HIV Activism Alive at AIDSWatch 2019

While other HIV conferences have felt complacent, AIDSWatch still centers activism. This year we spoke back to the CDC Director.

April 8, 2019 By Andrew Spieldenner, PhD

You may have heard: HIV advocates protest. We made a movement; we built our own health services and organizations; we held government institutions and representatives accountable.

In the past two decades, there's been a distinct drop off in that kind of activism. Maybe it's because of the professionalization of HIV (and the growth of 'AIDS, Inc.' as an industry). Maybe it's because of the success of HIV treatment and the growth of HIV clinical services (which are not inherently activist) over identity-based community groups (which tend towards an activist center).

AIDSWatch 2019 happened at the start of this month. Dr. Robert Redfield, Director of the federal Centers for Disease Control and Prevention (CDC) and longtime HIV researcher, spoke to a packed auditorium of over 500 people living with HIV and our allies. After reviewing the pillars of the federal End the Epidemic plan and epidemiological profiles of high-incidence areas, as well as key rural counties, Dr. Redfield pointed out how treatment and access to care helps those "infected." After saying "infected" several more times, activists interrupted the CDC Director. He apologized, then did it again. The activists gave him a list of stigmatizing language, and he repeated it.

Signs began to go up.

AIDS, Inc. does not speak for me

No MHS

I'm a person, not a cluster

My body, my rights

Stop policing Black bodies

PrEP – where's the money

FOSTA/SESTA affects US – end it!

Stop erasing trans rights

The PrEP4All Collaboration took advantage of the disruption to call out questions about enforcing the federal patent on tenofovir for PrEP, a story that broke earlier that week in The Washington Post.

The Q & A session consisted of questions solicited from various community groups. The session did not go as planned: questions remained unanswered. The non-answers further enflamed the room, and people continued to call out. It was clear that there was a confluence of concerns involved in these raised voices. The New York Daily News carried the story but only focused on one aspect. As someone who was there, I want to highlight the three main takeaways from the action: stigmatizing language, tenofovir patent, and Molecular HIV Surveillance.

Stigmatizing Language

Language is always political, revealing values about the world. This has never been more evident than in the HIV epidemic. Activists developed the Denver Principles in 1983, which begins: "We condemn attempts to label us as 'victims,' a term which implies defeat, and we are only occasionally 'patients,' a term which implies passivity, helplessness, and dependence upon the care of others. We are 'People With AIDS.'"

As Dr. Redfield continued to call people living with HIV "infected," he invoked discourses about us as "dirty", vectors of disease, and pariahs in our communities. We have fought against these discourses for decades, and we are unwilling to move backward and permit government officials and agencies to stigmatize us. While Dr. Redfield asked for us to be patient, we must remind him that – after more than two decades in the field – his lack of awareness and concern about stigmatizing people living with HIV is disheartening, to say the least.

Tenofovir Patent

As reported in The Washington Post, the use of tenofovir for PrEP was developed jointly by the pharmaceutical company and the US government. This is not an uncommon arrangement – often universities where drugs are developed share the patent. The US government has not enforced the patent though, leaving the profits for the pharmaceutical company.

The PrEP4All Collaboration asked about resourcing for PrEP accessibility, as well as for non-clinical HIV prevention services. These issues and questions are pivotal, as funding for non-clinical services has been reduced in the past decade. Robust community building and addressing structural conditions that perpetuate HIV disparities are beyond the scope of HIV clinical services.

Molecular HIV Surveillance

The CDC launched Molecular HIV Surveillance (MHS) nationally over a year ago. MHS takes the blood used in resistance testing (standard clinical practice for people living with HIV to start or change medication regimen) in phylogenetic sequencing to compare with other strains. When a particular phylogenetic sequence appears multiple times in a year, it is considered a "cluster" to be monitored more closely by the state health department. The members of the clusters are then identified for several programs, including linking to healthcare services and partner notification often implemented through the established Sexually Transmitted Infection (STI) Disease Intervention Specialists (DIS).

MHS identifies those already marginalized – people out of care, without access to life-saving diagnostic and clinical services due to challenges because of racism, homophobia, sexism, transphobia, xenophobia, poverty, mental health, substance use, or some combination of these. MHS relies on health departments to manage the investigation in a way that does not further marginalize us. And not every health department has the history, the will or the resources to adequately engage.

There is a lot of concern in the HIV community about MHS. The US People living with HIV Caucus has partnered with the Legacy Project, Positive Women's Network-USA, Thrive SS, Sero Project, Reunion Project, International Community of Women Living with HIV/North America and Positively Trans to produce a 4-part webinar series on MHS. The first one – which frames MHS within the context of law enforcement – had 160 participants. The next two feature community leaders with government officials: one that looks at the science and the other to examine MHS specifically. The final one will be a town hall for the HIV community to convene and strategize.

Moving Forward

Dr. Redfield may have been surprised at his reception at AIDSWatch. There are a lot of other HIV conferences where no one would have said anything. AIDSWatch is not like those other convenings: AIDSWatch remains centered on people living with HIV.

Are there challenges? Every year. Our movement is rocky and many of our allies still have challenges with making space for us. CDC and other public health agencies continue to make policies that affect us without consulting us in any meaningful way. Together, we can inspire each other to speak our truths, to resist stigmatizing actions and language, and to raise questions about the systems that continue to see us as passive consumers waiting for our pills.

Language is political: it reveals values about who we are and what we do. We are people living with HIV.

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http://beta.docker.poz.com/blog/hiv-community-holds-cdc-director-accountable-aidswatch-2019