Getting to the Table: A Look at the Current Work of Networks of People Living With HIV

November 3, 2017 By Andrew Spieldenner, PhD

At the Funders Concerned About AIDS 2017 Annual Meeting, the opening plenary was titled “PLHIV Networks: A good idea in the 80s, an even better idea today.” In my first blog, I asserted that there has been a resurgence of networks of people living with HIV. In 2015, the Sero Project found 71 of them for their Network Empowerment Project. More have popped up since – including Positively Trans, new chapters of the Positive Women’s Network-USA, Texans Living with HIV, U=U, Thrive SS, and more. After reading that blog, a friend and colleague asked me, “Why now?” Why this resurgence?

People come to things they feel strongly about, where they feel they belong. In the last twenty years, the tables for us - as people living with HIV - have shrunk. Where once we were welcomed to Board of Directors or senior management at AIDS Service Organizations or other HIV non-profits – even sought out as advisors and partners, we are now seen as “consumers” or relegated solely to positions meant to recruit other people living with HIV into services. We were once invited to the table, now we are not - at least in meaningful ways. Whether talking with a group of long-term (mostly White) HIV survivors or a group of young Black gay men living with HIV, I hear a similar mantra, “I just don’t feel like I have a place.” As HIV organizations see us as clients/consumers/widgets for services, we have seen them less likely to take the lead on controversial topics publicly. For two examples, I look to the support of HIV viral suppression science, and the move to repeal HIV criminalization laws.

There’s a reason U=U is compelling and many people living with HIV are rallying around the message “Undetectable = Untransmittable”. U=U is a campaign to promote the information that virally suppressed people living with HIV cannot transmit the disease. Whereas viral suppression science appeared in the HIV research literature in articles early as 1999, it was proven a decade later in randomized control trials. The International AIDS Society announced in 2012 new guidelines to support and encourage services intended to promote virologic suppression for people living with HIV. Five years later, in September 2017, the federal Centers for Disease Control and Prevention (CDC) recognized that people living with HIV who are virally suppressed will not transmit HIV. The U=U campaign and the network of people activated by it have been in meetings with organizations, health departments and federal partners to force the issue forward. Now that the CDC has endorsed the science, I hope to see the changes at HIV service organizations and

clinics in terms of: information given to people living with HIV about sex, substance use and risk; changes in organizational websites, educational materials and curricula that incorporate these messages; shifts in partner disclosure policies; how messaging about HIV virologic suppression and Pre-Exposure Prophylaxis is incorporated in HIV and STI testing protocols and in-service trainings. While CDC should be at the forefront of forcing this issue, I suspect that U=U and its allies will continue to lead this charge.

California State Bill 239 (SB239) was a multi-year effort by Californians for HIV Criminalization Reform - a diverse group of legal rights agencies, community activists, and LGBT and HIV advocacy organizations. Inspired by similar work done in Iowa and Colorado, the California coalition met regularly, developed core principles, and attempted to keep center the voices of people living with HIV. Like any coalition, there were some uneven moments in engagement. Sometimes the tensions were between grassroots activists and more professionalized advocates; at other points, the workload was uneven - with some hardcore work sessions followed by months of waiting. State legislators were brought into the process and, after discussion, Assemblymember Todd Garcia and Senator Scott Wiener introduced the bill. At every step, different organizations asked for changes in the bills - even threatening to kill it. The coalition discussed each challenge, with particular attention to the people living with HIV activists and networks involved. I first became part of this effort in a training conducted with Colorado-based activist, Barb Cardell (Vice Chair of the United States People living with HIV Caucus). I became an active member of the coalition when I moved to California this past summer, even meeting with legislators as a constituent concerned they support the bill. Through these processes, SB 239 was passed in the State Assembly and Senate, with Governor Brown signing the bill into law on October 6, 2017.

In both examples, institutions that would describe themselves as friends and allies of people living with HIV - including the local and federal agencies that have funded HIV services over the decades - either are slow to implement these changes or did not support these measures. It was through a collective voice of networks of people living with HIV and our allies that these were advanced.

So the question: why now?

As Waheedah Shabazz-El, the Regional Organizing Director for Positive Women's Network-USA, often says, "if you're not at the table, then you're on the menu."

That's why.
