

Federal AIDS Policy Partnership HIV Recommendations for the Biden Administration

The following document is being submitted to the Biden transition team by the Federal AIDS Policy Partnership (FAPP), a national coalition of local, regional, and national organizations advocating for federal legislation and policy seeking to ultimately end the HIV epidemic in the United States.

FAPP is managed by a Convening Group that consists of at-large members and a liaison from each of the affiliated working groups. The following pages are largely the work of the FAPP Work Groups¹ with some crosscutting issues from the Convening Group. A complete list of the 44 endorsing organizations can be found at the end of this document.

Given that FAPP is largely focused on the domestic epidemic, this document primarily makes recommendations for the U.S., Washington, DC, and the U.S. territories including Puerto Rico and the Virgin Islands. Our colleagues in the Global AIDS Policy Partnership (GAPP) have created recommendations more directly focused on the global epidemic, and we strongly urge the Administration to accept their recommendations. We list additional transition recommendations of many allied organizations and coalitions that work on issues that are intersectional with HIV at the end of this document.

We are encouraged by President-elect Joe Biden's and Vice President-elect Kamala Harris's strong record of support in working to end the HIV epidemic in the U.S. President-elect Biden's proposed goal of ending the HIV epidemic by 2025 is ambitious and bold. It will require an intensive focus and partnership with the communities most impacted by HIV. We strongly urge you to adopt the recommendations below, and we stand ready to provide our assistance to end the HIV epidemic.

Questions regarding these recommendations may be addressed to the FAPP co-chairs: Kathie Hiers with AIDS Alabama at kathie@aidsalabama.org or Mike Weir with NASTAD (National Alliance of State and Territorial Directors) at mweir@NASTAD.org.

¹ AIDS Budget & Appropriations Coalition, HIV Health Care Access Working Group, HIV Prevention Action Coalition, Research Working Group, Ryan White Work Group, Structural Interventions Working Group

Overview

The United States has made significant progress in responding to the HIV epidemic. Treatment and biomedical prevention advances – and the innovative research and development behind them – have revolutionized our ability to end the HIV epidemic and have provided lifesaving interventions to millions of people worldwide. Even with these advances, since 2013, new HIV diagnoses have plateaued around 38,000 per year. This comes after years of steady progress in reducing new diagnoses and new science that increases the effectiveness of treating and preventing HIV.

In 2019, the Trump Administration announced a new initiative to end the HIV epidemic in the U.S. that seeks to reduce new HIV transmissions by 75% by 2025 with an ultimate goal of 90% by 2030.² The Trump Administration also implemented policies that run counter to these goals – policies that the Biden Administration will need to immediately end. Additionally, achieving these goals will require centering racial equity through intentional work to dismantle white supremacy and undo structural racism. There must also be coordinated leadership from the White House and its executive agencies, as well as funding that targets the underlying structural inequities and bolsters our crumbling public health infrastructure.

We have the tools to end the HIV epidemic, but those tools must be expanded and focused within communities most impacted by HIV. In 2018, Black women accounted for 58% of new HIV diagnoses among women, but just 13% of the U.S. female population. In the U.S. South, gay and bisexual Black and Latinx men accounted for over 70% of new diagnoses among gay, bisexual, and other men who have sex with men. The Centers for Disease Control and Prevention (CDC) estimates that over half of Black transgender women are living with HIV. One in six Latinx people who are living with HIV are unaware of their status. Black people living with HIV are seven times more likely than white people to die from the virus.³ These disparities are rooted in centuries of discrimination and persistent structural inequities in health care, housing, economic opportunity, and education. President-elect Biden has promised to address structural racism in the U.S.; addressing HIV disparities within communities of color by enacting federal policies to increase health equity, reduce barriers to healthcare access, and address syndemics such as sexually transmitted infections (STIs), viral hepatitis, tuberculosis (TB), housing stability, and substance use are integral to accomplishing that goal.

As our nation has been battling the COVID-19 pandemic, it has become abundantly clear that we have failed to adequately invest in our public health infrastructure. The impact of COVID-19 on public health and health care systems stalled many HIV prevention and

² Department of Health and Human Services. (October 2020). *What Is Ending the HIV Epidemic: A Plan for America?* <u>https://www.hiv.gov/federal-response/ending-the-hiv-epidemic/overview</u>

³ Centers for Disease Control and Prevention. (September 2020) *Health Disparities in HIV/AIDS, Viral Hepatitis, STDs, and TB: African Americans/Blacks*. <u>https://www.cdc.gov/nchhstp/healthdisparities/africanamericans.html</u>

treatment programs around the country and strained the capacity of the public health workforce, as well as its resources. The COVID-19 response, like HIV, must target investments to communities most impacted to increase access to health care, prevention, testing, and treatment.

The Administration must commit to building on our recent successes. Priorities must include the Ending the HIV Epidemic Initiative and the immediate end to several current policies that harm communities vulnerable to HIV. We must also prioritize the needs of people living with HIV (PLWH), address health disparities, and produce structural change that will improve health outcomes. With your Administration's leadership and support, we can achieve an end to the HIV epidemic by reducing new HIV transmissions, ensure PLWH have unfettered access to effective HIV treatment, and lessen, and ultimately, eliminate health disparities experienced in impacted communities.

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SECTION 1: HIV PREVENTION

There has been incredible progress in the fight against HIV over the last 35 years. Through investments in HIV prevention and testing, hundreds of thousands of new HIV diagnoses have been prevented, and the number of people who are aware of their HIV status has increased from 81% in 2006 to 87% currently. Research funded by the National Institutes of Health (NIH) found that HIV treatment not only saves the lives of PLWH, but PLWH on effective antiretroviral therapy (ART) and who are durably virally suppressed cannot sexually transmit HIV – proving that HIV treatment is prevention.⁴ From 2014 to 2017, pre-exposure prophylaxis (PrEP) use increased from 6% to 35%.⁵ PrEP alone has the potential to avert approximately 48,000 additional HIV transmissions over the next five years, supporting President-elect Biden's ambitious and bold goals to end the HIV epidemic in five years.

Even with these biomedical prevention advances, progress has stalled with new HIV diagnoses remaining around 38,000 per year with the majority of new diagnoses disproportionately impacting underserved populations.⁶ The National HIV/AIDS Strategy: Updated to 2020 (NHAS)^{7,8} goal of reducing new HIV transmissions cannot be realized until the nation aggressively responds to pervasive and unmitigated stigma and discrimination against communities disproportionately impacted by HIV that diminishes our best efforts to combat one of the greatest public health challenges of our time.

The following recommendations were developed by the HIV Prevention Action Coalition.

Recommendation on HIV Prevention Funding

- Requested Action: The President should increase HIV prevention funding in the Centers for Disease Control and Prevention (CDC) budget for fiscal year FY2022 and beyond to meet the goals of ending HIV.
- **Rationale:** Until FY2020, the first year of the Ending the HIV Epidemic Initiative, HIV prevention funding remained relatively flat for several fiscal years. In order to meet the

⁴ Eisinger, R.W., Dieffenbach, C.W. & Fauci, A.S. (2019, January 10). HIV viral load and transmissibility of HIV infection: undetectable equals untransmittable. *Journal of the American Medical Association*. 2019;321(5):451-452. doi:10.1001/jama.2018.21167.

⁵ Finlayson, T., et al. (2019, July 12). Changes in HIV Preexposure Prophylaxis Awareness and Use Among Men Who Have Sex with Men — 20 Urban Areas, 2014 and 2017. *MMWR*. Rep 2019;68:597–603. DOI: http://dx.doi.org/10.15585/mmwr.mm6827a1

⁶ HIV.gov. (30, June 2020). U.S. Statistics. <u>https://www.hiv.gov/hiv-basics/overview/data-and-trends/statistics</u>

⁷ The National HIV/AIDS Strategy for The United States: Updated To 2020. https://files.hiv.gov/s3fs-public/nhas-update.pdf ⁸ On December 1, 2020 the Office of Infectious Disease and HIV/AIDS Policy released the draft HIV National Strategic Plan: A Roadmap to End the HIV Epidemic (2021-2025). FAPP encourages the Biden Administration and HHS to work with advocates to ensure public comment recommendations are included in the final HIV National Strategic Plan.

goals of NHAS and the Ending the HIV Epidemic: A Plan for America Initiative (EHE)⁹, additional resources are needed at CDC and the U.S. Department of Health and Human Services (HHS). Though we have made improvements in HIV prevention efforts at CDC and elsewhere, we still have over 38,000 new HIV diagnoses every year. Increased investments are critical to expand comprehensive prevention programs and to successfully reach vulnerable individuals. Adequate resources are necessary to carry out increased HIV testing programs, targeted interventions, public education campaigns, and surveillance activities.

The CDC's Division of HIV Prevention (DHAP), through partnerships with state and local public health departments, and community-based organizations, has expanded targeted, high-impact prevention programs that work to address racial and geographic health disparities in HIV transmissions. Additionally, CDC's national surveillance system is a key tool in identifying people and regions most impacted by the epidemic and tailoring prevention efforts to communities disproportionately impacted.

Recommendation on Increased Focus on Populations Disproportionately Impacted by HIV

- Requested Actions: Administration officials in the Office of the President, HHS, CDC, and throughout the federal government should expand and increase funding for programs designed to specifically address the disproportionate impact of HIV on vulnerable populations through high impact prevention and targeted interventions to reduce disparities.
- Rationale: Increases in new HIV diagnoses are occurring disproportionally in certain populations, and the federal government should prioritize its resources to focus on these populations. Special account should be given to men who have sex with men (MSM), young people (particularly young Black and Latinx MSM), ethnic and racial minority communities, people in the South, transgender women, cisgender Black and Latina women, people who inject drugs, and sex workers. These groups make up the majority of new HIV diagnoses and our prevention efforts should specifically reach these groups. Agencies within HHS should continue to prioritize their HIV prevention efforts for aforementioned vulnerable populations. The CDC and state and local governments should create and expand programs which prioritize their HIV prevention efforts for populations being disproportionately impacted and should be utilizing every prevention tool available. The South's larger and more geographically dispersed population of PLWH creates unique challenges for prevention and treatment.

⁹ The Ending the HIV Epidemic: A Plan for America. (2020, February). <u>https://files.hiv.gov/s3fs-public/ending-the-hiv-epidemic-flyer.pdf</u>

Recommendations on Biomedical Prevention

- Requested Actions: The Administration should make the implementation and scale up of pre-exposure prophylaxis (PrEP), post-exposure prophylaxis (PEP), and treatment-asprevention (TasP) priorities in our nation's response to HIV prevention.
 - The Administration must ensure these interventions are prioritized by incorporating them into CDC grantees' high impact prevention and EHE activities and be included alongside HIV education and outreach activities, testing programs, and surveillance programs.
 - The Administration should ensure full implementation of the U.S. Preventive Services Task Force (USPSTF) grade A recommendation for PrEP. Qualified Health Plans and other Affordable Care Act (ACA) compliant private insurance plans should be covering PrEP and necessary testing, labs, and medical visits. This item is further discussed in the HIV Treatment and Care section.
 - The Administration should ensure that *Ready, Set, PrEP*, is structured to specifically reach populations disproportionately impacted by HIV and where PrEP uptake is low. The Administration should provide additional resources and funding for *Ready, Set, PrEP* to expand enrollment in the program.¹⁰
 - The Administration should continue to update messaging from the federal government to enforce the scientific consensus that a person living with HIV who has reached an undetectable viral load is unable to transmit HIV (Undetectable = Untransmittable).
- Rationale: Biomedical interventions, such as PrEP, PEP, and TasP, are proven and effective means of HIV prevention. PrEP is the use of antiretroviral medications to prevent acquisition of HIV. According to the CDC, there are over 1.2 million people in the U.S. who have a substantial risk for HIV acquisition and for whom PrEP would be appropriate,¹¹ but only 18% (219,700) had received a prescription for the medication in 2018. Many populations that are disproportionately affected by HIV are still unaware that PrEP exists, how it can benefit them, and how to pay for it. For example, PrEP coverage for whites is four to seven times as high as for Black and Latinx individuals. HHS's *Ready, Set, PrEP* program, which provides access to PrEP for people who are uninsured, has been drastically underutilized and is not reaching. PEP is a course of HIV medicines taken within 72 hours after a potential exposure to HIV to prevent the virus from replicating and taking hold.

¹⁰ Please see previous submitted recommendations from the HIV Prevention Action Coalition for the Ready, Set, PrEP Program. <u>http://federalaidspolicy.org/hpac-ready-set-prep-recommendations/</u>

¹¹ Smith, D.K., Van Handel M., Grey J. (2018, December 28). Estimates of adults with indications for HIV pre-exposure prophylaxis by jurisdiction, transmission risk group, and race/ethnicity, United States, 2015. *Ann Epidemiol*. 2018 Dec;28(12): 850-857. DOI: <u>10.1016/j.annepidem.2018.05.003</u>

Research funded by the NIH found that HIV treatment not only saves the lives of PLWH, but PLWH on effective ART and who are durably virally suppressed cannot sexually transmit HIV – proving that HIV treatment is prevention.¹²

Recommendation on Access to Comprehensive Sexuality Education

- Requested Actions: Increased funding should be provided in the President's FY2022 budget to the CDC Division of Adolescent and School Health (DASH), the Teen Pregnancy Prevention Program (TPPP), and the Department of Education to increase capacity to provide sexual health education that encompasses the full spectrum of sexual relationships. Both the mandatory and discretionary abstinence-only-untilmarriage (AOUM) and sexual risk avoidance (SRA) programs should be eliminated in the President's first budget.
- Rationale: One in five new HIV diagnoses are among young people between the ages of 13 and 24; however, only 43% of high schools and 18% of middle schools teach CDC's recommended sexual health topics. Between fiscal year FY1982 and FY2017, the U.S. government spent over \$2 billion on ineffective AOUM and SRA programs in the U.S. and \$1.6 billion in foreign assistance to promote AOUM and SRA.¹³ There's a need for increased surveillance and research efforts, and schools need support to implement quality sexual health education, support student access to health care, and enable safe and supportive environments. A major consequence of this lack of education is that only half of young PLWH are aware of their status. AOUM programs are ineffective; they are unethical, harmful, and stigmatizing and withhold information from young people.

Recommendation on Access to Syringe Service and Harm Reduction Programs:

- Requested Actions: The Administration should support full access to Syringe Service Programs (SSPs), including federal funding for syringes. All restrictions on federal funding for SSPs should be removed and not included in the Administration's future budget requests, and the Administration should work with Congress to ensure that SSP restrictions are not in the legislative language of appropriations bills.
- Rationale: The current restrictive appropriations language on purchasing syringes must be lifted. Syringe service programs are an effective tool for HIV and hepatitis prevention and should be more utilized as a means of infectious disease prevention. HHS has said that SSPs are a proven, evidence-based tool in HIV and hepatitis prevention.¹⁴ Numerous studies have shown SSPs are a cost-effective means to lower

¹² HIV viral load and transmissibility of HIV infection: undetectable equals untransmittable. *Journal of the American Medical Association*. DOI:<u>10.1001/jama.2018.21167</u>.

¹³ Santelli, J. S., et al. (2017, September 1). Abstinence-only-until-marriage: An updated review of US policies and programs and their impact. *Journal of Adolescent Health* 61.3 (2017): 273-280. <u>https://doi.org/10.1016/j.jadohealth.2017.05.031</u>

¹⁴ The Centers for Disease Control and Prevention. *Summary of Information on The Safety and Effectiveness of Syringe Services Programs (SSPs)*. <u>https://www.cdc.gov/ssp/syringe-services-programs-summary.html</u>

HIV and hepatitis transmissions, reduce the use of drugs, and help connect people to medical treatment.^{15,16,17} Available data suggest that up to 70% of new hepatitis C (HCV) transmissions are among people who inject drugs. There is a critical intersection of the opioid, hepatitis, and HIV epidemics in the U.S. As evidenced in 2015 in Scott County, Indiana, communities are vulnerable for HIV and HCV outbreaks where injection drug use is high and access to SSPs, substance use treatment, and other health care services are low.¹⁸ These services are urgently needed, and adequate funding would provide a critical down payment for services needed to help stop the spread of opioid-related infectious diseases. Without serious attention, the human and financial consequences and costs will continue to be extraordinary.

Recommendation to Repair Damage from Title X Rule

- Requested Actions: We urge the Administration to take swift action to ameliorate the damage done by the Trump Administration rule¹⁹ devastating the Title X family planning program by:
 - 1. Issuing an executive order directing HHS to cease applying the rule and undertake emergency rulemaking to rescind the rule
 - 2. Directing providers to adhere to the CDC's nationally recognized, evidencebased guidelines for family planning services²⁰
 - Awarding new grants to jurisdictions that remain un- or underserved by Title X, including the six states with no Title X-funded health centers (Hawaii, Maine, Oregon, Utah, Vermont, and Washington)
 - 4. Request at least \$954 million in the President's FY2022 Budget for Title X
- Rationale: In March 2019, the Trump Administration published a final rule that has devastated the Title X family planning program, including leading to the loss of more than 1,000 service sites—which had provided 1.5 million patients with Title X-funded services in 2018—from the program.²¹ Title X is a critical program in efforts to reduce new HIV, hepatitis, and STIs transmissions; health centers offer sexuality education services, counsel on the importance of condoms, prescribe PrEP to communities

¹⁵ Patel, M. R., et al. (2018, April 1). Reduction of Injection-Related Risk Behaviors After Emergency Implementation of a Syringe Services Program During an HIV Outbreak. *JAIDS*. 2018;77(4);373-382. doi: 10.1097/QAI.00000000001615

¹⁶ Abdul-Quader, A. S., et al. (2013, November). Effectiveness of Structural-Level Needle/Syringe Programs to Reduce HCV and HIV Infection Among People Who Inject Drugs: a Systematic Review. *AIDS Behav.* 2013;17(9);2878-92. <u>doi: 10.1007/s10461-013-0593-y.</u>

¹⁷ Nguyen, T. Q., et al. (2014, November). Syringe Exchange in the United States: A National Level Economic Evaluation of Hypothetical Increases in Investment. *AIDS Behav.* 2014;18(11); 2144-2155. doi: <u>10.1007/s10461-014-0789-9</u>

¹⁸ Conrad, C. et al. (2015, April 24). Community Outbreak of HIV Infection Linked to Injection Drug Use of Oxymorphone — Indiana, 2015. *MMWR*. 64(16); 443-444 <u>https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6416a4.htm</u>

¹⁹ Department of Health and Human Services. (2019, March 4). *Compliance with Statutory Program Integrity Requirements*. 84 FR 7714. <u>https://www.federalregister.gov/documents/2019/03/04/2019-03461/compliance-with-statutory-program-integrity-requirements</u>

²⁰ Loretta, G., et al. (2014, April 25). Providing Quality Family Planning Services: Recommendations of CDC and the U.S. Office of Population Affairs. *Morbidity and Mortality Weekly Report* 63. <u>https://www.cdc.gov/mmwr/preview/mmwrhtml/rr6304a1.htm</u> ²¹ Dawson, D. (2020, February). Trump Administration's Domestic Gag Rule Has Slashed the Title X Network's Capacity by Half. Guttmacher Institute <u>https://www.guttmacher.org/article/2020/02/trump-administrations-domestic-gag-rule-has-slashed-titlex-networks-capacity-half</u>

disproportionately impacted, administer HIV tests, and offer testing and treatment for STIs that may make a person more susceptible to HIV transmission. In 2019 alone, Title X-funded health centers administered almost one million HIV tests, with over 3,600 having a positive result.²²

SECTION 2: HIV TREATMENT AND CARE

Early and uninterrupted access to health care is critical for PLWH to stay healthy and is important to our nation's public health. Health insurance coverage allows individuals living with HIV to receive the care and treatment they need to stay healthy and to suppress the virus. With viral suppression, individuals with HIV can live near normal life expectancies and their risk of sexually transmitting HIV drops to zero.

The Patient Protection and Affordable Care Act (ACA) opened doors to health care coverage for many PLWH for the first time. Prior to the ACA, only 16% of individuals living with HIV had private health coverage and 28% were uninsured. Forty percent of people with HIV relied on Medicaid coverage – a percentage that has grown since 2014. The ACA's expansion of the Medicaid program has been the main driver of coverage increases for PLWH.²³

The ACA must be sustained and strengthened if we are to make significant strides toward ending HIV in the U.S. Stronger protections are needed within the Marketplaces to ensure coverage and services are affordable and that individuals, particularly those with chronic conditions like HIV, have access to the range of services and medications that they need to stay healthy. In addition, the Medicaid program must be maintained as an entitlement program with a federal and state match financing mechanism that allows Medicaid programs to respond to fluctuations in demand, medical innovations, and public health emergencies. Medicaid must be expanded in every state to reduce the growing health disparities across states that have not expanded Medicaid. The rising cost of prescription drugs also must be addressed to keep lifesaving treatments affordable and accessible.

The following recommendations were developed by the HIV Health Care Access Working Group.

²² Fowler, C., et al. (2020, September). *Family Planning Annual Report: 2019 National Summary*. Office of Population Affairs. <u>https://opa.hhs.gov/sites/default/files/2020-09/title-x-fpar-2019-national-summary.pdf</u>.

²³ Dawson, L., Kates, J. (2020, September 24). *Insurance Coverage and Viral Suppression Among People with HIV, 2018*. Kaiser Family Foundation. <u>https://www.kff.org/hivaids/issue-brief/insurance-coverage-and-viral-suppression-among-people-with-hiv-2018/</u>

Recommendation Regarding ACA Marketplace Activities

- Requested Action: We urge the Administration to restore comprehensive outreach, education, and enrollment funding to support people's access and awareness of the ACA's Marketplaces as a source of comprehensive health coverage.
- Rationale: The ACA's Marketplaces have helped people living with HIV, HCV, and other pre-existing conditions access previously unavailable health care coverage. In addition to ensuring plans meet certain quality standards, Marketplaces also provide enrollment and navigation assistance that make private health insurance more understandable and help people find the coverage that works best for them. Far from making this coverage more accessible, the current Administration has eviscerated funding for community-based navigators, resulting in decreased assistance for vulnerable populations.²⁴

Recommendation Regarding Medicaid

- Requested Actions: Rescind both Centers for Medicare and Medicaid Services (CMS) letters inviting states to submit 1115 Medicaid Waiver applications involving work and community engagement requirements²⁵ and inviting states to re-write the Medicaid statute and receive a block-grant, reducing funding and creating a financial incentive to cut services and enrollment.²⁶ CMS should reject any pending waivers seeking work requirements and other barriers to care.
- Rationale: The Medicaid program is a critical source of health coverage and access to health care for PLWH. A significant portion of PLWH in care count on the Medicaid program for health care and treatment.²⁷ Medicaid not only promotes the individual health of PLWH, but by providing uninterrupted access to care and treatment, it is also an effective public health intervention.²⁸ The Trump Administration invited states to utilize 1115 Medicaid Waivers as a tool to shrink their Medicaid programs and place unacceptable barriers to accessing coverage, like requiring individuals to document 80 hours of employment per month to qualify. In January 2018, CMS issued a State Medicaid Director Letter inviting states to submit waiver applications involving these work and community engagement requirements.²⁹ CMS subsequently issued another

https://clinicalinfo.hiv.gov/sites/default/files/guidelines/documents/AdultandAdolescentGL.pdf

²⁴ Cloud, H. (2018, September 13). *Navigator Funding Cuts Will Leave Many Marketplace Consumers on Their Own*, Center on Budget and Policy Priorities. <u>https://www.cbpp.org/blog/navigator-funding-cuts-will-leave-many-marketplace-consumers-on-their-own</u>

²⁵ Centers for Medicaid Services. (2019, January 11) Dear State Medicaid Director Letter, *Opportunities to Promote Work and Community Engagement Among Medicaid Beneficiaries SMD # 18-002*. <u>https://www.medicaid.gov/federal-policy-guidance/downloads/smd18002.pdf</u>.

²⁶ Centers for Medicare & Medicaid Services. (2020, January 30) Dear State Medicaid Director Letter, *Healthy Adult Opportunity SMD# 20-001*. <u>https://www.medicaid.gov/sites/default/files/Federal-Policy-Guidance/Downloads/smd20001.pdf</u>.

 ²⁷ Kaiser Family Foundation. (2019, October 1). *Medicaid and HIV*. <u>https://www.kff.org/hivaids/fact-sheet/medicaid-and-hiv/</u>
 ²⁸ Panel on Antiretroviral Guidelines for Adults and Adolescents. (2019, December 18) *Guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents*. Department of Health & Human Services.

²⁹ Dear State Medicaid Director Letter, *Opportunities to Promote Work and Community Engagement Among Medicaid Beneficiaries SMD # 18-002*: <u>https://www.medicaid.gov/federal-policy-guidance/downloads/smd18002.pdf</u>.

letter inviting states to re-write the Medicaid statute and receive a block-grant, reducing funding and creating a financial incentive to cut services and enrollment.³⁰ To date, 19 states have sought work requirements, and many others have used Medicaid waivers to implement restrictive policies like premiums, lockout periods, and reductions in benefits.³¹ These waivers and the guidance that has fueled them are also at odds with the nation's ambitious goal of ending the HIV epidemic. Given the critical role that Medicaid plays for people living with and at increased risk of HIV, federal guidance should promote the public health role Medicaid plays, not undermine it.

Recommendation on PrEP Guidance

- Requested Action: We urge the Administration to quickly issue guidance requiring insurance plans to follow clinical guidelines for PrEP laid out by the CDC.³²
- Rationale: In June 2019, USPSTF finalized a Grade A recommendation for PrEP. The USPSTF final recommendation is a necessary step to increase access to this highly effective prevention tool, furthering the goal of ending the HIV epidemic. Guidance is necessary from federal and state regulators to ensure that private insurance plans and Medicaid programs interpret the USPSTF guidelines in line with current science and clinical recommendations. According to the CDC PrEP Guidelines, there are a number of services in addition to the medication itself that are integral to the PrEP intervention. To ensure meaningful access to PrEP, and to avoid a "bait and switch" for consumers seeking a prescription for PrEP with the understanding that it is available without cost sharing, these services must be covered without cost sharing (there is precedent for this with regard to polyp removal during a USPSTFrecommended colonoscopy).³³ Moreover, the PrEP pipeline is rapidly evolving, with multiple forms of PrEP, including a generic. ^{34,35} Individuals must have access to the PrEP medication that is clinically appropriate for them – and to be consistent with the ACA preventive services requirements, that medication must be available with no cost sharing.³⁶

https://www.medicaid.gov/sites/default/files/Federal-Policy-Guidance/Downloads/smd20001.pdf.

³¹ Kaiser Family Foundation. *Medicaid Waiver Tracker: Approved and Pending Section 1115 Waivers by State.* https://www.kff.org/medicaid/issue-brief/medicaid-waiver-tracker-approved-and-pending-section-1115-waivers-by-state/

³² US Public Health Service. (2017). *Pre-exposure Prophylaxis for the Prevention of HIV Infection in the United States: A Clinical Practice Guideline*. <u>https://www.cdc.gov/hiv/pdf/risk/prep/cdc-hiv-prep-guidelines-2017.pdf</u>.

https://www.avac.org/sites/default/files/infographics/AR2018_The_Future_ARV_Based_Prevention.pdf.

³⁰ Dear State Medicaid Director Letter, *Healthy Adult Opportunity SMD# 20-001*.

³³ CCIIO. Affordable Care Act Implementation FAQs – Set 12. <u>https://www.cms.gov/CCIIO/Resources/Fact-Sheets-and-FAQs/aca_implementation_faqs12.html</u>.

³⁴ AVAC. (2018, October) *The Future of ARV-Based Prevention and More*.

³⁵ Long-acting injectable forms of PrEP are currently undergoing clinical trials and could be available in the next several years. Given that these products will utilize a different administration route, there are additional considerations for how the USPSTF recommendation will need to be updated.

Recommendation Regarding ACA Marketplace Standards

- Requested Actions: We urge the Biden Administration to reverse harmful changes implemented by the Trump Administration and implement more comprehensive standards regarding Essential Health Benefits (EHB), network adequacy, and plan affordability in the expected Notice of Benefit and Payment Parameters for 2022 and accompanying Letter to Issuers.
- Rationale: While the ACA implemented comprehensive coverage reforms, the Trump Administration has weakened the ACA's consumer protections and affordability measures, systematically undermining access to comprehensive health coverage. Through the Notice of Benefit and Payment Parameters rule issued each year by CMS, the Administration has enacted a number of harmful changes to the ACA's Marketplace rules, including making subsidies less generous to consumers; allowing states and insurers more flexibility to scale down their EHB requirements; adding more paperwork requirements for low-income enrollees; and shifting oversight of non-discrimination in health care to under-resourced state regulators.³⁷

Recommendations to Rising Medication Costs and Access Challenges

- Requested Actions: We urge the Administration to take a holistic approach to improving medication access particularly for communities most impacted by HIV, including:
 - Strengthen non-discrimination protections in the ACA to explicitly prohibit adverse tiering and cap out-of-pocket drug costs.
 - Protect access to third-party medication assistance, including through manufacturer co-pay assistance programs.
 - Study Medicaid, Medicare Part B, and Medicare Part D pricing innovations (e.g., through authority provided by the Center for Medicare and Medicaid Innovation), including value-based purchasing and reference pricing, and assess feasibility of scaling up across public and private payers. Explore options to reduce out-of-pocket costs for Medicare beneficiaries.
 - For any administrative or congressional action aimed at lowering the list price of medications, assess impact on 340B programs and ensure that savings are reinvested in public health programs to preserve critical infrastructure and services.

³⁷ Please see past comments of the Federal AIDS Policy Partnership: HIV Health Care Access Working Group on the Notice of Benefit and Payment Parameters. <u>Plan year 2019</u>. <u>Plan year 2020</u>. <u>Plan year 2021</u>.

Rationale: Access to affordable medications continues to be a critical priority for people living with and at increased risk for HIV. High deductibles, increased use of co-insurance, and adverse tiering practices all contribute to access challenges and potential disruptions in treatment.³⁸ The rising prices of prescription drugs, compounded by the opaque nature of rebating practices and tighter formulary controls exerted by public and private payers, are contributing to consumer access challenges, with disproportionate impact on people with complex conditions. Indeed, the price of HIV medications have steadily increased over recent years, as has the out-of-pocket cost for patients.³⁹

Recommendations Regarding Short-Term, Limited Duration Insurance (STLDI) Plans and Association Health Plans:

- *Requested Action:* We urge the Administration to do the following:
 - Rescind the final tri-agency rule published in August 2018 ("Short-Term, Limited-Duration Insurance" 83 Fed. Reg. 150, 38212 (August 3, 2018)) and return to the previous 2016 regulation ("Excepted Benefits; Lifetime and Annual Limits; and Short-Term, Limited-Duration Insurance," 81 Fed. Reg 75, 316-18 (Oct. 31, 2016)).
 - Rescind the final Department of Labor (DOL) rule published in June of 2018 ("Definition of "Employer" Under Section 3(5) of ERISA—Association Health Plans," 83 Fed. Reg. 120, 28912 (June 21, 2018)).
- Rationale: HHS took regulatory action in 2016 to limit short-term plan duration to under three months, finding that plans were being marketed and sold as a limited and unregulated substitute for comprehensive insurance coverage and not as an actual short-term, limited duration product. Short-term, limited duration plans are intended as temporary coverage for individuals facing short gaps in insurance—for example, in between jobs—and are not a substitute for long-term, comprehensive coverage.⁴⁰ The Trump Administration, however, removed this important protection in 2018, allowing short-term plans with a maximum coverage period of 364 days. This regulation has meant that consumers are more likely to unknowingly enroll in coverage that will not actually provide meaningful access to care and treatment when they need it most. It has also weakened the individual markets by driving younger, healthy consumers to non-ACA regulated plans, in direct contravention of

https://jamanetwork.com/journals/jamainternalmedicine/article-abstract/2759735

³⁸ Kirzinger, A., Muñana, C., Wu, B., & Brodie, M. (2019, June 11) *Data Note: Americans' Challenges with Health Care Costs.* Kaiser Family Foundation. <u>https://www.kff.org/health-costs/issue-brief/data-note-americans-challenges-health-care-costs/</u>. Finding that three in ten of all adults reported not taking their medicines as prescribed at some point in the past year because of the cost.

³⁹ McCann, N. C., Horn, T. H., Hyle, E. P. & Walensky, R. P. (2020, February 23). HIV Antiretroviral Therapy Costs in the United States, 2012-2018. *JAMA Internal Medicine*. 2020;180(4):601-603.

⁴⁰ U.S. House of Representatives Committee on Energy and Commerce. (2020, June 25). *Shortchanged: How the Trump Administration's Expansion of Junk Short-Term Health Insurance Plans is Putting Americans at Risk.* <u>https://drive.google.com/file/d/1uiL3Bi9XV0mYnxpyaIMeg_Q-BJaURXX3/view.</u>

the shared risk goals of the ACA. Similarly, DOL finalized another rule in 2018 changing the definition of "Employer" Under Section 3(5) of ERISA-Association Health Plans, expanding non-ACA compliant association health plans. Like the STLDI rule, this rule leaves consumers with access to sub-par coverage and threatens the viability of the individual market.⁴¹ Both rules have been challenged in court.

Recommendation Regarding the Section 1557 Final Rule

- Requested Action: Regulations erasing protections against discrimination on the basis of gender identity should be immediately rescinded, and broad protections should be re-established.
- Rationale: The strength of our country's health care system can be measured by the ability of marginalized communities to access comprehensive, non-discriminatory health care and coverage. The Trump Administration has regularly attacked underserved communities, including transgender people, immigrants, and people with limited English proficiency, and has taken numerous steps to undermine important civil rights protections in access to health care. Regulations reinterpreting the ACA's nondiscrimination protections (Section 1557) have erased explicit protections against discrimination on the basis of gender identity and, despite the Supreme Court's recent decision in *Bostock v. Clayton County, Georgia*, have failed to include sexual orientation protections as well. In regulations published on June 19, 2020, the Administration has now narrowed the scope of entities subject to nondiscrimination enforcement and has eliminated explanations of the types of discriminatory practices prohibited by law.⁴²

SECTION 3: THE RYAN WHITE HIV/AIDS PROGRAM

The Ryan White HIV/AIDS Program (RWHAP) is the largest source of federal funding directed solely to providing HIV treatment and care for PLWH. The RWHAP, which is administered by the Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB), serves over 567,000 clients, with 88.1% of clients achieving viral suppression in 2019 compared to just 50% of PLWH nationwide. Since its passage in 1990, the RWHAP has been a crucial and bipartisan supported federal program that has helped hundreds of thousands of PLWH to access HIV-related services not covered by insurance plans, in many cases by assisting with the purchase of insurance. The Ryan White Program serves the most vulnerable people with HIV; almost three-quarters of Ryan White clients are members of racial or ethnic minority groups and

⁴¹ Timothy J. (2019, May 14). *The Past and Future of Association Health Plans*. Commonwealth Foundation. <u>https://www.commonwealthfund.org/blog/2019/past-future-association-health-plans</u>.

⁴²Center for Medicare & Medicaid. (2020, June 19). *Nondiscrimination in Health and Health Education Programs or Activities, Delegation of Authority*. 85 FR 37160. <u>https://www.federalregister.gov/documents/2020/06/19/2020-</u> 11758/nondiscrimination-in-health-and-health-education-programs-or-activities-delegation-of-authority

almost two-thirds of Ryan White clients are living at or below 100% of the federal poverty level (FPL); and more than 90% are living at or below 250% of FPL. Funding from the RWHAP supports primary medical care, HIV medications, oral health, care, essential support services, technical assistance (TA), clinical training, and the development of innovative models of care. The RWHAP is unique as it enables it recipients to provide services at across the HIV continuum of prevention, care and treatment:

- Testing to identify undiagnosed HIV and outreach to connect them to care
- Case management to keep patients in care
- Transportation to medical appointments
- Food and nutrition services
- Life-sustaining medications through the AIDS Drug Assistance Program (ADAP)
- Emergency Housing
- Treatment adherence counseling
- Additional services not covered by most private insurance plans

Each of these services help people to live long, healthy lives and assist people in reaching and maintaining an undetectable HIV viral load which helps prevent new transmissions. The RWHAP has proven uniquely effective in connecting PLWH to life-saving care and treatment and keeping them in care.

The RWHAP is flexible enough to fill vital gaps in the health care landscape for PLWH both in states that have chosen to expand Medicaid and in states that have not. For that reason, HIV organizations throughout the U.S. urge the Administration to ensure that the Ryan White Program remains strong and intact in its role in ensuring a comprehensive response to the epidemic.

The Administration should continue to support the vital role of the RWHAP in addressing the HIV public health crisis. The RWHAP continues to play a critical role for many of our nation's most vulnerable citizens even after much of the ACA has been enacted by addressing coverage gaps, affordability of care, and the provision of HIV services to those left out of reform. The RWHAP continues to meet unaddressed needs of essential care and financial support services that only the Ryan White Program provides.

The Ryan White Program has helped create a model for HIV service providers to help find PLWH, link them to care and ensure effective treatment. The Administration therefore must continue to maintain and leverage this model of high-quality, costeffective care and services delivery developed over the past three decades.

The following recommendations were developed by the Ryan White Work Group.

Recommendation Regarding Ryan White HIV/AIDS Program Funding During COVID-19

- *Requested action:* We recommend the Administration:
 - Propose increased funding for the Ryan White Program consistent with a growing epidemic and need, ensuring that the program's funding formulas and structure support integrated efforts to end the HIV epidemic.
 - Prioritizes increased funding for the Ryan White Program in any stimulus proposals by at least \$500 million.
- Rationale: The COVID-19 pandemic has left Ryan White Program clients and other low-income people with HIV even more medically and economically vulnerable. The \$90 million included in the CARES Act, H. R. 748, was an important first step in helping programs funded by the RWHAP begin to address the immediate needs of their patients. As the impacts of the pandemic spread and accelerate throughout the country, additional funding for the Ryan White Program is needed across all of the program's parts to help PLWH stay in care and on treatment; help maintain access to care and treatment during the economic downturn; meet the needs of people who now are without health insurance; and help prevent and contain the spread of COVID-19. In addition, state Ryan White Programs anticipate losing significant resources due to reduced contributions from their state budgets. During the last recession, the Ryan White Program was a critical safety net for individuals who lost employer-sponsored insurance and had no other source of care, spurring waiting lists for AIDS Drug Assistance Program (ADAP) services and delays in care. Investment in this program is critical to ensure that no person living with HIV loses access to services during the COVID-19 pandemic and in the economic aftermath. The Ryan White Program needs increased funding (at least \$500 million) in the next COVID-19 response bill.

Recommendation Regarding the Ryan White HIV/AIDS Program

- Requested Action: The HIV community does not request a modernization of the Ryan White/HIV AIDS Program at this time. The HIV community must be included in any discussions about the modernization of the Ryan White HIV/AIDS Program. Community engagement is critical to the success of the program. The Ryan White Work Group can be a conduit for discussion.
- Rationale: Given the uncertainty around the ACA's legal challenges, the Ryan White
 Program cannot be modernized until the healthcare system is stabilized. The Ryan
 White Program is incredibly successful at providing care for PLWH and it must
 remain as the safety-net. When the HIV community requests a modernization of the
 legislation, Administration officials should set up a body or task force to work with
 community advocates as well as the Congress to evaluate and lay out practical,
 legislative and political steps for the next modernization of the Ryan White Program.
 In the interim, through a task force or body, the Administration should assess any

changes to the health care system and the impact of the past Administration's Executive Orders and health system impacts before any modernization of the Ryan White Program is proposed.

The Ryan White Program must be used to dramatically improve both treatment and potential prevention outcomes in communities where PLWH are not receiving the health benefits of being in care, on treatment and virally suppressed. A valued quality of the Ryan White Program is its responsiveness to the unique needs of individuals, clinics, and jurisdictions. This flexibility is essential as communities use the Ryan White Program in conjunction with other resources to increase access to the expanding number of people diagnosed with HIV in need of treatment, care and supportive services."

The Work Group also reiterates the following principles announced in previous years on our future approach to creating community agreement:

- With full implementation of the ACA, the Ryan White Program is necessary to fill gaps in covered services and covered populations and to continue to provide vital enabling and support services.
 - Services Gaps in Private Insurance Exchange Plans
 - Gaps in Covered Populations
- Any changes to the Ryan White Program must also ensure stability during transition periods for clients as they move between coverage eligibility under the ACA and beyond.
- TA and transitional funding must be provided to Ryan White Grantees and Subgrantees so that such agencies will continue to be able to provide HIV treatment and care.
- The Ryan White Program must continue to address not only gaps in financing care and treatment, but also the quality of care and treatment provided.
- Ryan White Program providers and models of care must be integrated into health reforms to ensure continued access to high quality care.
- The Ryan White Program should additionally support implementation of the NHAS's goals to reduce incidence, increase treatment, and reduce disparities with funding levels set at amounts in support of these goals.
- Racial/ethnic disparities should continue to be specifically addressed within the framework of the Ryan White CARE Act.
- The Ryan White HIV/AIDS Program should ensure delivery of services including transportation services, food and other nutrition services, linguistic services, case management, substance abuse and mental health treatment, early intervention, legal and housing services.

SECTION 4: HIV RESEARCH

HIV research supported by the NIH is far reaching and has supported innovative basic science for better drug therapies, behavioral, biomedical and combination prevention interventions and a HIV cure, and has saved and improved the lives of millions around the world. While HIV treatment and prevention are the primary beneficiaries of HIV research, advances in basic medicine funded through HIV research at NIH has led to new vaccines, treatments and medication for many other diseases such as cancer, Alzheimer's, kidney disease and tuberculosis.

The following recommendations were developed by the FAPP Research Work Group.

Recommendation Regarding HIV Research Funding

- Requested Actions: Fully fund HIV research at NIH/National Institute of Allergy and Infectious Diseases (NIAID) and Office of AIDS Research (OAR), including government research on HIV comorbidities such as TB, STIs, and viral hepatitis.
- Rationale: We strongly urge the Administration to support HIV research by recommending funding levels commensurate to the most recently available OAR Professional Judgement Budget. The latest budget recommendation of at least \$3.845 billion annually will support the continuation of ongoing studies and fund research areas of critical need, including HIV vaccines and cure research. A strong and well-funded HIV research agenda has shown to have numerous cross-disease benefits, most recently in the search and development of tools to combat COVID-19. These historical investments combined with new, increasing dollars will put the nation and the world on the path to end the HIV epidemic by ushering in the next generation of tools and prospective cures. Additionally, we strongly recommend the Administration to fully fund research on significant HIV syndemics/comorbidities such as TB, STIs, and viral hepatitis that continue to impact the health and lives of PLWH and communities vulnerable to HIV.

Recommendation Regarding Clinical Trials Demographics

- **Requested Action:** Implement policy that authorizes the recruitment of pregnant and lactating people into clinical trials, for HIV and comorbidities research, when appropriate and possible.
- Rationale: Existing clinical trial investigators have often been reluctant to include pregnant and lactating people as participants, citing concerns about the safety of the carrying parent, the fetus, and the infant. While these concerns are not without merit, they do not obviate the need to explore the safety measures that would make such inclusion possible. This is especially true in the context of the current pandemic, as we severely lack sufficient information about the effects of COVID-19 on

pregnancy and pregnant persons. Efforts to increase inclusion and participation of pregnant and lactating people, such as the Task Force of Research Specific to Pregnant Women and Lactating Women (PRGLAC), have generated important findings and recommendations to guide policymakers and researchers.⁴³ However, these efforts and advisory bodies lack the authority and power of the President's office to bring about necessary changes. Unfortunately, the impact continues to be that far too few pregnant people are included in clinical trials and, as a result, the promising benefits of such research do not extend to those who are pregnant and lactating. The next Administration should implement the recommendations made by PRGLAC, along with recommending funding to support the recruitment of pregnant and lactating persons as central to the research agenda.

Recommendation Regarding Researchers

- Requested Action: Create new research opportunities and funding lines to prioritize HIV and infectious disease research led by scientists representing the communities most directly impacted by these diseases.
- *Rationale:* The true subject matter experts who have the most intimate knowledge of HIV are the communities most affected by the HIV epidemic. This includes, but is not limited to, Black and Brown communities, gay and bisexual men, transgender individuals, people who use drugs, and sex workers. Despite the fact that members of these communities' hold lived experience that will benefit the research pipeline, they are rarely provided opportunities to lead the direction and administration of clinical trials. The next Administration should establish recruitment programs and training initiatives to provide more opportunities for community members in leadership of clinical trials and should explore funding requirements or dedicated funding streams for trials that include investigators from a diverse array of relevant backgrounds and experiences. Additionally, diversifying the pipeline with new and incoming HIV researchers will help reverse a troublesome trend being seen by NIAID, with a precipitous drop in R01 (unsolicited) research applications in recent years. NIH leadership theorize that the drop in research applications indicates an erosion in the HIV research workforce and shift among young researchers away from pursuing HIV and infectious diseases research. Opening funding opportunities and recruitment of researchers that are representative of communities can help fill the gap in talent and create a more diverse HIV workforce needed to make EHE a reality.

Recommendation Regarding Fetal Tissue Research

 Requested Action: Immediately end the restriction on the use of federal funds for intramural or extramural fetal tissue research, and disband the superfluous and conflicted review by the Fetal Tissue Ethics Advisory Board.

⁴³ Task Force on Research Specific to Pregnant Women and Lactating Women. (2018, September). *Report to Secretary, Health and Human Services, and Congress*. <u>https://www.nichd.nih.gov/sites/default/files/2018-09/PRGLAC_Report.pdf</u>

Rationale: Research utilizing fetal tissue has been an ethically compliant research strategy vital to the development of current and future biomedical interventions, including a vaccine and cure for HIV. This critical research is already subject to the NIH's own rigorous scientific peer review process which has been in place for decades. Additional review is not only unnecessary but infuses ideology into a process that should be purely scientific. One-third of the members of this new Ethics Advisory Board are affiliated with a lobbying group that seeks to end fetal tissue research and has no other scientific expertise,⁴⁴ relevant or otherwise, a clear sign that the makeup of the Board is biased towards one viewpoint regardless of the scientific merits. This board should be disbanded, and erroneous restrictions should be ended to allow for researchers funded by the U.S. government to pursue biomedical research with every single available tool.

Recommendation Regarding Vaccine Hesitancy and the FDA

- Requested Action: Confront vaccine hesitancy with transparency and strong public health messaging; restore public confidence in the Food and Drug Administration (FDA) and CDC.
- Rationale: A majority of Americans across all political affiliations are concerned that politics is playing a greater role than science in the development of an eventual vaccine for COVID-19. Most Americans say they would also worry about the safety of a vaccine approved too quickly,⁴⁵ and this sentiment risks spilling over to other future vaccines for infectious diseases like HIV, TB, and HCV. In order to best secure the nation's health and our ability to overcome the current pandemic, the Administration must do everything in its power to invest and cultivate vaccine confidence. Vaccine hesitancy is driven by many factors ranging from a proliferation of false conspiracy theories to the deep legacy of medical and systemic racism in scientific research. The best way to restore public trust is to implement transparency throughout ongoing trials and oversight of vaccine studies. The federal government should prioritize community engagement of historically marginalized groups in the development of vaccines. Lastly, given mishaps associated to COVID-19 vaccine approval and questionable trial design, the government must restore the regulatory power of the FDA to ensure stringent ethical trial standards, and capabilities in rigorous evaluation that is characteristic of this world-renowned agency. Doing so, will further restore the public confidence in future vaccines and therapeutics that undergo FDA approval.

⁴⁴ Goldstein, A. (2020, August 4). *Fetal Tissue Research Advisory Board Convenes, with a Strong Anti-Abortion Tilt*. The Washington Post. <u>https://www.washingtonpost.com/health/fetal-tissue-research-advisory-board-convenes-with-a-strong-anti-abortion-tilt/2020/08/04/f138d08a-d5c7-11ea-930e-d88518c57dcc_story.html</u>

⁴⁵ Silverman, E. (2020, August 31). *Poll: Most Americans Believe the Covid-19 Vaccine Approval Process is Driven by Politics, Not Science*. STAT. <u>https://www.statnews.com/pharmalot/2020/08/31/most-americans-believe-the-covid-19-vaccine-approval-process-is-driven-by-politics-not-science/</u>

Recommendations on Structural Interventions Research and Data

- Requested Action: Support a bold agenda for HIV research, especially related to structural interventions and their role as a cost-effective means of HIV prevention, treatment, and care as well as their ability to be brought to scale.
 - Establish a federally supported Structural Interventions Research Committee within OAR to advance coordination, communication, and furtherance of research throughout Federal agencies, especially HHS, CDC, NIH, Treasury, Veterans Affairs (VA), United States Department of Agriculture (USDA), HUD, and DOL.
 - Call on HRSA/HAB's Division of Policy and Data to monitor and track provision of food and nutrition services and employment services and their related health outcomes and cost savings, reporting on this annually, to demonstrate the nationwide impact of these programs. HAB already collects data on housing.
 - Call on HUD's Office of Policy Development and Research to research the efficacy of various housing approaches and their impact on ensuring PLWH link to care, maintain care, and have improved health and well-being.
 - Call on HHS' Administration for Community Living/National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) to research vocational rehabilitation needs of PLWH, effective government and community-based service responses, and their impact on HIV care and prevention outcomes and the quality of life and well-being of PLWH.
- Rationale: While current research points to the broad impact of social and economic determinants of health on the epidemic, targeted research and data collection is needed to understand: the housing, nutritional, employment and other needs of PLWH and those at greater risk for HIV; the relationships between structural interventions and the physical/mental health outcomes of PLWH; the relationship between provision of structural interventions and prevention outcomes; and outcomes related to service provision through HHS, DOL, and HUD.

SECTION 5: HIV STRUCTURAL ISSUES

Biomedical treatment and prevention alone will not end the U.S. HIV epidemic. The complex, structural and societal factors that are responsible for most health disparities – the social determinants of health – must be addressed in tandem. The HIV epidemic in the U.S. continues to disproportionately impact communities subject to severe economic and social inequities like inadequate access to health care, behavioral health challenges, lack of employment and educational opportunities, food insecurity, housing instability, limited transportation infrastructure, HIV criminalization, the burden of

disproportionate incarceration, barriers to prevention and health care for new immigrants and more. To compound matters, each category of disparity is magnified through the lenses of racism, homophobia, transphobia, and other forms of stigma and discrimination.

The disproportionate impact of HIV on racial and ethnic minorities must be acknowledged. Racism is a public health issue, and until the structure of discrimination is corrected, disparities in health outcomes for Black and Brown communities will persist. Funding support and access to structural interventions is one step toward rebalancing systems of historic inequity.

Effectively addressing the social determinants of health is key to advancing community health outcomes and public health. It is a project that will take our entire society. For the purposes of this document, we confine ourselves to time-tested, evidence-based interventions that have been shown to directly benefit PLWH and contribute to the EHE goals of prevention, quality care and improving health outcomes.

For many persons living with or vulnerable to HIV, successful prevention and care requires culturally competent services to address these barriers, and evidence demonstrates that interventions to ensure adequate housing, food, employment, transportation, and other critical enablers of health care are both essential and cost-effective. In fact, without them, the best biomedical treatment will be ineffective.

The following recommendations are submitted on behalf of the FAPP Structural Interventions Working Group:

Recommendations on Funding Structural Interventions

- Requested Actions: Expand federal resources to address social and economic determinants of health, including stable, affordable housing; medically-informed food; employment services; medical transportation; legal services; harm reduction, and other supports that sustain treatment and prevention goals and promote health for PLWH.
 - Maintain medically tailored meals, congregate meals, and food bank services in the RWHAP. Receipt of these services is associated with better viral suppression and health for PLWH.
 - Support efforts to expand Medicare coverage of nutrition-based interventions, such as medically tailored meals. The Administration should support Congressional efforts to improve outcomes and reduce costs through evidence-based interventions for Medicare patients with chronic illnesses, such as <u>H.R. 6774</u>, the Medically Tailored Home-Delivered Meals <u>Demonstration Pilot Act of 2020</u>.
 - The Administration should promote efforts to finance <u>nutrition-based</u>

interventions for individuals participating in Medicaid, such as 1915(c) and 1115 waivers, which have been used to improve nutrition services to targeted populations, and combined applications for SNAP and Medicaid.

- Request funding for the HOPWA program at levels commensurate with the epidemic and increase federal investments in the HUD Housing Choice Voucher program and other HUD-administered Permanent Supportive Housing programs.
- Request \$4.5 million for a cross-agency HIV care and prevention employment services initiative with the DOL in collaboration with HHS to address employment needs of PLWH and key populations placed at greater vulnerability to HIV.
- CMS and HHS should support efforts to modernize the use of Medicaid and Medicare to cover medically tailored nutrition, medical transportation services, supportive housing operating costs and subsidies, and employment related services.
- Include services that promote safety from violence and healing from the longterm effects of trauma.
- Rationale: Structural interventions to address the needs of PLWH in our nation are chronically underfunded. Studies repeatedly show that, in addition to improving individuals' quality of life, supportive services facilitate connection and retention in care, are key to adherence, and reduce health-risk behavior. In turn, supportive services and trauma-informed approaches have been shown to improve health outcomes and reduce costs. PLWH who are food insecure routinely forego critical medical care including medical appointments, prescriptions, and other treatment, and are less likely to be virally suppressed.

Recommendations on Adequate and Safe Housing for Those Living With HIV

- Requested Actions: Increase funding in the housing portfolio at the Department of Housing and Urban Development (HUD) for the Housing Opportunities for Persons with AIDS (HOPWA) program. Eliminate eligibility restrictions to accessing HUD programs related to drug use or drug-related convictions.
- Rationale: The only federal program dedicated to the housing needs of PLWH and their families, HOPWA provides housing assistance and related services for lowincome PLWH and their families. HOPWA funds are used for a wide range of housing, social services, program planning, and development costs, including the acquisition, rehabilitation, or construction of housing units; costs for facility operations; rental assistance; and short-term payments to prevent homelessness. HOPWA funds also may be used for health care and behavioral health services, nutritional services, case management, assistance with daily living and other supportive services. Crucially these services help PLWH to maintain stability in their treatment program and

contribute to PLWH having longer, healthier lives. However, implementation of the long-awaited HOPWA formula update without additional resources would result in more than 3,000 households losing assistance and facing imminent threat of homelessness.

Recommendations on Structural Interventions Interagency Federal Taskforce

- Requested Actions: The Office of National AIDS Policy (ONAP) should appoint an ONAP Structural Interventions Interagency Federal Taskforce to further the goals of NHAS and EHE, document proven structural interventions, and provide recommendations to Federal Agency partners.
- Rationale: The next Administration can fulfill the goals of EHE by expanding research and use of proven structural interventions to prevent HIV and enhance care. The membership of the Taskforce should combine leading representatives of key Federal programs, community service providers, policymakers and advocates, including strong and diverse participation of PLWH. Taskforce deliverables would include: a survey of need; a catalogue of existing research resources and gaps; and notes from the field by community-based partners resulting in a comprehensive report, including detailed, time-delimited recommendations for achievable action steps.

Recommendations on Structural Interventions Training and Technical Assistance

- **Requested Actions:** Invest in enhancing the continuum of care through increased and dedicated capacity building and technical assistance (TA).
 - Recommend that training and TA on the importance of and access to housing, food and nutrition services, and employment services for PLWH be provided in HHS by HRSA/HAB, including within AETC programming, for HIV care providers; by the CDC, for HIV prevention providers; and by HUD, by the Office of HIV/AIDS Housing for HOPWA providers and representatives from Administration for Community Living (ACL).
 - HRSA/SPNS programs should target social and economic determinants of health; specifically, the importance of structural interventions in highly impacted jurisdictions/communities, facilitation of cross-sector multidirectional training, and collaboration and service coordination.
 Outcomes should include integration of assessment of structural intervention needs at intake and follow up throughout HIV care and prevention service delivery, with delivery of or linkage to appropriate information, services and resources.
 - **Rationale:** The changing epidemic requires a responsive system of care to ensure the prevention and treatment of HIV. Dedicated training that addresses the shifting policy landscape and new opportunities for access to coverage is imperative if we are to end the epidemic.

Recommendation on HIV Criminalization:

- Requested Actions: The Department of Justice (DOJ) should work with national criminal justice organizations, community stakeholders, including networks of PLWH, to develop national guidelines on (a) the use of condoms and other disease prevention mechanisms as evidence of criminal intent or criminal conduct, and (b) meaningful access to clean syringes. The DOJ should work with CDC to create federal HIV antistigma incentives to states that encourage states to repeal their HIV-specific criminal laws. The Administration should support Congressional efforts to address HIV criminalization, such as H.R. 6054: REPEAL HIV Discrimination Act of 2020.
- Rationale: In the U.S., more than 30 states and several territories have at least one law that applies only to PLWH, including HIV-specific criminal laws that punish alleged exposure, non-disclosure, and transmission of HIV, and laws that increase penalties for PLWH who are convicted of prostitution or solicitation offenses. Since their enactment, "HIV criminalization laws" have perpetuated stigma and discrimination against PLWH and undermined public health efforts to end the domestic HIV epidemic. Laws that criminalize the possession of sterile syringes significantly increase HIV and hepatitis transmission risk among people who inject drugs, including transgender people who use hormones. In some jurisdictions, condom possession is used as evidence of sex work. People who engage in sex work in those jurisdictions are less likely to carry condoms, which increases HIV, hepatitis, and STI transmission risk.

Recommendations on CDC Molecular HIV Surveillance

- **Requested Actions:** The CDC should address privacy, security, and criminalization concerns with molecular HIV surveillance (MHS).
- Rationale: Led by the CDC, MHS is the process of tracing networks of HIV transmission by using HIV genomic sequence data that is obtained when a person living with HIV gets a resistance test. Health departments are tasked with identifying the people involved in a "transmission cluster" and offering them prevention and health care services. There are several issues with MHS: lack of engagement with PLWH and community, HIV criminalization, and lack of data security protections. Over 30 states have laws criminalizing HIV transmission, exposure, or nondisclosure. So long as these criminal laws exist, MHS could, even unintentionally, place PLWH at risk for prosecution. This is of particular concern for communities that already face high levels of surveillance and criminalization, independently of HIV status, including Black people, immigrant communities, other people of color, people who trade sex, people who use drugs, and people who live on the street.

Recommendations on Strengthening the HIV Workforce and Supporting the Involvement and Hiring of People Living with HIV

- Requested Actions: Implement policy that encourages the recruitment, hiring, and training of PLWH and bolsters our public health and HIV workforce. Support targeted loan-repayment legislation and executive actions to help ensure a robust and wellqualified infectious diseases and HIV and clinical workforce
- Rationale: The HIV workforce is strained at every level from pre-novice to expert. A key to ending the epidemic is having a well-informed and committed public health workforce. We need to honor the experience and hire people who live with HIV day to day. A person's lived experience should mandate a professional salary because this is a specialized skill, which not only benefits outreach programs but the employee themselves. Policy makers must center the communities most impacted by the epidemic in leadership and decision-making when crafting policies and solutions in any and all efforts to end the epidemic.

A <u>study</u> of the HIV workforce in 14 southern states found that more than 80% of the counties had no experienced HIV clinicians, with the greatest disparities in rural areas. The coronavirus pandemic has further stretched the current HIV clinical workforce, making it even more urgent to address this gap. We urge the Administration to take the recommended actions in addressing shortages to address the root causes of workforce shortages.

Additionally, building the infrastructure needed to end the HIV epidemic requires thousands of new hires to retain the 400,000 PLWH who have fallen out of care and the over one million more people needed on PrEP. This is particularly urgent now, with the ever-evolving science of treatment and prevention. The Ryan White Program AIDS Education & Training Centers (AETCs) are a national network of HIV experts that provide continuing education and training programs and clinical consultation for healthcare providers on the latest HIV treatment and care approaches and technologies. Such education and training continue to be vital to the success of the HIV workforce.

Recommendations Regarding the Military Service of People Living with HIV or Hepatitis B (HBV)

- Requested Action: Reform Department of Defense (DOD) and Service-level policies to allow otherwise qualified people living with HIV or HBV to enlist, commission, and deploy on contingency deployments if they meet objective health metrics demonstrating that their medical condition does not present a risk to themselves or others in a deployed environment.
- Rationale: Discrimination fostering misinformation and stigma with respect to HIV or

HBV is especially pernicious when perpetuated by government officials. Essentially unchanged since the late 1980's, current military policies regarding the deployment, enlistment and commissioning of people living with HIV or HBV are based on outdated and inaccurate ideas about these medical conditions. Given current medical treatments and prevention technologies, there is simply no longer any reason to prevent people living with HIV or HBV from serving in any capacity in the U.S. military. Eliminating the discriminatory policies of the largest employer in the world will reverberate not only in the U.S. but across the globe.

SECTION 6: HIV FUNDING - BUDGET AND APPROPRIATIONS

Decades of declines in federal, state, and local public health funding have led to the deterioration of public health infrastructure. In order to meet the goals of the NHAS and EHE, adequate funding for federal HIV and related programs will be necessary. Without such rapid funding increases, the U.S. epidemic will continue to outrun our response, increasing the long-term need for HIV treatment and increasing future costs. Public spending on accelerated scale-up will generate historic health benefits and savings sufficient to offset or exceed the required investments.

Years of stagnant funding have placed immense resource constraints on core public health programs and the services they are able to provide. Funding for non-defense discretionary programs, that includes public health, remains too low – well below both 2010 levels and historical levels as a share of our economy. Many of the programs highlighted below have not had core funding increases in the last decade, all the while seeing substantial increases in demand for their services. For example, STI programs from 2003-2019 were level funded, resulting in a 40% reduction in buying power. STI data from 2018 shows that combined cases of chlamydia, gonorrhea, and syphilis diagnoses are nearing 2.4 million cases a year – up 30% in five years. Additional resources will help to restore programmatic cuts.

With additional funding, programs will have the opportunity to restore cuts to a number of critical health programs, and to respond to a number of public health concerns facing the country, including the HIV, STI, and hepatitis epidemics.

The following recommendations were developed by the AIDS Budget and Appropriations Coalition.

Recommendations on Sustained Federal Investment in Responding to the HIV Public Health Crisis:

• **Requested Actions:** We ask the Administration to increase funding in the FY2022 budget and appropriations for each of the following discretionary domestic

programs by at least the amounts listed below. These programs are critical to ending the HIV epidemic:

- HRSA, Ryan White HIV/AIDS Program, all parts (+\$168 m);
- CDC, Division of HIV/AIDS Prevention (+\$67.1 m);
- CDC, Division of Adolescent and School Health (+\$66.9 m);
- CDC, Division of STD Prevention (+\$1.34 b);
- CDC, Division of Viral Hepatitis (+\$95 m);
- CDC, Division of TB Elimination (+\$60.7 m);
- CDC, Opioid Related Infectious Diseases program (+\$48 m);
- HUD, HOPWA (+\$20 m);
- Minority AIDS Initiative (MAI) (includes the Minority HIV/AIDS Fund and crossagency MAI programs) (+\$165.9 m);
- NIH, HIV specific research (+\$426 m);
- HHS' Office of Adolescent Health Teen Pregnancy Prevention Program (level funding);
- The Title X Family Planning Program (+\$667.6 m);
- o HRSA Community Health Centers; and
- Substance Abuse and Mental Health Services Administration (SAMHSA).

Note that these funding requests were developed for the FY2021 appropriations cycle. Once FY2021 appropriations are signed into law, our coalitions will update these request numbers and communicate them to the Office of Management and Budget. These do not include funding for the EHE Initiative, which is listed below.

Rationale: While current funding does not fully meet HIV care and prevention needs, we must build on the extraordinary progress we have made to date. A significant scale up in investments in these programs is required in order to end the HIV epidemic. FAPP's requests, as well as the FY2020 funding levels, can be found <u>here</u>.

The core hepatitis governmental public health program is funded through the CDC's Division of Viral Hepatitis. This program has been chronically underfunded, making it difficult for programs to expand screening, vaccination, and linkage to care and treatment. There are several other barriers to the elimination of hepatitis, including inadequate surveillance, screening, and linkage to care, vaccination, and difficulty reaching vulnerable communities. A significant investment of resources and identification of people living with hepatitis and improved linkage to care and treatment, especially for those populations disproportionately impacted, is critical to ending hepatitis in the U.S.

As your Administration prepares your FY2022 Budget Request, we urge you to prioritize investments in our nation's public health infrastructure. FY2022 will be the first budget cycle since 2011 that will not be burdened by the budget caps

established in the Budget Control Act. The COVID-19 pandemic has magnified our failure to adequately fund public health programs that keep people safe and healthy. These programs are truly vital in the defense of our nation and should be treated as so in the federal budget. We also urge you to resist any attempts to reimpose budget caps that would put restrictions on our public health systems.

Recommendation Regarding the Ending the HIV Epidemic Initiative

- **Requested Action:** We ask that the Administration support significant new investments for the EHE Initiative in the following operating divisions by at least the amounts listed below:
 - CDC DHAP for testing, linkage to care, and prevention services (+\$365 m);
 - HRSA RWHAP to expand comprehensive treatment for newly diagnosed PLWH (+\$95 m);
 - HRSA Community Health Centers to increase clinical access to prevention services, particularly PrEP (+\$87 m);
 - The Indian Health Service (IHS) to address the combat the disparate impact of HIV on American Indian/Alaska Native populations (+\$27 m); and
 - NIH Centers for AIDS Research to expand research on implementation science and best practices in HIV prevention and treatment (+\$4 m).

Note that these funding requests were developed for the FY2021 appropriations cycle. Once FY2021 appropriations are signed into law, our coalitions will update these request numbers and communicate them to the Office of Management and Budget.

Rationale: In FY2020, an additional \$261 million was appropriated for 48 counties, the District of Columbia, San Juan, P.R., and seven rural states⁴⁶ where the burden of new HIV transmissions are the highest to create plans to end the HIV epidemic in their jurisdictions as part of the EHE Initiative. In order to fully implement jurisdictional plans, we ask the Administration to support increased funding for the Initiative. FY2021 funding will build on this planning process and will help jurisdictions transition from planning into implementation. In order to see success, a significant number of new resources is required. The EHE Initiative is meant to compliment already existing and effective HIV treatment, prevention, and research programs. We ask that these increases are not at the cost of decreases to other vital public health programs.

Recommendation Regarding HIV Funding to Respond to COVID-19

• **Requested Action:** We urge the Administration to urgently work with Congress to pass a COVID-19 response bill which includes emergency funding for HIV prevention, care and treatment, and housing programs. Because many of these programs are

⁴⁶ HHS. Phase 1 EHE Jurisdictions. <u>https://files.hiv.gov/s3fs-public/Ending-the-HIV-Epidemic-Counties-and-Territories.pdf</u>

funded through federal, state, and local resources, we also ask that emergency funding for state and local government be included in a response package.

Rationale: The COVID-19 pandemic has impacted HIV and infectious disease programs across this country. With many state and local health departments, community health centers, and Ryan White providers adjusting how they continue to provide HIV services while responding to COVID-19, increased funding will be required to prevent disruptions to care. As the economic impact of COVID-19 continues to be felt in communities disproportionately impacted by COVID-19 and HIV, we ask your Administration to ensure people have access to safety net programs. Programs like the RWHAP, Community Health Centers, Medicare, Medicaid, and HOPWA are vital to ensuring people can continue to access lifesaving treatment and prevention services regardless of their financial situation.

SECTION 7: CROSS CUTTING OR INTERSECTIONAL ISSUES

Recommendation Regarding Declaring Racism a Public Health Emergency

- Requested Action: HHS should declare racism a public health emergency and determinate of health. HHS should establish an advisory body to take steps to address the ways racism and white supremacy adversely impacts the lives and health of Black, Latinx, Native American/Indigenous, Middle Eastern, and Asian/Pacific Islander communities.⁴⁷
- Rationale: The urgency of immediate action and the need to center anti-racism efforts in our public health responses is highlighted by the COVID-19 pandemic that is disproportionately impacting Black, Latinx, and Native American lives. Communities of color in the U.S. are disproportionately impacted by HIV, STIs, and hepatitis. African Americans, more than any other racial/ethnic group, continue to bear the greatest burden of HIV in the U.S. We must recognize and address the impact that inadequate housing, under-resourced schools, police brutality, mass incarceration, food deserts, joblessness and underemployment, poverty, low access to health care, and violence have on public health.

Recommendation Regarding the Office of National AIDS Policy

 Requested Action: The President should reestablish and appoint staff, including a Director, to the White House Office of National AIDS Policy (ONAP), within the Domestic Policy Council, and charge them with leading development and

⁴⁷ Please see previous letter submitted to CDC from the Federal AIDS Policy Partnership standing in solidarity with over 1,200 current CDC employees who signed <u>a letter</u> to the agency's senior leadership on internal systemic racism. <u>https://www.nastad.org/sites/default/files/Uploads/2020/fapp_support_letter_to_cdc.pdf</u>

implementation of NHAS and the EHE Initiative and coordinate the domestic policy of reaching the global goals of ending the pandemic by 2030.

Rationale: Under previous Administrations, ONAP served as the lead entity for setting the Administration's HIV policies priorities and engaged in overseeing government-wide efforts to improve the nation's response to the HIV epidemic. This role included working across the federal government to support and monitor the implementation of NHAS. While HHS's Office of Infectious Disease and HIV/AIDS Policy (OIDP) led the most recent NHAS update (*HIV National Strategic Plan: A Roadmap to End the HIV Epidemic (2021-2025) (HIV Plan)*), all future NHAS implementation and update activities should be moved back to ONAP to ensure participation from all federal agencies. ONAP must ensure recommendations submitted through public comment⁴⁸ are included in the final HIV National Strategic Plan. ONAP should also begin to reconvene a Federal Interagency Working Group to foster collaboration across the Administration.

The federal government's EHE Initiative currently only includes agencies within HHS. This leads to core public health and HIV programs, including HOPWA, DOD, and the VA, not playing an active role within implementation and planning. To address this shortfall, ONAP should be charged with developing a comprehensive, national EHE Initiative that includes all federal agencies and jurisdictions. Like NHAS, ONAP leading EHE will be instrumental in ensuring there is accountability, continuity, and consistency between all segments of the federal government.

It is imperative that the Administration embrace a coordinated approach to the syndemics of HIV, hepatitis, and STIs. Implementation of the newly released plans addressing each of these epidemics must, therefore, be coordinated across ONAP and OIDP.

ONAP should also coordinate with the National Security Council, the Office of the Global AIDS Coordinator, and international bodies to ensure that the U.S.'s response to the global HIV pandemic is fully integrated with other prevention, care, and treatment efforts around the world.

Recommendation Regarding the Office of Infectious Disease and HIV/AIDS Policy

 Requested Action: Support OIDP within the Office of the Assistant Secretary for Health (OASH). OIDP should ensure the appointment of diverse and qualified individuals to key advisory panels.

⁴⁸ Department of Health and Human Services. (2020, December 2). *Request for Information: HIV National Strategic Plan 2021-2025 Available for Public Comment.* 85 FR 77472. https://www.federalregister.gov/documents/2020/12/02/2020-26586/request-for-information-hiv-national-strategic-plan-2021-2025-available-for-public-comment

Rationale: OIDP leads the development and implementation of the Viral Hepatitis National Strategic Plan for the United States — A Roadmap to Elimination 2021-2025 (Hepatitis Plan), which calls for the elimination of hepatitis in the U.S.⁴⁹ To address the STI epidemic, OIDP worked with federal partners throughout HHS and other federal departments to create the nation's first STI National Strategic Plan. In order to address hepatitis and STIs in the U.S., a meaningful federal implementation plan must be a priority, along with the funding needed to make a significant impact on the epidemics. OIDP will need the resources, staff, and leadership to ensure both these plans are implemented successfully.

OIDP administers the MAI Fund on behalf of OASH and the Office of the Secretary. The goals of MAI are to reduce new HIV diagnoses, improve HIV-related health outcomes, and reduce HIV-related health disparities for racial and ethnic minority communities. MAI resources supplement other federal HIV funding and are designed to encourage collaboration between agencies, breaking down silos in order to increase capacity and target funding to programs that demonstrate effectiveness. In FY2019, MAI was funded at \$53.9 million, which was used to support 9 continuation projects and activities in support of EHE.

OIDP must leverage community members and experts to advise and sit on its five federal advisory committees and workgroups, including the Presidential Advisory Council on HIV/AIDS (PACHA).

Recommendation Regarding Racial Justice Training

- Requested action: Support federally contracted agencies in their attempts to dismantle white supremacy by holding racial justice trainings, including those trainings that employ critical race theory with appropriate evaluation metrics.
- Rationale: The recent Executive Order on Combating Race and Sex Stereotyping banning federal agencies and federally funded organizations from administering certain racial justice trainings threatens the progress that has been made against the domestic HIV epidemic. In the U.S. and elsewhere, HIV is driven by racism and racist effects on housing, access to health care, mass incarceration, and employment. Without a grounding in critical race theory and the understanding of structural racism's impacts on the HIV epidemic, agencies cannot be adequately successful in their attempts to prevent new HIV diagnoses and care for PLWH. The Administration should restore and increase funding to agencies that specifically commit to ending structural racism and the racist underpinnings of the HIV epidemic. In turn, the Administration itself should pledge to hold such trainings for leadership and all

⁴⁹ Please see a previous letter submitted to OIDP from Hepatitis Appropriations Partnerships on the draft Viral Hepatitis National Strategic Plan: A Roadmap to Elimination 2021-2025. https://www.nastad.org/sites/default/files/Uploads/2020/national viral hepatitis plan comments 10.8.20.pdf

federal employees involved in the administration of federal funding and guidance related to HIV. The Executive Order on Combating Race and Sex Stereotyping must be revoked.

Recommendation Regarding the Public Charge Rule

- **Requested Action:** The Administration should immediately rescind the *Inadmissibility* on *Public Charge Grounds* rule.
- Rationale: On August 14, 2019, the U.S. Department of Homeland Security (DHS) finalized the Inadmissibility on Public Charge Grounds rule that allows U.S. Citizen and Immigration Services to deny immigrants seeking admission to the U.S. or seeking to change their status to "lawful permanent resident" to individuals who have received social services, such as SSI, cash assistance, SNAP benefits, housing assistance, or Medicaid (with exceptions) for more than 12 months in a 36-month period.⁵⁰ The rule was challenged in the courts, but as of September 11, 2020, has been in effect nationwide. We have grave concerns that this rule creates a chilling effect, deterring immigrants from seeking services for themselves or their children who may be eligible because they are U.S. citizens. This chilling effect means that people are living without critical support, especially in this time of economic crisis, when so many are struggling to ensure that they have appropriate shelter, food, and medical care, which may in itself increase the risk of illness, such as COVID-19 or HIV. In order to end the HIV epidemic, we need to ensure that people who are living with or are at risk of HIV feel empowered to seek the care they need, whether it's an HIV test, HIV prevention services like PrEP, or treatment for HIV. By erecting barriers to that care, the Administration is undermining our national goal of ending the epidemic, undermining efforts to fight the devastating effects of COVID-19 and placing the health and well-being of U.S. citizen members of a family that includes an immigrant who has not yet achieved permanent resident status in jeopardy.

Recommendation Regarding Aging Population Living with HIV

- Requested Action: ONAP should establish and resource a cross-governmental working group to address issues related to an aging population living with HIV. Issues that should be addressed include long term effects of living with HIV and earlier treatments (such as inflammation), social isolation, multiple morbidity, polypharmacy, and the need to emphasize maintenance of function.
- Rationale: Thanks to improvements in the effectiveness of treatment with ART, PLWH who are diagnosed early in their infection, and who get and stay on ART can keep the virus suppressed and live long and healthy lives. For this reason, nearly half of people living with diagnosed HIV in the U.S. are aged 50 and older. Adults over age

⁵⁰ Homeland Security Department. (2019, August 14). *Inadmissibility on Public Charge Grounds. Vol* 84-157, pgs. 4192 – 41508, <u>https://www.federalregister.gov/documents/2019/08/14/2019-17142/inadmissibility-on-public-charge-grounds</u>.

50 living with HIV make up 46% of the clients served by the RWHAP. In 2018, 92% of clients aged 50 and older receiving RWHAP HIV medical care were virally suppressed, which was higher than the national RWHAP average. However, with this longer life expectancy, aging PLWH may exhibit many clinical characteristics commonly observed in aging: multiple chronic diseases or conditions, the use of multiple medications, changes in physical and cognitive abilities, and increased vulnerability to stressors. Older PLWH may face different issues than their younger counterparts, including greater social isolation and loneliness. The health needs of the increasing number of PLWH who are reaching older ages have become a significant public health issue and we must address their unique needs.

Recommendation Regarding Overturning Executive Order on Schedule F

- Requested Action: Immediately overturn the Executive Order on creating schedule F in excepted service.⁵¹
- Rationale: This Executive Order issued on October 21, 2020, puts risk to career, nonpartisan scientists and researchers employed by the federal government. Scientists that are shifted into this new job category are offered less protections from termination and makes it easier for the government to hire unqualified, politically aligned candidates to fill these key positions. This in particular impacts scientists and research in policy creation roles within the federal government, that require interpretation of evidence and data to draft and recommend policy, regulation, and guidance such as public health. In turn, this Executive Order may have a chilling effect in bringing qualified individuals into these positions and additionally stock the federal government with individuals with partisan, political interests. The HIV community can ill-afford any loss of the relationships and leaders within the federal government that have devoted their careers to end the HIV epidemic. Unjustified firings and removal of HIV scientists and researchers will be a tragic loss of capacity and institutional knowledge needed in our nation's HIV and COVID-19 responses.

Recommendation Regarding the Global Gag Rule

- Requested Action: Reverse the Trump Administration's Protecting Life in Global Health Assistance⁵² policy, otherwise known as the global gag rule, to ensure equitable access to lifesaving health care and medical research.
- **Rationale:** The global gag rule prohibits recipients of federal funding from providing legal abortion services or referrals, while also barring advocacy for abortion law reform even if it's done with non-U.S. funds. The policy allows access to abortion

 ⁵¹ The White House. (2020, October 21). *Executive Order on Creating Schedule F in The Excepted Service* <u>https://www.whitehouse.gov/presidential-actions/executive-order-creating-schedule-f-excepted-service/</u>
 ⁵² The White House. (2017, January 23). *Presidential Memorandum Regarding the Mexico City Policy*. <u>https://www.whitehouse.gov/presidential-actions/presidential-memorandum-regarding-mexico-city-policy/</u>

only in cases of rape, incest, or if a pregnant person's life is at risk. The policy has wrought a wide range of detrimental consequences. Pregnant people will suffer from disruptions in reproductive health services. The policy causes more unintended pregnancies, higher rates of maternal mortality, and an increase in unsafe abortions. The policy is undoing decades of work to integrate sexual and reproductive health services with HIV services. Vulnerable populations, and MSM in particular, are experiencing significant health service disruptions as a result of the global gag rule. These disruptions in care and health services directly impact HIV research by making it more difficult to enroll people of reproductive potential and key populations into clinical trials. Researchers rely upon the free flow of accurate information to ensure the ethical and successful administration of their trials. Investigators are required to share all potential benefits and consequences of their research with participants, and sometimes recruit potential participants through their medical providers who offer or refer to abortion services or need to discuss abortion related to benefits and consequences of their trial. The pool of providers able to offer these services, and also recruit in the populations they need to reach, has been greatly reduced which has impaired clinical research. When researchers are forced to limit participation in trials by people of reproductive potential and key populations, the people who truly suffer are those populations and science itself.

Recommendation Regarding COVID-19

- Requested Action: Better integrate HIV, STI, hepatitis, and harm reduction infrastructure and networks into COVID-19 response, including support for colocation of COVID-19 testing and vaccination services and ensuring inclusion of PLWH in vaccine distribution plans.
- Rationale: COVID-19 is fueled by the same structural inequities and systemic racism that have led to significant disparities across a number of infectious diseases. HIV, STD, hepatitis, and harm reduction networks are skilled at meeting people where they are and reaching communities that have not been well served by formal health care systems. However, COVID-19 funding and services have been silo-ed at the state and local levels, with a missed opportunity to leverage existing expertise and infrastructure. For instance, only three health department HIV prevention programs reported being integrated into their state's Epidemiology and Laboratory Capacity (ELC) COVID-19 activities. It is important to reverse this trend before vaccine distribution begins so that we ensure that communities, people who use drugs, and LGBT individuals are included in vaccine education, prioritization, and distribution strategies.

RECOMMENDED TRANSITION AND COMMUNITY DOCUMENTS

- Global AIDS Policy Partnership (GAPP)
- <u>Act Now END AIDS: Community Roadmap Executive Summary 2020</u>
- Ending the HIV Epidemic in the United States: A Roadmap for Federal Action
- U.S. Global Health Leadership for a Safer and More Equitable World
- Hepatitis Appropriations Partnership (HAP)

ENDORSEMENTS AND SIGN-ONS:

The ACT NOW: END AIDS Coalition

African American Health Alliance

AIDS Alabama

AIDS Alliance for Women, Infants, Children, Youth & Families

AIDS Foundation Chicago

The AIDS Institute

AIDS United

amfAR, The Foundation for AIDS Research

Amida Care

APLA Health

Association of Nurses in AIDS Care

AVAC

Black AIDS Institute

Cascade AIDS Project

Center for Health Law and Policy Innovation

Collaborative Solutions, Inc.

Community Access National Network (CANN)

Elizabeth Glaser Pediatric AIDS Foundation

The Food Is Medicine Coalition

Georgia AIDS Coalition

GLMA: Health Professionals Advancing LGBTQ Equality

HealthHIV

Health GAP

HIV + Hepatitis Policy Institute

HIV Medicine Association

Human Rights Campaign

iHealth

JSI (John Snow, Inc.)

Los Angeles LGBT Center

NASTAD

National Black Gay Men's Advocacy Coalition

National Black Women's HIV/AIDS Network, Inc. National Coalition for LGBT Health National Coalition of STD Directors National Family Planning & Reproductive Health Association National Working Positive Coalition NMAC Positive Women's Network-USA Prevention Access Campaign Professional Association of Social Workers in HIV/AIDS (PASWHA) Ryan White Medical Providers Coalition San Francisco AIDS Foundation Treatment Action Group The Well Project