FILLING IN THE GAPS
A PLHIV NETWORKS RESPONSE TO THE
NHAS FEDERAL IMPLEMENTATION PLAN
DEC
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EXECUTIVE SUMMARY

As the national “network of networks,” U.S. People Living with HIV Caucus has taken the lead on several issues that people living with HIV face, including addressing national HIV plans and policies that affect us. The PLHIV networks that make up the HIV Caucus are in direct contact with tens of thousands of people living with HIV throughout the United States. These unique abilities and access informed our work and led us to create Demanding Better: An HIV Federal Policy Agenda by People Living with HIV: the most comprehensive federal policy vision for people living with HIV to date, created collaboratively by all national networks of people living with HIV in the U.S..

The U.S. People Living with HIV Caucus reviewed the National HIV/AIDS Strategy 2022-2025 (NHAS) Federal Implementation Plan, which was released on August 29, 2022, and created this document in response: Filling the Gaps: A PLHIV Networks response to the NHAS Federal Implementation Plan. Our review of the Implementation Plan was, as all of our advocacy is, guided by the analysis and recommendations set forth in Demanding Better. In this document we address what is and is not included in the Implementation Plan and provide concrete recommendations to our federal partners. It is one part of our larger, ongoing effort to hold the federal government accountable for protecting and upholding our health, human rights and quality of life.

Importantly, the recommendations contained herein are not exhaustive of the actions the federal government must take to fully support people living with HIV in the ways we need. Rather, they are reflective of priority actions we see as necessary to fill in the gaps in the Implementation Plan within the three-year time span provided in the NHAS.

Our response to the Implementation Plan mirrors the structure and priorities laid out in Demanding Better by focusing on five thematic areas that must be centered in every aspect of the federal HIV response:

1. structurally integrate of communities most impacted by the domestic epidemic into advisory and decision-making roles within the HIV response;
2. address racial and gender inequities in the HIV epidemic;
3. attend to sex workers and immigrants within the response
4. uphold human rights for people living with HIV; and
5. measurably commit to improve quality of life and quality of care for people living with HIV, especially for those aging with HIV.

To address each of these issue areas, we have identified gaps in the Implementation Plan and suggested concrete recommendations for the relevant federal agencies and offices, which are broadly delineated on the pages that follow. As networks of people living with HIV who are directly impacted by the federal government’s response to the domestic epidemic, we will continue to monitor and evaluate the domestic HIV response, and seek to partner with relevant federal agencies in working to realize the vision of the NHAS 2022-2025: The United States will be a place where new HIV infections are prevented, every person knows their status, and every person with HIV has high-quality care and treatment, lives free from stigma and discrimination, and can achieve their full potential for health and well-being across the lifespan.
In July 2021, the U.S. People Living with HIV Caucus (HIV Caucus) published *Demanding Better: An HIV Federal Policy Agenda by People Living with HIV.*[1] The first set of policy recommendations created collaboratively by all national networks of people living with HIV in the U.S., *Demanding Better* lays out a clear roadmap for the federal administration, Congress, and federal agencies to achieve their goal of ending the HIV epidemic by 2030 in the United States with a focus on protecting human rights and improving quality of life for people living with HIV. *Demanding Better* serves as the most comprehensive federal policy vision for people living with HIV to date and should be looked to as a roadmap for all stakeholders concerned about the domestic HIV epidemic.

On World AIDS Day of the same year, the White House Office of National AIDS Policy (ONAP) issued the National HIV/AIDS Strategy (NHAS), 2022-2025.[2] The NHAS establishes the goals, strategies and objectives that the federal government must implement to comprehensively address the domestic HIV epidemic. The four NHAS goals are: 1) prevent new HIV infections; 2) improve HIV-related health outcomes of people with HIV; 3) reduce HIV-related disparities and health inequities; and 4) achieve integrated, coordinated efforts that address the HIV epidemic among all partners and stakeholders.

On August 29, 2022, ONAP released the National HIV/AIDS Strategy’s accompanying Federal Implementation Plan (Implementation Plan).[3] The Implementation Plan outlines the priority actions, policies and programs that federal agencies plan to take over the next four years to further the NHAS’s vision and goals. Similar to the NHAS, the Implementation Plan both makes significant progress and has significant gaps.

This document serves as our response to the Implementation Plan. In it, we highlight the strengths and weaknesses of the Implementation Plan and provide recommended guideposts and activities that the federal government should prioritize in addition to those laid out in *Demanding Better.*

Importantly, these recommendations are not exhaustive of the actions the federal government must take to fully support people living with HIV in the ways we need. Rather, they are reflective of some priority actions we, as the U.S. PLHIV Caucus, see as necessary to fill in the gaps in the Implementation Plan within the three-year time span provided in the NHAS.
Our response to the Implementation Plan mirrors the structure and priorities laid out in *Demanding Better* by focusing on five thematic areas that must be centered in every aspect of the federal HIV response:

1) structurally integrate communities most impacted by the domestic epidemic into advisory and decision-making roles within the HIV response;
2) address racial and gender inequities in the HIV epidemic;
3) attend to sex workers and immigrants within the response
4) uphold human rights for people living with HIV; and
5) measurably commit to improve quality of life and quality of care for people living with HIV, especially for those aging with HIV.

As the Implementation Plan is well underway, we ask that reports on progress of the Implementation Plan and any new developments or additions to the Implementation Plan be provided to the public twice a year. The gaps identified in this document should be addressed and reflected in any reports on the progress of the Implementation Plan. As networks of people living with HIV who are directly impacted by the federal government’s response to the domestic epidemic, we will continue to monitor and evaluate the domestic HIV response, and seek to partner with relevant federal agencies in working to realize the vision of the NHAS 2022-2025:

*The United States will be a place where new HIV infections are prevented, every person knows their status, and every person with HIV has high-quality care and treatment, lives free from stigma and discrimination, and can achieve their full potential for health and well-being across the lifespan.*[4]

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**About the US People Living with HIV Caucus**

People living with HIV networks are organized formations created, led by, and accountable to the estimated 1.2 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. U.S.-based networks of people living with HIV have united as the U.S. People Living with HIV Caucus (HIV Caucus) to demand a federal HIV response that protects and upholds our health, human rights and quality of life.

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 that 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 *Demanding Better: An HIV Federal Policy Agenda by People Living with HIV*; the most comprehensive federal policy vision for people living with HIV to date, created collaboratively by all national networks of people living with HIV in the U.S.. That living policy agenda continues to inform our advocacy and guide the recommendations we convey to administrative officials, lawmakers and other key stakeholders in addressing the health and human rights of people living with HIV.

[4] *Id. at ii.*
The 2022-2025 National HIV/AIDS Strategy affirmed the importance of the meaningful involvement of people with HIV/AIDS (MIPA) in program design and implementation.

People with HIV are central to the response to the epidemic and must be included in all elements of programming and service delivery to achieve the Strategy’s goals. People with HIV must be included in program design and implementation, quality improvement initiatives, and campaigns; engaged as peers in prevention and care services; employed in HIV service delivery organizations; and involved in large-scale structural and policy initiatives.[5]

The NHAS further acknowledged that “There is a lack of ongoing, diverse, meaningful, and engaged community input in some HIV programs and services.”[6]

What’s actually in the NHAS Federal Implementation Plan

Nowhere in the Implementation Plan is an overarching federal commitment to involving those constituencies most directly impacted by HIV policymaking and service delivery in sustainable, accountable, and transparent processes to inform, monitor, evaluate, and provide guidance on the domestic HIV response. For example, in ten pages of actions to implement Goal 2: Improve HIV-Related Health Outcomes for People Living with HIV, there is not a single commitment to involve people living with HIV or networks of people living with in defining priorities, setting relevant desirable health outcomes, or evaluating how well systems and services are meeting our needs.

The Ryan White HIV/AIDS Program (RWHAP) is perhaps the simplest opportunity to administratively deepen
MIPA in federal HIV programming because the RWHP already legislatively requires the structured inclusion of people living with HIV on planning councils and advisory boards.[7] While one RWHP-related activity slightly narrows the definition of “community engagement” to pertain specifically to people living with HIV[8], generally Implementation Plan activities call for “community engagement” in the most general terms, without clarity about what would constitute “engagement,” and without measures for accountability or success.[9] For example:

Conduct community engagement activities to directly engage RWHP stakeholders, recipients, and nontraditional organizations in order to share key messages about HIV care and support and the RWHP in order to better engage those out of care.[10]

The Implementation Plan makes important advances by committing to “[i]dentify opportunities to strengthen the capacity of the aging services network to meet the needs of older adults with HIV/AIDS through coordination across its multiple TA resource centers”[11] and to “[c]ollaborate among ACL, CDC, HRSA, NIH, and SAMHSA to develop and monitor indicators to measure quality of life for people with HIV in the NHAS.”[12] Nevertheless, there is no articulated commitment even to basic input from people living with HIV in informing these processes or measuring success.

What’s needed

For the goals of the NHAS to be met, those setting policies that impact services and programs must ensure that directly impacted constituencies have an organized voice in decision-making. This includes integrating opportunities for input that account for the race, gender, and class inequities that consistently plague the domestic HIV response.

A federal response grounded in MIPA would structurally support decision-making by people living with HIV from communities that are disproportionately affected by the domestic epidemic, especially Black, Latinx and Indigenous people, those aging with HIV, youth, those living in the Deep South, people who use drugs, immigrants, the LGBTQ+ community, cisgender and transgender women, people with incarceration experience, and sex workers. The RWHP

[7] Health Res. & Servs. Admin., Ryan White HIV/AIDS Program Legislation (February 2021) https://ryanwhite.hrsa.gov/about/legislation (for example, under the RWHP Part A, individuals who make decisions about the allocation of resources on jurisdictional planning councils must meet certain requirements, including “reflectiveness” of the local epidemic and “representation” in filling various types of membership categories).
[10] National HIV/AIDS Strategy Implementation Plan, supra note 3, at 47; see also id. at 35 (“Identify and share successful strategies for community engagement in planning, development, and implementation of HIV care and treatment strategies among RWHP and EHE initiative recipients.”).
[12] Id. at 31.
is an imperfect and under-resourced example of the ways that MIPA can be formalized and structured through policies and practices. There are administrative avenues, resources and activities that could more robustly institutionalize MIPA throughout the Ending the HIV Epidemic jurisdictional plans, HIV prevention, testing, care, and supportive services.[13]

While it is not feasible to provide for individual input from the estimated 1.2 million people living with HIV and the millions more accessing HIV-related services in the U.S, it is feasible to ensure structured and formal involvement of regional and national networks of people living with HIV, and of other organized groups of constituent stakeholders throughout the domestic HIV response. PLHIV Networks were created to ensure meaningful avenues of engagement by taking input from and 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.

Despite abounding opportunities to create a clear commitment to the formal and structured engagement of PLHIV Networks in the federal response, the Implementation Plan fails to do so. For example, the Implementation Plan includes the following advisory activity: The Presidential Advisory Council on HIV/AIDS [PACHA] will provide, on an ongoing basis, recommendations for effective implementation of the NHAS, as well as monitor progress of its implementation. During at least one of its meetings, the Council will review the progress of federal agencies and nonfederal stakeholders in implementing the NHAS.[14]

PACHA is designated with this critical role in advising on, informing and monitoring the NHAS. Thus a relatively simple structural solution, as highlighted in the original Demanding Better: An HIV Federal Policy Agenda For People Living with HIV, would be to institutionalize participation by networks of people living with HIV on PACHA itself. This and related recommendations are summarized in the following page.

[13] Id. at 26, 28.
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<tr>
<th>Criteria</th>
<th>Recommended Activities</th>
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<tr>
<td>Structural MIPA</td>
<td>Recharter the Presidential Advisory Council on HIV/AIDS (PACHA), the Office of AIDS Research Advisory Council (OARAC), and the CDC/HRSA Advisory Committee (CHAC) 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.</td>
<td>Office of the President, CDC, NIH</td>
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<td>Structural MIPA</td>
<td>Require that all future HIV initiatives contain MIPA indicators for federal, state, and local advisory and decision-making bodies with purview over HIV policy, including local EHE jurisdictional planning processes. This must include engagement with and resource allocation for PLHIV Networks representing communities most impacted in the relevant jurisdiction.</td>
<td>Office of the President, HHS[15]</td>
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<tr>
<td>Structural MIPA</td>
<td>Create formalized processes to engage and fund PLHIV networks to monitor, evaluate and advise on the current Implementation Plan as well as future updates to, or iterations of, the Implementation Plan.</td>
<td>Office of the President/ONAP</td>
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<tr>
<td>Structural MIPA</td>
<td>Require each agency implicated in the NHAS include a formal commitment to measurable and accountable MIPA in future updates to, or iterations of, the Implementation Plan. Each agency should be tasked with a commitment to MIPA-driven activities that go beyond general commitment to “community engagement” to concrete and clear metrics for the structured inclusion of people living with HIV from communities that are disproportionately affected by the epidemic.</td>
<td>Office of the President/ONAP</td>
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<tr>
<td>Structural MIPA</td>
<td>Require all agencies to commit to increasing the number of people living with HIV who are hired for consultant and expert roles in future updates to, or iterations of, the Implementation Plan.</td>
<td>Office of the President/ONAP</td>
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<td>RWHAP</td>
<td>Partner with and fund PLHIV Networks to develop standards to improve MIPA in RWHAP Planning Councils. This must include assessing and implementing capacity-building and accountability mechanisms in the bylaws, policies and practices of RWHAP Planning Councils that will better support people living with HIV.</td>
<td>HRSA</td>
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<tr>
<td>RWHAP</td>
<td>Partner with and fund PLHIV networks to develop policies and practices to improve and ensure HRSA oversight over RWHAP Planning Councils. This must include updating and amending RWHAP Planning Councils Grievance Processes to include clear guidelines and protections for PLHIV and other community members who need to communicate disagreements or complaints outside of funding.</td>
<td>HRSA</td>
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[15] The Department of Health and Human Services houses a number of agencies and offices that touch on HIV care and prevention. In this document, when we make a recommendation to the Department of Health and Human Services, we implicitly include the relevant offices and agencies therein.
ISSUE AREA 2:

The federal HIV response must advance racial and gender equity

What the NHAS says

The NHAS named five “priority populations” in order to expand and improve services in communities most impacted by the HIV epidemic in the U.S., namely i) gay, bisexual, and other men who have sex with men, in particular Black, Latino, and American Indian/Alaska Native men; ii) Black women; iii) transgender women; iv) youth aged 13–24 years; and v) people who inject drugs.[16]

What’s actually in the NHAS Federal Implementation Plan

The Implementation Plan addresses racial and gender equity by focusing on actions to reduce racial/ethnic and gender disparities. For example, there are actions that work toward preventing discrimination and stigma by leveraging existing legal protections, advancing research, and supporting the collection and assessment of data – all of which are important steps.[17] Additionally, the five priority populations named in the NHAS are specifically and consistently addressed in actions throughout the Implementation Plan.[18]

We applaud the Office of National AIDS Policy (ONAP) for rejecting a “general public” approach to the HIV response (which implicitly affirms white, cisgender, able-bodied, middle class norms) and explicitly prioritizing many forms of racial and gender equity in research, care and resource allocation in the Implementation Plan. However, we note that there is a lack of explicit inclusion and focus on transgender men and non-binary people throughout the Implementation Plan.

As was reflected in Demanding Better, equitable funding is an important component for addressing and reducing racial/ethnic disparities. The Implementation Plan largely fails to designate funding opportunities specifically for activities, initiatives, or programs led by people, networks, or organizations most impacted by racial and gender inequities in the federal response, including Black, Latinx, and Indigenous communities as well as women, queer, transgender and non-binary people. For example, the Implementation Plan contains over 30 actions pertaining to community-based organizations (CBOs). None of those actions specifically designate that the CBO should be led by a community that is disproportionately impacted by the HIV epidemic. Even Strategy 3.1.5, which specifically addresses the goal of creating funding opportunities to address racial/ethnic disparities, fails to include an action to fund programs or activities led by people, networks, or organizations most impacted by racial and gender inequities in the federal response.

[18] Id. at 32, 36. (For example, the Implementation Plan includes actions to meet the NHAS objective to “assist states in protecting people with HIV from violence, retaliation, and discrimination associated with HIV status, homophobia, transphobia, xenophobia, racism, substance use, and sexism” and to address the “social and structural drivers of health and as they relate to communities and persons experiencing most risk,” including Black, Latinx, and Indigenous, and other people of color.)
What's needed

Overall, the Implementation Plan mentions research, funding opportunities, and creation of resources for communities and persons most vulnerable to HIV in the U.S., including Black, Latinx, Indigenous and other people of color. The explicit focus on advancing racial equity in the HIV response is a critical step in the right direction. A focused commitment to transgender men and nonbinary individuals living with HIV must be added to the NHAS Implementation Plan, along with commitments to resource organizations led by, accountable to, and serving Black, Latinx and other communities of color. We look forward to monitoring how the government further defines, executes, and elaborates on actions to address racial and gender inequities in the federal response.

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<tr>
<td>Advancing Racial and Gender Equity</td>
<td>Require every agency implicated in the NHAS Implementation Plan to include measurable actions that explicitly advance racial and gender equity in the HIV response in future updates to, or iterations of, the Implementation Plan.</td>
<td>Office of the President/ONAP</td>
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<tr>
<td>Advancing Racial and Gender Equity</td>
<td>Require that agencies better incorporate the needs of transgender men and non-binary people living with HIV in future updates to, or iterations of, the Implementation Plan by acknowledging them in applicable activities, naming the specific needs of these populations, and incorporating them into the appropriate actions.</td>
<td>Office of the President/ONAP</td>
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<tr>
<td>Advancing Racial and Gender Equity</td>
<td>Require that funding opportunities for HIV services prioritize resourcing grantees led by and accountable to members of the communities to be served, such as Black and Latinx-led organizations addressing the HIV epidemic through a racial equity lens and women- and trans-led organizations addressing the HIV epidemic through a gender equity lens.</td>
<td>HHS</td>
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<tr>
<td>Advancing Racial and Gender Equity</td>
<td>Conduct a targeted needs assessment to capture and assess the unique needs of non-binary people and transgender men living with HIV. This assessment can be used to intentionally include these populations into future HIV plans.</td>
<td>HRSA</td>
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ISSUE AREA 3:
The federal HIV response must attend to sex workers and immigrants living with HIV

What the NHAS says
The Office of National AIDS Policy made significant progress in the NHAS by acknowledging that sex workers and immigrants (among others) have unique circumstances that “warrant specific attention.”[19] That document began the process of identifying and naming important gaps in addressing the needs of sex workers and immigrants, including the deleterious impact of intersectional stigma, marginalization and criminalization.

What’s actually in the NHAS
Federal Implementation Plan
We were disappointed to see that the Implementation Plan did not meaningfully build on the progress of the NHAS by committing to specific actions to address the above-mentioned gaps. For example, neither of the two strategies that directly pertain to sex workers and immigrants (Strategies 3.1.2 and 3.1.4) contained any actions that name either of those populations.[20]

What’s needed
The federal response must design actions that will further the rights, health and safety of sex workers or immigrants. We encourage all future updates to, or iterations of, the Implementation Plan to be explicit in naming and addressing the unique needs of sex workers and immigrants living with HIV.

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<td><strong>Meaningful Inclusion of Sex workers and Immigrants</strong></td>
<td>Require that relevant agencies include activities that are specifically designed to improve the rights, health and safety of sex workers and immigrants in future updates to, or iterations of, the Implementation Plan.</td>
<td>Office of the President/ONAP</td>
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<td><strong>Meaningful Inclusion of Sex workers</strong></td>
<td>Conduct, and publicly publish, a study on the unintended impacts on the health and safety of people engaged in transactional sex in relation to the 2018 anti-sex trafficking bill known as SESTA/FOSTA. Submit a report on human trafficking investigations and prosecutions in connection with the same, and for other purposes. The planning, implementation, and assessment of the above-mentioned study and report must be undertaken in close collaboration with sex workers and sex worker-led organizations.</td>
<td>HHS, DOJ</td>
</tr>
<tr>
<td><strong>Meaningful Inclusion of Sex workers</strong></td>
<td>Engage and fund community-based organizations led by sex workers, especially sex workers living with HIV from Black, Latinx, Indigenous, and other people of color communities, in developing, implementing and analyzing programs, policies and procedures in the federal HIV response.</td>
<td>HHS</td>
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<tr>
<td><strong>Meaningful Inclusion of Immigrants</strong></td>
<td>Engage and fund community-based organizations led by immigrants, especially immigrants living with HIV, in developing, implementing and analyzing programs, policies and procedures in the federal HIV response, such as AIDS Education and Training Center curriculums.[21]</td>
<td>HHS</td>
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<td><strong>Meaningful Inclusion of Sex workers</strong></td>
<td>Require EHE-funded jurisdictions to demonstrate a commitment to decriminalizing commercial sex work, including addressing loitering laws and condoms as evidence laws.</td>
<td>CDC</td>
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<td><strong>Meaningful Inclusion of Sex workers</strong></td>
<td>Issue recommendations to end state and local policies that rely on condom possession as evidence of sex work. Include a statement that addresses how such policies harm HIV prevention, testing, and clinical care efforts and may place sex workers at risk for violence.</td>
<td>DOJ, CDC</td>
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<td><strong>Meaningful Inclusion of Immigrants</strong></td>
<td>Analyze and address regulatory barriers that prevent immigrants living with HIV from accessing systems of care by conducting outreach and education around the recently finalized public charge rule.[22]</td>
<td>USCIS, CDC, OGA</td>
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ISSUE AREA 4:
The federal HIV response must uphold human rights for people living with HIV by addressing stigma, eliminating HIV criminalization, and halting invasive, dangerous and non-consensual HIV surveillance practices.

What the NHAS says
The federal government helped to cause the gross expansion of HIV-specific criminal laws in the early 1990s by recommending and incentivizing states to implement them.[23] Although HIV criminalization is primarily – and not exclusively – the purview of state criminal law, the federal government has a responsibility to remit that harm and help to end HIV criminalization.

The Biden administration, and the Office of National AIDS Policy (ONAP) in particular, has been clear in their commitment to ending HIV criminalization as a necessary component to ending the HIV epidemic in the U.S.[24] Indeed, the NHAS contains the clear statement that:
"To end the HIV epidemic, public health, criminal justice, and legislative systems must work together to ensure that laws protect the community, are evidence-based and just, and support public health efforts. When a law meant to protect the public is not working as intended, is unjust, and may be hurting efforts to keep communities healthy, common solutions must be found to better meet public health and public safety goals. States should repeal or update these outdated laws and practices."[25]

What's actually in the NHAS
Federal Implementation Plan
Columbia, and Puerto Rico, and their alignment with current scientific evidence on HIV prevention, treatment, and transmission, with a focus on those within state and local criminal justice systems, legislative systems, and law enforcement.”[26] This is similar to actions called for in the Repeal Existing Policies that Encourage and Allow Legal (REPEAL) HIV Discrimination Act of 2022, HR 6111, but lacks the interdepartmental collaboration called for in the legislation.

Second, the Implementation Plan further calls for CDC to “Work with partners to develop and disseminate a tool for policymakers to assess intersections of their HIV criminalization and data privacy laws to determine alignment with science”[27] This is a tremendous opportunity to address concerns about Molecular HIV Surveillance (MHS) and Cluster and Detection Response (CDR) that PLHIV Networks, HIV advocacy organizations, and human rights advocates have raised for years.

Laws protecting the privacy of health data and permitting sharing 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.[28] Without such safeguards, the risk remains that a person’s molecular HIV data could be intentionally or negligently shared in ways that create vulnerability for criminal or civil liability, inadvertent disclosure, stigma, or risks to physical safety, employment and housing. Thus, Demanding Better called on the federal government to incorporate actions that will 1) strengthen community oversight and accountability on HIV data surveillance activities, 2) reduce the variation in data protections and security standards across state jurisdictions, 3) shield public health data from criminal, civil, and immigration legal matters, and 4) address the lack of informed consent for participation in MHS. None of those concerns were incorporated into the Implementation Plan.[29]

What’s needed
Multiple departments, including and beyond the CDC, can leverage the power of the federal response to end HIV criminalization. Similar to the requirements in the REPEAL HIV Discrimination Act, we recommend collaboration between the Office of National AIDS Policy, the Department of Justice, the Department of Defense, and the Department of Health and Human Services to assess, analyze, monitor, report on, and support efforts to address HIV criminalization in state and federal laws, policies, and practices. We also encourage departments and agencies to think creatively about how they can use existing programs, activities and funding streams to incentivize progress on ending HIV criminalization.

[27] Id. at 33.
[29] The CDC’s proposed activity 3.1.1 was a step towards acknowledging the risk of potential misuse of MHS/CDR data in civil, immigration, and/or criminal proceedings. However, alone it is not enough to allay community concerns and justify the required use of MHS throughout all jurisdictions. The CDC must craft stronger safeguards to more meaningfully address our deep concerns about the intersections of HIV criminalization and molecular HIV data. National HIV/AIDS Strategy Implementation Plan, supra note 3, at 33.
Following consultations with and input from networks of people living with HIV, the President’s Advisory Council on HIV/AIDS (PACHA) unanimously passed the Molecular HIV Surveillance and Cluster Detection and Response Resolution (Resolution) on October 14, 2022 addressing many of the data privacy and human rights concerns about MHS/CDR implementation.[30]

Currently, all jurisdictions are required to implement MHS activities as a condition of Integrated HIV Surveillance and Prevention funding.[31] PACHA recommends that the CDC re-consider that approach and instead direct public health authorities to adapt their MHS/CRD strategies to account for local conditions. They should meaningfully engage with key stakeholder and people living with HIV to “determine if MHS strategies should be implemented in their jurisdiction, and if implementation happens, how MHS activities can be implemented in a manner that does not pose harm to people living within that jurisdiction.”[32] This would give CDC-funded jurisdictions the option of halting MHS activities until safeguards (including and not limited to concrete firewalls protecting public health research and surveillance data from access by law enforcement, corporations, criminal legal courts, immigration enforcement and youth detention and protective services systems) are implemented and the human rights concerns of people living with HIV are addressed.

PACHA also recommends assessing the efficacy and cost effectiveness of MHS activities relative to other interventions; requiring “plain language notifications” to people living with HIV on the types of surveillance conducted with opt-out options for the use of MHS data for CDR activities; and funding jurisdictions to create a Community Advisory Board specifically focused on MHS/CDR and composed mostly of people living with HIV.

PACHA’s inclusion of networks of people living with HIV in developing, crafting and revising their recommendations to address MHS/CDR human rights and privacy violations is an example of the importance of MIPA. Informed by lived experience and direct contact with tens of thousands of people living with HIV throughout the United States, PLHIV networks are able to speak to on-the-ground concerns and help develop policies that better respect our basic rights and dignity. Now, the Implementation Plan should be updated to reflect PACHA’s recommendations.

[32] Id. at 3.
[33] Id. at 3-4.
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<td>Ending Criminalization of PLHIV</td>
<td>Require that relevant agencies (including and not limited to DOJ, HRSA, and CDC) include activities that promote the reform or repeal of state HIV criminalization laws in future updates to, or iterations of, the Implementation Plan</td>
<td>Office of the President/ONAP</td>
</tr>
<tr>
<td>Ending Criminalization of PLHIV</td>
<td>Require each Ending the HIV Epidemic in the U.S. (EHE) initiative jurisdictions to include a specific plan with goals, deliverables, outcomes, and a timeline aimed at reforming or repealing HIV criminalization laws and policies. The plans should include engagement with people living with HIV who have experienced incarceration to address the residual impacts of criminalization, including access to adequate treatment and care.</td>
<td>CDC</td>
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<tr>
<td>Ending Criminalization of PLHIV</td>
<td>Update guidance on the use of criminal and civil law to discriminate against and criminalize people living with HIV, including the use of general criminal laws to arrest and prosecute people living with HIV. Assess, analyze, monitor, report on, and support efforts to address HIV criminalization in state and federal laws, policies, and practices.</td>
<td>Office of the President/ONAP, DOD, DOJ, HHS</td>
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<td>MHS/CDR</td>
<td>Partner with the CDC to incorporate the recommendations made by PACHA in their Resolution on Molecular HIV Surveillance and Cluster Detection Response on any future updates to, or iterations of, the Implementation Plan. This must include the recommendations that the CDC update its guidance to public health authorities on the implementation of CDR specific to MHS activities through its HIV-related notice of funding opportunity (NOFO) announcements and other channels to include the following:</td>
<td>Office of the President/ONAP</td>
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<td>• Guidance to direct public health authorities to adapt their MHS/CDR strategies to account for local conditions, including meaningfully engaging with key stakeholder and people living with HIV to “determine if MHS strategies should be implemented in their jurisdiction, and if implementation happens, how MHS activities can be implemented in a manner that does not pose harm to people living within that jurisdiction.”[34] Local adaptations should include the possibility of a jurisdiction-wide moratorium on all MHS activities until safeguards (including concrete firewalls protecting public health research and surveillance data from access by law enforcement, corporations, criminal legal courts, immigration enforcement and youth detention and protective services systems) are implemented and the human rights concerns of people living with HIV are addressed.</td>
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<td></td>
<td>• Fund jurisdictions to create a Community Advisory Board specifically focused on MHS/CDR and composed mostly of people living with HIV.</td>
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<td></td>
<td>• Fund and provide technical assistance for conducting and evaluating activities to assess the efficacy and cost effectiveness of MHS activities relative to other interventions</td>
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[33] Id. at 3-4.
| MHS/CDR | Pause all MHS activities until the below is completed:  
| - Partner with PLHIV networks to develop community engagement standards for the development of future HIV-related data collection, use, sharing and storage.  
| - Partner with PLHIV networks to develop strong guidance on HIV data collection, sharing, and use.  
| - Require that EHE jurisdictions, as a condition of funding, certify in writing that surveillance data will 1) not be used for other purposes, create firewalls to protect public health data from improper use, and set limitations on the length of time data may be stored.  
| - Require EHE jurisdictions, as a condition for funding, include a written plan to end laws and practices that criminalize people living with HIV.  
| - Partner with PLHIV networks to develop informed consent standards and practices. | CDC |

| Stigma | Create a national stigma index, modeled after successful state and local stigma indexes. | CDC |

| Stigma | Require jurisdictions submitting EHE plans to create and resource clear, actionable MIPA-driven initiatives to reduce HIV-related stigma and other intersectional stigmas as part of their EHE commitments. | CDC |
ISSUE AREA 5:
The federal HIV response must improve Quality of Life and Quality of Care for People Living with HIV, with a focus on those Aging with HIV

What the NHAS says

NHAS indicators set quantitative targets and measure progress. For example, Indicator 6 is to “Increase viral suppression among people with diagnosed HIV to 95% from a 2017 baseline of 63.1%.”[35] They are an accountability mechanism that help the government, stakeholders, and the general public assess whether the federal response is moving towards goals. They are a clear indication of what the federal government response believes is, and is not, important to capture, measure and assess.

The NHAS committed to addressing quality of life for people living with HIV through the creation of a new, developmental indicator to measure the wellbeing of people living with HIV.[36] This was a significant development away from the approach that previous national HIV strategies have taken: namely defining success for people living with HIV by viral loads and medical appointments. Instead, this NHAS committed to crafting a new indicator that would better capture and document the social and structural determinants of health that impact the lived experience of people living with HIV.

What’s actually in the NHAS Federal Implementation Plan

The Implementation Plan adopted a quality of life indicator that includes five domains: self-reported health, unmet need for mental health services, unemployment, food insecurity, and housing instability. Specifically, the new quality of life indicators are:

**Indicator 9:** Increase the proportion of people with diagnosed HIV who report good or better health to 95% from a 2018 baseline of 71.5%.

**Indicator 10:** Decrease by 50% the proportion of people with diagnosed HIV who report an unmet need for services from a mental health professional from a 2017 baseline of 24.2%.

**Indicator 11:** Decrease by 50% the proportion of people with diagnosed HIV who report ever being hungry and not eating because there wasn’t enough money for food from a 2017 baseline of 21.1%.

**Indicator 12:** Decrease by 50% the proportion of people with diagnosed HIV who report being out of work from a 2017 baseline of 14.9%.

**Indicator 13:** Decrease by 50% the proportion of people with diagnosed HIV who report being unstably housed or homeless from a 2018 baseline of 21.0%.[37]

We applaud ONAP for developing a multi-dimensional quality of life indicator that includes social and structural determinants of health in the Implementation Plan. While those categories are not exhaustive of quality of life, it is remarkable that the NHAS goes beyond the biomedical to reflect a more complex and holistic approach to measuring wellness for people living with HIV. The five additional indicators of progress focused on quality of life show that the administration is committed to

[36] Id. at 24, 80.
capturing, measuring and assessing quality of life in a way that better reflects the structural and systemic barriers that impact the lived experiences of people living with HIV.

The next step is accountability for achieving those indicators over the next three years. To that end, the NHAS Federal Interagency Workgroup (FIW), which is comprised of the 10 federal departments, has committed to “meet regularly to coordinate activities within and across departments and agencies, identify opportunities to better align and accelerate federal efforts, apply lessons learned from epidemiological data and research findings, monitor progress toward the indicator targets, course correct as needed, and report on national progress.”[38]

What’s needed

Measuring quality of life is not equivalent to improving quality of life. The federal government must do more than “identify opportunities” and “monitor progress” over the next three years. Implementation Plan activities must go further to affirmatively improve quality of life and whole-person care for people living with HIV. Ultimately, assuring quality of life for people living with HIV deserves its own pillar in future HIV Plans, 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 includes emotional, mental, psychological, spiritual, and physical safety, security and wellbeing. It encompasses more than can be reflected in this section. For example, some of our recommendations specifically pertain to the RWHAP. As the largest federal program designed specifically for people with HIV in the U.S., RWHAP is responsible for providing healthcare, treatment, and a range of support services in an attempt to ensure that people with HIV are able to access and remain in care. [39] Support services that aim to address the social determinants of health (such as, food and nutrition, mental health, and housing services) often fail to meet the needs of people living with HIV. Thus strengthening RWHAP is important for improving the quality of life of people living with HIV. It is, however, by no means the only agency or program responsible for improving the quality of life of people living with HIV.

This section will highlight four specific shortcomings in the Implementation Plan:
1. addressing the specific needs of older people with HIV and long-term survivors,
2. ensuring employment and economic security for people living with HIV,
3. upholding sexual and reproductive rights of people living with HIV, and
4. addressing concerns about the impact of the “status neutral” approach on the quality and quantity of services for people living with HIV.

We look forward to working with our federal partners to continue to nuance, iterate and develop ways to strengthen the federal HIV response to improve quality of life for people living with HIV.

[38] Id. at 3.
The Implementation Plan should specifically address older adults living with HIV and long-term survivors

People who are 50 years and older living with HIV already constitute a near majority of all people living with HIV in the U.S. and are projected to constitute an overwhelming majority by 2030.[40] Older adults living with HIV and long-term survivors need a federal response that addresses unmet needs in access to adequate housing, food and nutrition, mental health and substance and alcohol use and treatment programs, employment and other socioeconomic support services, long-term care and other resources for health.[41]

The NHAS made an important commitment to improving the quality of life of older adults living with HIV and long-term survivors in Objective 2.5: “Expand capacity to provide whole-person care to older adults with HIV and long-term survivors.”[42] We recommend that older adults living with HIV and long-term survivors be added as a priority population in all future updates to, or iterations of, the National HIV/AIDS Strategy and Implementation Plan so that activities would be fully integrated throughout the federal response.

There are also opportunities to support the health and wellbeing of older adults living with HIV and long-term survivors in alignment with the Older Americans Act (OAA).[43] The OAA, historically and as re-authorized in 2020, requires that funding be targeted to those with the “greatest social need.”[44] New state guidance issues in August 2021 specifically defines the priority populations in alignment with a recent executive order from President Biden to include: “individuals who are Black, Latino, and Indigenous and Native American persons, Asian Americans and Pacific Islanders, and other persons of color; members of religious minorities; lesbian, gay, bisexual, transgender, and queer (LGBTQ+) persons; persons with disabilities; and persons who live in rural areas.”[45]

We appreciate the Administration for Community Living (ACL) activity to “[a]ssist states in the implementation of the 2021 State Plan Guidance provisions related to equity and older adults with HIV”[46] and make further recommendations for how older adults living with HIV and long-term survivors can be prioritized in State Plans and the federal response more generally.

[45] Id. at 3.
2: The Implementation Plan should ensure employment and economic security for people living with HIV

Employment status is one factor in the NHAS’s multidimensional approach to quality of life, illustrating the importance of the connections between employment, physical, mental, and economic health, and quality of life. Unfortunately, the Implementation Plan fails to outline meaningful actions to improve the employment challenges that people living with HIV face. No federal agency has taken responsibility for increasing access to the key information, services, and resources that people living with HIV need to utilize employment as a route to addressing poverty and social marginalization. The ongoing flow of thousands of people living with HIV from poverty in their working years to poverty in their older years is only maintained, if not entrenched, by the federal government’s refusal to address unique and profound gaps in access to employment-related information, services, and resources of people living with HIV.

3: The Implementation Plan should uphold sexual and reproductive health and rights of people living with HIV

The failure to address the reproductive and sexual health and rights of people living with HIV has been endemic to the federal response since the first National HIV/AIDS Strategy in July 2010.[47] We commend the Office of National AIDS Policy for incorporating more of a focus on sexual and reproductive health in this Implementation Plan than previous plans. However, the majority of sexual and reproductive health-related activities relate to HIV prevention or better integrating HIV service into existing sexual and reproductive health care settings.[48] The Implementation Plan lacks activities specifically designed to improve or expand access to comprehensive sexual and reproductive health care services for people already living with HIV.[49] This dearth of focus and resources for the sexual and reproductive health and rights of people living with HIV is especially troubling in the context of the grievous, rising state-level attacks on abortion, contraceptive access, and gender affirming care.

4: The Implementation Plan should specifically address concerns about the impact of the “status neutral” approach on the quality and quantity of services for people living with HIV

While status neutral activities are fully incorporated in the Implementation Plan under the broad umbrella of addressing HIV stigma, we include this subsection under the Quality of Life section due to questions about the impact the status neutral approach could have on the quantity and quality of services and care for people living with HIV.

The status neutral approach aims to address the stigma and structural barriers that are major obstacles to HIV prevention and care by using a “one door” approach to HIV prevention and care. In this approach, an HIV test spurs action regardless of the result of the test. Whether a person’s result is negative or positive (i.e. regardless of their HIV status), they will be connected to appropriate services.[50]

The goal of the status neutral approach – to advance health equity and drive down disparities by embedding HIV prevention and care into routine care – is commendable. We do, however, have outstanding concerns about the integration of status neutral activities throughout the federal response:

First, none of the status neutral-related activities in the Implementation Plan require consultation with people living with HIV or organizations led by directly impacted communities.[51] Networks of people living with HIV must be included in the planning, implementation and assessment of the rollout of the status neutral approach.

Second, it is not clear where status neutral funding will come from. We are concerned that, without guaranteed funding and support, already underfunded states and federal agencies will feel compelled to stretch funds traditionally used for people living with HIV to include those not living with HIV.

Third, there must be robust protections to ensure that the care and services for people living with HIV are not adversely impacted. This includes transparency and accountability in documenting the impact that status neutral activities have on services and programs specifically designed for people living with HIV.


[51] The Implementation Plan includes actions that name approaches to serving and meeting the needs of specific populations of people living with HIV but falls short of engaging people living with HIV in creating, informing, and executing its approaches. See generally National HIV/AIDS Strategy Implementation Plan, supra note 3.
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<thead>
<tr>
<th>Criteria</th>
<th>Activities/Guideposts</th>
<th>Dept</th>
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<tbody>
<tr>
<td>Older people living with HIV &amp; long-term survivors</td>
<td>Add older adults living with HIV and long-term survivors as a priority population in funding opportunities and throughout the federal response.</td>
<td>Office of the President/ONAP</td>
</tr>
<tr>
<td>Older people living with HIV &amp; long-term survivors</td>
<td>Require agencies to incorporate actions to further the whole-person care, including provision of support services, to older adults living with HIV and long-term survivors throughout the Implementation Plan (i.e. within all goals and strategies) in future updates to, or iterations of, the Implementation Plan.</td>
<td>Office of the President/ONAP</td>
</tr>
<tr>
<td>Older people living with HIV &amp; long-term survivors</td>
<td>Require agencies to incorporate actions to further the whole-person care, including provision of support services, to older adults living with HIV and long-term survivors throughout the Implementation Plan (i.e. within all goals and strategies) in future updates to, or iterations of, the Implementation Plan.</td>
<td>Office of the President/ONAP</td>
</tr>
<tr>
<td>Older people living with HIV &amp; long-term survivors</td>
<td>Ensure long-term care, end of life care, and hospice care are available and accessible for all those aging with HIV who need these services.</td>
<td>HHS</td>
</tr>
<tr>
<td>Older people living with HIV &amp; long-term survivors</td>
<td>Address the mental health and substance use needs of older adults with HIV and long-term survivors through focused programming, resource allocation, and integration of service delivery.</td>
<td>HHS, SAMHSA</td>
</tr>
<tr>
<td>Older people living with HIV &amp; long-term survivors</td>
<td>In Older Americans Act State Plans, require states to 1) include goals, objectives, strategies and outcomes pertaining to serving older adults living with HIV and 2) regularly document and describe their progress serving older adults living with HIV as part of regular reporting.</td>
<td>ACL</td>
</tr>
<tr>
<td>Older people living with HIV &amp; long-term survivors</td>
<td>Ensure that activities and initiatives designed for older adults living with HIV and long-term survivors address the racial/ethnic and socioeconomic inequities that impact BIPOC communities</td>
<td>Office of the President/ONAP</td>
</tr>
<tr>
<td>Improve Quality of Life and Quality of Care for People Living with HIV</td>
<td>Add a Quality of Life pillar to the federal EHE plan.</td>
<td>HHS</td>
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<tr>
<td>Improve Quality of Life and Quality of Care for People Living with HIV</td>
<td>Provide EHE jurisdictions with funds, guidance, and technical assistance to create a Quality of Life pillar in their jurisdictional plans.</td>
<td>CDC</td>
</tr>
<tr>
<td>Improve Quality of Life and Quality of Care for People Living with HIV</td>
<td>Fully integrate services that address the social determinants of health throughout RWHAP. Services that must be better integrated include food and nutrition services, comprehensive sexual and reproductive health care, screening and intervention for lifetime abuse and intimate partner violence, and mental health, psychological, spiritual, and emotional support services.</td>
<td>HRSA, SAMSHA, USDA</td>
</tr>
<tr>
<td><strong>Employment and Economic Security for People Living with HIV</strong></td>
<td>Lift the RWHAP prohibition on using supportive services funds to address job readiness and employment services needs.</td>
<td>HRSA</td>
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<tr>
<td><strong>Employment and Economic Security for People Living with HIV</strong></td>
<td>ONAP, HRSA, the Department of Labor (Employment &amp; Training Administration), and the Department of Education (Rehabilitation Services Administration) must coordinate to 1) identify direct funding through new and existing initiatives and 2) develop strategic, systemic responses to the employment-related needs of people living with HIV by, for example, establishing employment and benefits counseling services.</td>
<td>Office of the President/ONAP, HRSA, DOL, ED</td>
</tr>
<tr>
<td><strong>Uphold Sexual and Reproductive Health and Rights of People Living with HIV</strong></td>
<td>Require EHE 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, abortion care, pregnancy care, breast/chest-feeding care, and contraceptive care.</td>
<td>CDC</td>
</tr>
<tr>
<td><strong>Uphold Sexual and Reproductive Health and Rights of People Living with HIV</strong></td>
<td>Require EHE jurisdictions to take 1) a firm stance against the criminalization of breast/chest-feeding for people living with HIV and 2) affirmative steps to educate child welfare agencies within the jurisdiction on the science around people living with HIV breast/chest-feeding.</td>
<td>CDC</td>
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<tr>
<td><strong>Status Neutral</strong></td>
<td>Partner with and fund PLHIV networks to develop policies and practices for the implementation of status neutral programming.</td>
<td>HHS</td>
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<tr>
<td><strong>Status Neutral</strong></td>
<td>Require that jurisdictions implementing status neutral programming document, assess and disclose how funds are used with specificity and regularity, including the impact on services and programs specifically designed for people living with HIV.</td>
<td>HHS</td>
</tr>
<tr>
<td><strong>Status Neutral</strong></td>
<td>Prohibit jurisdictions from using funds dedicated to the care and support of people living with HIV from being used to resource or serve people who are not living with HIV. Rather status neutral programming should be implemented with new funding streams.</td>
<td>HHS</td>
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APPENDIX
ACRONYMS AND OTHER SHORTHAND

ACL - Administration for Community Living (HHS)
AIDS - acquired immune deficiency syndrome
CBO - community-based organization
CDR - cluster detection and response
CDC - Centers for Disease Control and Prevention (HHS)
DOD - U.S. Department of Defense
DOJ - U.S. Department of Justice
DOL - U.S. Department of Labor
EHE - Ending the HIV Epidemic in the U.S.
ED - U.S. Department of Education
EOP - Executive Office of the President
HHS - U.S. Department of Health and Human Services
HIV - human immunodeficiency virus
HIV Caucus - U.S. People Living with HIV Caucus
HRSA - Health Resources and Services Administration (HHS)
HUD - U.S. Department of Housing and Urban Development
LGBTQI+ - lesbian, gay, bisexual, transgender, queer, and intersex
NIH - National Institutes of Health (HHS)
NHAS - National HIV/AIDS Strategy 2022-2025
OGA - Office of Global Affairs (HHS)
ONAP - Office of National AIDS Policy (White House)
PLHIV - People Living with HIV
RWHAP - Ryan White HIV/AIDS Program (HRSA)
SAMHSA - Substance Abuse and Mental Health Services Administration (HHS)
USCIS - United States Citizenship and Immigration Services (DHS)
USDA - United States Department of Agriculture