



# **DEMANDING BETTER:**

## **An HIV Federal Policy Agenda by People Living with HIV**

### **EXECUTIVE SUMMARY**

Networks of people living with HIV in the United States have come together as the U.S. People Living with HIV Caucus (HIV Caucus) to outline our policy agenda for the federal response to the HIV epidemic. People living with HIV networks are organized formations created, led by, and accountable to the estimated 1.1 million people living with HIV in the United States. They are vehicles through which we, as people living with HIV, can define our own agenda, choose our own leaders, and speak with collective voices.

For stakeholders in the federal government, the HIV Caucus brings a unique lens, informed by lived experience, to the development of policies to ensure better care, treatment, and quality of life for people living with HIV. The networks which make up the HIV Caucus have been involved as service providers, have run programs that serve people living with HIV, and have built community-based organizations and advocacy initiatives from the ground up. We are in direct contact with tens of thousands of people living with HIV throughout the United States.

These unique abilities and access inform our work and led us to create this living policy agenda to collect our expertise into a road map for lawmakers and other key stakeholders to use in addressing the HIV epidemic at the federal level.

**This policy agenda contains recommendations in 5 issue areas which must be centered in every aspect of the federal HIV response:**

- 1. Concretely elevating the meaningful involvement of people living with HIV and disproportionately impacted communities in the HIV response;**
- 2. Proactively creating an affirming human rights environment for people living with HIV by addressing stigma, eliminating HIV criminalization, and halting molecular HIV surveillance;**
- 3. Addressing inequities in the federal response by attending to racial and gender disparities;**
- 4. Adding sex workers and immigrants living with HIV as priority populations throughout the federal response; and**
- 5. Affirmatively committing to improving quality of life for people living with HIV.**

To address each of these issue areas, we have suggested concrete recommendations for the associated executive agencies, the HIV National Strategic Plan, and the Ending the HIV Epidemic Plan, which are broadly delineated on the pages that follow.

**Concretely elevating the meaningful involvement of people living with HIV and disproportionately impacted communities in the HIV response**

Staff federal bodies addressing the epidemic, such as the Office of National AIDS Policy, with people living with HIV from the communities most impacted by the epidemic and recharter the HIV advisory boards of the federal agencies to include a minimum of two seats for representatives of the HIV Caucus.

Develop a process to solicit input from, engage and consult with the HIV Caucus, and include meaningful involvement of people living with HIV indicators in the final version of the HIV National Strategic Plan and in updates to the Ending the HIV Epidemic Plan.

**Proactively creating an affirming human rights environment for people living with HIV**

Identify stigma-reduction activities that partners in the HIV response can engage in, require Ending the Epidemics jurisdictions to create plans that incorporate these activities, and resource people living with HIV networks to develop and implement stigma-reduction initiatives.

Utilize data collection tools and interventions that examine structural change.

Promote advocacy efforts to remove punitive laws and policies, like HIV criminalization, by acknowledging the federal government's role in creating them and making clear commitments in federal plans to end HIV criminalization.

Declare a moratorium on molecular HIV surveillance and partner with people living with HIV networks to develop standards for obtaining informed consent; privacy protections; and security, sharing, and storage protocols.

Implement community generated standards in all aspects of the federal HIV response and ensure funding is in place for training and compliance.

**Addressing inequities in the federal response: attend to racial and gender disparities**

Explicitly include racial and gender disparities as elements of the HIV epidemic to be addressed in all funding opportunities and create grant opportunities for and led by these populations.

Require Ending the Epidemic jurisdictions to target resources to Black, Indigenous, and other people of color, especially those who are also gay and bisexual men, people of trans experience, people who use drugs, sex workers, and immigrants.

Require jurisdictions and grantees to provide care services to dependents while people living with HIV receive services and to screen for intimate partner violence.

**Adding sex workers and immigrants living with HIV as priority populations throughout the federal response**

Push to prohibit the practice of using condom possession as evidence of sex work and eliminate federal policies conflating sex work and human trafficking.

Prioritize and require commitments to the decriminalization of sex work, including restrictions of individuals with sex work-related or drug-related convictions from accessing federal programs and services.

Ensure health care is accessible regardless of immigration status.

Add sex workers and immigrants as priority populations in the federal HIV response and fund programs led by and serving them accordingly.

Fund language services, particularly those that are in-person, and require certain grantees to staff certified medical interpreters or train staff on interpretation utilization.

**Affirmatively commit to improve quality of life for people living with HIV**

Create a minimum standard of care and quality of life for people living with HIV, promulgate regulations requiring those providing health care to people living with HIV to conform to those standards, and monitor and report how these standards are being upheld.

Establish access to online and in-person benefits counseling/advisement for people living with HIV; design system to improve portability of benefits between jurisdictions; and create programs to train, recruit, and hire people living with HIV into the HIV workforce and other employment opportunities.

Fully fund Housing Opportunities for People with AIDS and other federal housing programs and enforce the Fair Housing Act to address housing discrimination.

Require the federal HIV programs to track and address housing for people living with HIV.

Improve the Supplemental Nutrition Assistance Program to account for regional differences, increase overall benefits, continue extensions of work requirements, and reduce administrative burdens for people living with HIV.

Improve, expand, and fund access to sexual and reproductive health care for people living with HIV, including transition-related care, and monitor this progress with metrics in the federal HIV response.

Fund research and create accessible guidelines for birthing people living with HIV to breast/chest-feed their children that do not include criminalization.