contributor [1]

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THE DANGEROUS DERADICALIZATION OF AIDS DISCOURSE: MEANINGS AND IMPLICATIONS FOR REPRESENTATIVE ACTIVISM

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Earlier this week, the Clinton Foundation announced the dramatic reduction of AIDS drug prices after its negotiations with several "generic" pharmaceutical manufacturers; the result was a cutting in half of the price of antiretroviral treatment for AIDS patients in several poor countries. While the news was welcome to most persons working on the issue, and while indeed many groups eagerly await specific details that might reveal problems or wonders in this deal, there is an underlying question that will remain unaddressed by technical evaluations of the new drug price reduction: what does it mean when a foundation headed by a person who--years ago--placed trade sanctions on countries attempting to import low-cost medicines now helps to procure such drugs and enters the spotlight of praise in the "AIDS community"?

The issue is not merely one of hypocrisy or even of repentant revelation and progressive reform. At issue, more generally, is the question of what the meaning of AIDS has become as it has travelled through so many powerful institutions and been altered by so many professional "institutionalists", and what the implications of this are for those people genuinely concerned about human well-being. The answer might be found in the frequently-expressed bitter remark from young public health students who now say that AIDS is getting "too much attention." Those who disagree with this perspective will, quite rightly, point to the disease's devastating toll and suggest that such attention is certainly justified and perhaps not even provided in adequate magnitude or appropriate programs. But, perhaps just as importantly, a second rebuttal is needed: that criticisms about one disease becoming too mainstream or too attractive for the institutional crowd assume that public health advocates are not fighting for general well-being, but rather battling against each other to steal the most funds from one another, like slaves competing for maximum output at the mill. If there is one thing that the AIDS activist movement has taught us over the last several years, it is this: that rather than fighting amongst ourselves over a fixed pot of money, those of us who stop thinking through the "cost-effective" framework and think through politically strategic paradigms can make the overall pot of money significantly larger, and can make our set of available options much wider. The funding provision may involve chaining ourselves to things, but the campaigns do in fact work, and few who review the history of AIDS activism can argue otherwise. To expand our paradigms simultaneously has also meant addressing the plain fact that diseases are not isolated and singular entities, but agents with reciprocal effects--that HIV rates affect TB rates, which affect community well-being and family stability (and vice versa), which in turn affect vulnerability to other diseases and social stresses and nearly everything else that matters to living a decent life.

Years ago, the paradigms used to address AIDS were focused on identifying specific "risk groups" and "targeting" them for interventions. These interventions were almost exclusively constructed though a "rational choice" framework (or what I've called "public health behaviourism")--a framework that wrongly assumes that poor women in economically-dependent relationships can negotiate sex, or that assumes that depressed men in the all-male barracks of South African mines (with a 42% injury rate) will care more about a disease that can kill them 10 years down the line than about finding some minor satisfaction through alcohol or sex. The paradigm even promotes "models" like Uganda, failing to account for the fact that much of the data coming out of such countries indicates that "prevention-only" measures were working only among the wealthier sectors, while the poor continue to suffer the greatest burden of disease. I have compared the realities of poverty and the rhetoric of public health behaviourism elsewhere (1); my task here is to argue that something very strange is going on if this behaviouristic paradigm has finally shifted to a new paradigm that addresses the issue of resource (mal)distribution and inequality--in particular, "access to antiretrovirals"--but in the midst of this, the Clinton Foundation, of all groups, has emerged as a central hero.

What is odd about this event is captured by the very framework of the Clinton initiative. I am not, here, referring to the extensive patent law strengthening done under the Clinton administration, which now ironically undermines in some ways the Clinton Foundation's own initiative; this set of issues around hypocrisy is obvious enough. What I am referring to is that the deal made by the
Foundation was narrowed to one about AIDS, and more specifically, antiretroviral drugs. This seems appropriate, but I will argue that while it may be technically competent, it is not politically so, and the press releases and narrowing of scope of the negotiations to just antiretroviral drugs avoided the core of the problem. Not only was the scope merely "narrowed", but it was done in a way to suggest that such price negotiations could not lead to questioning of intellectual property issues, and more importantly, could not be used for diseases besides AIDS. This was merely an "AIDS drug access agreement". And AIDS will supposedly be solved through existing behaviouristic prevention measures and a few of these new types of drug negotiations. In essence, the deal moves us back towards the days when AIDS was treated as a singular entity, a problem to be addressed without asking questions of why it has appeared the way it has, and why it continues to sustain itself in the way it does (that is, why it remains a disease of the poor).

The Foundation focused on the drug price reduction as an AIDS issue, and AIDS as now primarily an "access to antiretrovirals" issue. If there is any sure indication that "access to antiretrovirals" has become a mainstream concern, this is it. And yet, as someone who has advocated for such access for nearly 7 years, this is a frightening phenomenon.

My concern is that lack of access to antiretrovirals is an indicator of something much broader, and AIDS is also a symptom of much more nested problems. If AIDS is appearing so often in the context of trade agreements, where the crash of primary commodity prices leads farmers to migrate to industrial centres and break off their marriages, making "monogamy" a nonsensical idea (2); if inequalities in access to jobs and education force women into prostitution as the means to survive (3); if the terms of inequitable worker contracts mean that depression and drug abuse are the two primary options for workers in the lowest income sectors (4, 5), then AIDS is not just a "syndrome", but an end-stage "symptom" of a much larger disease.

What is problematic, then, is that as "access to antiretrovirals" has become part of the centre of AIDS discourse, two camps have appeared to negotiate the phrase's meaning. On one side we have the Clinton Foundation, who through technical interventions and isolated negotiations will attempt to disguise its past and avoid coming to terms with patenting and other structural problems as it "solves" the pandemic through the most elite forms of politics: closed-door negotiations. On the other hand, there are those that recognize that "access to antiretrovirals" is merely a group of code words that indicate, most broadly, "the right to resources needed for a decent life." The lack of antiretrovirals in poor countries is part of a broader problem of lack of medicines; this, in turn, is symptomatic of a broader problem of inappropriate resource distribution, which in turn indicates dramatic power inequalities. That form of thinking is precisely what the Clinton Foundation's press releases seem to try to hinder, arguing that this selective price reduction was AIDS-specific, and something that the elites can take care of.

The distinction is not minor, for it brings us to bear upon our role as self-described "activists"--a term that, all too often, carries with it the most extreme forms of self-promotion and self-righteousness, and often a vulnerability to injure those who we claim to advocate for. The problem with treating AIDS as just a disease, and not a symptom of broader inequalities, is that this prescription is more frequently coming from "activists" who have lost touch with the context of the statements they receive from those they claim to represent. In the letters and editorials of papers in neighbourhoods and cities most affected by AIDS, the disease is not merely a concern about drugs. Drugs are crucial; but talk about inequality in access to drugs are also representative--they are indicators, social markers (like conspiracy theories or public protest) that something much deeper is going wrong. And the hegemony exerted by activists who lose this sense is a hegemony that is indeed very dangerous, because it inflates a desire for personal heroism and self-promotion and neglects the structural inequalities few are willing to approach for fear of being left out of elite conversation. The new public health advocates struggle with the task of understanding medicine distribution technicalities and little else; they do not ask if there are other avenues to approach, or even if this is merely one recipe torn apart and read in isolation, because they have forgotten (or have never learned) that this recipe was part of a much larger cookbook. AIDS is reduced to an issue of "access to antiretrovirals", rather than having "access to antiretrovirals" be a representative AIDS issue that serves to hint at the direction of the fuel tanks supplying the biggest fire in human history.

All too often, the "structural problems" fuelling the fire are declared impossible for public
campaigning; too difficult for effective activism, or--worse yet--the domain of lunatics and extremists. Once again, the common, day-to-day forces in AIDS activism prove such contentions wrong. At universities across the U.S., U.K., and Canada, students are engaging with activist groups in "the South" to alter university drug development policies in line with the community needs of those who have been excluded from research benefits (www.essentialmedicines.org [2]); in other parts of the U.S., even as federal funds get shredded under neo-conservative fiscal policies, activists have kept pressure on local governments to preserve key social services by promoting ballot initiatives among the poor; elsewhere, labour policies are becoming central parts of AIDS activism movements, which are winning battles to improve housing and terms of contracts after involving mine workers and other affected persons more centrally in the campaigning process. The key, then, to maintaining a representative discourse on AIDS is to diffuse power in this manner and consistently expand the meaning of AIDS to its structural causes rather than its most visible and easily acceptable end-points; the commonality between all of these effective "structural interventions" is that they are operated with a sense of caution, and a fear of exerting dangerous hegemony that forces those involved to re-think what it at stake. Rather than taking a mainstream issue and carving out a field of power within it, these campaigns are directing themselves in the opposite direction: taking an issue that is already mainstream ("access to antiretrovirals") and asking what is unrepresentative about it, what is missing from its ranks ("access to general resources needed for decent life"). And who better to ask than those who are most affected; those who do not gain entrance into the drug price negotiations of the Clinton Foundation (but, importantly, have gained access to the core of South African AIDS activism, 6)?

This article may be written as a formulaic prescription, and the more educated groups will criticize my simplicity and extravagance even as I discuss hegemony and preach humility. Their criticisms may be warranted; but in spite of that, a healthy warning should remain: that the fear of hegemony, the fear of being unrepresentative, can drive us much farther towards improving each others' livelihoods than any attempt to force our issues to be arbitrated by the mainstream sources of power in isolation from the core of active suffering, or to force social space into our preconceived visions by selectively filtering the voices and livelihood realities of those we claim to defend.

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References:

(1) AIDS, Empire and Public Health Behaviorism: http://zmag.org/content/showarticle.cfm?SectionID=2&ItemID=3988 [3]


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