

On “Activism”

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By Judy Auerbach

As the International AIDS Conference (aka “AIDS 2012”) approaches, it is fitting to consider the meaning of activism in the response to the epidemic. Historically, not only is the conference a venue for sharing scientific findings, program experiences, and policy implications at a huge, global scale (the conference attracts over 25,000 attendees and is broadcast in real time in many electronic forms), but it is also a site for protest and activism. It is typical for AIDS activists from around the world to organize marches in the streets of the host city, demonstrations in the exhibit hall—which have included trashing the booths of pharmaceutical companies—, and disruptions of large, plenary sessions where dignitaries are speaking. The audiences for and objects of these actions are the conference attendees themselves, high-level policy makers, private industry, and, perhaps most importantly, the media, as AIDS activists have at least one gripe with all of these groups (and, like everyone else, are savvy manipulators of the press).

Notwithstanding possible personal discomfort with some of these tactics, everyone involved in the response to AIDS for the past four decades acknowledges the essential role AIDS activists have played as the “moral authority” in the response. In the early years, activists pushed for new and faster drug development to keep people with HIV alive, and clamored for access to and availability of condoms to keep people from transmitting or acquiring infection in the first place. As additional and more effective modes of treatment and prevention emerged, activists cajoled governments and funders into making them available at lower costs to people around the world. Throughout the decades, AIDS activists also have drawn attention to the social inequalities reflected in the epidemic—with respect to who is disproportionately getting infected and the stigma, discrimination, and human rights violations attendant with vulnerability and infection—and they have held governments and communities accountable for these disparities. This is the classic image of the AIDS activist—a member of a community who joins others in protest and pushes for changes in policy and funding. And there will be thousands of them at AIDS 2012.

But, there will be another group of activists, who often are not thought of in this way, who also will populate AIDS 2012. These are what I call

“scientist-activists,” and they generally comprise two groups. The first are those scientists—laboratory, clinical, behavioral, social—who pursue science with clear policy and social change objectives. These are individuals who share many of the perspectives of community activists, and who use their perches in academic and other research establishments to advance science in service to social good—whether that be in the area of HIV treatment, care and support, prevention, or policy. They help make the argument that the response to HIV epidemics should be evidence “informed” (if not “based”), rather than driven by ideological or political agendas or cultural belief systems (I know, these are contested notions, but bear with me for the sake of making a point); and they help provide the evidence itself and present it not only to other scientists, but to decision-makers as well.

The other group of scientist-activists are those, like me, who *struggle within the scientific establishment* to make changes to it to better address the HIV epidemic. The most vocal cadre of such folks are social scientists who have been attempting for decades to broaden the scope of the HIV research response from its narrow and hegemonic biomedical paradigm, which focuses on the biological and behavioral processes of individuals and valorizes the randomized controlled trial as the gold standard of evidence of what works with such individuals with no recognition of the role of context and complexity in human life. Some social scientists make it their project to lob critiques of biomedical science and dismiss it out of hand as flawed. Others, like myself, work to integrate the sensibilities of social science into biomedicine, using some of the critiques of our comrades, but acknowledging that the social organization of the scientific enterprise—with its hierarchy of disciplines and reward systems that places social science at the bottom—means that the “game” is effectively the biomedics and we have either been invited or have forced our way into playing with them on their turf.

What this means is a daily experience of bashing one’s head against the wall, having to make the case for social science theory, conceptualizations and methodologies over and over again, and watching them continually forced back into the biomedical paradigm (“*well, if we need to look at context, we can do cluster randomized controlled trials!*”). We are usually “an N of one” in the room full of biomedical scientists, so there is also the “token” role to play. Whenever there is a reference to behavioral or social considerations, all eyes turn toward us as the resident, and often only, expert in the room, and the expectation that we will nod and smile with gratitude that they’ve thought to be inclusive. But, more often than not, our suggestion of doing things quite differently is ignored, if not actively resisted (“*How can it be HIV prevention if you don’t have an HIV incidence outcome in your study; and how can it be “evidence” if it isn’t from a randomized controlled trial?*”).

Our activism from within science is also played out in the various volunteer activities characteristic of being part of the scientific community—planning committees for meetings and conferences; journal editorial boards, advisory groups for research funders, etc. More often than not, our role on these bodies is to fight for the inclusion of social science topics and social scientists as speakers, authors, or grantees.

I would say that all this activism has had an effect. At the least, the HIV field has grown to adopt what it calls a “combination” frame that articulates the importance of linking biomedical, clinical, social, behavioral, and policy analyses and responses. Moreover, the biomedical community has adopted some social science constructs—the most recent being “social determinants of health” – as important directions in basic and applied research. But, at the same time, they have appropriated these constructs, acting as if they have just invented them, disregarding a robust extant literature in the social sciences, and putting their biomedical overlay onto them (witness the U.S. CDC’s agenda in “social determinants of health” and “structural interventions”). In this situation, the job of social scientist activists, like myself, becomes that of re-appropriating the science and educating the biomedical community of all the work that already exists in this arena that need not be reinvented—just read.

In the end, most of us engaged in the struggle against AIDS are, in one way or another, activists. Scientists are members of communities, too, and we carry our histories, identities, and personal connections to the epidemic no differently than so-called “community” activists. Our tactics and venues may be different, but we all share a goal of shaking things up in the arenas in which we engage, to enable change to occur that we believe will have the greatest impact on ending the epidemic and the social disparities (including within the organization of science) it makes visible.

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