



POSITIVE WOMEN'S NETWORK
USA

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December 14, 2020

Honorable Alex Azar, Secretary
Admiral Brett Giroir, Assistant Secretary
U.S. Department of Health and Human Services
200 Independence Avenue SW
Washington, DC 20201

Re: Comments from Positive Women's Network-USA on Federal Register Notice 85 FR 77472 - Draft HIV National Strategic Plan 2021-2025

Dear Secretary Azar and Assistant Secretary Admiral Giroir:

Positive Women's Network -USA (PWN) is a national membership body led by and for women and people of trans experience living with HIV. Our work focuses on building leadership and power among the communities most impacted by the HIV epidemic -- especially transgender women, low-income women living with HIV, and Black and Latinx communities -- to ensure policies are grounded in human rights and social justice. The PWN Board of Directors are entirely women living with HIV (WLHIV), including women of trans experience. Staff are majority WLHIV and majority Black, Indigenous and People of Color (BIPOC). In addition to our national membership, PWN has formally affiliated, member-led regional chapters and a mobilizable base in twenty states. We particularly focus much of our organizing and advocacy work on the Deep South, where over half of all U.S. WLHIV reside. We envision a world where all self-identified women living with HIV can live long, healthy, and dignified lives, free from stigma and discrimination. As a part of this mission, we support rights-based policies, grounded in racial, gender and economic justice.

PWN members and leaders helped to inform and craft the previous National HIV/AIDS Strategy, have played a key role in implementation of the End the Epidemic plans in local and state jurisdictions, and among other key roles, have had members serve on the President's Advisory Council on HIV/AIDS, the CDC/HRSA Advisory Committee, and the Office of AIDS Research Advisory Council. We bring a unique lens informed by lived experience to our analyses of strategies to end the HIV epidemic and ensure better care and treatment for PLHIV and the communities at greatest risk.

Collectively, we represent more than estimated 300,000 women and transgender people living with HIV. We appreciate the opportunity to provide comments on the draft *HIV National Strategic Plan: A Roadmap to End the HIV Epidemic (2021-2025)*, released by the Department of Health and Human Services' Office of Infectious Disease and HIV/AIDS Policy (OIDP) on December 1, 2020. Below we summarize our comments based on the three questions that OIDP has posed for reflection.

1. Do the draft plan's goals, objectives, and strategies appropriately address the HIV epidemic?

We are pleased to see the commitment to person-first language in the Plan, but we are disappointed that the Plan only briefly notes the importance of involving people living with HIV (PLHIV). The Plan notes some important structural and systemic issues that must be addressed in order to effectively address the U.S. HIV epidemic, including systemic racism, culturally relevant services, language barriers, trauma, stigma, HIV

criminalization, safe and affordable housing for PLHIV, expansion of syringe exchange services, and poverty. We urge the Department of Health and Human Services (DHHS) to work in partnership with PLHIV networks to create measurable and meaningful commitments to evaluate success in these areas.

Limitations to the Plan's goals, objectives and strategies mainly fall in these categories:

1a. Inadequate attention to social determinants of health, especially racism.

The Plan is overly focused on biomedical interventions and does not give adequate attention in its proposed indicators and strategies to addressing social and structural determinants of health. The COVID-19 pandemic has revealed significant inequities in and limitations to current public health approaches. It is no accident that while effective HIV treatment and biomedical prevention options have been available for years, tools like PrEP and viral suppression have failed to achieve our collective goal of ending onward transmission because of the reliance on systems that are already largely broken to deploy them and when a foundation for affordable healthcare access is absent. Ending the HIV epidemic and eliminating health inequities will not be possible without a more serious commitment to address the social determinants of health that confront the priority populations identified in the draft HIV National Strategic Plan (a list which needs to be explicitly expanded to include sex workers and immigrants). At the top of this list are racism and racial injustice.

Racism, especially as it takes shape via anti-Black racism and xenophobia, underpin the devastating history of inequities in the HIV response, and circumscribe a legacy of criminalization and incarceration in the U.S. These interlinked forms of violence disproportionately harm the priority populations identified in the HIV National Strategic Plan. High levels of health risks and poor health outcomes are inseparable from the race-driven criminalization and incarceration patterns that disproportionately harm Black and brown communities, as well as those who are transgender, gender nonconforming and non-binary, lesbian, gay and bisexual, immigrant, and sex worker communities, and, increasingly, cisgender women. HHS must lead the efforts to stop using incarceration to deal with poverty, public and mental health conditions, because incarceration only exacerbates the problem.

DHHS must:

- Declare racial injustice a public health emergency in the U.S. Key structural intervention needs resulting from systemic and societal racism include a) safe and healthy housing for all experiencing homelessness and unstable housing; b) food and nutrition services; and c) employment services optimized for communities disproportionately impacted by HIV and the racism-driven parallel of unequal access to quality education and employment.
- Invest in, hire, and collaborate with Black leadership in defining priorities for and responses to the domestic HIV epidemic.
- Commit to protecting the safety, wellbeing, and human rights of immigrants of any immigration status at and within our borders by ensuring access to privacy, confidentiality, HIV prevention, care and treatment, and language-appropriate services.
- Require ongoing racial justice and trans sensitivity training for all federal employees and all employees at federally funded programs.

1b. Meaningful Involvement of People with HIV/AIDS (MIPA)

PLHIV are central to the HIV response. We have been responsible for mass shifts in the ways that HIV is understood, prevented, treated, and addressed: our activism, choices and actions have built organizations, fought stigma and advanced science. We are a powerful and under-utilized resource that, when supported and



engaged appropriately, can dramatically improve efficacy of public health interventions and programs, reduce HIV transmission and improve quality of life and health outcomes for PLHIV.

We are concerned by the Plan's lack of specifics concerning the Meaningful Involvement of People living with HIV/AIDS (MIPA), a global standard for the HIV response endorsed by the U.S. and more than 140 other countries. The Plan reduces concerns of PLHIV and the contexts in which we manage our HIV diagnosis largely to treatment adherence and a vaguely discussed notion of stigma.

Nowhere in the Plan are federal agencies, efforts or initiatives explicitly required to partner with PLHIV networks; the Plan lacks any specific accountability to the community of PLHIV. We insist that the collective voices and organized leadership of PLHIV, as represented in national and local PLHIV networks, be viewed as essential partners when crafting or changing HIV policy; prevention, care and treatment guidelines; data collection and surveillance practices; the HIV research agenda; in the design of HIV service delivery; and in all aspects of monitoring and evaluation. The best way to achieve this is by consulting and involving PLHIV networks as critical stakeholders and partners at every level of policy and program decision-making that so profoundly affects our lives. MIPA requires resources, planning and accountability and we demand that these be included in the plan with commensurate metrics, indicators, strategies, and funding.

Our recommendations to achieve this include:

- The Office of HIV/AIDS and Infectious Disease Policy should develop a formal and regular process to solicit input from, engage and consult with the U.S. People Living with HIV Caucus, as the representative collective of all U.S.-based national people living with HIV networks.
- Staffing in the Office of National AIDS Policy must include PLHIV from the communities most impacted by the epidemic, including Black gay and bisexual men, Black cisgender women, and transgender women of color.
- Meaningful Involvement of People Living with HIV indicators must be included in the final version of the HIV National Strategic Plan. This should include indicators for each federal, state, and local advisory and decision-making body with purview over HIV, including local "end the HIV epidemic" jurisdictional planning processes, to have requirements to include meaningful PLHIV engagement and leadership from the communities most impacted by the domestic epidemic.

2. Are there any critical gaps in the HIV Plan's goals, objectives, and strategies? If so, please specify the gaps.

We note some critical gaps in the HIV Plan: a commitment to improving the quality of life and quality of care for the estimated 1.2 million PLHIV is notably absent. Any specific prevention, healthcare and human rights needs of transgender people are entirely absent from the Plan. Protecting the rights and meeting the healthcare needs of sex workers and undocumented immigrants is also critical to addressing the domestic HIV epidemic.

2a. Ensuring quality of life and quality of care for people living with HIV.

PLHIV are more than our viral loads. Disparities and inequities faced by PLHIV must be considered, not just whether or not we are virally suppressed. Viral suppression is not, and never will be, an acceptable proxy for our well-being. We demand a continuum of care that values our emotional, mental, psychological, spiritual *and* physical wellness, as we age with HIV regardless of whether we are virally suppressed or not.

A "status neutral" approach must not dilute or deprioritize the need to care for and protect the human rights of the estimated 1.2 million people already living with HIV in the United States. Onward HIV transmission will only be reduced when PLHIV are safe and have stable access to high-quality healthcare and treatment. It is



impossible to achieve the Plan's goal of "ending the HIV epidemic" without focused attention on the holistic well-being of PLHIV.

The vast majority of PLHIV in the U.S. suffer from multiple oppressions and traumas stemming from racism, poverty, sexism, transphobia, homophobia, xenophobia and stigmas related to mental illness and substance use, in addition to stigma and health challenges arising from our HIV diagnoses. These barriers exist both inside and outside the HIV service delivery system and must be addressed across federally funded programs serving PLHIV, not only in HIV-specific programs.

To adequately serve the quality of care and quality of life needs of PLHIV, the Plan must strengthen its explicit commitments to:

- **Employment and economic justice for people living with HIV.**

Employment and vocational rehabilitation programs serving low-income people and people with disabilities will inevitably serve PLHIV. Yet no steps have historically been taken to ensure that individuals providing services in these settings will refrain from stigmatizing people living with HIV or making inaccurate assumptions about what we are and are not capable of doing. The Department of Labor (DOL) national workforce development programs, and the state and local programs funded and regulated by them rarely, if ever, prioritize health care and prevention outcomes in their measures of success, or implement strategies for effectively addressing employment needs of the priority populations of the HIV National Strategic plan. At the same time, resources of DOL's workforce development and the Department of Education's vocational rehabilitation systems rarely are - and must be - directed to the network of employment programs that have emerged specifically to respond to the employment and quality of life needs of people living with HIV with delivery of culturally relevant, non-stigmatizing, non-discriminatory, trauma-informed services.

- **Address and control healthcare costs for people living with HIV.** Most PLHIV live in poverty and struggle to meet basic survival needs, including food, housing, and healthcare. The Plan does not address out-of-pocket costs for medications or healthcare for PLHIV.

- **Sexual and reproductive healthcare for people of all genders living with HIV.** There is no mention in the plan of ensuring quality and non-stigmatizing sexual and reproductive healthcare for PLHIV (and only one mention of reproductive healthcare at all, but only as it pertains to primary HIV prevention). People of all genders living with HIV require sexual and reproductive healthcare; unfortunately, this is one of the sites where we suffer from the greatest stigma, lack of understanding, and discrimination from healthcare providers. High quality, non-stigmatizing sexual and reproductive healthcare for all people living with HIV is crucial to ensure our well-being. For transgender people living with HIV, it is especially important that gender-affirming care is provided and that providers and clinicians are well-versed on our options and rights.

- **Trauma-informed care and services.** We are pleased to see that trauma-informed care and trauma-informed service delivery models are included in the Plan. PLHIV live with trauma and its downstream effects at rates well above the general population. The Plan should strengthen its explicit commitments to integrate trauma-informed service delivery for PLHIV. This could include: mandatory trainings on trauma-informed approaches for all staff including clinicians, providers, administrators, and peer workers; data collection on rates of intimate partner violence, post-traumatic stress disorder symptoms, substance use, depression, stigma, social isolation; implementation and evaluation of trauma-informed primary care models in clinics serving PLHIV; integration of evidence-based responses to PTSD into existing funded clinical services, including therapy, psychiatry, medication adherence, and substance abuse treatment; and fostering collaborations between organizations addressing violence and trauma and those providing care and services to PLHIV.



- **Addressing enacted, internalized, interpersonal, community, and institutional stigma.** While we appreciate that there is an indicator designed to address stigma, we are unclear what the baseline survey from 2018 references and it is unfortunate that the Global Stigma Index has not been referenced in the Plan. HIV stigma comes in many forms. HIV criminalization is one form of institutionalized stigma, and the language on HIV criminalization as a problem must be strengthened. The Plan makes a mistake in relegating the harms of HIV criminalization as stemming solely from HIV-specific criminal laws. PLHIV are routinely prosecuted for “HIV crimes” under general criminal and public health statutes as well as under provisions of the Uniform Code of Military Justice that do not even mention HIV. Moreover, the phenomenon harms all PLHIV as well as HIV prevention; it is not a problem affecting only those prosecuted.

2b. Addressing the specific prevention, healthcare, and human rights needs of people of trans experience.

Although the Plan recognizes transgender women as a priority population, there is nothing beyond that recognition to demonstrate a true understanding of what is needed to reduce HIV-related health disparities and inequities for transgender people living with HIV. The Plan must look beyond a biomedical solution, one relying on viral suppression as indicators of success or failure. Rather, the Plan must provide goals, objectives, and strategies that recognize the dignity and autonomy of transgender people and make explicit recommendations on policies necessary to meet this goal.

Transgender people face discrimination in all aspects of life, from housing to health care, from public accommodations to policing, from employment to education. Black, Indigenous and other transgender people of color face even higher rates of discrimination and violence in these settings. For transgender PLHIV, it can be nearly impossible to find culturally relevant and non-stigmatizing health services and providers. The challenge of finding affirming and competent health care providers has been made only more traumatic by the Trump administration’s re-interpretation of §1557 of the Affordable Care Act to remove nondiscrimination protections on the basis of gender identity in health care settings.

2c. Sex worker rights, leadership, and engagement

The HIV National Strategic Plan must uphold sex worker rights and ensure that sex workers are meaningfully engaged in HIV prevention and care activities. Sex workers are at elevated risk for community violence and service delivery settings often marginalize sex workers. The Plan should assure that competent and non-stigmatizing HIV services are provided to sex workers and that sex workers can participate in HIV services without fear of judgment, criminalization, or confidentiality violations. Sex workers should be meaningfully engaged as partners in designing and implementing HIV prevention and care policies and programs.

2d. Ensuring access to a robust HIV prevention and care infrastructure for immigrants

Recent actions including attempts to redefine public charge and an overall climate of hostility towards immigrants have created tremendous barriers to engagement of immigrant communities in healthcare service delivery. To achieve the prevention and care goals of the HIV National Strategic Plan, immigrants of any legal status must be assured HIV prevention, care and facilitative services, must be able to participate safely and without repercussions in HIV programs, and must be able to access unfettered treatment.

3. Do any of the HIV plan’s goals, objectives and strategies cause concern? If so, please specify the goal, objective or strategy, and describe the concern regarding it.

The fourth goal, *Achieve Integrated, Coordinated Efforts That Address the HIV Epidemic among All Partners and Stakeholders*, is a laudable goal, focused on expanding partnerships, improving efficiency, and promoting sustainability of the HIV response. We share these ambitions. However, we are gravely concerned about some of the assumptions, strategies and tactics being promulgated towards this end. **Specifically, we have grave**



concerns about the continued and expanded use of HIV genomic sequencing data, cluster detection, and practices generally referred to as “molecular HIV surveillance.” Page 50 of the Plan cites as promising practice the “Use of new HIV surveillance techniques. CDC has supported several jurisdictions to detect possible HIV infection clusters more quickly and then coordinate swift responses across programs to get needed prevention and treatment services to people who need them” and the Plan goes on to set as *Objective 4.3 Enhance the quality, accessibility, sharing, and use of data, including HIV prevention and care continuum data and social determinants of health data.*

This objective and the rationale and strategies underlying it cause us great concern. The practices of molecular HIV surveillance, cluster detection, and sequencing of HIV genomes without consent from the individuals involved have come under immense scrutiny in recent years and as networks representing PLHIV we strongly oppose these practices for several reasons. Because it is conducted without knowledge or consent, molecular HIV surveillance undermines trust in the public health system and in individual healthcare providers and clinicians and reduces willingness of PLHIV to engage in HIV care and treatment. Communities heavily burdened by HIV are also those with deep distrust of the medical system, for justifiable reasons. The risk of having personal health data taken without consent, then having it sequenced and shared, also without consent, can present a deterrent to people even wanting to access HIV screening and testing. Laws protecting the privacy of this data and permitting sharing and use of molecular HIV data vary widely from state to state and there is no current national standard that would uniformly protect misuse of this data for people living with HIV. As acknowledged in the Plan, dozens of states have laws criminalizing PLHIV. The practice of molecular HIV surveillance, cluster detection, and corresponding public health investigations create vulnerabilities for inadvertent disclosure, stigma, risks to physical safety, employment, and housing, and even criminal liability for PLHIV. Molecular HIV surveillance and cluster detection practices must be stopped immediately and have no place in a national HIV plan. Sharing of HIV data is a sensitive issue and must be thoughtfully considered in real, meaningful partnership with networks of people living with HIV, **before** it is implemented.

Thank you for the opportunity to provide comments on the draft *HIV National Strategic Plan: A Roadmap to End the HIV Epidemic (2021-2025)*. We welcome the opportunity to discuss these comments and concerns with you in more detail.

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