# All of Us?

In a blog post titled “Ending the Epidemic: What Happens to Us?” Andrew Spieldenner, PhD, vice chair of the U.S. People Living With HIV Caucus, asks where folks with the virus fit in. Below is an edited excerpt.

November 18, 2019 By Andrew Spieldenner

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As more regions and jurisdictions develop Ending the Epidemic (EtE) plans, I am left wondering what happens to us, the community of people living with HIV? How do we mobilize people living with HIV to participate and get our diverse voices and needs heard in these initiatives? Or are we relying on a few key leaders?

Most of the EtE plans in the United States focus on these pillars: increasing HIV testing so everyone knows their status, increasing clinical access and usage for both HIV prevention and treatment, and increasing surveillance so resources can be directed. While these are laudable goals, I am a little skeptical that these particular programs will end the HIV epidemic.

I understand the science behind each of these strategies. I get how—in an ideal world—they would operate in a complementary way to reduce HIV transmission and improve HIV health. But I also recognize the limits of these strategies in dealing with our actual lives.

How do these EtE plans address the structural conditions (such as poverty, racism, sexism, homophobia, transphobia, ableism—just to name a few) that made us vulnerable to HIV in the first place? Treatment will not change these larger structural contexts.

I take my HIV meds daily (unless I forget!). But I also understand that my HIV meds will not ameliorate financial stress, help with my feelings of social isolation, pay for my therapist and ensure a livable wage and job security.

In HIV, we used to understand that we could not separate how people lived from their HIV health outcomes. We fought for housing and Ryan White support services. Now, it seems we are reduced to people who take pills.

This can change. If the Centers for Disease Control and Prevention (CDC) required health departments to meaningfully engage community groups (and funded it), then the EtE plans might have a chance at success. If the health departments reached beyond the few people who sit on various planning councils and permitted these community voices to have real power in decision-making, then there could be some innovative policies and actions.

Instead, I am afraid of the same-old, same-old: plans with vague HIV testing initiatives, linkage to care services, a few standard HIV prevention behavior change interventions and an aggressive surveillance system that targets the most marginalized people living with HIV; plans that are meant to augment health departments and not build up community-led responses.

The CDC can hold health departments accountable to community engagement. It is a common tactic to require grantees to conduct activities in a certain way. The CDC has required health departments to conduct names reporting in HIV surveillance, have advisory groups to approve HIV health promotion materials and implement certain activities as part of their HIV portfolio (such as community planning, HIV testing, surveillance, linkage to care and behavior change interventions). Why can't the CDC provide more robust demands for community engagement?

I am worried that our needs as people living with HIV are reduced to treatment adherence. What about treatment access? Harm reduction and mental health services? Poverty reduction and affordable housing? Eliminating HIV criminalization laws? Support for immigrants? Sexual and reproductive health?

Our issues are broader than our meds. Access and adherence are contingent on considering the context of our lives.

The CDC and health departments cannot "end the epidemic" without the meaningful involvement of people living with HIV. And that means seeing us as partners in developing, implementing and evaluating the EtE plans.