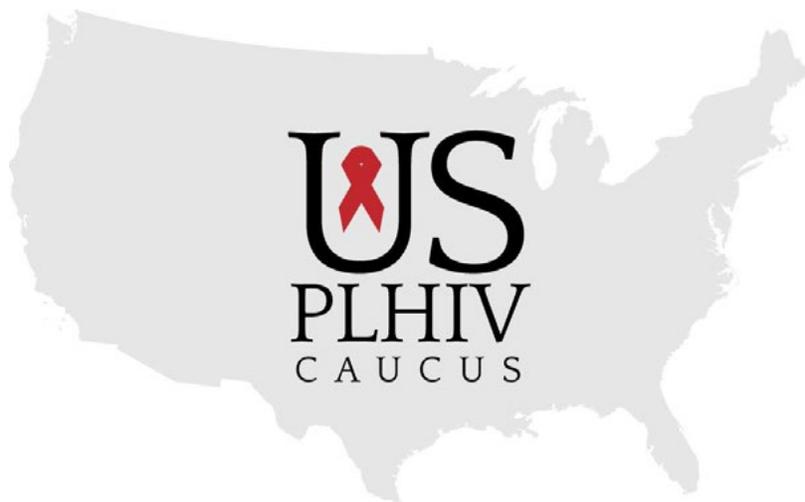


---

# **DEMANDING BETTER:**

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



# ACKNOWLEDGMENTS

This document was a collaborative effort informed by our relationships with thousands of people living with HIV throughout the United States, as well as our lived experience.

Authors contributed thought leadership as well as writing, research, reflection, and editing time. We are grateful to Martha Cameron, Barb Cardell, Marco Castro-Bojorquez, Cecilia Chung, Tami Haught, Vanessa Johnson, Ronald Johnson, Naina Khanna, Kamaria Laffrey, Lorenzo Lewis, Mark Misrok, Heather O'Connor, Venita Ray, Malcolm Reid, Bamby Salcedo, Linda Scruggs, Waheedah Shabazz-El, Andrew Spieldenner, Kiara St. James, Sean Strub, and Evany Turk for their contributions.

We are additionally especially indebted to Tyler Barbarin, Breanna Diaz, Kelly Flannery, Jennie Smith-Camejo, and Allie Watson for thought leadership, writing, editing, research, and communications support on this momentous project.

We dedicate this agenda to the many people living with HIV who paved the way for our understanding of HIV as an issue of justice, and on whose shoulders we stand. Some are still with us and too many have been lost along the way.

May this collective set of priorities, created jointly by U.S. based networks of people living with HIV for the first time ever, assure a better world for all of us.

For Mary. For Marco. For Deloris. For Loren. For Juanita.



# TABLE OF CONTENTS

I. Executive Summary	4
II. Background	7
III. Issue Areas and Recommendations	10
1. Issue Area 1. Concretely Elevate Meaningful Involvement of People Living with HIV and Disproportionately Impacted Communities in the HIV Response	10
2. Issue Area 2. Proactively Create an Affirming Human Rights Environment for People Living with HIV: Address Stigma; Eliminate HIV Criminalization and Halt Molecular HIV Surveillance	13
3. Issue Area 3: Addressing Inequities in the Federal Response: Attend to Racial and Gender Disparities	21
4. Issue Area 4. Add Sex Workers and Immigrants Living with HIV as Priority Populations Throughout the Federal Response	24
5. Issue Area 5. Affirmatively Commit to Improving Quality of Life for People Living with HIV	28



# **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.



# **DEMANDING BETTER:** **An HIV Federal Policy Agenda by** **People Living with HIV**

## **BACKGROUND**

### **About Us**

We are networks of people living with HIV (PLHIV networks) in the United States. PLHIV networks are organized formations created, led by, and accountable to the estimated 1.1 million people living with HIV (PLHIV) in the United States. PLHIV networks are vehicles through which we, as PLHIV, can define our own agenda, choose our own leaders, and speak with a collective voice.

Our networks represent communities most impacted by the epidemic in the United States: Black gay and bisexual men living with HIV in the U.S. South, Black cisgender and transgender women living with HIV, transgender women of color living with HIV, Latinx people living with HIV, survivors of HIV criminalization, and people aging with HIV. Our constituencies are diverse – including groups organized around race, gender, age, gender identity, sexual orientation, and immigration status – and we work across coalitions and communities on issues that impact us.

PLHIV networks bring a unique lens, informed by lived experience, to the development of policies to ensure better care, access to treatment, and quality of life for PLHIV. As PLHIV, we understand HIV-related stigma, discrimination, and structural conditions -- including racism, homophobia, sexism, transphobia, xenophobia, ableism, and poverty -- in direct, embodied ways. Many of us have been involved as service providers, have developed and led programs that serve PLHIV, and have built community-based organizations (CBOs) and advocacy initiatives from the ground up. We are in direct contact with tens of thousands of PLHIV throughout the United States and are consequently able to identify and, where resources

allow, respond to emerging trends quickly.

There is a marked difference between collaborating with or taking input from individual PLHIV and engaging with organized formations of PLHIV. Processes to take input from or consult with individuals living with HIV generally have no available mechanisms for, nor resources to support, community accountability. Nor do they provide real avenues to support engagement by PLHIV representing the communities most affected by HIV, who may be facing various barriers that circumscribe their ability to effectively participate in decision-making or advisory processes. Thus, working with individual PLHIV is frequently tokenizing and disempowering to PLHIV and reinforces the inequities in race, gender, and class that have framed dominant discourse and policymaking on the HIV epidemic to date.

The United States People Living with HIV Caucus (HIV Caucus) emerged in 2010 from the need for a national voice for PLHIV. The HIV Caucus is composed of members Global Network of People Living with AIDS -- North America, International Community of Women with HIV/AIDS -- North America, National Working Positive Coalition, Positively Trans, Positive Women's Network-USA (PWN), Reunion Project, SERO Project, and THRIVE SS. As a national "network of networks," the HIV Caucus has taken the lead on several issues that PLHIV face, including addressing national HIV plans and policies that affect us.<sup>1</sup> The HIV Caucus has been a coordinating partner with AIDS United and Treatment Access Expansion Project at AIDSWatch, the national HIV advocacy day, bringing together hundreds of PLHIV and allies from around the country each year in Washington, D.C., to engage legislators and federal agencies.

It is long past time for national leadership on HIV

to make this shift towards formally recognizing PLHIV networks as necessary partners to help organize, inform, and implement the federal domestic response. Put simply, you cannot end the HIV epidemic without us. This is no longer a demand – it is an absolute imperative. It is in this spirit of partnership that we bring the below analysis of the current federal response and our recommendations forward.

## **Contextualizing the Federal Response to the United States HIV Epidemic**

The federal response to the domestic HIV epidemic is situated within a larger context of politics and culture, including sex negativity, HIV-related stigma, racism, homophobia, transphobia, sexism, classism, and the criminalization of poverty. As a result, since the first cases of AIDS were reported 40 years ago, and while health care providers, clinicians, and community advocates organized to develop compassionate approaches, the political response itself has been plagued by an overall lack of will to actively value, invest in, and affirm the lives of those communities most impacted by the domestic HIV epidemic -- the same communities our networks represent.

For nearly 30 years, the U.S. did not have a comprehensive, national plan to address the HIV/AIDS epidemic. Critical programs and policies to provide health care and treatment to PLHIV, especially the Ryan White HIV/AIDS Program, and various initiatives to prevent HIV funded by the Centers for Disease Control and Prevention (CDC), collectively formed a patchwork response to the domestic epidemic. This fragmented approach to HIV was ironic given that the U.S. engaged with other countries to develop their annual national plans (known as Country Operational Plans, or COPs) as a required component of the funding process under the President's Emergency Plan for AIDS Relief (PEPFAR), established in 2003<sup>2</sup>. However, it was also inevitable – prior to the adoption and enactment of the Patient Protection and Affordable Care Act (ACA), health insurers were legally permitted to discriminate against people

with pre-existing conditions<sup>3</sup>, such that PLHIV in the U.S. were not generally eligible for private or employer-sponsored health insurance coverage<sup>4</sup>, and relied on a medley of social and health related services to fill in the gaps.

In the mid-2000s, as early data began to show that viral suppression in PLHIV would reduce the likelihood of onward HIV transmission, epidemiologists began making the case that any successful plan to “end the HIV epidemic” would have to rest on a foundation of two primary bedrocks:

1. Aggressive HIV testing to identify new diagnoses and
2. Medical treatment to suppress the viral loads of those living with HIV.

This became known as the “test and treat” model. Some advocates pushed to expand the model's frame first to “testing, linkage, and care” (TLC), then to TLC+, in a discursive recognition that successfully implementing widespread and early HIV treatment for those who receive a positive diagnosis requires first that people living with HIV are in medical care and that they were likely to need other services and support in order to facilitate access to that medical care.<sup>5</sup>

### ***The United States National HIV/AIDS Strategy: 2010-2020***

The Obama administration's release of a 2010-2015 National HIV/AIDS Strategy for the United States (NHAS, or the NHAS)<sup>6</sup> in July 2010 represented a significant milestone. The NHAS was a White House-level document, complete with the Presidential seal. It was designed as the first cross-government response to HIV, explicitly requiring leadership and action by multiple federal agencies, along with involvement from other stakeholders including the private sector and faith sector, to achieve four major goals:

1. reducing new HIV transmissions;
2. increasing access to care and improving health outcomes for people living with HIV;
3. reducing HIV-related health disparities; and
4. achieving coordination in the national HIV response.<sup>7</sup>

Operational components of NHAS, such as the CDC's Enhanced Comprehensive Prevention Plans (ECHPP) and the "Twelve Cities" approach<sup>8</sup>, represented early stages in a geographical approach to test-and-treat type strategies.

In 2015, the NHAS was updated and re-released with new language, new metrics, and a 2020 timeframe for achievements.<sup>9</sup> The four-goal structure remained, with added emphasis on increasing HIV testing and linking people who tested positive to care; providing support to retain PLHIV in care; achieving viral suppression; and focusing HIV efforts on populations most impacted by HIV, including people in the southern states.<sup>10</sup>

### ***The Ending the HIV Epidemic Plan: 2019-present***

In January 2019, the U.S. Department of Health and Human Services (HHS) released a ten-year operational plan setting targets of reducing the number of new HIV acquisitions in the United States by 75 percent by 2025, then by at least 90 percent by 2030, through a geographic focus on the 48 hardest-hit counties and the seven states with a "substantial number of HIV diagnoses in rural areas."<sup>11</sup>

This plan is known as the Ending the HIV Epidemic Plan (EHE) and rests on four pillars:

1. diagnose;
2. treat;
3. prevent (through "proven interventions, including pre-exposure prophylaxis and syringe services programs;" and
4. respond to "potential HIV outbreaks to get needed prevention and treatment services to those who need them."<sup>12</sup>

The fourth and final pillar relies on invasive, nonconsensual HIV surveillance activities known broadly as molecular HIV surveillance (MHS) or cluster tracing.<sup>13</sup> Funding has been appropriated from Congress in fiscal years 2020 and 2021 to support the launch of the EHE.<sup>14</sup>

The EHE in its current iteration is viewed by PLHIV networks as deeply flawed in its equation of PLHIV and our viruses to problems that must be surveilled without our consent and managed and controlled via treatment, rather than attending to us as equal

citizens with claims to human rights and dignity. We also believe the EHE is necessarily limited in its effectiveness due to its overly biomedical focus, lack of attention to structural and social issues, and failure to partner with PLHIV networks on developing a robust plan and corresponding budget for meaningful community engagement at the federal and jurisdictional level.

### ***The HIV National Strategic Plan: 2021-present***

In early December 2020, as the second NHAS was coming to a close, HHS released a draft of a third iteration of a national HIV strategy for public comment, renaming it the HIV National Strategic Plan for 2021-2025 (HIV Plan). A major intent of the draft updated plan was to align the HIV national strategy with the EHE federal initiative. After a brief comment period, the outgoing Trump administration released the 2021-2025 update in mid-January 2021.<sup>15</sup>

PLHIV networks submitted comments on the draft plan, including the HIV Caucus and PWN. The HIV Caucus's and PWN's comments highlighted shortcomings and gaps in the draft plan, notably:

1. the importance of involving organized PLHIV networks;
2. serious concerns with the draft plan's inclusion of the use of HIV genomic sequencing data, cluster detection, and data derived from MHS;
3. lack of inclusion of immigrants and sex workers in the draft plan;
4. inadequate attention to structural determinants of health, most notably racism and racial inequities; and
5. inadequate attention to improving the quality of life of people living with HIV.<sup>16</sup>

We are disappointed to note that PLHIV networks' recommendations were largely not addressed in the final version of the HIV Plan released in January 2021.

The below set of policy recommendations seeks to offer a path forward that will strengthen the overall domestic federal response through a specific focus on improving the structures themselves via which the HIV response is organized and led, along with

concrete improvements to major policies guiding that response in the U.S. as of July 2021– the HIV Plan and the EHE. Again, because the HIV epidemic and response are situated within and rest on broader systems, this document also identifies some policy areas of broader focus that must be considered as foundational to creating a safe, dignified, and rights-based environment for people living with and most vulnerable to acquiring HIV.

---

## ISSUE AREAS AND RECOMMENDATIONS

### Issue Area 1. Concretely Elevate Meaningful Involvement of People Living with HIV and Disproportionately Impacted Communities in the HIV Response

#### *Meaningful Involvement of People Living with HIV: Defining the Issue*

CDC’s Notice of Funding Opportunity PS20-2010 acknowledges that “[r]eaching and maintaining viral suppression among people with HIV is the most effective way to reduce new infections.”<sup>17</sup> Biomedical tools needed to meet this already exist, such as antiretrovirals, pre-exposure prophylaxis, and post-exposure prophylaxis. The primary impediments to “ending the HIV epidemic” are structural and social; thus, visible, organized, and effective leadership by PLHIV in all aspects of the HIV response is more important than ever.

PLHIV are, by necessity, intimately familiar with factors that place individuals and communities at risk for acquiring HIV in the first place, such as barriers to accessing care and treatment and challenges to living a full and healthy life with dignity. When PLHIV are effectively involved in program and policy development, implementation, and monitoring, the relevance and effectiveness of strategies improve. Moreover, raising visibility of PLHIV and elevating their voices and experiences can help decrease HIV-related stigma and discrimination.

Meaningful involvement of people with HIV/AIDS (MIPA) is a globally recognized principle first articulated in the Denver Principles in 1983 and

endorsed by the United Nations Programme on HIV/AIDS (UNAIDS), the body that coordinates global action on the HIV/AIDS epidemic.<sup>18</sup> As UNAIDS explains, at its most basic level, MIPA does two important things:

1. Recognizes the important contribution that people living with and affected by HIV/AIDS can have in the response to the epidemic as equal partners; and
2. Creates a space within society for involvement and active participation of PLHIV in all aspects of that response.<sup>19</sup>

The HIV Caucus has put forth a body of work that further articulates MIPA within a modern U.S. context to acknowledge that MIPA must fully integrate a lens around racial, gender, class, and other axes of power and privilege to be truly “meaningful.” The HIV Caucus definition of MIPA goes beyond merely accounting for HIV-positive status to include representation and expertise from constituencies that are disproportionately affected by the epidemic. Within the U.S. and territories, this means that true MIPA must account for regional differences as well as intentionally developing and supporting leaders living with HIV from marginalized communities, especially Black and Latinx people, youth, people who use drugs, immigrants, the LGBTQ community, cisgender and transgender women, people with incarceration experience, sex workers, people aging with HIV, and so many others.

There is no “one-size-fits-all” model to assure meaningful engagement of community, and it takes time for government and public health partners to build trust with communities that have been harmed by multiple systems. Through real and ongoing partnership with organized, constituency-led formations that reflect most impacted communities, like PLHIV networks, these nuances can be addressed over time.

Involving PLHIV networks in decision-making and implementation translates into concrete benefits for public health leadership, including: pre-existing community trust and cultural humility that facilitates development and implementation of strong programs; a real-time sense of challenges and opportunities on the ground;

informed analysis of the myriad and complex effects of interlocking stigma and discrimination; increased effectiveness of policies and programs; and improved sustainability of projects and organizations.

This space within society can be formalized through various mechanisms. For example, in the Ryan White Part A program, jurisdictional planning councils composed of individuals who make decisions about the allocation of resources are legislatively mandated to meet requirements including “reflectiveness” of the local epidemic and “representation” in filling various types of membership categories.<sup>20</sup> The legislation also mandates that 33 percent of planning council members are people who receive Ryan White Part A services and who do not have a conflict of interest as staff, paid consultants, or board members of Part A funded entities.<sup>21</sup> In addition, guidance followed by the Global Fund reflects clear commitments to this type of structured civil society participation by requiring its Country Coordinating Mechanisms to “show evidence of membership of people that are both living with and representing people living with HIV” and of people from and representing “key populations.”<sup>22</sup>

### ***MIPA: Opportunities to Strengthen Meaningful Involvement of People Living with HIV in the Federal Domestic HIV Response***

The federal domestic HIV response can be strengthened through true partnership with PLHIV networks. The collective voices and organized leadership of PLHIV, as represented in national and local PLHIV networks, must be viewed as essential to 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 the policy and program decision-making that so profoundly affect our lives.

*True MIPA requires resources, planning and accountability, and these must be included in the plan with commensurate metrics, indicators, strategies, and funding.*

Currently, neither the HIV Plan nor the EHE have real mechanisms that incorporate the core tenants of MIPA: organized, ongoing, and meaningful engagement with PLHIV. The HIV Plan does not explicitly require federal agencies, efforts, or initiatives to partner with PLHIV networks and lacks any specific accountability to the community of PLHIV. While PS20-2010, an implementation component of the EHE, acknowledges the importance of community engagement as part of its “respond” pillar and requires that 25 percent of funds be designated towards “community engagement,” the CDC’s definition of engagement<sup>23</sup> is limited and poorly defined.

Similarly, the three national advisory bodies providing guidance to federal agencies on HIV policy – the President’s Advisory Council on HIV/AIDS (PACHA), the CDC/HRSA Advisory Committee on HIV, Viral Hepatitis and STD Prevention and Treatment (also known as CHACHSPT or CHAC), and the Office of AIDS Research Advisory Council (OARAC) -- currently have no formal guidance mandating organized involvement from PLHIV networks, although some of them require representation of PLHIV.<sup>24</sup>

Established in 1993 during the Clinton administration, the Office of National AIDS Policy (ONAP) is tasked with coordinating an integrated response to the domestic and global HIV epidemic, specifically on matters of prevention, treatment and care. ONAP also oversaw community engagement efforts, utilizing both virtual and in-person mechanisms to hear from, connect with, and be accountable to PLHIV.<sup>25</sup>

Unfortunately, the Trump administration shut down ONAP, leaving a significant gap in coordination and dismantling an avenue for community engagement and feedback on federal HIV policy and initiatives like the HIV Plan and EHE.<sup>26</sup>

The Biden administration recently reconstituted ONAP as part of the Domestic Policy Council and appointed Harold Phillips, a Black, gay man openly living with HIV, as director to lead that office.<sup>27</sup> This is a positive step forward in embodying meaningful involvement of people living with HIV. To support that, it is more important than ever that this newly

constituted ONAP be equipped to meet the needs of PLHIV. Doing so requires ONAP to be robustly staffed, resourced, and supported to lead the federal response, and to directly engage PLHIV networks as part of its mandate.

## Recommendations for Issue Area 1 - Meaningful Involvement of People Living with HIV

Recommended Agency, Federal Body, or Policy	Recommended Action(s)
White House/Office of the President of the United States	<ol style="list-style-type: none"> <li>1. Require ONAP staffing structure to include diverse PLHIV from the communities most impacted by the epidemic, including Black gay and bisexual men, Black cisgender women, and transgender women of color.</li> <li>2. Recharter PACHA, CHAC and OARAC to each include at least two standing seats for designated representatives of the HIV Caucus, to be filled by the HIV Caucus utilizing representatives of our own choosing.</li> </ol>
Department of Health and Human Services	<ol style="list-style-type: none"> <li>1. 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 HIV Caucus, as the representative collective of all U.S.-based national PLHIV networks.</li> <li>2. Amend the HIV Plan to include measurable metrics for formal engagement of PLHIV networks.</li> <li>3. Amend the EHE and future funding related to it to:</li> <li>4. Redefine community engagement beyond resourcing already developed plans, including paid consultation and decision-making on all aspects of the EHE by PLHIV networks;</li> <li>5. Apply such a commitment to community engagement across the EHE plans – beyond but including the “cluster detection and response” pillar.</li> <li>6. Amend the EHE, the HIV Plan, and require future HIV initiatives to require MIPA indicators for federal, state, and local advisory and decision-making bodies with purview over HIV, including local EHE jurisdictional planning processes. The required MIPA indicators should include meaningful PLHIV engagement and leadership from the communities most impacted by the domestic epidemic.</li> </ol>

PLHIV 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 underutilized 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. The federal response can structurally achieve this by making a formal commitment to measurable MIPA.

## **Issue Area 2. Proactively Create an Affirming Human Rights Environment for People Living with HIV: Address Stigma; Eliminate HIV Criminalization and Halt Molecular HIV Surveillance**

### **2A. Addressing HIV-Related Stigma.**

#### ***HIV-Related Stigma: Defining the Issue***

HIV-related stigma and other intersectional stigmas persist among and against PLHIV. Intersectional stigma refers to the ways that multiple kinds of stigmas - around gender identity, sexual orientation, socioeconomic class, mental health, history of drug use, incarceration, and/or sex work - are compounded for some PLHIV.<sup>28</sup> These have deleterious impacts on people's lives, as they experience further marginalization from communities and institutions. Intersectional stigma also can result in being targeted by multiple punitive laws and policies, as well as bias and discrimination in health care, law enforcement, employment and education.

Where most of the literature places HIV-related stigma either as a psychodynamic model (how people feel) or related to a public health outcome (clinical usage), PLHIV experience stigma throughout every part of their lives. Legal frameworks such as HIV criminalization provide powerful proof of institutionalized stigma. Stigma affects how PLHIV find support,<sup>29</sup> whether PLHIV are successful in pursuing education and employment,<sup>30</sup> and overall quality of life<sup>31</sup>.

The result of these stigmas is often seen in the lack of social protections provided to the diverse communities of PLHIV. Criminalization based on HIV-status is one clear aspect of this, yet PLHIV face multiple vulnerabilities. Punitive laws around sex work and drug use affect PLHIV, as well as how intensive policing disproportionately affects the Black community, people of transgender experience, people with disabilities, and immigrants in the U.S. The EHE notes that HIV-related stigma, homophobia, and transphobia are contributing barriers to a successful HIV response, yet there is no clear initiative in the \$670 million plan to address and dismantle these barriers.<sup>32</sup>

In order to address these issues, the Global Network of People with HIV/AIDS (GNP+) developed the People Living with HIV Stigma Index (Stigma Index).<sup>33</sup> The Stigma Index is a community-led way to document stigma in a country and develop action plans to address it. The Stigma Index has been conducted in over 100 countries with over 100,000 people living with HIV involved.<sup>34</sup> In the U.S., the attempt to conduct the Stigma Index was cut short due to funding.<sup>35</sup>

#### ***HIV-Related Stigma: Opportunities to Strengthen the Federal Response***

The HIV Plan envisions "every person with HIV ha[ving] high-quality care and treatment and liv[ing] free from stigma and discrimination," and HIV-related stigmas in the form of interpersonal, community, health system, and structural stigma and discrimination are acknowledged as a barrier to achieving public health goals throughout it.<sup>36</sup> HIV-related stigma is framed as a problem, a challenge to overcome, and a barrier throughout the HIV Plan, which proposes some concrete and useful strategies to address this: developing and implementing campaigns and resources to reduce HIV-related stigma;<sup>37</sup> training health care staff on stigma and discrimination;<sup>38</sup> increasing health literacy among patients; supporting communities to address HIV-related stigma;<sup>39</sup> reframing public health and HIV messaging campaigns that may perpetuate stigma;<sup>40</sup> and developing and implementing evidence-based interventions designed to reduce HIV-related stigma and discrimination in public health and health care systems<sup>41</sup>. Indeed, HIV-related stigma and discrimination may be the problem and barrier to achieving HIV prevention, care, and treatment goals most consistently identified throughout the HIV Plan.

Despite this overwhelming acknowledgment that HIV-related stigma represents a tremendous barrier, there is only one indicator within the HIV Plan that holds the federal response accountable to address this. It holds measurable success solely at the individual level, suggesting the use of a 10-item questionnaire to assess whether individuals diagnosed with HIV are experiencing reduced stigma.<sup>42</sup> The HIV Plan and broader federal HIV response would benefit from ensuring

that its metrics to assess success in reducing or eliminating HIV-related stigma are grounded in what PLHIV are asking for and that they seek to address individual, community, and structural HIV-related stigma and discrimination.

## Recommendations for Issue Area 2A - Addressing HIV-Related Stigma

<b>Recommended Agency, Federal Body, or Policy</b>	<b>Recommended Action(s)</b>
Department of Health and Human Services	<ol style="list-style-type: none"> <li>1. In partnership with PLHIV networks, identify specific stigma-reduction activities that health departments, AIDS Service Organizations (ASOs) and Community-Based Organizations (CBOs), health clinics and other partners in the HIV response can engage in.</li> <li>2. Require grantees to address employment barriers at all levels for PLHIV as an important way to combat stigma.</li> <li>3. Resource PLHIV networks to develop and implement stigma-reduction initiatives that reflect the intersectional kinds of stigma that impact the local community of PLHIV.</li> </ol>
HIV National Strategic Plan	<ol style="list-style-type: none"> <li>1. Center the lived experience of intersectional stigma amongst PLHIV, inclusive of Black, Indigenous, and other people of color; people of transgender experience; gay and bisexual men; sex workers; people who use drugs; immigrants; and people who are incarcerated and in other institutional settings.</li> <li>2. Utilize data collection tools and interventions that go beyond individual feelings and examine structural change, such as, the GNP+ Stigma Index 2.0. This could include building and resourcing PLHIV networks.</li> </ol>
Ending the HIV Epidemic Plan	<ol style="list-style-type: none"> <li>1. Require jurisdictions to have clear, actionable, resourced community-led initiatives to reduce HIV-related stigma and other intersectional stigmas.</li> <li>2. Identify resources that work towards community-led stigma reduction and community resilience building in its portfolio.</li> <li>3. Promote advocacy efforts to remove punitive laws and policies and acknowledge how they contribute to HIV-related stigma.</li> </ol>

## **2B. Eliminating HIV Criminalization**

### ***HIV Criminalization: Defining the Issue***

HIV criminalization is the unjust use of criminal laws, policies, and practices to police, regulate, control, and punish PLHIV based on their HIV-positive status. HIV criminalization laws exist at the state level and vary in scope from state to state.<sup>43</sup> HIV-specific laws may criminalize a range of activities including alleged HIV non-disclosure prior to sex, potential or perceived HIV exposure through many different means, or unintentional transmission of the virus.<sup>44</sup> Although these laws do not exist in every state or territory in the U.S., PLHIV have been convicted or received sentence enhancements based upon their HIV status even when no HIV-specific statute exists,<sup>45</sup> and even when no risk of HIV transmission was scientifically possible.<sup>46</sup>

By contributing to an environment where PLHIV can be targeted and punished, HIV criminalization laws present a deterrent to achieving federal HIV prevention and care goals, while institutionalizing HIV stigma as part of the legal system. Furthermore, data from several states with HIV criminalization laws provide evidence of racial and gender bias in their application, disproportionately enforced against Black and Latinx gay and bisexual men and cisgender and transgender women.<sup>47</sup>

HIV criminalization inflicts long-lasting harm on PLHIV, their families, and their communities. A prosecution or investigation related to HIV status itself and negative media attention may lead to violations of confidentiality, job loss, housing insecurity, complications with custody arrangements, and more. A conviction under an HIV criminalization law may lead to a person being placed on a sex offender registry, which has implications for stigma, childcare, housing, employment, food security, and mental and emotional well-being.<sup>48</sup> Thus, the practice of criminalization is in direct opposition to strategies that seek to improve access to and sustained connection to prevention and treatment methods for the most vulnerable populations.<sup>49</sup>

### ***HIV Criminalization: Opportunities to Strengthen Federal Leadership***

Both the HIV Plan and EHE advise state governments to reform or repeal HIV criminalization laws and practices,<sup>50</sup> but do not provide resources or requirements in their respective plans.

EHE does not require its priority jurisdictions to address criminalization in their plans,<sup>51</sup> leaving it up to each jurisdiction to decide for themselves whether to address their respective HIV criminalization laws.<sup>52</sup>

The HIV Plan recognizes the detrimental impact HIV criminalization has on PLHIV, noting how it fuels HIV-related stigma and discrimination.<sup>53</sup> To achieve the goal of ending HIV-related stigma and discrimination, the HIV Plan provides one strategy that calls for reforming state HIV criminalization laws to be rooted in science and public health strategies.<sup>54</sup> It also identifies the need to educate legislators, prosecutors and law enforcement on HIV transmission risks.<sup>55</sup>

Federal leadership on the HIV response has an important role to play in creating an affirming legal, social, and political climate for people living with and vulnerable to HIV to engage in health care and have all their human rights protected.

## Recommendations for Issue Area 2B - Eliminating HIV Criminalization

Recommended Agency, Federal Body, or Policy	Recommended Action(s)
HIV National Strategic Plan	<ol style="list-style-type: none"> <li>1. Draw clear connections between criminalization and the disparate health outcomes of various groups such as Black, Indigenous, and other people of color, sex workers, and those who use drugs.</li> <li>2. Strengthen the focus on negative consequences of criminalization on access to and retention in HIV care and treatment.</li> </ol>
Ending the HIV Epidemic Plan	<ol style="list-style-type: none"> <li>1. Acknowledge the federal government’s role in creating HIV criminalization laws and make equal commitments to repeal these laws.</li> <li>2. Require EHE jurisdiction plans to include clear commitments to support state efforts to reform or repeal HIV criminalization laws as a condition for funding.</li> <li>3. Call for EHE jurisdictions that are being funded to engage with PLHIV who have experienced incarceration to address the residual impacts of criminalization, including access to adequate treatment and care.</li> </ol>
Congress	<ol style="list-style-type: none"> <li>1. Pass a Repeal Existing Policies that Encourages and Allow Legal (REPEAL) HIV Criminalization Act that is consistent with current HIV decriminalization advocates’ understanding and strategy and that incentivizes states to reform or repeal their respective laws.</li> </ol>

### 2C. Declare a Moratorium on Molecular HIV Surveillance Until Adequate Safeguards Protecting the Privacy and Autonomy of People Living with HIV Are Implemented

#### ***Molecular HIV Surveillance: Defining the Issue***

Molecular HIV surveillance (MHS) refers to the practice of using HIV genetic material to compare with other HIV genomic sequences to determine whether acquisitions are similar enough to be related to each other and therefore linked. For PLHIV, MHS begins in the clinical setting by which during a medical visit, often early in an individual’s diagnosis, blood is drawn and from it HIV genetic material is sequenced, stored in a database, and shared with other databases. For public health purposes, MHS is primarily used for “cluster detection,” or the practice of identifying instances when it appears there may be multiple linked HIV acquisitions appearing within a short amount of time, thereby triggering a public health investigation and response. Of notable concern, the processes of HIV genomic sequencing, data

storage, and data sharing -- essential to MHS -- are conducted without an individual’s consent and knowledge.

As PLHIV networks, we strongly oppose these practices for several reasons that generally fall into the following categories, some of which are interlinked:

1. Lack of informed consent from PLHIV;
2. Lack of consultation or meaningful engagement with PLHIV in development and implementation of MHS;
3. Wide variation in state-level data sharing environments and legal protections for MHS data;
4. Risk of potential data misuse in civil, immigration, and/or criminal proceedings;
5. Concerns about breaches of privacy and confidentiality; and
6. Lack of consistent standards for competency in the HIV disease investigation intervention workforce to attend to sensitivities around stigma, culture, and violence.

***Lack of consent from and consultation with people living with HIV.***

PLHIV generally do not know, nor have consented, to having our HIV genomic sequence data collected, shared, stored, and utilized in this way by public health authorities. This is a fundamental breach of trust. Due to the lack of informed consent, MHS may undermine trust in the health system, deterring people from seeking HIV screening and testing in the first place and from engaging in health care once diagnosed. This presents a serious problem for “ending the HIV epidemic” efforts. PLHIV tend to be from communities that already have justifiable distrust of medical and research institutions, as well as public health authorities, and may have made significant efforts to overcome that distrust to participate in their health care.<sup>56</sup>

HIV clinicians and health care providers frequently go to great lengths to ensure safety and confidentiality for their patients – and cannot opt out of the use of this medical information for surveillance purposes.<sup>57</sup>

While PS20-2010, which is an implementation component of the EHE, acknowledges the importance of community engagement as part of its “respond” pillar and requires that 25 percent of funds be designated toward “community engagement,”<sup>58</sup> this is too little, too late, considering that several years ago, the CDC’s PS18-1802 mandated funded health departments to tackle MHS as a core component of their prevention efforts<sup>59</sup>.

***Wide variation in state-level data sharing environments and legal protections for MHS data.***

Laws protecting the privacy of health 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.<sup>60</sup> The National Association of State and Territorial AIDS Directors (NASTAD) produced an analysis of the legal and regulatory HIV data privacy environment in ten states and found wide variation in how well HIV data is protected and under what conditions personally identifiable data may be shared without the

person’s consent, including sharing HIV data with law enforcement.<sup>61</sup> In particular, NASTAD’s report found that:

“In general, statutes provided health departments with authority to disclose personally identifiable HIV data without consent (emphasis added) for the following general purposes: surveillance, investigation, or control of communicable disease; treatment, payment, research, or health care operations; justifiable public health need. Within this broad statutory authority, a few states enumerated specific allowable and unallowable health department HIV data-sharing activities (particularly for data-sharing related to law enforcement and research). However, the vast majority of statutory schemes used more general language giving discretion to health departments and their legal counsel to act under fairly broad authority as long as the statute’s purposes were met. This lack of specificity in state laws places great importance on health department internal data-sharing policies and gatekeeping functions.”<sup>62</sup>

While every state had protections for reducing data shared with law enforcement, states vary on the strength of the legal protections in place to compel a health department to produce HIV data, and which data may be shared, for law enforcement purposes. Ultimately, much is left up to the discretion of the health department’s legal counsel. Further, there is substantial variation in legal authority to share personally identifiable information of PLHIV for research purposes.<sup>63</sup>

***Risk of potential data misuse in civil, immigration, and/or criminal proceedings.***

As acknowledged in the HIV Plan, over 30 states still have laws criminalizing PLHIV, and even more prosecute PLHIV under other general criminal laws, including assault.<sup>64</sup> Among PLHIV, Black and Latinx people, sex workers, queer and trans people,<sup>65</sup> immigrants, those who are unhoused or marginally housed,<sup>66</sup> people who use drugs, and people who live with mental illness are already frequently targeted by law enforcement.<sup>67</sup> In criminal prosecutions for alleged HIV exposure,

prosecutors may seek to introduce evidence that the defendant or plaintiff is part of a transmission cluster.<sup>68</sup> Judges, prosecutors and juries may be biased due to stigma and may also not understand the science enough to know its limitations (for example, MHS cannot currently demonstrate direct transmission, only whether viruses are closely related). For immigrants of any legal status, it is unclear what protections exist if MHS data were presented in immigration proceedings. This creates further vulnerability for communities already vulnerable to surveillance and policing.

### ***Concerns about breaches of privacy and confidentiality.***

Attention from public health departments and from media linked to “cluster detection” investigations can disclose private health information of PLHIV, even inadvertently. One newspaper in Seattle went so far as to publicly identify a street on which an “HIV outbreak” was happening and to name that the people involved were unhoused, sex workers, and/or drug users.<sup>69</sup> This type of disclosure presents a risk of further targeting from police for PLHIV. Worse, it is well documented that PLHIV have lost jobs,<sup>70</sup> housing, and even their lives<sup>71</sup> as a consequence of disclosure of HIV status. These types of irresponsible actions by public health officials can literally put our lives at risk.

### ***Health department workforces do not have consistent standards for training and implementation that protect people living with HIV from possible harm.***

While the CDC recognizes the need for the public health workforce to receive training in culture and diversity,<sup>72</sup> it is unclear to what extent contact tracers, disease investigators, or cluster detection responders are receiving specific training in the nuances of HIV stigma, disclosure and privacy sensitivities, and risks for community violence and criminalization. Cultural competence is a necessary skill for members of the public health workforce engaged in such sensitive activities, and recommendations from experts support ensuring that under-represented populations, such as PLHIV, are involved in developing effective health solutions.<sup>73</sup>

Dr. George Ayala and other PLHIV have called for not offering partner notification services where PLHIV and other socially marginalized groups are criminalized<sup>74</sup> if the risks of doing so outweigh the benefits.<sup>75</sup> Anecdotally, there are many examples of public health HIV contact tracing activities paving the way for inadvertent disclosure of HIV-positive status in employment settings, housing, and with family members. Significant and ongoing workforce training is necessary to ensure safety for people living with and vulnerable to HIV who may be involved in cluster detection investigations.

In summary, the practice of MHS, 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. MHS and cluster detection practices must be stopped immediately and have no place in any national HIV plan until significant steps are taken to address these concerns. Sharing of HIV data is a sensitive issue and must be thoughtfully considered in real, meaningful partnership with PLHIV networks before it is further implemented.

### ***Opportunities to strengthen HIV data privacy and sharing protections***

Currently, MHS comprises one of four pillars of the EHE.<sup>76</sup> Recent federal budgets have prioritized CDC funding for cluster detection and response<sup>77</sup>, and the CDC is essentially requiring health departments funded under EHE efforts systematically implement and/or scale MHS activities.<sup>78</sup> The HIV Plan also highlights MHS and cluster detection and response among “activities that exemplify improved integration and coordination of efforts” -- which is one of the four primary goals of the HIV Plan.<sup>79</sup> Further, the HIV Plan explicitly names the need to improve coordination “across partners to quickly detect and respond to HIV outbreaks” as a strategy.<sup>80</sup>

The HIV Plan explicitly calls for “enhanc[ing] the quality, accessibility, sharing, and use of data, including HIV prevention and care continuum data and social determinants of health data,” and goes on to describe data sharing across disparate systems as a top priority.<sup>81</sup> Such an expansion of

MHS without strong and consistent data privacy and confidentiality laws, coupled with boundaries on the sharing of HIV genomic sequence data and identifiable information about PLHIV, is dangerous and irresponsible.

Health departments describe the CDC's 2011 guidance on HIV data privacy and security as a crucial resource in informing their own internal data privacy policies.<sup>82</sup> That guidance explicitly states that "data collection and use policies should reflect respect for the rights of individuals and community groups and minimize undue burden."<sup>83</sup> It calls for training of individuals who have access to identifiable health information in policies and

procedures for data sharing, laws governing data sharing, procedures for storing data – but does not require any training in, for example, specific sensitivities around HIV stigma, criminalization, and other dangers of HIV-positive status disclosure.<sup>84</sup>

PLHIV networks are not alone in their call for adequate legal safeguards and community education on MHS. AIDS United's Public Policy Committee has issued a strong set of principles and recommendations to guide the use of MHS.<sup>85</sup> We support many of these recommendations and have provided additional recommendations below:

### Recommendations for Issue Area 2C - Molecular HIV Surveillance

Agency, Federal Body, or Policy	Recommended Action(s)
Department of Health and Human Services	<ol style="list-style-type: none"> <li>1. Work in collaboration with PLHIV networks to develop and implement a process to obtain informed consent from PLHIV before HIV genomic sequence data is collected, analyzed, stored, and/or shared.</li> <li>2. Issue a public statement that affirmatively clarifies that HIV genomic sequence data cannot be used in criminal, civil, or immigration proceedings.</li> <li>3. Work in collaboration with the HIV Caucus to develop consistent national standards on HIV data security, sharing, and storage that explicitly prohibit sharing HIV genomic sequence data with law enforcement, immigration enforcement, employers, and other relevant entities and which limit the amount of time HIV data can be stored and how it may be shared.</li> </ol>
Ending the HIV Epidemic Plan	<ol style="list-style-type: none"> <li>1. Remove the requirement that EHE-funded jurisdictions conduct MHS activities.</li> <li>2. Prohibit EHE-funded jurisdictions from conducting MHS activities if they cannot meet the security, storage, and data-sharing standards described above.</li> </ol>
HIV National Strategic Plan	<ol style="list-style-type: none"> <li>1. Remove MHS and all cluster detection and response activities from the HIV Plan until the above issues have been addressed.</li> </ol>
White House Office of National AIDS Policy	<ol style="list-style-type: none"> <li>1. Declare an immediate moratorium on the further collection, use, and sharing of MHS data in public health efforts until the above standards are achieved.</li> <li>2. Develop community engagement standards that require active involvement from PLHIV networks in any future development of HIV-related data collection, use, sharing, and storage.</li> </ol>

Centers for Disease Control and Prevention	<ol style="list-style-type: none"> <li>1. Require that any jurisdictions funded to conduct MHS prove they can meet the standards created above.</li> <li>2. Require certification from state and local jurisdictions that public health officials will comply with CDC data security guidance and only share data with law enforcement pursuant to a valid, enforceable court order issued following notice to the subject(s). Effective notice should both inform subjects that their data has been sought and provide them an opportunity to oppose disclosure in court.</li> <li>3. Fund initiatives to educate public health department staff and legal counsel on the legal safeguards and required processes and protections for disclosing public health information to law enforcement.</li> <li>4. Make funding for MHS and research based on MHS contingent upon such certification.</li> <li>5. Partner with the HIV Caucus to develop and implement a curriculum for relevant public health workforce staff inclusive of content on HIV stigma, HIV criminalization, cultural sensitivities on HIV, and risks of HIV status disclosure.</li> <li>6. Require that all staff involved in disease investigation, contact tracing, partner notification, MHS, and cluster detection response receive this training.</li> <li>7. Require that HIV genomic sequence data be stored in an anonymized form that cannot be re-identified. This should include the use of advanced anonymization techniques that make molecular surveillance data resistant to re-identification by algorithms or humans.</li> <li>8. Develop standardized, publicly available disclosures to ensure that PLHIV are informed of routine and potential use of their identifiable health information, including any contemplated use of individual, identifiable treatment information and resistance testing results, and including their right to object to having their data used in this this way.</li> </ol>
--	---

### Issue Area 3: Addressing Inequities in the Federal Response: Attend to Racial and Gender Disparities

#### *Addressing Racial and Gender Inequities in the Federal Response: Defining the Issue*

**Racial Inequities.** HIV has a disproportionate impact on Black, Latinx, and Indigenous communities which is inadequately addressed by every domestic HIV plan. The CDC has consistently found that Black and Latinx communities are disproportionately affected by HIV compared to other racial/ethnic groups. For example, while Black individuals represented 13 percent of the U.S. population, they represented 41 percent of PLHIV in 2018 CDC data.<sup>86</sup> While Latinx individuals represented 18 percent of the population, 23 percent of PLHIV were Latinx in the same year.<sup>87</sup> In the U.S., gay and bisexual men - particularly Black, Latinx and Indigenous - constitute the majority of new HIV diagnoses, yet this is not reflected in funding and resources for community-led programs.<sup>88</sup>

Among cisgender and transgender women, Black women are disproportionately affected by HIV as compared to women of other races/ethnicities.<sup>89</sup> From 2014-2018, the rate of new HIV acquisitions among cisgender Black women was 13 times that of white women and four times that of Latinx women.<sup>90</sup> Further, in 2017, Black Americans had an age-adjusted HIV-related death rate of 6.6 per 100,000, compared to 0.9 per 100,000 for white Americans.<sup>91</sup>

The impacts of structural racism<sup>92</sup> are not limited to relative rates of HIV acquisition. They impact all areas of life, including economic opportunity and justice, well-being, and mental health care. Until structural racism and racism within the HIV epidemic is explicitly recognized and addressed, the HIV epidemic will not end. Expanding biomedical responses without attention to the racism that prevents Black, Latinx, and Indigenous people from accessing HIV prevention, care, and treatment in the first place will only further the racial disparities in the HIV epidemic. Instead, the focus must be on structural and social drivers of health; dismantling oppressive, discriminatory systems; and understanding and ameliorating the

effects of understandable medical mistrust.

**Gender Inequities.** Women, including women of trans experience, account for about a quarter of the domestic HIV epidemic.<sup>93</sup> In 2018 alone, an estimated 7,189 cisgender women and 554 transgender women were newly diagnosed with HIV in the United States.<sup>94</sup> The single largest percentage increase in the number of persons living with HIV from 2014 through 2018 by gender was among transgender women.<sup>95</sup> Gender disparities are also racialized and geographic: Black, Latinx, and other women of color represent a majority of women living with HIV in the United States and a majority of new HIV acquisitions.<sup>96</sup>

Black cisgender women, who live at the intersection of anti-Black racism and gender-based oppression, are disproportionately impacted by HIV.<sup>97</sup> Cisgender women with HIV are concentrated in the South, which in 2018 had more reported HIV acquisitions (3,988) among adult women and adolescents than any other region.<sup>98</sup>

In health care settings, stigma and bias against transgender people may compromise access to quality services, as well as policies restricting what can be covered by payer sources. Transgender people face discrimination in all aspects of life, from housing to health care, from public accommodations to policing, from employment to education. Again, race and gender intersect in complex ways: Black, Indigenous, and other transgender people of color face even higher rates of discrimination and violence in these settings. In health care settings, stigma and bias against transgender people itself may compromise access to quality services, as well as policies in the form of structural stigma that restrict what can be covered by payer sources. While important moves have been made to restore non-discrimination protections, for transgender people living with HIV, it can still be nearly impossible to find culturally relevant and non-stigmatizing health services and providers.

Transgender and cisgender women living with and at risk for HIV face severe challenges to accessing services, health care, and information they need, including socioeconomic and

structural barriers such as poverty, cultural inequities, and intimate partner violence (IPV).<sup>99</sup> Women living with HIV are more likely to receive some care, but less likely to be retained in care, as compared to the statistical average person living with HIV.<sup>100</sup>

The rates of death among PLHIV reflect this disparity, as cisgender women, transgender women, Black people, people of more than one race, and people in the South saw smaller gains in their rates of deaths from HIV from 2010 until 2018 than other PLHIV, and women are more likely to die of HIV related complications than men.<sup>101</sup> Higher percentages of cisgender women and transgender women who are clients of the Ryan White HIV/AIDS Program are living below the federal poverty line than men.<sup>102</sup> Fifty-five percent of women living with HIV report experiences of intimate partner violence, and the associated trauma can also lead to poor treatment outcomes and higher transmission risks.<sup>103</sup> Without focused attention to racial and gender inequities, these interrelated disparities will continue to persist.

### ***Racial and Gender Disparities: Opportunities to Strengthen Federal Leadership***

As noted above, both the EHE and the HIV Plan do not provide enough focus and concrete steps to address gender or racial disparities as they pertain to PLHIV. The racial inequalities of the federal response can be more firmly grasped by reviewing the way funding is provided to grantees as part of the EHE plan.<sup>104</sup> The first three Notice of Funding Opportunities<sup>105</sup> make no mention of racial disparities as it pertains to HIV, except to give an example of a program focused upon Black men who have sex with men.<sup>106</sup> However, addressing the needs of Black, Latinx, and Indigenous people who are disproportionately affected by the epidemic is not mentioned in any of these three funding opportunities.<sup>107</sup> Even when Black, Latinx, Indigenous, and people of color do begin to be noted as under-served populations, there is no focus outside of viral suppression<sup>108</sup> or access to PrEP.<sup>109</sup> HIV-related stigma as it intersects with racial disparities is only mentioned in one funding

opportunity, and there it is not substantively addressed.<sup>110</sup>

As with racial disparities, cisgender women<sup>111</sup> and transgender people are generally not prioritized in funding decisions. When women are mentioned, it is generally in the context of PrEP access or testing,<sup>112</sup> not sexual and reproductive health care needs, care-taking responsibilities, or the other unique needs of women. Even when women are addressed in funding opportunities, these opportunities are grossly underfunded when compared to the scale of the issues.<sup>113</sup>

While racial disparities have been more fully addressed in the HIV Plan, which includes concrete commitments to strengthen civil rights laws,<sup>114</sup> its discussion of other social and structural drivers of health which result in racial disparities is lacking.<sup>115</sup> While these issues<sup>116</sup> are addressed more broadly as they relate to all under-served populations, there are no commitments to address these issues directly as to how they impact Black, Latinx, and Indigenous communities.<sup>117</sup>

Similarly, gender disparities also receive a more complete, yet still inadequate treatment in the HIV Plan. We are pleased to see that transgender and Black women are noted as priority populations.<sup>118</sup> Further, the need to scale up trauma-informed services is included as a goal.<sup>119</sup> The need for comprehensive, supportive services for transgender individuals as well as a discussion of the challenges that exist is present; however, the indicators of success are biomedical indicators of viral suppression.<sup>120</sup> Still, the HIV Plan makes no mention of sexual and reproductive health,<sup>121</sup> of gender specific disparities in employment and housing, and other challenges to care and well-being that exist, such as care-taking responsibilities, discrimination based upon gender, and mistrust of medical professionals.

## Recommendations for Issue Area 3 - Inequities in the Federal Response

Recommended Agency, Federal Body, or Policy	Recommended Action(s)
White House/Office of National AIDS Policy	<ol style="list-style-type: none"> <li>1. Explicitly center racial equity throughout the federal HIV response by including Black, Latinx, Indigenous, and other people of color as priority populations in funding opportunities.</li> <li>2. Explicitly include racial and gender disparities as elements to be addressed in all grant funded opportunities.</li> </ol>
Department of Health and Human Services	<ol style="list-style-type: none"> <li>1. Fund via grants Black-led organizations addressing the epidemic through a racial equity lens.</li> <li>2. Fund programs led by women and people of trans experience to address the HIV epidemic through a gender equity lens.</li> </ol>
End the HIV Epidemic Plan	<ol style="list-style-type: none"> <li>1. Require that jurisdictional resources be targeted for 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.</li> <li>2. Create funding opportunities that specifically address social and structural drivers of health as they relate to Black, Indigenous, and other people of color.</li> <li>3. Prioritize funding for organizations run by members of the communities to be served.</li> <li>4. Require grantees to include intimate partner violence screenings in health care and supportive service settings.</li> <li>5. Require jurisdictions to create and fund programs that provide care-taking services for the dependents of PLHIV while they are receiving services.</li> </ol>
HIV National Strategic Plan	<ol style="list-style-type: none"> <li>1. Include a racial and gender equity lens that is informed by the direct inclusion of community by hiring them as staff in federal agencies and paying them for their work.</li> <li>2. Utilize multiple factors to gauge the success of the HIV Plan outside of viral suppression.</li> </ol>

## **Issue Area 4. Add Sex Workers and Immigrants Living with HIV as Priority Populations Throughout the Federal Response.**

### ***Sex Workers Living with HIV: Defining the Issue***

Sex workers are at a greater vulnerability for acquiring HIV and other STIs than the general population.<sup>122</sup> For transgender women, those who had ever done sex work were over 25 times more likely to be living with HIV (15.32 percent) than the general population (0.6 percent).<sup>123</sup> This is due to various social and structural factors that create substantial barriers to HIV prevention, treatment, and care, such as criminalization of sex work, lack of employment protections for sex workers, and intersections between poverty and sex work, which may increase vulnerability in the first place.

Criminalization of sex work takes many different forms, including targeted and often racist,<sup>124</sup> homophobic, and/or transphobic policing of people perceived to be engaged in sex work under various forms of loitering laws, “condoms as evidence” laws—which create a structural barrier to sex workers protecting their own sex health—and intersections with HIV criminalization laws.<sup>125</sup>

Sex workers are also at increased risk for violence from community and from law enforcement,<sup>126</sup> and, in many U.S. states and territories, bear the brunt of HIV-related prosecutions, convictions, and sentence enhancements.<sup>127</sup> Practices such as “cluster detection and response,” under the umbrella of MHS activities embedded in the EHE’s implementation, have even led to media disclosures that specifically name streets where sex workers and people who use substances live and/or work.<sup>128</sup> HIV services and government programs may themselves stigmatize and structurally exclude people in the sex trade.<sup>129</sup>

To truly end the HIV epidemic, the HIV Plan must assure that competent and non-stigmatizing HIV services are provided to sex workers and that sex workers can safely participate in HIV services and benefit from other publicly funded programs without fear of judgment, criminalization, exclusion, or confidentiality violations. To ensure this is possible, sex work

must be fully decriminalized; HIV-related sentence enhancements for sex work must be repealed; and sex workers, especially from Black, Indigenous and people of color communities, should be meaningfully engaged as partners in designing and implementing HIV prevention, care, and anti-stigma efforts.

### ***Immigrants Living with HIV: Defining the Issue***

Immigrants have been excluded from most health services due to legislative and regulatory exclusions.<sup>130</sup> Even with the advent of the ACA, millions of undocumented individuals remain unable to access health care and other services that support access to health care.<sup>131</sup> In addition, fear for safety and language injustice persist as barriers, particularly in the last five years.

Regulatory barriers have been erected to prevent immigrants living with HIV from accessing systems of care they need and have a right to, including health care.<sup>132</sup> These barriers have fueled medical mistrust and service avoidance among immigrant communities, specifically Black, Latinx, and Asian communities – communities that intersect with the HIV Plan’s named priority populations.<sup>133</sup> For example, in 2019, the Trump administration promulgated a rule radically redefining the “public charge” test, essentially punishing some immigrants for relying on public programs like health care, housing and nutrition programs.<sup>134</sup> While the Trump administration’s rule has been blocked, the chilling effect<sup>135</sup> will be long-lasting and will exacerbate health disparities.

In addition to traditional medical service providers, the U.S. Immigration and Customs Enforcement (ICE) has been utilized and is tasked with providing care to immigrants in detention centers.<sup>136</sup> Carceral systems, including ICE detention centers, have consistently failed to provide quality and competent health care to immigrants living with HIV. ICE’s gross medical negligence has led to the death of some.<sup>137</sup> Roxsana Hernández and Johana Medina, both transgender women, sought asylum in the U.S. based on their HIV status, but were denied medical care and died in ICE custody. Despite the legal requirement to provide immigrants in detention with medical treatment and care, ICE

refused to provide HIV treatment for Hernandez, resulting in her death.<sup>138</sup> The HIV Plan cannot ignore the detrimental impact detention and incarceration has on migrants living with HIV -- this must be included in any plan to address the HIV epidemic, regardless of someone's immigration status.

For non-English speaking immigrants, language barriers may play a role in exacerbating health disparities for marginalized communities.<sup>139</sup> The HIV Plan briefly mentions language barriers but fails to convey the ways that culture is embedded in language, and thus that translation and interpretation go beyond a straightforward word-for-word translation. Language justice is about access, in terms of its accessibility and engagement with communities. It is about making health terms and information understood and communicated within cultural context, with cultural relevance, so that community members can make thoughtful health choices and assert their decisions. To achieve the prevention and care goals of the HIV Plan, immigrants of any legal status and immigrants who do not speak, read, or write English must be assured high-quality HIV prevention, care and facilitative services; must be able to participate safely and without financial or legal repercussions in HIV programs; and must have unfettered access to treatment.

### ***Opportunities to Strengthen the Federal Domestic HIV Response for Sex Workers and Immigrants***

The HIV Plan currently recognizes five populations as "priority populations":

1. gay, bisexual, and other men who have sex with men, in particular Black, Latino, and American Indian/Alaska Native men;
2. Black women;
3. transgender women;
4. youth aged 13-24; and
5. people who inject drugs.<sup>140</sup>

Notably absent from the HIV Plan are sex workers and immigrants, two communities that have specific needs in relation to HIV and which are often structurally absent from decision-making and advisory processes, for a range of reasons.

While the final version of the HIV Plan does minimally mention sex work and immigration status in the context of stigma and discrimination,<sup>141</sup> it fails to articulate a commitment to address these needs systematically throughout the federal response, for example within HIV prevention and care efforts; nor does the HIV Plan articulate concrete strategies that could better meet the goal of reducing HIV-related stigma and discrimination for these populations, improve their engagement in health care, and eliminate barriers to HIV prevention efforts.

## Recommendations for Issue Area 4 - Sex Workers and Immigrants as Priority Populations

Recommended Agency, Federal Body, or Policy	Recommended Action(s)
White House/Office of the President	<ol style="list-style-type: none"> <li>1. Advocate for legislation to prohibit the practice of using condom possession as evidence of sex work</li> <li>2. Modify or eliminate existing federal policies that conflate sex work and human trafficking and that prevent sex workers from accessing services such as health care, HIV prevention, and support.</li> <li>3. Work with the Office of the Global AIDS Coordinator to repeal “anti-prostitution pledge” requirements entirely from PEPFAR and anti-trafficking funds.</li> <li>4. Ensure health care access regardless of an individual’s immigration status.</li> <li>5. Prioritize funding to community-based organizations led by and/or serving immigrant populations.</li> </ol>
Department of Health and Human Services	<ol style="list-style-type: none"> <li>1. Implementation plans for the HIV Plan should address training of health care professionals to end stigma and discrimination against those who are involved in the sex trade.</li> <li>2. Prioritize funding for harm reduction and rights-based health care services for sex workers of all genders and all ages.</li> <li>3. Require meaningful engagement of Black, Latinx, Indigenous, and other people of color communities-- especially PLHIV, people who use drugs, immigrants, sex workers, people of trans experience, and gay and bisexual men--in HIV planning and resourcing in every health jurisdiction.</li> <li>4. Fund CBOs to strategize, inform, and implement programs and policies in the HIV response.</li> <li>5. Develop and implement community-accountability models for public health jurisdictions to ensure that those most marginalized are indeed reached.</li> </ol>
Centers for Disease Control and Prevention	<ol style="list-style-type: none"> <li>1. Issue a statement that explains how laws that rest on condom possession as evidence of sex work harm HIV prevention, testing, and clinical care efforts and may place sex workers at risk for violence.</li> </ol>
Congress	<ol style="list-style-type: none"> <li>1. Pass the SAFE Sex Worker Study Act of 2021</li> <li>2. Pass the HEAL for Immigrant Families Act of 2021</li> <li>3. Pass the American Dream and Promise Act of 2021</li> <li>4. Repeal exclusions and eliminate policies that prevent and/or hinder individuals with commercial sex and drug-related convictions from applying for and/or receiving student loans, public housing or housing assistance, public assistance, or other government-funded social services.</li> </ol>

<p>HIV National Strategic Plan</p>	<ol style="list-style-type: none"> <li>1. Add sex workers as a priority population.</li> <li>2. Add immigrants, of any legal status, as a priority population.</li> <li>3. Explicitly recommend resourcing for community-led organizations and programs for people of color, especially in the following communities: people living with HIV, people who use drugs, immigrants, sex workers, people of trans experience, and gay and bisexual men.</li> <li>4. Discourage “general public” approaches in the HIV response. This “general public” affirms a white, cisgender, able-bodied, middle class norm that excludes everyone else.</li> <li>5. Explicitly name and call for addressing the criminalization of sex work and stigma and discrimination against sex workers as a barrier to HIV prevention, care, and anti-stigma efforts.</li> <li>6. Prioritize funding and partnership opportunities with community-based organizations led by and for sex workers.</li> <li>7. Prioritize funding for in-person interpreters and other translation services for people with limited English proficiency.</li> <li>8. Prioritize funding immigrant-led and immigrant- serving community-based HIV organizations for communication and health literacy programs.</li> <li>9. Require AIDS service organizations (ASOs) to staff certified medical interpreters and/or train staff on proper interpreter utilization.</li> <li>10. Ensure that translation includes understanding cultural contexts and frameworks for health, disease, and treatment options.</li> </ol>
<p>End the HIV Epidemic Plan</p>	<ol style="list-style-type: none"> <li>1. Require EHE-funded jurisdictions to demonstrate a commitment to decriminalizing commercial sex work, including addressing loitering laws and condoms as evidence laws.</li> <li>2. Require EHE-funded jurisdictions to include resources for community mobilization of sex workers to respond to violence and discrimination.</li> </ol>

## **Issue Area 5. Affirmatively Commit to Improving Quality of Life for People Living with HIV.**

### ***Improving Quality of Life for People Living with HIV: Defining the Issue***

Although there are more than a million PLHIV in the United States, quality of life for PLHIV has long been an afterthought in the federal HIV response. While the HIV Plan makes “improv[ing] the health-related quality of life” for people aging with HIV a “key commitment”<sup>142</sup> and also seeks to both develop and scale interventions to improve quality of life for people living with HIV,<sup>143</sup> it does not do so in a broad and inclusive way. Both descriptions of quality of life included in the HIV Plan focus on viral loads, viral suppression, and other health-related outcomes.<sup>144</sup> While these biomedical markers are components of the quality of life for PLHIV, they are not an acceptable proxy for a well-rounded understanding of well-being or quality of life.

Instead, the HIV Plan and other federal responses to HIV must value and create concrete metrics for emotional, mental, psychological, spiritual, and physical wellness - irrespective of viral suppression. Quality of life for PLHIV must be measured by a key set of metrics in any plans to address the HIV epidemic, and the federal HIV response must acknowledge that commitments to quality of life for people living with HIV must continue as long as people living with HIV are here. The human right to quality of life for people living with HIV, and the federal government’s responsibility to assure that, does not end even when we get to zero new HIV acquisitions. Thus, quality of life for people living with HIV deserves its own pillars in the HIV Plan and the EHE, along with commensurate strategies, metrics, and indicators to measure success.

Quality of life is interrelated with social and structural drivers of the HIV epidemic and of worse health outcomes for some PLHIV. It is interlinked with and inseparable from upholding human rights for people living with HIV, as described above. For decades, far too little attention has been paid in the federal government’s HIV response to the social and structural drivers of

inequity. While the HIV Plan includes some of these important social and structural factors, such as systemic racism, safe and affordable housing, access to culturally competent, trauma-informed health care, and gender disparities, it could be strengthened by concrete commitments to strategies and solutions. The EHE is completely missing an explicit analysis of and commitment to social and structural drivers of inequity. Until these factors are addressed explicitly and with firm commitments, any plan to address the national HIV epidemic will be unsuccessful and will not adequately address the needs of PLHIV.

There is a lack of consensus in the academic and medical community on the specific dimensions of quality of life, but it is generally understood as being multifaceted and concerning a person’s own perception of their well-being and level of functioning in important areas of their life.<sup>145</sup> There are various scales that have been utilized in measuring the quality of life of people living with HIV.<sup>146</sup> One omnipresent problem is that most of these metrics focus on biomedical markers, and inadequate research has been done on what quality of life means for people living with HIV beyond these markers.

Additional research is required to determine what scale and metrics are the best measure(s) of the quality of life for people living with HIV, with an understanding that this metric may be different for individuals who are Black, Indigenous, and other people of color; cisgender; transgender; sex workers; immigrants; and of different geographies, due to racism, poverty, homophobia, transphobia, and lack of language justice.<sup>147</sup>

### ***Opportunities to Strengthen the Federal Domestic HIV Response for Quality of Life for People Living with HIV***

Priorities that continue to arise in conversations with our PLHIV networks concerning quality of life include employment; economic justice; health care costs and quality; the availability of non-stigmatizing and high-quality sexual and reproductive health care for PLHIV; access to trauma-informed care and services; and ending enacted, internalized, interpersonal, community, and institutional stigma.

Any plan to end the HIV epidemic must center these priorities and include them as concrete metrics in its plan.

### Recommendations for Issue Area 5 - Quality of Life for People Living with HIV

<b>Recommended Agency, Federal Body, or Policy</b>	<b>Recommended Action(s)</b>
Department of Health and Human Services	<ol style="list-style-type: none"> <li>1. Promulgate regulations requiring private insurers to uphold the HIV Plan’s minimum standard of care for all PLHIV.</li> <li>2. Lead the creation of report cards<sup>148</sup> on the state of quality of life for PLHIV in the country and the quality of care provided by federally funded programs and services.</li> </ol>
National Institutes of Health	<ol style="list-style-type: none"> <li>1. Fund research into developing a standard quality of life assessment for people living with HIV focused on quality of life outside of biomedical indicators.</li> </ol>
Centers for Medicare and Medicaid Services	<ol style="list-style-type: none"> <li>1. Adopt the minimum standard of care developed in the HIV Plan and incorporate it into care provided by CMS.</li> </ol>

<p>HIV National Strategic Plan</p>	<ol style="list-style-type: none"> <li>1. Set a minimum standard for quality of life for PLHIV which includes: <ol style="list-style-type: none"> <li>a. Opportunities for employment and education for all people living with HIV.<sup>149</sup></li> <li>b. Increasing the ease of transferring benefits across jurisdictions.</li> <li>c. Access to long-term sustainable housing for people living with HIV.<sup>150</sup> This should include senior housing for aging PLHIV and housing for PLHIV with dependents.</li> <li>d. Services for people living with HIV should incorporate access to nutrition service programs, including SNAP.<sup>151</sup></li> </ol> </li> <li>2. PLHIV who receive health care from any payer source should have a minimum standard of care<sup>152</sup> which: <ol style="list-style-type: none"> <li>a. Is culturally relevant and affirms and funds the sexual and reproductive health care needs of people with HIV at all life stages and of all gender identities, including transgender women.<sup>153</sup> This should include reporting mechanisms which are easily understood by and communicated to people living with HIV;</li> <li>b. Provides mental health services and the choice of mental health provider to people living with HIV;</li> <li>c. Provides affordable health care coverage, where total health care costs (inclusive of premiums, medications, copays, etc.) do not exceed 9.83 percent<sup>154</sup> of the income of a person living with HIV; and</li> <li>d. Practices trauma-informed care, including screening and intervention for lifetime abuse and intimate partner violence, in HIV clinical and community-based settings.</li> </ol> </li> <li>3. Express support from the federal government for the repeal of HIV criminalization, which acknowledges the role it played in advancing these laws; education to state legislatures on their harms; and conditioning funding on their modernization or repeal.</li> <li>4. The incorporation and study of accurate stigma metrics.<sup>155</sup></li> <li>5. Require that all materials on HIV-related services be translated into the primary languages spoken in the jurisdiction and incorporate translation services into clinical and supportive service settings for people living with HIV.</li> <li>6. Incorporate quality of life surveys into federally funded clinical and supportive service settings, with the aim of using the data to connect people to additional support, including psychological, spiritual, and emotional support systems.</li> </ol>
------------------------------------	--

## **5A. Establishing a Strong Safety Net for People Living with HIV**

### ***Economic Justice and Employment for People Living with HIV***

Economic justice does not have a set definition but can be understood as principles and practice that allow for PLHIV to live without negative employment or economic consequences related to their health status, disability, sex, gender or gender expression, sexual orientation, family responsibilities, and/or race or ethnicity.

Maintaining access to health care and economic stability can entrap PLHIV in poverty. Policies for ongoing eligibility for Supplemental Security Income (SSI)/Social Security Disability Income (SSDI), Medicaid/Medicare, AIDS Drug Assistance Programs (ADAPs), Housing Opportunities for Persons with AIDS (HOPWA), and other programs designed to improve health and well-being, are complex and serve as disincentives to employment for people living with HIV or other chronic health conditions and disabilities.<sup>156</sup> The lack of assistance to understand and navigate these policies can also serve as a disincentive or barrier to employment for enrolled PLHIV concerned about protecting their health and well-being and that of their families.

In addition, the lack of portability of benefits can prevent PLHIV from relocating to environments where they might thrive. PLHIV who are economically reliant on or choose employment receive little to no access to employment-related information, services, or resources to enable well-informed decisions about work or facilitate self-determined plans for employment and economic health and well-being.

Economic justice for PLHIV must also include a commitment to recruiting and training community members to join the expanded HIV workforce. PLHIV are the subject matter experts on programs that support PLHIV and are expert navigators. We encourage a creative approach to valuing lived experience as qualification for these positions beyond formal education requirements. When adding PLHIV to the HIV workforce, they must be at all levels of leadership, not simply

relegated to the frontline staff, peer support staff, or testing and outreach.

Access for all PLHIV to non-discriminatory, non-stigmatizing employment-related information, services, and resources has not been developed in most of the country, nor prioritized by public health or workforce development systems, despite more limited access to disability benefits, and high rates of poverty, unemployment, and underemployment for PLHIV. The public health system response to HIV has deferred attention to employment needs of PLHIV to the workforce development system, which does not prioritize health and well-being strategies or outcomes, nor implement policies or training, to ensure effective, responsive service delivery based on understanding distinct needs and issues of priority populations disproportionately impacted by HIV.

## Recommendations for Issue Area 5A - Economic Justice and Employment

<b>Recommended Agency, Federal Body, or Policy</b>	<b>Recommended Action(s)</b>
White House/Office of the President of the United States	<ol style="list-style-type: none"> <li>1. ONAP to be responsible for convening a federal and community workgroup including representation of the Employment and Training Administration (ETA) of the Department of Labor, the Department of Education, the Department of Housing and Urban Development, the Department of Justice, the Social Security Administration, the Centers for Medicaid and Medicare Services (CMS), HHS Health Resources and Services Administration HIV/AIDS Bureau (HRSA/HAB), PLHIV networks, and other community leaders to outline strategies to eliminate economic and employment inequities for PLHIV and facilitate self-determined transitions to work without risk to health and well-being.</li> </ol>
HIV National Strategic Plan	<ol style="list-style-type: none"> <li>1. Establish access to benefits counseling/advisement for PLHIV enrolled in or eligible for SSI/SSDI, Medicaid/Medicare, ADAPs, HOPWA, and other programs designed to improve health and well-being, for well-informed and well-supported employment-related decision-making and transitions of PLHIV allowing maximal protection of health care, financial, and housing supports.</li> <li>2. Assign responsibility to the Social Security Administration (SSA), CMS, HRSA/HAB, and HUD Office of HIV/AIDS Housing (HUD/OHH) for collaborating with community leaders to evaluate program policies for impacts on considering and navigating employment transitions for PLHIV and for identification of updates needed to policies designed to reduce barriers and disincentives to working and optimize health and well-being.</li> <li>3. Design portability of benefits between jurisdictions so PLHIV can more as needed or desired.</li> <li>4. Require a formal HIV workforce recruitment and training program to hire PLHIV and commit to a targeted number or percentage of PLHIV in the HIV workforce.</li> <li>5. Revise policy of the HRSA/HAB to allow direct service responses to employment needs of PLHIV within the Ryan White HIV/AIDS Program (RWHAP), recategorizing employment services as allowable for funding among RWHAP supportive services addressing core needs of PLHIV.</li> <li>6. Ensure implementation of a RWHAP-centered community-led PLHIV employment initiative, with designated funding from the ETA, and ETA's collaboration in its implementation with HRSA/HAB.</li> <li>7. Establish ongoing training in the AIDS Education and Training Centers (AETCs) of HRSA/HAB for HIV service providers on employment service delivery, linking and partnering with the workforce development and vocational rehabilitation systems, and interactions between work earnings and health care/treatment coverage, financial, and housing benefits.</li> </ol>

Congress	<ol style="list-style-type: none"> <li>1. Require SSA to update long-unchanged work incentive policies and calculations to increase the ability of PLHIV and other people with disabilities and chronic health conditions to attempt working with increased health coverage, financial, and housing security.</li> <li>2. Require SSA to fund the establishment of accessible online information resources accurately reflecting policies applicable in each U.S. state and territory.</li> <li>3. Allocate additional funds for SSA's Work Incentives Planning and Assistance (WIPA) program to more realistically scale up staffing proportionate to needs of PLHIV and other disabled SSI/SSDI beneficiaries for individualized in-person and remote benefits counseling/advisement, from considering work through transitions to employment.</li> <li>4. Include designated funds to address employment needs of PLHIV through public health and workforce development collaboration in the upcoming reauthorization of the Workforce Innovation and Opportunity Act (WIOA).</li> </ol>
----------	---

***Housing as a Human Right and Necessary Precursor to Care and Treatment for People Living with HIV***

It has long been understood by PLHIV, researchers, activists, and policy makers that housing is a form of health care for people living with HIV.<sup>157</sup> Despite this knowledge, housing instability remains a primary concern for PLHIV,<sup>158</sup> as many federal housing programs are underfunded and under-resourced.

PLHIV are at a much higher risk of being unstably housed or homeless than the general population. In 2016, the U.S. Department of Housing and Urban Development (HUD) Office of HIV/AIDS Housing published data showing that an estimated 145,366 PLHIV in the United States, or about 12 percent of all PLHIV, have a current unmet housing need.<sup>159</sup> This data showed that 44 percent needed ongoing assistance to pay rent, 36 percent sought supportive housing placement, and 20 percent had short-term emergency assistance needs to secure or maintain housing.<sup>160</sup>

A lack of stable housing is not only an issue of a lack of shelter for PLHIV. Numerous studies have shown that it has a deleterious effect on the health outcomes for PLHIV, including mental health outcomes.<sup>161</sup> A lack of stable housing also affects a person's ability to obtain and maintain employment.<sup>162</sup>

These effects are not experienced equally by all PLHIV. Instead, there are stark differences in housing instability, and its effects, based upon an individual's race, age, and gender. People of transgender experience are more likely to be unstably housed than cisgender men and women.<sup>163</sup> Black, Indigenous, and other people of color are also more likely to be homeless in America when compared to the national average and white American.<sup>164</sup> In order to effectively implement any federal response to addressing the HIV epidemic and the health and equality of life for PLHIV, housing insecurity will need to be addressed.

## Recommendations for Issue Area 5A - Housing

Recommended Agency, Federal Body, or Policy	Recommended Action(s)
White House/Office of the President of the United States	<ol style="list-style-type: none"> <li>1. Call for HOPWA to be funded at \$600 million in the President’s Budget Request.</li> <li>2. Call for Increased funding for federal housing programs relied on by people living with HIV such as Housing Choice Vouchers, rental assistance, and subsidized housing in the President’s budget request.</li> </ol>
Department of Justice	<ol style="list-style-type: none"> <li>1. Enforce the Fair Housing Act to address discrimination against women; immigrants; LGBTQ individuals; Black Indigenous, and other people of color; and people with criminal convictions.</li> </ol>
HIV National Strategic Plan	<ol style="list-style-type: none"> <li>1. Include concrete housing metrics in the implementation plan, such as: 90 percent of PLHIV are in long-term stable housing.</li> <li>2. Include concrete commitments that people aging with HIV have access to senior housing.</li> </ol>
Ending the HIV Epidemic Plan	<ol style="list-style-type: none"> <li>1. Consider housing availability and create metrics and programs to increase housing access among people living with HIV in developing jurisdictional plans.</li> <li>2. Address the quality of life metrics created by the HIV Plan in creating jurisdictional plans.</li> </ol>

### **Food and Nutrition Security for People Living with HIV**

Many PLHIV rely on federally funded programs to access essentials like food and nutrition services, often through the Supplemental Nutrition Assistance Program (SNAP). This can be demonstrated by membership data collected by Positive Women’s Network - USA, which consistently indicates that between 40-50 percent of the women and people of trans experience living with HIV who are members of the organization depend on SNAP to feed themselves and their families.<sup>165</sup>

These food assistance programs are critical for PLHIV to receive good nutrition, which in turn supports overall health, helps with immune system function, and can help maintain a healthy weight, which helps with the absorption of HIV medicines. Reducing the stress associated with food insecurity also improves the overall quality of life for PLHIV. Further, a recent study showed that the rate of HIV diagnoses is associated with a state income limit for SNAP eligibility, meaning the higher the income limits a state imposes is related

to higher numbers of HIV acquisitions.<sup>166</sup>

Currently, many SNAP eligibility requirements are harsh, and the benefits are insufficient. In 2018, SNAP benefits averaged only \$1.40 per person, per meal.<sup>167</sup> Even the maximum benefit, which is the equivalent of \$1.86 per meal, does not cover the cost of a meal in 99 percent of continental counties and Washington, DC.<sup>168</sup> Benefits at this level cannot support an individual’s or family’s nutritional needs. While the benefits are intended to be supplemental, many participants contend that the benefits levels are too low to assist them with purchasing food for the month.

SNAP is a program with very low rates of fraud, but its administrative burdens often make it so those who need the benefits cannot access them. While some of the harsh requirements have been relaxed during the pendency of the COVID-19 pandemic, more long term changes are required for the benefits of the program to be realized by everyone who needs them. These burdens include lengthy applications, high documentation requirements, in-person interviews, and the need to recertify or reapply to maintain benefits.

These requirements prevent some individuals who are eligible for SNAP from receiving them, though they could use the benefits to lift themselves and their families out of poverty. An example of this can be seen in a recent Michigan study, which found that half of SNAP recipients who lost their

benefits during their first year of enrollment were still eligible for SNAP when they left the program.<sup>169</sup> These burdens and the inadequate benefits hinder a program which could be an important mechanism to improving the quality of life for PLHIV.

## Recommendations for Issue Area 5A - Food and Nutrition Security

<b>Recommended Agency, Federal Body, or Policy</b>	<b>Recommended Action(s)</b>
Department of Agriculture	<ol style="list-style-type: none"> <li>1. Account for local and regional costs of living in determining SNAP benefit levels.</li> <li>2. Continue the SNAP extensions of the 3-month work requirement period implemented during the COVID-19 pandemic.</li> <li>3. Incentivize states to remove additional administrative SNAP burdens and work requirements.</li> <li>4. Simplify the administrative burdens of SNAP by continuing the elimination of in person visits, permitting online recertification, increasing waivers, telephonic benefits applications, and extending recertification periods. This could also be achieved by providing funding to states to receive the technology required for implementing telephonic benefit applications and online recertifications.</li> </ol>
Congress	<ol style="list-style-type: none"> <li>1. Repeal the ban on SNAP and TANF for individuals with felony drug convictions contained in 21 U.S. Code § 862a.</li> <li>2. Increase SNAP's maximum allotment by 15 percent and raise the minimum benefit to \$30 per month from its current level of \$16 per month.</li> </ol>

## **5B. Improving Health Care Access and Quality of Health Care for People Living with HIV**

### ***Health Care Access for People Living with HIV***

About 50 percent of PLHIV in the U.S. are not receiving regular HIV-related care.<sup>170</sup> It is therefore unlikely that these individuals, and potentially more, are receiving other kinds of care they need, including mental health care, sexual and reproductive health care, and specialty care. A multitude of factors lead to this, but often, the prohibitive costs of health care, stigmatizing experiences in health care settings, and discrimination are to blame.

Twelve states have still not expanded Medicaid,<sup>171</sup> even given the incentives under the ACA and the recent COVID-19 relief packages. In states where Medicaid has been expanded, only 5 percent of people remain uninsured, compared to the 19 percent in states where Medicaid has not been expanded.<sup>172</sup> A majority of the states that have not adopted Medicaid expansion are in the South, where approximately 45 percent of all PLHIV in the United States reside.<sup>173</sup>

Even the Ryan White HIV/AIDS Program fails to adequately provide the wrap-around services that clients need to be successful and live full, healthy lives. Further, out-of-pocket costs for prescription medications<sup>174</sup> and copays for care visits can still be prohibitively expensive for PLHIV. Even with the benefits gained from the ACA, problematic health insurance practices, like copay accumulators,<sup>175</sup> are on the rise, which could also increase cost for PLHIV.

The federal response to HIV does not address the need for quality and non-stigmatizing sexual and reproductive health care for people already living with HIV.<sup>176</sup> People of all genders living with HIV require sexual and reproductive health care; unfortunately, this is one of the areas where people living with HIV suffer from the greatest stigma, lack of understanding, and discrimination from health care providers. High quality, non-stigmatizing sexual and reproductive health care for all PLHIV is crucial to ensure well-being. For transgender people living with HIV, finding

gender-affirming care in a non-discriminatory setting is essential to health and well-being.<sup>177</sup> This is especially true as many states are currently undermining the rights of transgender individuals. Further, postnatal people who are living with HIV can face stigma and even criminalization for their choice to breastfeed. Access to abortion care, birth control, and other family planning tools are also severely restricted in many states. Culturally relevant, non-stigmatizing, and comprehensive sexual and reproductive health care is essential to the quality of life of PLHIV.

While the HIV Plan mentions trauma-informed care and service delivery models, no explicit commitments are mentioned, and it is not included in other areas of the federal response to HIV. It is well documented that people living with HIV live with trauma and its downstream effects at rates well above the general population. A lack of explicit commitments to providing care and services that are trauma-informed will lead to stigmatizing and harmful experiences for the PLHIV who access these care programs.

It is important to note that issues related to HIV related health care are not equally distributed among PLHIV. The brunt of these problems is borne by Black, Indigenous, and other people of color, LGBTQ individuals, immigrants, cisgender women, and transgender women living with HIV, who face co-occurring oppressions like racism, sexism, and economic oppression.

## Recommendations for Issue Area 5B - Improving Health Care Access

Recommended Agency, Federal Body, or Policy	Recommended Action(s)
HIV National Strategic Plan	<ol style="list-style-type: none"> <li>1. Revise the definition of quality of care to include a quality of life metric and a standard of care that is easily understood by PLHIV.</li> <li>2. Make explicit commitments to integrate trauma-informed service delivery for people living with HIV in all federal plans to end the HIV epidemic, such as mandatory trainings on trauma-informed approaches for clinicians, providers and administrators; 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 people living with HIV; 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 people living with HIV.</li> <li>3. Develop a minimum standard of care for people with HIV who receive health care from any payer source. Such a standard should be adopted by CMS as well as by the Ryan White Program and any other payers. The following components should be included:               <ol style="list-style-type: none"> <li>a. Culturally relevant care that affirms the sexual and reproductive health care needs of people with HIV at all life stages and of all gender identities, including transgender women.</li> <li>b. High-quality clinical care – including affordable, accessible medication and insurance payment in areas where Medicaid has not been expanded under the ACA.</li> <li>c. Trauma-informed care practices, including screening and intervention for lifetime abuse and intimate partner violence, in HIV clinical and community-based settings.</li> <li>d. Services that facilitate PLHIV access to care as needed, including: childcare, transportation, substance use and mental health services, and housing.</li> <li>e. Define and implement a standard of gender-responsive care for people with HIV that includes the above sets of services. Prioritize funding for models that meet this standard within programs, such as the Ryan White Program.</li> </ol> </li> <li>4. Acknowledge racial injustice as a driver of the epidemic and include these factors in the response.</li> <li>5. Expand the response beyond biomedical solutions and consider the role of culture, structural drivers of health, and solving for root cause analysis.</li> </ol>
White House/Office of the President of the United States	<ol style="list-style-type: none"> <li>1. Support increased funding for the Ryan White HIV/AIDS Program to \$2.768 billion in FY 2022.<sup>178</sup></li> <li>2. Support universal health care plans, including Medicare for All.</li> </ol>

Department of Health and Human Services	<ol style="list-style-type: none"> <li>1. Remove barriers to accessing 75/25 waivers through the Ryan White HIV/AIDS Program.</li> <li>2. Rescind 85 FR 29164, which expressly permits insurers to adopt copay accumulator adjustment policies (CAAPs), and implement a rule disallowing this practice.</li> </ol>
Congress	<ol style="list-style-type: none"> <li>3. Pass the HIV Epidemic Loan-Repayment Program (HELP) Act of 2021</li> <li>4. Pass the Medicare For All Act of 2021</li> <li>5. Pass the Equality Act of 2021</li> </ol>

### 5C. Inclusion of Sexual and Reproductive Health and Rights for People Living with HIV

People of all genders living with HIV require sexual and reproductive health care; unfortunately, this is one of the sites where people living with HIV suffer from the greatest stigma, lack of understanding, and discrimination from health care providers. High quality, non-stigmatizing sexual and reproductive health care for all people living with HIV is crucial to ensure well-being and overall health. Yet, there is little mention in the HIV Plan ensuring quality and non-stigmatizing sexual and reproductive health care for people living with HIV, limited to how it pertains to raising awareness of HIV and improving integrated services.<sup>179</sup> The inclusion of the sexual and reproductive health and rights of people living with HIV is essential to ending the epidemic.

***Ensuring High-Quality, Non-Stigmatizing, Trans-Inclusive, and Culturally Relevant Sexual and Reproductive Health Care for People Living with HIV***

The first goal of the HIV Plan is “to prevent new HIV infections” by, in part, increasing awareness of HIV, increasing knowledge of HIV status, and increasing capacity of health care delivery systems to prevent and diagnose HIV.<sup>180</sup> To meet this goal, the HIV Plan notes the need to better utilize non-primary care providers, such as STD specialty clinics, Title X family planning sites, and OB-GYN visits.<sup>181</sup> We echo the need to utilize opportunities and

to increase competency of the public health workforce in providing care for people living with HIV, especially to people who may not have regular access to a primary care provider for whom these encounters may be one of their rare entry points into the health care system.

But more than just utilizing these providers as ways to diagnose and prevent HIV, the HIV Plan should prioritize the overall sexual and reproductive health needs of people living with HIV, regardless of viral suppression. Sexual health, sexual pleasure, and reproductive health care and rights are cornerstone human rights<sup>182</sup> which must be a priority in the HIV response. It is not enough to increase testing and awareness in sexual and reproductive health care settings. The HIV Plan must consider the distinct sexual and reproductive health needs of people living with HIV. Also, cisgender women living with HIV who are receiving HIV-related medical care frequently are not offered sexual and reproductive health services or are referred elsewhere, even though women living with HIV are at elevated risk for gynecological complications.<sup>183</sup>

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 their options and rights. Transgender people face high rates of discrimination, stigma, and lack of trans-competent care in health care settings. According to the National Transgender Discrimination Survey, of surveyed participants, one in three transgender people delayed or avoided preventive health care out

of fear of discrimination or disrespect.<sup>184</sup> Moreover, in the reproductive health care context, in a study of obstetrician-gynecologists, 80 percent had no trans-specific health care training in residency and only 33 percent reported feeling comfortable in providing care to transmasculine patients.<sup>185</sup>

### ***Addressing Breast/Chest-feeding for People Living with HIV***

The HIV Plan does not address breast/chest-feeding anywhere, although it does discuss HIV care as it relates to pregnant women<sup>186</sup> on two occasions.<sup>187</sup> These discussions focus on testing pregnant people for HIV, on which the health care system already receives a high rating,<sup>188</sup> and biomedical research into tools to prevent both HIV and pregnancy in women. The HIV Plan ignores and fails to advance whole swaths of the experience that must be navigated by people living with HIV who would like to become pregnant and parent.

Choices on how parents feed their infants are complex and multifaceted. People who parent should be given the full range of options, and a complete understanding of the risks and benefits of each, prior to making these decisions. In other countries, PLHIV are not discouraged from breast/chest-feeding; rather, they are educated on their options to do so safely. Yet, the CDC discourages PLHIV from breast/chest-feeding and has not provided guidance to medical professionals on ways to assist patients who would like to breast/chest-feed their children.<sup>189</sup> We know PLHIV can have healthy, HIV-negative babies, and are capable of making informed decisions about breast/chest-feeding.<sup>190</sup> However, they must be given support and information from their care team. Further, they should not fear criminalization or interventions from medical professionals or child protection systems in response to how they choose to feed their children.

These inadequacies in our systems of navigating pregnancy and breast/chest-feeding disproportionately affect Black and Latinx women, transgender, and gender non-conforming people, who acquire HIV at higher rates than the rest of the country and contend with the intersecting oppressions of racism, stigma, and sexism in

encounters with the health care system. They face higher maternal mortality rates, and once they have children, BIPOC individuals are also more likely to be limited in options of how to feed their children and steered away from breast/chest-feeding. The HIV Plan must recognize the impact that racial health disparities, including structural racism, and poverty has on options PLHIV have children and to breast/chest-feed their children.

## Recommendations for Issue Area 5C - Sexual and Reproductive Health and Rights

<b>Recommended Agency, Federal Body, or Policy</b>	<b>Recommended Action(s)</b>
Department of Health and Human Services	<ol style="list-style-type: none"> <li>1. Finalize and implement the proposed rule, “Ensuring Access to Equitable, Affordable, Client- Centered, Quality Family Planning Services,” RIN 0937-AA11, which would strengthen the Title X family planning grant program and reverse the domestic gag rule.</li> <li>2. Fully integrate comprehensive sexual and reproductive health care throughout the Ryan White Program.</li> <li>3. Work with networks of people living with HIV to develop HIV-related guidelines on breast/chest-feeding to ensure they are up to date, reflect best practices and complexities of child feeding, and are consistent across disciplines; develop comprehensive postpartum guidelines for people living with HIV.<sup>191</sup></li> </ol>
National Institutes of Health	<ol style="list-style-type: none"> <li>1. Develop and promote a research agenda on breast/chest-feeding that leverages existing findings, seeks novel applications of relevant data, and addresses knowledge gaps.</li> <li>2. Partner with other agencies to disseminate research findings in an accessible way to providers and people living with HIV.</li> </ol>
HIV National Strategic Plan	<ol style="list-style-type: none"> <li>1. Include goals and metrics that focus on improving the sexual and reproductive health of PLHIV, including metrics for increased rates of recommended second Pap smear screening for newly diagnosed women, counseling on fertility desires and intentions, and increased rates of screening for intimate partner violence among women living with HIV in care.</li> <li>2. Support informed consent standards that accurately and fully inform people of the implications of transition-related care, regardless of age, gender, or gender expression.</li> <li>3. Discuss and fund research into safe practices for people living with HIV to breast/chest-feed children.</li> </ol>
Ending the HIV Epidemic Plan	<ol style="list-style-type: none"> <li>1. Require jurisdictions to create and provide sexual and reproductive health care guidance for providers to deliver to people living with HIV which includes information on how to access transition-related care, pregnancy care, breast/chest-feeding care, and contraceptive care.</li> <li>2. Require jurisdictions to fund programs for providing comprehensive, culturally competent sexual and reproductive health care to people living with HIV, such as training programs for providers and ways for people living with HIV to access funds to pay for transition-related care, pregnancy care, breast/chest-feeding care, and contraceptive care.</li> <li>3. Require jurisdictions to take a firm stance against the criminalization of breast/chest-feeding for people living with HIV and to take affirmative steps to educate child welfare agencies within the jurisdiction on the science around people living with HIV breast/chest-feeding.</li> </ol>

Congress	<ol style="list-style-type: none"> <li>1. Pass the Real Education and Access for Healthy Youth Act of 2021</li> <li>2. Pass the Women’s Health Protection Act of 2021</li> <li>3. Pass the Equal Access to Abortion Coverage in Health Insurance (EACH) Act of 2021</li> <li>4. Pass the Abortion Is Health Care Everywhere Act of 2021</li> </ol>
----------	--

## Endnotes

- 1 See, e.g., U.S. People Living with HIV Caucus [hereinafter HIV Caucus], *Opportunities and Mechanisms for Involving People Living with HIV/AIDS in the Nat’l HIV/AIDS Strategy’s Implementation* (July 2011), <https://drive.google.com/file/d/1ryFJk-akJQgFBiMx-hkc-6widiME-2mf-/view>; HIV Caucus, *Moving Towards Positive Health, Dignity and Prevention* (July 2011), <https://drive.google.com/file/d/1xv5K3eVKtcOc-UVoCz-tVBkvYCisSfkM/view>.
- 2 See generally, Country and Regional Operational Plans, U.S. Dep’t of State, <https://www.state.gov/country-operation-al-plans> (last visited June 24, 2021).
- 3 Elizabeth Guo et al., *Eliminating Coverage Discrimination Through the Essential Health Benefit’s Anti-Discrimination Provisions*, 107 Am. J. Pub. Health 2 (2017), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5227931/>.
- 4 Jennifer Kates & Lindsey Dawson, *Insurance Coverage Changes for People Under the ACA*, Kaiser Family Foundation (2017), <https://www.kff.org/health-reform/issue-brief/insurance-coverage-changes-for-people-with-hiv-under-the-aca/>.
- 5 Michael J. Mugavero et al., *Health care system and policy factors influencing engagement in HIV medical care: piecing together the fragments of a fractured health care delivery system*, 52 Clinical Infectious Disease, suppl. 2, S238, S238-39 (2011), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3106258/>.
- 6 Off. of Nat. AIDS Pol’y, Exec. Off. of the President, National HIV/AIDS Strategy (2010) [hereinafter *National Strategy*], [hivgov-prod-v3.s3.amazonaws.com](http://hivgov-prod-v3.s3.amazonaws.com).
- 7 *Id.* at 9.
- 8 U.S. Dep’t of Health and Human Services, 12 Cities Strategy, <https://www.hiv.gov/sites/default/files/NHAS-HHS-12.pdf> (last visited June 24, 2021).
- 9 Off. of Nat. AIDS Pol’y, Exec. Off. of the President, National HIV/AIDS Strategy Updated to 2020 (2015) [hereinafter *Updated National Strategy*], [https://obamawhitehouse.archives.gov/sites/default/files/docs/national\\_hiv\\_aids\\_strategy\\_update\\_2020.pdf](https://obamawhitehouse.archives.gov/sites/default/files/docs/national_hiv_aids_strategy_update_2020.pdf).
- 10 *Id.* at 8-11.
- 11 Off. of Infectious Disease and HIV/AIDS Pol’y, *What Is Ending the HIV Epidemic in the U.S.?*, HIV.gov (June 2, 2021), <https://www.hiv.gov/federal-response/ending-the-hiv-epidemic/overview>.
- 12 Off. of Infectious Disease and HIV/AIDS Pol’y, *Key Strategies in the Plan*, HIV.gov (May 8, 2020), <https://www.hiv.gov/federal-response/ending-the-hiv-epidemic/key-strategies>.
- 13 Positive Women’s Network-USA, *Ending the Epidemic Requires Consent and Community Leadership*, <https://www.pwn-usa.org/trainings-resources/policy-advocacy/ete-factsheet-2019/> (last visited June 28, 2021).
- 14 Consolidated Appropriations Act of 2020, Pub. L. No. 116-94; Consolidated Appropriations Act of 2021, Pub. L. No. 116-260.
- 15 U.S. Dep’t of Health and Human Services, *HIV National Strategic Plan: A Roadmap to End The Epidemic for the United States 2021-2025* (2021) [hereinafter *HIV Plan*], <https://hivgov-prod-v3.s3.amazonaws.com/s3fs-public/HIV-National-Strategic-Plan-2021-2025.pdf>.
- 16 The comments expressed serious concern with the draft HIV Plan’s inclusion of the use of HIV genomic sequencing data, cluster detection, and data derived from molecular HIV surveillance. The comments further offered specific ways in which the draft HIV Plan could be strengthened, for example, by adding explicit commitments to employment and economic justice for PLHIV, sexual and reproductive health care for people of all genders living with HIV, and explicitly addressing the prevention, health care, and human rights needs of immigrants, of people of trans experience, and of sex workers. HIV Caucus Comments on National HIV Strategy, U.S. People Living with HIV Caucus (Dec. 13, 2020), <https://www.hivcaucus.org/blog/hiv-caucus-comments-on-nation->

- [al-hiv-strategy](#); PWN's Comment on the Draft HIV National Strategic Plan 2021-2025, Positive Women's Network (Dec. 17, 2020), <https://www.pwn-usa.org/pwns-comment-on-the-draft-hiv-national-strategic-plan-2021-2025/>.
- 17 U.S. Dep't of Health and Hum. Serv., Notice of Funding Opportunity, CDC-RFA-PS20-2010, 1, 3 (Jan. 23, 2020), <https://www.cdc.gov/hiv/pdf/funding/announcements/ps20-2010/CDC-RFA-PS20-2010.pdf>.
- 18 The Denver Principles, UNAIDS (1983) [https://data.unaids.org/pub/externaldocument/2007/gipa1983denverprinciples\\_en.pdf](https://data.unaids.org/pub/externaldocument/2007/gipa1983denverprinciples_en.pdf)
- 19 *The Greater Involvement of People Living with HIV (GIPA)*, UNAIDS (2007) [https://data.unaids.org/pub/briefingnote/2007/jc1299\\_policy\\_brief\\_gipa.pdf](https://data.unaids.org/pub/briefingnote/2007/jc1299_policy_brief_gipa.pdf)
- 20 Health Res. and Servs. Admin., *Ryan White HIV/AIDS Program Legislation* (February 2021) <https://hab.hrsa.gov/about-ryan-white-hivaids-program/ryan-white-hivaids-program-legislation>.
- 21 HIV Health Care Services Program, ch. 6A, subch.XXIV (codified at 42 U.S.C. § 300ff-12(b)(5)(C)).
- 22 The Global Fund, *Country Coordinating Mechanism Policy Including Principles and Requirements*, (2018), [https://www.theglobalfund.org/media/7421/ccm\\_countrycoordinatingmechanism\\_policy\\_en.pdf](https://www.theglobalfund.org/media/7421/ccm_countrycoordinatingmechanism_policy_en.pdf).
- 23 Notice of Funding Opportunity, CDC-RFA-PS20-2010, at 10; 13 (Jan. 23, 2020), <https://www.cdc.gov/hiv/pdf/funding/announcements/ps20-2010/CDC-RFA-PS20-2010.pdf>.
- 24 See Dep't of Health and Hum. Serv., *Charter of the CDC/HRSA Advisory Committee on HIV, Viral Hepatitis and STD Prevention and Treatment* 1, 3 (2020), <https://www.cdc.gov/faca/committees/pdfs/chachspt/chachspt-charter-508.pdf>; Dep't of Health and Hum. Serv., *Charter - Office of AIDS Research Advisory Council* 1, 3 (2018), [https://www.oar.nih.gov/sites/default/files/OARAC\\_Charter\\_2018\\_508.pdf](https://www.oar.nih.gov/sites/default/files/OARAC_Charter_2018_508.pdf); but see, Dep't of Health and Hum. Serv., *Charter - Presidential Advisory Committee on HIV/AIDS* 1, 4, (2020) <https://hivgov-prod-v3.s3.amazonaws.com/s3fs-public/pacha-charter-2020.pdf>.
- 25 See White House, President Obama, *National HIV/AIDS Strategy* (2009) <https://obamawhitehouse.archives.gov/administration/eop/onap/nhas/activities>.
- 26 Dan Tracer, Report: *Trump Closes Down White House Office of AIDS Policy*, Queerty (Jan. 20, 2017) <https://www.queerty.com/report-trump-closes-white-house-office-aids-policy-20170120>.
- 27 See Dep't of Health and Hum. Serv., *White House Appoints Harold Phillips to lead Office of HIV National AIDS Policy*, (June 9, 2021) <https://www.hiv.gov/blog/white-house-appoints-harold-phillips-lead-office-national-aids-policy>.
- 28 Lisa Bowleg et al. "It's an Uphill Battle Everyday": Intersectionality, Low-Income Black Heterosexual Men, and Implications for HIV Prevention Research and Interventions, 14 *Psychology of Men & Masculinity* 1, 25-34 (2013), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3591486/>.
- 29 Frank H. Galvan et al., *HIV Stigma and Social Support among African Americans*, 22 *AIDS Patient Care and STDs* 5, 423-436 (2008), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2831751/>.
- 30 Joseph S. Lightner et al., *Associations of internalized and anticipated HIV stigma with returning to work for persons living with HIV*, 16 *PLOS ONE* 6 (2021), <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0252783>.
- 31 William L. Holzemer et al., *Exploring HIV Stigma and Quality of Life for Persons Living With HIV Infection*, 11 *J. of the Ass'n of Nurses in AIDS Care*, no. 3, May-June 2009, 161-168, <https://www.sciencedirect.com/science/article/abs/pii/S1055329009000338>.
- 32 *What Is Ending the HIV Epidemic in the U.S.?*, HIV.gov (June 2, 2021), <https://www.hiv.gov/federal-response/ending-the-hiv-epidemic/overview>.
- 33 The People Living with HIV Stigma Index, <https://www.stigmaindex.org/> (last visited June 28, 2021).
- 34 *What is the People Living with HIV Stigma Index?*, The People Living with HIV Stigma Index, <https://www.stigmaindex.org/about-the-stigma-index/what-is-the-people-living-with-hiv-stigma-index/> (last visited June 28, 2021).
- 35 *USA Louisiana*, The People Living with HIV Stigma Index, <https://www.stigmaindex.org/country-report/usa-louisiana/> (last visited June 28, 2021); *USA Michigan*, The People Living with HIV Stigma Index, <https://www.stigmaindex.org/country-report/usa-michigan/> (last visited June 28, 2021); *USA New Jersey*, The People Living with HIV Stigma Index, <https://www.stigmaindex.org/country-report/usa-new-jersey/> (last visited June 28, 2021); c.f., Andrew R. Spieldenner et al., *From Consumer to Community-Based Researcher: Lessons from the PLHIV Stigma Index*, in *Narrating Patienthood: Engaging Diverse Voices on Health, Communication, and the Patient Experience* 151 (2019) (describing the data collection process).

36 HIV Plan, *supra* note 15, at 8.

37 *Id.* at 32.

38 *Id.* at 36; 47.

39 *Id.* at 38; 47.

40 *Id.* at 49.

41 *Id.* at 51.

42 HIV Plan, *supra* note 15, at 4.

43 See Center for HIV Law and Policy, *HIV Criminalization in the United States* (July 2020), <https://www.hivlawandpolicy.org/sites/default/files/HIV%20Criminalization%20in%20the%20US%20%282020%29.pdf>.

44 *E.g.*, S.C. Code Ann. § 44-29-145 (2016); Ga. Code Ann. § 16-5-60(c) (2016).

45 See *e.g.*, *Lopez v. State*, 288 S.W.3d 148, 154 (Tex. App. 2009) (remanding the case for a new trial due to the trial court's erroneous admission of extraneous acts. However, the aggravating factor in the HIV positive defendant's conviction on two counts of aggravated sexual assault was the deadly weapon of his bodily fluids).

46 See *e.g.*, *Hall v. Commonwealth*, 1997 Va. App. Lexis 782, (Va. Ct. App. 1997) (unpublished) (finding a defendant's biting of a store employee and breaking his skin following a shoplifting incident supported the inference that the defendant "intended to infect [him] with AIDS, a deadly disease" which satisfied the requisite statutory element of malicious intent).

47 Trevor Hoppe, *Punishing disease: HIV and the criminalization of sickness*, U.C. Press (2017).

48 Elizabeth Weill-Greenberg, *The Push to End 'Punishment Fever' Against People with HIV*, *The Appeal* (April, 11, 2019), <https://theappeal.org/the-push-to-end-punishment-fever-against-people-with-hiv/>.

49 Trevor Hoppe, *Punishing disease: HIV and the criminalization of sickness*, U.C. Press (2017).

50 HIV Plan, *supra* note 15, at 46; *HIV Criminalization and Ending the HIV Epidemic*, Cts. for Disease Prevention and Control (June 24, 2021), <https://www.cdc.gov/hiv/policies/law/criminalization-ehe.html>.

51 *HIV Criminalization and Ending the HIV Epidemic*, Cts. for Disease Prevention and Control (June 24, 2021) (recommending but not requiring reform to HIV criminalization laws), <https://www.cdc.gov/hiv/policies/law/criminalization-ehe.html>.

52 Compare Fla. Dep't of Health, *Florida's Unified Ending the HIV Epidemic Draft Plan*, (2019) (containing no mention of HIV criminalization reform), <http://www.floridahealth.gov/diseases-and-conditions/aids/ehe/documents/draft-fl-unified-ehe-plan.pdf>, with Ga. Dep't of Hum. Res., *Ending the HIV Epidemic in Georgia*, 53 (2020) (containing goals to reform HIV criminalization laws), <https://static1.squarespace.com/static/5e50179ca696a950a547f95d/t/5ff32fb4fc8ee327dd607adf/1609773001220/GA+EHE+Plan+12.2020.pdf>.

53 HIV Plan, *supra* note 15, at 46.

54 *Id.* at 46-47.

55 *Id.* at 46.

56 Laura M. Bogart et al., *HIV-Related Medical Mistrust, HIV Testing, and HIV Risk in the National Survey on HIV in the Black Community*, 45 *Behav. Med.*, no. 2, 134, 142 (2019), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6783255/pdf/nihms-1052568.pdf>.

57 See *State Laboratory Reporting Laws: Viral Load and CD4 Requirements*, Ctrs. for Disease Prevention and Control (Feb. 1, 2021), <https://www.cdc.gov/hiv/policies/law/states/reporting.html>.

58 U.S. Dep't of Health and Hum. Serv., *Notice of Funding Opportunity, CDC-RFA-PS20-2010*, 1, 10, 13 (Jan. 23, 2020), <https://www.cdc.gov/hiv/pdf/funding/announcements/ps20-2010/CDC-RFA-PS20-2010.pdf>.

59 U.S. Dep't of Health and Hum. Serv., *Notice of Funding Opportunity, CDC-RFA-PS18-1802*, 1, 26 (June 27, 2017), <https://www.cdc.gov/hiv/pdf/funding/announcements/ps18-1802/cdc-hiv-ps18-1802-nofo.pdf>.

60 *HIV Data Privacy and Confidentiality Legal & Ethical Considerations for Health Department Data Sharing*, NASTAD 1, 3 (June 2018), <https://www.nastad.org/sites/default/files/Uploads/2018/nastad-hiv-data-privacy-06062018.pdf>.

- 61 *Id.*
- 62 *Id.*
- 63 *Id.* at 8.
- 64 HIV Plan, *supra* note 15, at 42.
- 65 *Failing to Protect and Serve: Police Department Policies Towards Transgender People*, Nat'l Ctr. for Transgender Equal. 1 (2019) <https://transequality.org/police>.
- 66 Savvas Georgiades, *The Dire Straits of Homelessness: Dramatic Echoes and Creative Propositions From the Field*, 25 J. of Hum. Behav. in the Soc. Env't, no. 6, 2015, at 630-642, <https://www.tandfonline.com/doi/abs/10.1080/10911359.2015.1011254>.
- 67 Jamie J. Hagen, *Compounding Risk for Sex Workers in the United States*, 50 NACLA Rep. on the Americas, no. 4, 2018, 395-397, <https://www.tandfonline.com/doi/abs/10.1080/10714839.2018.1550984>.
- 68 Diane I. Scaduto et al., *Source identification in two criminal cases using phylogenetic analysis of HIV-1 DNA sequences*, 107 Proc. of the Nat'l Acad. of Sci., no. 50, Dec. 2010, 21242-21247, <https://www.pnas.org/content/107/50/21242>; Ana B. Abecasis et al., *Phylogenetic analysis as a forensic tool in HIV transmission investigations*, 32 AIDS, no 5, Mar. 13, 2018, 543-554, <https://pubmed.ncbi.nlm.nih.gov/29280759/>.
- 69 Ryan Blethen, *North Seattle HIV cluster among drug users and homeless people worries health officials*, Seattle Times, (April 19, 2019), <https://www.seattletimes.com/seattle-news/health/north-seattle-hiv-cluster-among-drug-users-and-homeless-people-worries-health-officials/>.
- 70 See, e.g., Lynn LaRowe, *Lawsuit alleges restaurant fired man for being HIV positive*, Texarkana Gazette (Oct. 24, 2020), <https://www.texarkanagazette.com/news/texarkana/story/2020/oct/25/lawsuit-alleges-restaurant-fired-man-being-hiv-positive/846593/>, and Kayla Epstein, *He revealed his HIV status to his employer. Then he was fired, a lawsuit alleges*, The Washington Post (Nov. 11, 2019), <https://www.washingtonpost.com/business/2019/11/11/he-revealed-his-hiv-status-his-employer-then-he-was-fired-lawsuit-alleges/>, for instances for job loss.
- 71 Alison Yager, *HIV Stigma Violently Rages On: We Must Do Better*, HIV Plus Magazine (July 19, 2014), <https://www.hivplusmag.com/stigma/law-crime/2014/07/19/hiv-stigma-violently-rages-we-must-do-better>.
- 72 *Action Plan - Public Health Workforce Development*, Ctrs. for Disease Prevention and Control, (July 2018), <https://www.cdc.gov/csels/dsepd/documents/ph-workforce-dev-action-plan-508.pdf>.
- 73 Crystal Jongen et al., *Health workforce cultural competency interventions: a systematic scoping review*, 18 BMC Health Serv. Rsch. 232 (2018), <https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-018-3001-5>.
- 74 *Building Skills for a More Strategic Public Health Workforce: A Call to Action*, Nat'l Consortium for Workforce Dev., (2019), <https://debeaumont.org/wp-content/uploads/2019/04/Building-Skills-for-a-More-Strategic-Public-Health-Workforce.pdf>.
- 75 See George Ayala et al., *Partner Notification: A Community Viewpoint*, 22 J. Int'l AIDS Soc'y, suppl. 3, 2019, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6639673/>.
- 76 *Key Strategies in the Plan*, HIV.gov (May 8, 2020), <https://www.hiv.gov/federal-response/ending-the-hiv-epidemic/key-strategies>.
- 77 *Ending the HIV Epidemic Funding*, HIV.gov (June 1, 2021), <https://www.hiv.gov/federal-response/ending-the-hiv-epidemic/funding>.
- 78 U.S. Dep't of Health and Hum. Serv., Notice of Funding Opportunity, CDC-RFA-PS20-2010, 1 (Jan. 23, 2020), <https://www.cdc.gov/hiv/pdf/funding/announcements/ps20-2010/CDC-RFA-PS20-2010.pdf>
- 79 HIV Plan, *supra* note 15, at 52, 53
- 80 *Id.* at 54, 56.
- 81 *Id.* at 50.
- 82 *HIV Data Privacy and Confidentiality Legal & Ethical Considerations for Health Department Data Sharing*, NASTAD 1, 3 (June 2018), <https://www.nastad.org/sites/default/files/Uploads/2018/nastad-hiv-data-privacy-06062018.pdf>.

- 83 *Data Security and Confidentiality Guidelines for HIV, Viral Hepatitis, Sexually Transmitted Disease, and Tuberculosis Programs: Standards to Facilitate Sharing and Use of Surveillance Data for Public Health Action*, Ctrs. for Disease Prevention and Control 1, 17 (2011), <https://www.cdc.gov/nchhstp/programintegration/docs/pcsidatasecurityguidelines.pdf>.
- 84 *See generally id.*
- 85 AIDS United, *AIDS United's Position on Using Molecular HIV Surveillance to Track HIV Transmission Networks*, Positive Women's Network-USA (June 12, 2021), <https://www.pwn-usa.org/aids-uniteds-position-on-using-molecular-hiv-surveillance-to-track-hiv-transmission-networks/>.
- 86 *What Is the Impact of HIV on Racial and Ethnic Minorities in the U.S.?*, *HIV.gov* (Feb. 1, 2021) <https://www.hiv.gov/hiv-basics/overview/data-and-trends/impact-on-racial-and-ethnic-minorities>.
- 87 *Id.*
- 88 *HIV and Men*, Ctrs. for Disease Prevention and Control (October 2020), <https://www.cdc.gov/hiv/group/gender/men/index.html>.
- 89 *Id.*
- 90 *Id.*
- 91 *Black Americans and HIV/AIDS: The Basics*, Kaiser Family Foundation (Feb. 7, 2020), [https://www.kff.org/hiv/aids/fact-sheet/black-americans-and-hiv-aids-the-basics/#endnote\\_link\\_448622-21](https://www.kff.org/hiv/aids/fact-sheet/black-americans-and-hiv-aids-the-basics/#endnote_link_448622-21).
- 92 Structural racism as defined by the Aspen Institute is "A system in which public policies, institutional practices, cultural representations, and other norms work in various, often reinforcing ways to perpetuate racial group inequity. It identifies dimensions of our history and culture that have allowed privileges associated with "whiteness" and disadvantages associated with "color" to endure and adapt over time. Structural racism is not something that a few people or institutions choose to practice. Instead it has been a feature of the social, economic and political systems in which we all exist." *Glossary for Understanding the Dismantling Structural Racism/Promoting Racial Equity Analysis*, The Aspen Institute, <https://www.aspeninstitute.org/wp-content/uploads/files/content/docs/rcc/RCC-Structural-Racism-Glossary.pdf> (last visited June 25, 2021).
- 93 *Persons Living with Diagnosed HIV Infection in the United States and Dependent Areas*, 2018, Ctrs. for Disease Control and Prevention (May 7, 2020), <https://www.cdc.gov/hiv/library/reports/hiv-surveillance/vol-31/content/living.html>.
- 94 *Id.*
- 95 *Id.*
- 96 Centers for Disease Control and Prevention, *Diagnoses of HIV Infection in the United States and Dependent Areas*, 2018, 31 HIV Surveillance Report 10 (Dec. 2018), <https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-2018-updated-vol-31.pdf>.
- 97 *Id.*
- 98 *Id.*
- 99 *Women and HIV in the United States*, Kaiser Family Foundation (2020) <https://www.kff.org/hiv/aids/fact-sheet/women-and-hiv-aids-in-the-united-states/#footnote-452735-10>.
- 100 *Selected National HIV Prevention and Care Outcomes*, Center for Disease Control and Prevention 13 (2016), <https://www.cdc.gov/hiv/pdf/library/slidesets/cdc-hiv-prevention-and-care-outcomes-2016.pdf>.
- 101 Karin A. Bosh et al., *Vital Signs: Deaths Among Persons with Diagnosed HIV Infection*, United States, 2010–2018, 69 *Morbidity and Mortality Weekly Rep.* 1717, 1717 (2020), <https://www.cdc.gov/mmwr/volumes/69/wr/mm6946a1.htm>.
- 102 *Ryan White HIV/AIDS Program Annual Client-Level Data Report*, Health Resources and Services Administration 5 (2020), <https://hab.hrsa.gov/sites/default/files/hab/data/datareports/RWHAP-annual-client-level-data-report-2019.pdf>.
- 103 Lindsey Dawson et al., *HIV, Intimate Partner Violence (IPV), and Women: An Emerging Policy Landscape*, Kaiser Family Foundation (2019), <https://www.kff.org/hiv/aids/issue-brief/hiv-intimate-partner-violence-ipv-and-women-an-emerging-policy-landscape>.
- 104 *See* Notice of Funding Opportunity Announcement, America's HIV Epidemic Analysis Dashboard, <https://ahead.hiv.gov/resources/funding/closed> (last visited June 25, 2021).

105 Notice of Funding Opportunities are announcements of the availability of federal funding through a financial assistance program. Dictionary of Terms, Ctrs. for Disease Control and Prevention, <https://www.cdc.gov/grants/dictionary/index.html#nofo> (last visited June 25, 2021). They importantly denote funding preferences and priorities for grantees, meaning that the information contained in these Notices will affect the focuses and people priorities in the applicants' proposals and the eventual programs which are funded.

106 Notice of Funding Opportunity, HRSA-20-079, 6 (Aug. 13, 2019), <https://www.hrsa.gov/grants/find-funding/hrsa-20-079>; Notice of Funding Opportunity, HRSA-20-089 (Aug. 13, 2019), <https://www.hrsa.gov/grants/find-funding/hrsa-20-089>; *see generally*, Notice of Funding Opportunity, CDC-RFA-PS19-1906, 1, 3 (June 12, 2019), <https://www.cdc.gov/hiv/pdf/funding/announcements/ps19-1906/cdc-hiv-PS19-NOFO.pdf>.

107 *See generally, id.*

108 Even a goal of achieving viral suppression is a racialized and unequal process, with fewer Black Americans living with HIV having viral suppression even when they are in care. Nicole Crepez et al., *Racial and Ethnic Disparities in Sustained Viral Suppression and Transmission Risk Potential Among Persons Receiving HIV Care* — United States, 2014, 67 *Morbidity and Mortality Weekly R.* 4, 113 (2018), <https://www.cdc.gov/mmwr/volumes/67/wr/mm6704a2.htm>.

109 *See, e.g.*, Notice of Funding Opportunity, HRSA-20-078, 1, 4 (Aug. 13, 2019), <https://www.hrsa.gov/grants/find-funding/hrsa-20-078>; Notice of Funding Opportunity, CDC-RFA-PS20-2010, 1, 22, 23 (April 1, 2020), <https://www.grants.gov/web/grants/view-opportunity.html?oppld=323863>; Notice of Funding Opportunity, HRSA-20-114, 1-2 (April 15, 2020), <https://www.hrsa.gov/grants/find-funding/hrsa-20-114>.

110 *See generally*, HRSA-20-112, (April 9, 2020), <https://www.hrsa.gov/grants/find-funding/hrsa-20-112>.

111 *See generally*, Notice of Funding Opportunity, CDC-RFA-PS19-1906, (June 12, 2019), <https://www.cdc.gov/hiv/pdf/funding/announcements/ps19-1906/cdc-hiv-PS19-NOFO.pdf>; Notice of Funding Opportunity, HRSA-20-079, (Aug. 13, 2019), <https://www.hrsa.gov/grants/find-funding/hrsa-20-079>; Notice of Funding Opportunity, HRSA-20-089 (Aug. 13, 2019), <https://www.hrsa.gov/grants/find-funding/hrsa-20-089>; Notice of Funding Opportunity, HRSA-20-078, (Aug. 13, 2019), <https://www.hrsa.gov/grants/find-funding/hrsa-20-078>; HRSA-20-112, 1,4 (April 9, 2020), <https://www.hrsa.gov/grants/find-funding/hrsa-20-112>;

112 *See* Notice of Funding Opportunity, HRSA-20-114, 1-2 (April 15, 2020), <https://www.hrsa.gov/grants/find-funding/hrsa-20-114>; Notice of Funding Opportunity, CDC-RFA-PS20-2010, 1, 22, 23 (April 1, 2020), <https://www.grants.gov/web/grants/view-opportunity.html?oppld=323863>.

113 A Notice of Funding Opportunity was released which focused on improving care and treatment coordination for Black women with HIV, however it was funded for only \$4,320,000 in FY 2020 out of the \$267 million that was spent on EHE programing. Notice of Funding Opportunity , HRSA-20-116, (April 15, 2020), <https://www.hrsa.gov/grants/find-funding/hrsa-20-116>. Based upon CDC data, one can estimate that Black women account for over 12% of the domestic HIV epidemic, Ctrs. for Disease Control and Prevention, *Estimated HIV Incidence and Prevalence in the United States, 2014–2018*, 25 *HIV Surveillance Report* 1, 45, 46 (2020), yet specifically directed funding for Black women was less than 2% of overall EHE funding.

114 HIV Plan, *supra* note 15, at 41.

115 *Id.* at 62.

116 *See infra*, Issue Area 5, pp. 54.

117 *See generally*, HIV Plan, *supra* note 15.

118 HIV Plan, *supra* note 15, at 3.

119 *Id.* at 45.

120 *Id.* at 40.

121 *See infra*, Issue Area 5C, pp.47-51.

122 *Miles to go: Closing Gaps, Breaking Barriers, Righting Injustice*, UNAIDS 14-15 (2018), [https://www.unaids.org/sites/default/files/media\\_asset/miles-to-go\\_en.pdf](https://www.unaids.org/sites/default/files/media_asset/miles-to-go_en.pdf).

123 Sandy E. James et al., *The Report of the 2015 U.S. Transgender Survey*, National Center for Transgender Equality (2016), <https://transequality.org/sites/default/files/docs/usts/USTS-Full-Report-Dec17.pdf>.

- 124 Jasmine Sankofa, *From Margin to Center: Sex Work Decriminalization is a Racial Justice Issue*, Amnesty International (2016), <https://www.amnestyusa.org/from-margin-to-center-sex-work-decriminalization-is-a-racial-justice-issue/>.
- 125 See, e.g., Fla. Stat. Ann. §§ 796.08(5), 775.082(3)(e), 775.083(1)(c) (2016).
- 126 *Alliance for a Safe & Diverse D.C., Move Along: Policing Sex Work in Washington, D.C.*, (2008), <https://dctranscoalition.files.wordpress.com/2010/05/movealongreport.pdf>.
- 127 See, e.g., Amira Hasenbush, *HIV Criminalization In Florida: Penal Implications for People Living with HIV/AIDS*, Williams Institute U.C.L.A. School of Law, 2 (2018) <https://www.hivlawandpolicy.org/sites/default/files/HIV-Criminalization-Florida-Oct-2018.pdf>; see also, Amira Hasenbush et al., *HIV Criminalization In California: Penal Implications for People Living with HIV/AIDS*, Williams Institute U.C.L.A. School of Law, 2 (2015), <https://williamsinstitute.law.ucla.edu/wp-content/uploads/HIV-Criminalization-CA-Dec-2015.pdf>.
- 128 Ryan Blethen, *North Seattle HIV cluster among drug users and homeless people worries health officials*, The Seattle Times, April 19, 2019, <https://www.seattletimes.com/seattle-news/health/north-seattle-hiv-cluster-among-drug-users-and-homeless-people-worries-health-officials/>.
- 129 13 C.F.R. § 120.110 (2017).
- 130 Jonathan Ross et al., *HIV outcomes among migrants from low- and middle-income countries living in high-income countries: a review of recent evidence*, 31 *Current Op. Infectious Disease* 1, 25-32 (2018), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5750122/>.
- 131 *Immigrants and the Affordable Care Act (ACA)*, Nat'l Immigr. Law Ctr. (Jan 2014), <https://www.nilc.org/issues/health-care/immigrantshcr/>.
- 132 On January 4, 2010, a new federal rule went into effect that lifted the 22-year restriction on immigration and travel to the United States for non-U.S. citizens living with HIV/AIDS. See 42 C.F.R. § 34.2(b)(6) (2008). Immigrants continue to face barriers in accessing health care. *Immigrants and the Affordable Care Act (ACA)*, Nat'l Immigr. Law Ctr. (Jan 2014), <https://www.nilc.org/issues/health-care/immigrantshcr/>.
- 133 HIV Plan, *supra* note 15, at 3.
- 134 See *Inadmissibility on Public Charge Grounds; Correction*, 84 Fed. Reg. 52357-01 (October 2, 2019). This rule was preliminarily enjoined by the U.S. District Court for the Northern District of Illinois and that injunction was upheld by the Seventh Circuit Court of Appeals, *Cook Cty. v. Wolf*, 962 F.3d 208, 234 (7th Cir. 2020), cert. dismissed sub nom. *Mayorkas v. Cook Cty.*, 141 S. Ct. 1292 (2021). On March 9, 2021, the Seventh Circuit lifted its stay, *Cook Cty. v. Wolf*, No. 20-3150, 2021 WL 1608766, at \*1 (7th Cir. Mar. 9, 2021) (unpublished), and the U.S. District Court for the Northern District of Illinois' order vacating the Public Charge Final Rule went into effect, *Cook Cty. v. Wolf*, 498 F. Supp. 3d 999, 1011 (N.D. Ill. 2020). When the vacatur went into effect, U.S. Customs and Immigration Services immediately stopped applying the Public Charge Final Rule to all pending applications and petitions that would have been subject to the rule. *Public Charge*, U.S. Customs and Immigr. Serv. (April 15, 2021), <https://www.uscis.gov/green-card/green-card-processes-and-procedures/public-charge>.
- 135 E.g., Melissa Jenco, *Study: Public charge rule having a chilling effect on immigrant families' use of public programs*, Am. Acad. P News (June 30, 2020), <https://www.aappublications.org/news/2020/06/30/immigrantfamilies063020>; Leighton Ku, *New Evidence Demonstrates That The Public Charge Rule Will Harm Immigrant Families and Others*, Health Affairs Blog (Oct. 9, 2019), <https://www.healthaffairs.org/doi/10.1377/hblog20191008.70483/full/>; Samantha Artiga et al., *Estimated Impacts of Final Public Charge Inadmissibility Rule on Immigrants and Medicaid Coverage*, Kaiser Fam. Found. (Sep. 18, 2019), <https://www.kff.org/racial-equity-and-health-policy/issue-brief/estimated-impacts-of-final-public-charge-inadmissibility-rule-on-immigrants-and-medicaid-coverage/>.
- 136 See 42 U.S.C. § 249(a) (2003); 42 C.F.R. § 34.7(a) (2003).
- 137 Mathew Rodriguez, *Trans Woman With HIV Dies During Release From ICE Custody After Being Denied Meds*, TheBody, June 4, 2019, <https://www.thebody.com/article/trans-woman-with-hiv-dies-during-release-from-ice-custody>; see also Tim Fitzsimons, *Transgender ICE detainee died of AIDS complications, autopsy shows*, NBC News, April 17, 2019, <https://www.nbcnews.com/feature/nbc-out/transgender-ice-detainee-died-aids-complications-autopsy-shows-n994836>.
- 138 Sandra E. Garcia, *Independent Autopsy of Transgender Asylum Seeker Who Died in ICE Custody Shows Signs of Abuse*, New York Times (Nov. 27, 2018), <https://www.nytimes.com/2018/11/27/us/trans-woman-roxsana-hernandez-ice-autopsy.html>.
- 139 HIV Plan, *supra* note 15, at 43.

- 140 *Id.* at 18.
- 141 *Id.* at 41, 42.
- 142 *Id.* at 3.
- 143 *Id.* at 43.
- 144 *See id.*
- 145 Vanessa Cooper et al., *Measuring quality of life among people living with HIV: a systematic review of reviews*, 15 Health Qual Life Outcomes 220 (2017). <https://doi.org/10.1186/s12955-017-0778-6>; *See also Quality of life for people living with HIV: what is it, why does it matter and how can we make it happen?*, Frontline AIDS p1, p4 (2018) [https://frontlineaids.org/wp-content/uploads/2019/02/quality\\_of\\_life\\_briefing\\_final\\_original.pdf](https://frontlineaids.org/wp-content/uploads/2019/02/quality_of_life_briefing_final_original.pdf).
- 146 *See, e.g., WHOQOL: Measuring Quality of Life*, World Health Organization (2012) <https://www.who.int/tools/whoqol>.
- 147 Vanessa Cooper et al., *Measuring quality of life among people living with HIV: a systematic review of reviews*, 15 Health Qual Life Outcomes 220 (2017). <https://doi.org/10.1186/s12955-017-0778-6>
- 148 *See e.g. State of Aging and Health in America 2013*, Centers for Disease Control and Prevention, US Dep't of Health and Human Services (2013) <https://www.cdc.gov/aging/pdf/State-Aging-Health-in-America-2013.pdf>.
- 149 For a longer discussion of how to attain these metrics pertaining to economic justice and employment *see infra*, Issue Area 5A, pp. 38-41.
- 150 For a more complete discussion of how to achieve housing goals, *see infra*, Issue Area 5A, pp.41-42.
- 151 *See infra*, Issue Area 5A, pp. 42-44 , for more on providing nutrition services for people living with HIV.
- 152 For more information on how to achieve these health care metrics, *see infra*, Issue Area 5B, pp. 44-47.
- 153 For more on what sexual and reproductive health care needs entail, *see infra*, Issue Area 5C, pp.47-51.
- 154 IRS Rev Proc. 2020-36 states that beginning January 1, 2021, the ACA 2021 affordability threshold will be 9.83%. This number should be adjusted for the quality of life standard each time the IRS alters its own affordability thresholds. Further, affordability should only be defined as total household income and should not be defined to include other investments or savings.
- 155 For a discussion of what these stigma metrics should include *see infra* Issue Area 2A, pp.11 .
- 156 David J. Martin, *Working with HIV*, Am. Psych. Ass'n (2011), <https://www.apa.org/pi/aids/resources/research/martin>.
- 157 Tim Murphy, *The Number-One Barrier to Ending HIV in U.S. Cities Is a Housing Crisis*, TheBody (2020), <https://www.thebody.com/article/barrier-to-ending-hiv-in-u-s-cities-housing-crisis>.
- 158 *See* Angela A. Aidala et al., *Housing Status, Medical Care, and Health Outcomes Among People Living With HIV/AIDS: A Systematic Review*, 106 Am. J. of Public Health e1, e1 (2016).
- 159 *Id.* at e2.
- 160 *Id.*
- 161 *Id.*; *see also* M-J Milloy et al., *Housing Status and the Health of People Living with HIV/AIDS*, 9 Current HIV/AIDS Report 364, (2012), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3693560/>.
- 162 *Employment and Homelessness*, National Coalition for the Homeless 1, 3-4 (2009) <http://nationalhomeless.org/wp-content/uploads/2014/06/Employment-Fact-Sheet.pdf>.
- 163 *State of Homelessness: 2020 Edition*, National Alliance to End Homelessness (2020), <https://endhomelessness.org/homelessness-in-america/homelessness-statistics/state-of-homelessness-2020/>.
- 164 *Id.*
- 165 *Economic Justice*, Positive Women's Network-USA, <https://www.pwn-usa.org/issues/policy-agenda/economic-justice/> (last visited June 29, 2021).

- 166 Aaron Richterman et al., *Policies affecting eligibility for the Supplemental Nutrition Assistance Program and HIV incidence in the United States*, *Open Forum Infectious Diseases* (2021), <https://doi.org/10.1093/ofid/ofab101>.
- 167 Sara Imperiale and Margaret Brown, *Now Is the Time to Improve SNAP for Food Insecure Families*, National Resource Defense Fund (2020), <https://www.nrdc.org/experts/sara-imperiale/now-time-improve-snap-food-insecure-families>.
- 168 *Id.*
- 169 Colin Gray, *Leaving benefits on the table: Evidence from SNAP*, 179 *J. of Public Economics* 104054 (2019), <https://doi.org/10.1016/j.jpubeco.2019.104054>.
- 170 U.S. Statistics, [HIV.gov](https://www.hiv.gov/hiv-basics/overview/data-and-trends/statistics) (2021), <https://www.hiv.gov/hiv-basics/overview/data-and-trends/statistics>.
- 171 *Id.*
- 172 Adam Searing and Adaora A. Adimora, *HIV and Medicaid Expansion: Failure of Southern States to Expand Medicaid Makes Elimination of HIV Infection in the United States Much Harder to Achieve*, *Georgetown Health Policy Institute* 1, 1 (2020), <https://ccf.georgetown.edu/2020/11/29/hiv-and-medicaid-expansion-failure-of-southern-states-to-expand-medicaid-makes-elimination-of-hiv-infection-in-the-united-states-much-harder-to-achieve/>.
- 173 *Id.*
- 174 For example, an investigation found that under a standard Medicare Part D benefit a person living with HIV would pay between \$3,000 to \$4,000 a year in out-of-pocket expenses for ART unless they qualify for low-income subsidies. Chien-Wen Tseng et al., *Medicare Part D and Cost-Sharing for Antiretroviral Therapy and Preexposure Prophylaxis*, *JAMA Network Open* (2020) doi:10.1001/jamanetworkopen.2020.2739.
- 175 Copay accumulator adjustment policies (CAAPs) prevents drug manufacturer coupons (like those from HIV drug manufacturers to offset the costs of prescriptions) from counting toward patients' annual deductibles or out-of-pocket cost limits. *Double Dipping: Insurance Companies Profit at Patients' Expense*, *AIDS Institute* 1, 3 (2021), [https://aidsinstitute.net/documents/2021\\_TAI\\_Double-Dipping\\_Final-031621.pdf](https://aidsinstitute.net/documents/2021_TAI_Double-Dipping_Final-031621.pdf).
- 176 *See supra*, Issue Area 5C, pp. 47-51.
- 177 *Doctors Agree: Gender-Affirming Care is Life-Saving Care*, *American Civil Liberties Union* (2021) <https://www.aclu.org/news/lgbtq-rights/doctors-agree-gender-affirming-care-is-life-saving-care/>.
- 178 Federal AIDS Policy Partnership, *HIV Community Funding Requests for FY 2022 Domestic HIV Programs*, (2021) <https://documentcloud.adobe.com/link/track?uri=urn:aaid:scds:US:17b842bc-691d-4f97-97ca-918b78ffd46a>.
- 179 HIV Plan, *supra* note 15, at 26, 37.
- 180 *Id.* at 24.
- 181 *Id.*
- 182 Natalia Kanem, *Sexual and Reproductive Health and Rights: The Cornerstone of Sustainable Development*, *UN Chronicle*, <https://www.un.org/en/chronicle/article/sexual-and-reproductive-health-and-rights-cornerstone-sustainable-development>.
- 183 Monique A. Tello et al., *Barriers to recommended gynecologic care in an urban United States HIV clinic*, 19 *J. Women's Health*, no. 8, 2010, 1515-1516, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2924785/>; see also *UNSPOKEN: Sexuality, Romance, and Reproductive Freedom for Women Living with HIV in the United States*, *Positive Women's Network-USA* (2013), <https://pwnusa.files.wordpress.com/2013/11/11-11-13srhr-pwn-usa.pdf>.
- 184 Jaime Grant et al., *Injustice at Every Turn: Report of the National Discrimination Survey*, *Nat'l Ctr. for Transgender Equal. & Nat'l Gay and Lesbian Task Force*, 82 (2011), [https://transequality.org/sites/default/files/docs/resources/NTDS\\_Report.pdf](https://transequality.org/sites/default/files/docs/resources/NTDS_Report.pdf).
- 185 Cecile Unger, *Care of the Transgender Patient: A Survey of Gynecologists' Current Knowledge and Practice*, *J. Women's Health* (December 2014), <https://doi.org/10.1089/jwh.2014.4918>.
- 186 Although the PLHIV networks appreciate this reference to pregnancy and HIV, we would recommend that future discussions are gender inclusive and recognize that not all people who bear children identify as women.

187 HIV Plan, *supra* note 15, at 27, 29.

188 *HIV Testing in the United States*, Kaiser Family Foundation (June 25, 2019), <https://www.kff.org/hiv/aids/fact-sheet/hiv-testing-in-the-united-states/>.

189 *Id.*

190 Katherine M. Jones et al., *Racial and Ethnic Disparities in Breastfeeding*, 10 *Breastfeeding Med.*, no. 4, 2015, 186, 193-94, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4410446/>.

191 *Id.*