shift towards advocating universal access to antiretroviral treatment. Today, access to these medicines in low and middle income countries has increased from a few thousand people in 2000 (well under one percent) to an estimated 5.2 million people (over forty percent) in 2010. Moreover the increases have been tremendously rapid and have picked up increasing speed: reflecting a 36 percent increase in one year and a 10-fold increase over five years.²¹ Partly because of broader access to antiretrovirals, declining mortality from AIDS is evident in Sub-Saharan Africa for the first time. These radical shifts in global approaches to AIDS treatment are remarkable given the extent of earlier political and economic opposition. Equally remarkable is that these shifts were motivated largely through

successful and broad-based AIDS treatment advocacy. Significantly for the broader argument posed in this paper, the impact of this shift has extended far beyond AIDS – as the figures above indicate, AIDS funding has motivated a broader (albeit uneven) outpouring of resources for global health more generally.

(3) *The Revival of AIDS Exceptionalism*

While the success of AIDS treatment advocacy has provoked unprecedented resources for global health and resulted in positive health outcomes in high prevalence countries, it has also reanimated exceptionalism debates. Contemporary exceptionalism arguments focus on the extent of money and other resources allocated to HIV/AIDS, exemplified by the argument that AIDS financing undermines health systems in developing countries, creating vertical programs that divert resources (human and financial) away from public health needs, leading to public sector inefficiency.²² Central to these critiques is the notion of an undue focus on a single disease fomenting an inappropriate and counter-productive epidemiological and political response. Thus for example England argues that AIDS funding exceeds the entire health budgets of many recipient countries, distorting their efforts to deal with existing health problems.²³ England argues that what is needed instead is “strengthened national healthcare systems that can deliver the range of services that countries need, according to their own priorities, not those of international lobby groups.”²⁴

Some critics reach even further arguing that these resource flows are sustained by exaggerations about the pandemic.²⁵ For

¹⁹ On prevention versus treatment arguments, see E. Marseille, P. B. Hoffman, and J. G. Kahn, “HIV prevention before HAART in Sub-Saharan Africa.” *The Lancet* 359, no. 9320, 2002, 1851-1856. On the preventive effects of antiretroviral therapies, see Pietro Vernazza, Bernard Hirschel, Enos Bernasconi, Markus Flepp, “HIV-positive individuals without additional sexually transmitted diseases (STD) and on effective anti-therapy are sexually non-infectious,” *Schweizerische Ärztezeitung/Bulletin des médecins suisses/Bollettino* 2008; 89:5.

²⁰ I explore this argument in full in “Rights’ and Wrongs: What Utility for the Right to Health in Reforming Trade Rules on Medicines?” *Health and Human Rights: An International Journal*, 10, no. 2, 2008.

²¹ UNAIDS and WHO, Global Facts and Figures 09 (2009), available online: http://data.unaids.org/pub/FactSheet/2009/20091124_fs_global_en.pdf

²² R. England, “The dangers of disease-specific programs for developing countries,” *British Medical Journal* 335, no. 565, 2007; R. England, “Writing is on the wall for UNAIDS,” *British Medical Journal*, 336, no. 1072, 2008, and Jeremy Shiffman, “Has donor prioritization of HIV/AIDS displaced aid for other health issues?” *Health Policy and Planning* 23, 2008, 95-100.

²³ R. England, “The dangers of disease-specific programs for developing countries,” *British Medical Journal* 335, no. 565, 2007, at p565.

²⁴ *Ibid.*

²⁵ Alan Whiteside and Julia Smith, “Exceptional

example, Chin argues that political correctness has collided with epidemiology when it comes to AIDS, leading to UNAIDS and AIDS activists actively inflating HIV/AIDS statistics in order to keep the disease on the political agenda and assure funding and jobs.²⁶ Indeed, Chin argues that these systematic overestimates of HIV prevalence globally fly in the face of contrary evidence suggesting that new HIV infections are likely to have peaked in the late 1990s. Similarly, Pisani argues that the ideology and money of the 'AIDS industry' has compromised effective action on HIV/AIDS, both by policy-makers and scientists.²⁷ Indeed, Pisani suggests that the lobbying successes of AIDS advocates has led to singularly ineffective policies, with "billions of dollars of taxpayer's money being shovelled down an ideological drain."²⁸

(4) *A defence of AIDS exceptionalism*

The re-emergence of exceptionalism charges in the face of greatly increased funding for AIDS raises questions about both its political and cultural sources and its intended outcomes. I will attempt only to answer the latter in this paper, particularly by pointing out that in its strict lexical sense 'exceptionalism' suggests a departure from the norm and a case to which a rule does not apply.²⁹ Thus, the charge of AIDS exceptionalism implies that AIDS funding represents a departure from a prior global norm regarding health funding. To the extent that this increase is argued to be harmful, unwarranted and even unethically achieved, the implication is that the prior global norm regarding health funding is to be defended. Viewed from this perspective, there are two possible avenues for addressing the exceptional treatment of AIDS: either reduce AIDS funding back to the level of all other global health funding (eradicate the

exception), or increase all other global health funding to the level of AIDS (alter the rule).

There is little moral basis on which to argue for the former, when one considers the uneven and insufficient nature of even current levels of DAH. Obstetric care, a major determinant of maternal mortality,³⁰ is not a priority of global health funders despite being the second leading cause of death in adult women globally (at 7.2 percent).³¹ Progress on this health inequity has been relatively stagnant, with maternal mortality decreasing globally at less than one percent between 1990 and 2005,³² a rate far below the 5.5 percent required to achieve Millennium Development Goal Five.³³ Moreover in many of the countries with the highest burden of maternal mortality, progress has not simply stagnated but reversed.³⁴ To accept that AIDS exceptionalism requires reduced funding is to relegate health inequities like maternal mortality to persistent neglect. The exceptional response to HIV/AIDS is therefore illegitimate only to the extent that it remains focused on HIV/AIDS to the detriment of other health needs. What is needed therefore is not eradication of the AIDS exception, but alteration of the general rule of neglecting broader global health inequities.

epidemics: AIDS still deserves a global response," *Globalization and Health*, 5, no. 15, 2009, p.2.

²⁶ James Chin, *The AIDS Pandemic: The Collision of Epidemiology with Political Correctness* (Oxford: Radcliffe Publishing, 2006).

²⁷ Elizabeth Pisani, *The Wisdom of Whores: Bureaucrats, Brothels and the Business of AIDS* (London: Granta, 2008).

²⁸ *Ibid*, p.12.

²⁹ These are Merriam Webster definitions.

³⁰ Paul Hunt and Judith Bueno de Mesquita, "Reducing Maternal Mortality: The contribution of the right to the highest attainable standard of health," University of Essex, Human Rights Centre, undated, p.4.

³¹ World Health Organization, Leading causes of women's death, available at http://gamapservers.who.int/gho/interactive_charts/women_and_health/causes_death/chart.html

³² World Health Organization, *Maternal Mortality in 2005: Estimates developed by WHO, UNICEF, UNFPA and the World Bank* (Geneva: WHO, 2007), quoted in Sofia Gruskin, Jane Cottingham, Adriane Martin Hilber, Eszter Kismodi, Ornella Lincetto, and Mindy Jane Roseman, "Using human rights to improve maternal and neonatal health: History, connections and a proposed practical approach," *Bulletin of the World Health Organization*, 86, no. 8, 2008, 589, p.589.

³³ Sofia Gruskin, Jane Cottingham, Adriane Martin Hilber, Eszter Kismodi, Ornella Lincetto, and Mindy Jane Roseman, "Using human rights to improve maternal and neonatal health: History, connections and a proposed practical approach," *Bulletin of the World Health Organization*, 86, no. 8, 2008, 589, p.589.

³⁴ World Health Organization, *World Health Report 2005: Making Every Women and Child Count* (Geneva: World Health Organization, 2005).

Similar arguments have been mounted by AIDS experts and scholars. Stephen Lewis, the former UN special envoy for AIDS in Africa, argues that

*AIDS exceptionalism is a perfectly defensible and descriptive concept ... I tramped the high-prevalence countries of Africa for more than five years; if I wasn't viewing the most exceptional communicable disease assault of the twentieth century, then the word 'exceptional' needs to be re-defined.*³⁵

Whiteside and Smith similarly recognize that while AIDS is exceptional, it should be part of a broader development agenda based on human rights and which aims to improve the health and well-being of societies as a whole.³⁶ Whiteside and Smith argue for example, that “the rapid scaling up of interventions to prevent mother-to-child transmission of HIV provide[s] an ideal platform to offer other maternal and child health, as well as sexual and reproductive health and rights services.”³⁷ Similarly, Yu et al argue that while some evidence supports that AIDS programs from global health partnerships occasionally divert resources, the overwhelming evidence indicates that these programs lead to improvements in primary care and population health, including because they draw attention and resources to regions and populations that are otherwise neglected.³⁸ Yu et al argue that these outcomes suggest not that AIDS programs be disbanded, but that current programs should be augmented so as to maximize the positive synergies of investment in HIV/AIDS and other priority health programs, and ... increase funding for universal primary health care.”³⁹

Viewed in this light, rather than illustrating misplaced political priority on a single

infectious disease, AIDS ‘exceptionalism’ in funding represents a welcome departure from a long-standing norm that tolerates grossly insufficient domestic and global allocations to health. I do not suggest that AIDS exceptionalism offers an effective solution to global health inequities, nor even that increased development for assistance can or should take the place of broader efforts to improve the social, political and economic determinants of health. Nor do I suggest that existing funding approaches are without significant structural limitations (PEPFAR’s exclusive contracting with US-based brand-name pharmaceutical companies to supply antiretroviral therapies and recent recession-related declines in development assistance for health are key cases in point). I argue rather that whatever its limitations, an exceptionalist approach to HIV/AIDS and AIDS treatment in particular, is causally responsible for increased levels of health funding consonant with the grave burden of illness, death and disease of HIV/AIDS in low and middle-income countries, and in particular across Sub-Saharan Africa. Thus, while AIDS exceptionalism may be somewhat of a political anomaly, it has acted as a transformative corrective to HIV/AIDS treatment policies that has produced tangible reductions in AIDS-related morbidity and mortality in high-prevalence countries

Whether this approach offers more broadly transformative outcomes regarding other global health inequities will depend on the path chosen by health funders and other institutional actors over the next years. Certainly the success of AIDS treatment advocacy suggests that the choices of such actors are inherently political and therefore susceptible to exogenous influence and definition. In this light, civil society actors, policy-makers and international organizations should utilize the normative, strategic and operational possibilities opened up by amplified AIDS funding as the thin edge of a considerably larger global health wedge.

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³⁵ Stephen Lewis, Presentation at the International AIDS Society Conference on Pathogenesis, treatment and Prevention, Cape Town, 2009, available at <http://healthdev.net/site/post.php?s=5611>

³⁶ Alan Whiteside and Julia Smith, “Exceptional epidemics: AIDS still deserves a global response,” *Globalization and Health*, 5, no. 15, 2009, p.5.

³⁷ Ibid.

³⁸ D. Yu, Y. Souteyrand, M. Banda, J. Kaufman, J. Perriens, “Investing in HIV/AIDS programs: Does it help strengthen health systems in developing countries?” *Global Health*, 4, no. 8, 2008.

³⁹ Ibid.

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