Around the Edges

In an opinion piece titled "Activism Around the Edges," writer Anna Forbes responds to an open letter by HIV researcher David Alain Wohl, MD, that urges AIDS activists to do more. Below is an edited excerpt.

November 13, 2017 By Anna Forbes

Dear Dr. Wohl,

As an AIDS activist since 1984, I am responding to your call on us to be as loud as we were in the 1980s and '90s. Did you notice when AIDS activism began to be less visible? It was soon after the advent of antiretrovirals, which quickly became available to most white, economically stable people in the United States. Once people with privilege had medication, it got quieter.

As we all know, adequate medical care did not reach the majority of people who needed it then and still has not, especially in heavily impacted countries. But poor people and heavily stigmatized people are not the ones with large amounts of time and resources to mobilize and act up.

Without financial stability, we spend time on work to pay rent and feed our families, while fitting in activism around the edges. Not surprisingly, we aren't as visible as we were when our movement included a lot of affluent people with more time to organize actions and money to get to conferences.

I work as an independent consultant because I have found that making strong activist statements (in person and in print) has a tendency to get me fired by employers who can't afford to have their staff pissing off their funders. I wanted very much to go to Paris for IAS 2017 [the International AIDS Society conference] and to Melbourne and to a host of other recent conferences. I always apply for scholarships to attend.

Increasingly, however, scholarships are going to people from lower-income countries, which is as it should be. But this precludes my participation because I don't have an employer to support travel costs. This is happening to lots of us. The activist silence that you noted at those meetings isn't primarily the result of fear, intimidation or disinterest. It is simply that, unlike you, we don't have a university paying the way.

This is the biggest difference between activists and other sectors of the HIV response (researchers, policymakers, service providers, etc.). No one pays us to be activists. A very small cadre of people (most of them unbelievably smart and dedicated people) work for organizations that pay them to

mobilize activism to change public policy and revise funding priorities. The rest of us do this work for free because we believe in it deeply. Unfortunately, our dedication does not pay the bills at home, cover the cost of getting to important venues or take care of the fines we incur when we commit civil disobedience to make urgently important points.

You remind us that it's not biting the hand that feeds us to question motives and demand action. In case you haven't noticed, few jobs are available in what we refer to as "AIDS Inc." If you are suggesting that people who work in HIV/AIDS-focused organizations should undertake more visible activism, that is a separate discussion.

To summarize, I encourage you to envision the population of HIV/AIDS activists prior to 1996, subtract about 80 percent from that total (desperate affluent people, mainly white men, living with HIV and their families and friends) and then consider the number that remains.

There are still lots of us, and our numbers continue to grow, especially in communities of color. But we are necessarily working more at the local level, with far fewer resources and mostly without the luxury of available time because we have to hold down day jobs. Take a look at how much you spent in total to attend the Paris conference this past summer. Then please explain to me how I was supposed to be there, "decrying the deadly slow pace of progress." Because I would have loved to have had the opportunity!

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