## Presidential Advisory Council on HIV/AIDS (PACHA)

## 74<sup>th</sup> Meeting

Martin Luther King Jr. Outpatient Center 12021 Wilmington Ave, Building 18
Conference Room 1511
Los Angeles, CA
September 19–20, 2022

### **Council Members—Present**

- Marlene McNeese, PACHA Co-Chair, Assistant Director, Houston Health Department, Houston, TX
- John Wiesman, Dr.P.H., M.P.H., PACHA Co-Chair, Professor, Gillings School of Global Public Health, Health Policy and Management, The University of North Carolina at Chapel Hill, Chapel Hill, NC
- Gregg H. Alton, J.D., San Francisco, CA
- Guillermo Chacón, President, Latino Commission on AIDS; Founder, Hispanic Health Network, New York City, NY
- Tori Cooper, M.P.H., Director of Community Engagement for the Transgender Justice Initiative, Human Rights Campaign, College Park, GA
- Raniyah Copeland, M.P.H., Principal, Equity & Impact Solutions, Los Angeles, CA
- Alicia Diggs, M.P.H., Manager, Office of Community Engagement, Center for AIDS Research, The University of North Carolina at Chapel Hill, Greensboro, NC
- Vincent Guillamo-Ramos, Ph.D., M.P.H., LCSW, RN, ANP-BC, PMHNP-BC, AAHIVS, FAAN, Dean and Professor, Duke University School of Nursing, Vice Chancellor, Nursing Affairs, Duke University, Durham, NC
- Jennifer Kates, Ph.D., Senior Vice President and Director of Global Health & HIV Policy, Kaiser Family Foundation, Washington, DC
- Marc Meachem, M.B.A., Head, External Affairs, ViiV Healthcare North America, Washington, DC
- Leo Moore, M.D., M.S.H.P.M., Medical Director for Clinic Services, Los Angeles County Department of Public Health, Los Angeles, CA
- Laura Platero, J.D., Executive Director, Northwest Portland Area Indian Health Board, Portland, OR
- Kayla Quimbley, National Youth HIV and AIDS Awareness Day Ambassador, Advocates for Youth, Columbus, GA
- Michael Saag, M.D., Associate Dean, Global Health, School of Medicine, and Professor of Medicine, Division of Infectious Disease, The University of Alabama at Birmingham (UAB); Director, UAB Center for AIDS Research, Birmingham, AL
- John Sapero, Director, Ending the HIV Epidemic, Collaborative Research LLC, Phoenix, AZ
- Carl Schmid, M.B.A., Executive Director, HIV+Hepatitis Policy Institute, Washington, DC
- Adrian Shanker, Founder and Executive Director, Bradbury-Sullivan LGBT Community Center, Allentown, PA

Justin C. Smith, M.S., M.P.H., Director, Campaign to End AIDS, Positive Impact Health Centers; Behavioral Scientist, Rollins School of Public Health, Emory University, Atlanta, GA

### **Council Members—Absent**

- Rafaelé Narváez, Co-Founder and Director of Health Programs, Latinos Salud, Wilton Manors, FL
- Ada Stewart, M.D., RPh, FAAFP, AAHIVS, HMDC, Lead Provider and HIV Specialist, Eau Claire Cooperative Health Centers (Now Cooperative Health), Columbia, SC
- Darrell P. Wheeler, Ph.D., M.P.H., M.S.W., Provost and Senior Vice President for Academic Affairs, Iona College, New Rochelle, NY

# Liaison: Centers for Disease Control and Prevention (CDC)/Health Resources and Services Administration (HRSA) Advisory Committee on HIV, Viral Hepatitis, and Sexually Transmitted Disease (STD) Prevention and Treatment

Wendy Armstrong, M.D., FIDSA, Professor of Medicine, Emory University; Executive Medical Director, Ponce de Leon Center, Grady Health System, Atlanta, GA

#### Staff

- B. Kaye Hayes, M.P.A., Deputy Assistant Secretary for Infectious Disease and Director, Office of Infectious Disease and HIV/AIDS Policy (OIDP); PACHA Executive Director, Designated Federal Officer; Office of the Assistant Secretary for Health (OASH), U.S. Department of Health and Human Services (HHS)
- Caroline Talev, M.P.A., PACHA Committee Manager, Senior Management Analyst, OIDP, OASH, HHS

### **Federal Partners**

- Laura Cheever, M.D., Sc.M., Associate Administrator, HIV/AIDS Bureau, Health Resources and Services Administration (HRSA)
- Miguel Gomez, Director, HIV.gov, Senior Communications Advisor, OIDP, HHS (*day 2 only*) Maureen M. Goodenow, Ph.D., Associate Director for AIDS Research, Director, Office of AIDS Research, National Institutes of Health (NIH)
- Timothy Harrison, Ph.D., Deputy Director for Strategic Initiatives and Senior Policy Advisor, OIDP, HHS
- Rick Haverkate, M.P.H., National HIV/AIDS & Hepatitis C Program Coordinator, Indian Health Service
- David Johnson, M.P.H., Deputy Assistant Secretary for Health—Regional Health Operations, OASH
- Robyn Neblett-Fanfair, M.D., M.P.H., Principal Deputy Director, Division of HIV Prevention, National Center for HIV, Viral Hepatitis, STD, and TB [Tuberculosis] Prevention (NCHHSTP), CDC
- Harold J. Phillips, M.R.P., Director, White House Office of National AIDS Policy (ONAP) Kristen Roha, M.S., M.P.H., Public Health Advisor for HIV, Substance Abuse and Mental Health Services Administration
- Michelle Sandoval-Rosario, Dr.P.H., M.P.H., CPH, Director, HIV Prevention through Active Community Engagement (PACE), OASH, HHS

Crystal Simpson, M.D., Medical Officer, Office of Medicare, Centers for Medicare & Medicaid Services (CMS)

Edwin Walker, J.D., Deputy Assistant Secretary for Aging, Administration for Community Living, HHS (day 2 only)

CAPT Samuel Wu, Pharm.D., Public Health Advisor, Office of Minority Health, HHS

## Day 1

## **Opening Remarks from the PACHA Co-Chairs**

Marlene McNeese and John Wiesman, Dr.P.H., M.P.H., PACHA Co-Chairs

Dr. Wiesman called the meeting to order at 1 p.m. PT. He described the agenda for the meeting. (This meeting was broadcast live online; the recorded broadcast is available <u>online</u>.)

Dr. Wiesman reported that while in Los Angeles, PACHA members visited three community organizations on the front lines of HIV prevention and treatment: REACH LA and the Trans Wellness Center on September 19 and Bienestar on September 20. The site visits illustrated the importance of a holistic approach that provides comprehensive services to people with HIV (PWH) and those at risk for HIV. Ms. McNeese added that site visits remind PACHA members and staff that their work does not take place in siloes and that communities face unique issues around the country. Her home state of Texas is challenging practices related to reproductive justice, maternal—fetal health, and access to pre-exposure prophylaxis (PrEP) for HIV. Ms. McNeese emphasized that PACHA and others must support evidence-based policies and practices. Ms. McNeese also summarized recent Federal funding and response to the monkeypox outbreak. She called on Congress to pass a budget that provides sufficient funding to respond to monkeypox and other public health crises.

Ms. McNeese congratulated longtime PACHA Executive Director B. Kaye Hayes, M.P.A., for being named the Deputy Assistant Secretary for Infectious Disease and OIDP Director.

## **Roll Call**

B. Kaye Hayes, M.P.A., Deputy Assistant Secretary for Infectious Disease, Director, OIDP; PACHA Executive Director; OASH, HHS

Ms. Hayes called the roll.

## Welcome

ADM Rachel L. Levine, M.D., Assistant Secretary for Health, HHS

ADM Levine thanked the Council members and community partners for working double-duty for more than two and a half years to fight the COVID-19 pandemic and HIV and now monkeypox. She acknowledged the exceptional work of the PACHA Co-Chairs and Ms. Hayes' outstanding leadership of PACHA and OIDP, as well as the contributions of other HHS staff, Federal and community partners, and the host organization for this meeting.

ADM Levine observed that Los Angeles is a priority jurisdiction under *Ending the HIV Epidemic: A Plan for America* (EHE). PACHA's efforts to advise HHS are enhanced by holding

meeting in priority jurisdictions, where it can visit community organizations, gather insights from local entities, and hear the voices of individual community members.

President Joseph Biden released the updated *National HIV/AIDS Strategy* (NHAS) on World AIDS Day (December 1) in 2021. The NHAS reflects a commitment to reenergize a whole-of-society response to HIV. In August 2022, the White House released the NHAS Federal Implementation Plan, which details commitments to policies, research, and other activities to meet the NHAS goals. In June, HHS launched a national, community-informed campaign to encourage uptake of antiretroviral therapy (ART), I Am a Work of ART.

During the International AIDS Conference (AIDS 2022) in Montreal, Canada, in July, ADM Levine and colleagues had the opportunity to visit a local STD treatment program that demonstrated innovative use of technology to provide services. Also at AIDS 2022, Harold J. Phillips, M.R.P., ONAP Director, announced that the U.S. government has adopted the message that undetectable equals untransmittable (U=U) to guide its efforts to prevent, diagnose, and treat HIV and encourages all countries to do the same. The U.S. government acknowledges what the science demonstrates: PWH who have an undetectable viral load cannot transmit the virus sexually. Offices across HHS have embraced this message and will use it going forward.

HHS announced three funding opportunities totaling nearly \$44 million to strengthen mental health and substance use services for vulnerable populations with or at risk for HIV. These grant programs reflect the Biden-Harris administration's commitment to providing accessible, evidence-based, culturally appropriate substance use prevention, treatment, and recovery services as part of HHS's new overdose prevention strategy. The strategy includes harm reduction approaches such as evidence-based syringe service programs, which help prevent the syndemic of HIV, hepatitis, and substance use. The grants are supported by the Minority HIV/AIDS Fund and aligned with the administration's priority of health equity. They target areas of the country with the greatest disparities in HIV-related health outcomes, and they align with the NHAS.

In addition, Secretary Becerra announced more than \$20 million in funding to expand HIV prevention, testing, and treatment services at 64 health centers nationwide as part of the EHE initiative. Health centers will leverage these awards to expand access to medication, prevent and treat HIV, and strengthen their partnerships with community organizations such as those funded by HRSA's Ryan White HIV/AIDS Program and local health departments. This funding is part of HHS's ongoing efforts to implement the EHE initiative by better coordinating and integrating services and building stronger partnerships to reach underserved communities in targeted jurisdictions. It brings the total number of health centers participating in EHE to nearly 400, offering the full continuum of HIV care from testing and prescribing PrEP to treating and connecting to care. Health centers and their community partners are crucial to attaining optimal HIV health outcomes among PWH, preventing further transmission of the virus, and ultimately ending this HIV epidemic once and for all, said ADM Levine.

ADM Levine thanked all of those on the front lines responding to monkeypox outbreaks in their communities and providing comprehensive care during this unprecedented time. She thanked the PACHA members for the work they do on the Council and in their communities every day to help end the HIV epidemic.

#### Discussion

ADM Levine said the whole-of-government response to monkeypox focuses on prevention through access to safe and effective vaccines, diagnosis, and treatment with potential effectiveness for monkeypox with tecovirimat (TPOXX) for those most at risk from severe complications of the disease—all with an emphasis on health equity. Notably, State health departments can braid their funding for HIV and monkeypox to serve communities that are at risk for both. For example, in cooperation with State and county health department leadership, community centers can offer monkeypox vaccination at the same time as HIV testing. ADM Levine acknowledged progress against monkeypox but cautioned against complacency.

Carl Schmid called for a federally funded national PrEP program. In the meantime, guidance from CDC and CMS' Center for Consumer Information and Insurance Oversight could instruct insurers on using correct coding so that people with private insurance are not charged for PrEP through cost sharing. Mr. Schmid hoped the U.S. government would address State efforts to limit PrEP access through court rulings and get the message out that PrEP is still available without cost sharing. ADM Levine agreed, noting that a focus on health equity is the opportunity to emphasize that everyone should have access to PrEP and ART.

## **Welcome from the Regional Hosts**

Sylvia Drew Ivie, J.D., Special Assistant to the President for Community Affairs, Charles R. Drew University of Medicine and Science, and Michael Mills, M.H.A., CEO, Martin Luther King, Jr. Outpatient Center

Mr. Mills said the new Martin Luther King, Jr. Outpatient Center provides a range of medical and behavioral care in one place, with a goal of improving health and well-being for the community, patients, and staff. The Center plays an essential role in south Los Angeles, which continues to suffer disproportionately from poor health, inherited from decades of structural racism. It is operated by the Los Angeles Department of Health Services. The Oasis program, which has long provided HIV prevention and treatment care in south Los Angeles, is in the process of moving to a new building, also located on the Drew University campus, where it will offer enhanced services.

Ms. Ivie observed that Drew University and the Martin Luther King, Jr. Outpatient Center are separate entities that were founded together after the 1965 Watts revolt and continue to work closely together. The university has offered HIV care and services for decades, currently through Drew Cares, a multidisciplinary effort aimed at excellence in HIV prevention, research, and service provision. The university provides free HIV testing, counseling, and referrals for community services through projects involving social workers, patient navigators, and others to bring people into care and retain them.

## **Update on Monkeypox**

Demetre Daskalakis, M.D., M.P.H., White House National Monkeypox Response Deputy Coordinator, Director, Division of HIV Prevention, NCHHSTP, CDC

Dr. Daskalakis was cautiously optimistic that the monkeypox outbreak is declining, based on current data. However, across the country, some jurisdictions see rates stabilizing while others are seeing increases. These trends represent in part the effects of natural immunity from infection

in some areas. Monkeypox vaccination efforts are aimed primarily at men who have sex with men (MSM), and data show disparities in cases and vaccinations among Black/African American and Hispanic/Latino MSM.

As ADM Levine mentioned, CDC recently announced that grantees with funding to address HIV and other sexually transmitted infections (STIs) can use that funding to address monkeypox (without special permission). The announcement sets a great precedent for combating a syndemic, said Dr. Daskalakis. He outlined some pilot programs specifically aimed at increasing health equity around monkeypox vaccination and encouraged meeting participants to contact their local health departments with ideas for ways to expand vaccination efforts.

Testing capacity has increased dramatically since the outbreak began. To accelerate treatment, CDC made it easier to access and complete the TPOXX request form. It also clarified the need to ensure access to TPOXX for those at highest risk for progression or worse disease. At least 2,600 people have received TPOXX, of which about 64 percent are non-White. About 540,000 vaccines have been delivered, mostly to White people, and efforts continue to address stigma and barriers to access. As more jurisdictions have access to vaccine, more people will have access to a second dose. Clinical trials are underway to assess the new JYNNEOS vaccine, and those trials include PWH. Data show communication has been effective in encouraging people to change their behavior to avoid monkeypox infection. A study also found that awareness about monkeypox, its transmission, and the vaccine are increasing.

#### Discussion

Dr. Daskalakis said it is not yet clear whether declines in monkeypox cases are the result of increased vaccination, behavior change, or diagnostics. The Federal government is developing a web page that will collate all related government-funded research. Efforts to increase vaccination are complicated by variations across jurisdictions in availability of a second dose. Other parts of the globe are also experiencing significant outbreaks. Dr. Daskalakis noted that NIH studies include women but are focused on populations overrepresented in the outbreak. Some jurisdictions are taking the opportunity to integrate monkeypox response with HIV and STI prevention and treatment work.

## **International AIDS Conference**

Michelle Graham, M.B.A., Program Manager, HIV.gov, BETAH Associates

Ms. Graham presented a video excerpt from a daily news show at AIDS 2022, produced by HHS staff who manage the website HIV.gov. The show featured interviews with scientists, researchers, and leaders in the field. PACHA members were among the expert speakers who offered reflections on the conference.

## **Update from the President's Emergency Plan for AIDS Relief** (PEPFAR)

Catherine Godfrey, M.D., Senior Technical Advisor, Office of the Global HIV/AIDS Coordinator, U.S. Department of State

PEPFAR support has helped countries facing high HIV burden achieve HIV epidemic control, with a significant investment in vulnerable populations. During the COVID-19 pandemic,

PEPFAR countries increased multimonth drug dispensing of ART and use of HIV self-tests; since 2020, 2 million more people are now using PrEP. PEPFAR programs served as a platform for pandemic response. The agency has invested \$15 million in strengthening care delivery systems, which include an expansive health care commodity supply chain.

PEPFAR's strategic goals emphasize sustainability, partnerships, science, and communications. Prevention efforts include the DREAMS program, a multisector initiative that offers customized, individualized support to meet the needs of adolescent girls and young women. PEPFAR has invested \$1 billion in DREAMS over the past 7 years. The program is implemented with assistance from a number of U.S. agencies with global reach, including CDC and the Peace Corps. PEPFAR promotes voluntary medical male circumcision, which could avert 1.8 million HIV infections by 2030. PrEP uptake has grown strongly since 2019, but Dr. Godfrey said the numbers appear to have stalled, and PrEP remains underused.

PEPFAR's treatment model focuses on a simple regimen—one pill per day that can be prescribed by most providers. It emphasizes people most at risk, including people over age 50 years. Dr. Godfrey noted that the need to engage and re-engage people in care is common for all chronic disease and should be normalized. PEPFAR research has found that the first 3 months of care appears to be ripe for special interventions to retain people in care over the long term. The aging of the population around the globe poses various challenges. Aging PWH bear a significant burden from other health conditions. PEPFAR and its colleagues are currently considering how to embed person-centered care for older adults, which must include many services that do not fall under PEPFAR's mandate, so partnerships will be critical.

#### **Discussion**

Dr. Godfrey explained that many people continue to see HIV as a young person's disease, which poses a barrier to reaching older PWH. Among older people, the target audience includes PWH who have been on treatment for a long time, those newly diagnosed with HIV, and those not in treatment, and the communication approach for each group is slightly different. Dr. Godfrey also observed that PEPFAR's mandate revolves around HIV care, so providing more holistic, comprehensive services takes partnerships, and PEPFAR is thinking through how to provide wraparound care.

## **Epidemiology of HIV in Los Angeles and Efforts to End the HIV Epidemic**

Mario J. Pérez, M.P.H., Director, Division of HIV and STD Programs, Los Angeles County Department of Public Health

Mr. Pérez explained that Los Angeles County is the largest county government in the country, serving 88 cities and 10 million people. The syndemic of communicable diseases has taxed everyone in the field. The county recognizes the need for HIV services and promotes a "no-wrong-door" mentality to ensure people are linked to the services they need, but some services remain underused. Mr. Pérez described progress on some performance indicators but noted that the COVID-19 pandemic and other factors have slowed this progress. PrEP uptake is growing, but not fast enough to meet 2025 targets.

Los Angeles County is facing a humanitarian crisis of homelessness, which appears to be increasing. PWH who are unhoused are less likely receive HIV care or stay in care, and they face high rates of comorbidities. The number of unhoused PWH has almost quadrupled over 6 years. Across the county's population of PWH, high rates of coinfection with other STIs persist, constraining the county's ability to meet its HIV goals. Decades of epidemic methamphetamine use contributes to many of the issues in Los Angeles County.

California offers a generous PrEP assistance program, so no one should face cost barriers, but enrollment in PrEP programs and persistence rates are lower than the county would like. Willingness to use PrEP is rising slowly, but actual use is increasing at too slow a rate. There county is seeing some increases in use among transgender people and Latinx MSM, but rates among Black MSM are too low and are not increasing. The county funds 12 PrEP Centers of Excellence to simplify access to routine testing and PrEP, as well as routine STI testing.

Among the strategies Los Angeles County has adopted in recent years are HIV self-test kits, more targeted testing for clinics on Skid Row, and expanded telehealth PrEP services. It is offering technical assistance to Federally Qualified Health Centers (FQHCs) and community clinics to overcome barriers to routine testing and other services. The county is investing in homelessness prevention, mental health assessments and consultation, and HIV cluster detection. One crosscutting strategy brought to the fore by the county's EHE steering committee is training for all providers on bias and medical mistrust. Another is the HIV Empowerment and Education program, which strives to find new avenues to engage communities affected by HIV through community-led teams that organize projects and activities. The county is trying to implement routine HIV testing in emergency departments. It has expanded syringe service programs. A contingency management program seeks to motivate people to access and re-engage in HIV care.

The county recognizes that the HIV workforce is eroding because many people are burned out and feel that they are constantly being asked to take on more responsibility. Without adequate support, Mr. Pérez feared that the field will no longer have the highly motivated, productive workforce it needs to end HIV. There is strong support for cross-training.

Mr. Pérez said the initial EHE emphasis on innovation has been stymied. Jurisdictions need optimal flexibility and partnerships around HIV and capacity to address HIV, other STIs, monkeypox, and methamphetamine simultaneously. The county needs increased funding that aligns with the goals of related public health programs. The massive resources deployed for COVID-19 should be applied to other infectious diseases. Capacity-building and workforce development are crucial and should be addressed with a 10-year national plan. Administrative barriers that contribute to people becoming homeless must be overcome.

## **Discussion**

Mr. Pérez proposed that the significant gains in PrEP uptake among transgender women may be the result of offering multiple access points through various trusted community organizations with strong cultural humility. Staff at those organizations understand and confront implicit bias. A welcoming presence on entry is key to taking the next step. Mr. Pérez said the county strives to create spaces where stigma, xenophobia, homophobia, and transphobia cannot survive, but he noted that homophobia in particular plays a role in low rates of monkeypox vaccine uptake, HIV testing, and PrEP uptake. He called for a national referendum on transphobia and violence,

pointing out that policies in some States are exacerbating the problem. Stigma is a social issue that cannot be addressed with HIV funding alone. Transgender and nonbinary people are always disproportionately affected by public health emergencies. Through the EHE initiative, the county has expanded its public health staff to increase its gender, racial, ethnic, and age diversity.

Viral hepatitis remains a concern. California has invested in making treatment for hepatitis C accessible to PWH for about a decade, but acute hepatitis persists.

## Addressing the Unique Needs in Los Angeles from a Community Perspective

Co-Facilitators: Raniyah Copeland, M.P.H., and Leo Moore, M.D., M.S.H.P.M., PACHA

Members

Panelists: Pastor Curt D. Thomas, Director, Momma's House

LaShonda Spencer, M.D., Professor of Pediatrics/Internal Medicine,

Infectious Diseases/HIV Specialist, Charles R. Drew University of Medicine and Science, and Clinic Director, OASIS Clinic, Martin Luther King, Jr.

**Outpatient Center** 

Carl Highshaw, M.S.W., CEO and Founder, Arming Minorities Against

Addiction & Disease (AMAAD) Institute

Richard L. Zaldivar, Founder and Executive Director, The Wall Las

Memorias Project

The co-facilitators noted that California has strong financial resources and liberal policies to support the HIV response, yet substantial challenges remain to ending HIV. The confounding problems of a COVID-19 pandemic and a monkeypox outbreak are taxing the workforce. This session sought to learn lessons from Los Angeles that could be applied elsewhere. Panelists introduced themselves and described their organizations, and co-facilitators posed questions for consideration.

## How are efforts to end HIV going in Los Angeles?

Dr. Spencer highlighted some problems not yet mentioned, such as the lack of affordable housing; underfunding for diagnosis and treatment of STIs, especially among women; and concurrent substance use and mental health concerns. She noted that the Oasis Clinic offers access to many services, including substance use and mental health counseling, thanks to the Ryan White program. Mr. Highshaw saw a steady march toward HIV prevention that can be achieved if the country stays the course. Mr. Zaldivar said that progress has stalled since the COVID-19 pandemic outbreak, and the workforce has been hit hard, but he believed there is energy around re-committing to the battle against HIV.

## How have COVID-19 and monkeypox affected your HIV response?

Mr. Zaldivar said there is no open conversation about the impact of the previous administration on immigrant populations, evidenced by the increase in hate crimes and overt racism. He said there are huge challenges around how to make the community feel whole and how to encourage individuals who have been traumatized to take a greater investment in their lives. Dr. Spencer added that PWH became increasingly worried and scared about the impact of COVID-19.

However, she said, that fear drew some of her patients back into care. Telehealth has helped, particularly for PrEP patients.

When the COVID-19 vaccine rolled out, Dr. Spencer said she spent a lot of time educating clients to counter the persistent medical mistrust, particularly among African Americans. On the other hand, demand for the monkeypox vaccine was very strong, even among some people who refused the COVID-19 vaccine. The pandemic has revealed the need for ongoing work to develop trust with patients and communities.

Mr. Highshaw said he was encouraged to see young people coming forward with ideas to improve community engagement. Youth must have a voice in the response.

Mr. Thomas said that during the pandemic, his organization has focused on ensuring that unhoused people remained in care by providing transportation to health care providers and smartphones for telehealth visits. None of his clients wanted the COVID-19 vaccine, but all of them wanted the monkeypox vaccine, because monkeypox lesions are visible.

## What strategies are effective for linking clients to care and retaining them in care?

Dr. Spencer said that employing patient navigators and others with lived experience makes a big difference, because patients relate to them. Having staff that reflect the clientele served is key. Another effective approach is offering an array of services and ensuring there is "no wrong door"—that is, services work together so that clients get what they need, no matter where they seek assistance. A multidisciplinary campus allows colleagues to share their work, collaborate, and make referrals.

Mr. Highshaw added that providing multiple services is key, as housing, mental health, and PrEP are all components of HIV care, along with many other factors. The AMAAD Institute sees itself as a social work organization that operates across the spectrum of social determinants of health (SDH).

Mr. Zaldivar said that services are not reaching enough people because the community is depressed. Many have expressed feelings of isolation, depression, fear, and burnout. The workforce faces mental health and spiritual crises. Drug use is a big problem in Los Angeles and other large cities in part because of the lack of jobs in livable communities. Ending HIV requires attention to substance use and mental health challenges as well as a livable wage. Mr. Zaldivar said it is time to revamp the approach to meet the goals.

## What works to retain the HIV workforce?

Dr. Spencer said that paying people what they are worth and providing opportunities for growth are both difficult but very important. Everyone in the field feels underpaid and overworked. Patient navigators in particular face painful situations routinely. Burnout is real, and self-care is important. Employers must train staff on how to recognize their own trauma and where to get help. Dr. Spencer added that young people in particular would benefit from more education and increased awareness about HIV, as many think that HIV has gone away. Dr. Moore agreed, noting the importance of building a pipeline that encourages people to join the HIV workforce.

Mr. Highshaw agreed that salaries are key, as neither clients nor staff can afford to live in Los Angeles. There must be a push to increase wages for patient navigators; they must feel stable to help others achieve stability.

Mr. Zaldivar noted that there are no support groups for people in the HIV workforce. He suggested a national mentorship program to improve the pipeline, with a focus on training people of color for leadership roles.

## How does homelessness affect HIV in Los Angeles, and what interventions have worked?

Mr. Thomas said housing costs in the area are exorbitant. His organization works closely with clients to meet immediate and specific needs of individual clients that can help them move into stable housing, ranging from obtaining a Social Security card to having access to a bath and clean clothes. He noted that the organization provides new, unused bedding, comfortable beds, and some name-brand clothing and other items so that each client feels important. Feeding the psyche and addressing mental health needs are important first steps. Checking in with clients frequently about their needs is effective. The organization also offers financial literacy training.

## What is needed to get more women of color into HIV care and to end HIV in women of color?

Dr. Spencer called for more outreach to people outside of the "HIV bubble," outside of obstetric and gynecologic care settings, and beyond reproductive age. Primary care providers need much more education about HIV and STIs. Providers need education on the status-neutral approach to screening for HIV and STIs, which is a relatively new concept. Providers should be screening women for HIV wherever they seek care. Ms. Copeland added that women of color shape their communities' cultures, and investing in HIV services for women specifically destignatizes PrEP, creating a positive ripple effect.

## What should PACHA focus on in the next year?

Mr. Highshaw proposed bringing more young people to the table to engage in decision making, because they bring fresh perspectives and different approaches. Dr. Spencer suggested promoting a status-neutral approach to screening for all providers, because the health care system does not provide the structure or time for providers to have conversations about sexual health in a primary care visit. Mr. Thomas recommended continuing the mechanisms started last year to provide housing immediately for PWH, connecting people to Medicaid and other services, and expanding the length of provided housing to 1–2 years so that people can maintain stability. Mr. Zaldivar advised amending national plans in light of the COVID-19 pandemic, with particular attention to building and sustaining the workforce.

### **Discussion**

Mr. Highshaw said that building a workforce that reflects the community and brings lived experience to the workplace requires a deliberate, intentional approach. It is easy to identify people when you make the effort.

To address hot spots or pockets of disease, Mr. Pérez said Los Angeles County seeks to build capacity in areas with a growing need for HIV services. It has also made clear to community-based providers where the county wants to see more services. For example, the county invested in two Trans Wellness Centers. It supported six wellness centers specifically for young, gay and

bisexual Latinx and Black men. Mr. Pérez said a hub-and-spoke model enables various service providers to bring their strengths and offer a wide menu of services, and the model can be adapted in response to emerging infections.

Mr. Pérez noted that an initiative to promote routine HIV screening in in the emergency department of a large academic medical center worked to identify PWH. However, emergency departments are overwhelmed, and adding anything to their burden requires constant negotiation and tradeoffs. Even systems that seem readily equipped to respond are not always able to do so.

## **PACHA to the People: Community Engagement Session**

The PACHA co-chairs invited all those participating (in person and virtually) to speak. Dr. Wiesman emphasized that PACHA is particularly interested in hearing about the situation in Los Angeles, especially examples of best practices and effective interventions as well as challenges. Key comments are summarized here according to the main themes.

### **Education and Communication**

- Increase Federal support for health education.
- Improve communication and messaging:
  - o Use simpler language, with less jargon and medical terminology.
  - Craft messages to the target audiences and ensure there are clear messages for cisgender and heteronormative people. Develop sexual health messaging for older people.
- Create space for multigenerational conversations to convey the history of HIV.
- Recruit young people to help with communication.
- Continue to educate about the basics of HIV transmission and prevention.
- Raise awareness about PrEP, postexposure prophylaxis (PEP), HIV care, and related services.
- Capture and communicate community outcomes data.
- Increase the representation of young, transgender, and intersex people on PACHA.
- Expand sex education.
- Employ community health workers to assist with sex education and STI prevention and to address medical mistrust.
- Educate about the concept of the medical home to support holistic care; the medical home can also identify people at highest risk during a health crisis.
- Emphasize the message of U=U broadly among providers, patients, and the community.

#### **Funding**

- Increase funding for Los Angeles County and allow more flexibility in spending. Specifically, allow funds to be used for housing, transportation, trauma counselling, general HIV education for PWH and the people who support them, community education, and mental and spiritual health.
- Increase funding for the Ryan White program to meet the increased demands and expectations placed on the grantees.
- Invest in shoring up capacity and infrastructure among small community-based organizations.

- The EHE initiative asks FQHCs to replicate in a few months what the Ryan White program developed over 30 years. FQHCs need more support for workforce training, information about partnering with community organizations, and guidance on integrating with local and State health departments.
- Invest in family-focused HIV care.
- Invest in wraparound services.
- Direct more funding to organizations that rely on social workers, case managers, and community health workers, who have the most impact on clients. Currently, most money goes to large organizations dominated by physicians.
- Fund programs that enable people to work through trauma and seek restorative justice.
- Fund programs that support continuity of care.

## **Policy**

- Push back against those trying to break down the wall separating church and state.
- Emphasize a more person-centered model of care to combat mistrust.
- Assess the value of programs developed as Special Projects of National Significance (SPNS) and extend funding for those that are successful.
- Create a national universal health care system.
- Enact policies to alleviate poverty, such as universal basic income.
- Acknowledge the benefits of holistic health services on prevention.
- Streamline the Housing Opportunities for Persons with AIDS (HOPWA) application process to make it work better for older PWH, pregnant women, and families. Increase supervision of HOPWA.
- Require collaboration across housing authorities.
- Consider the needs of rural communities.
- Pursue immigration reform, given increases in disease in migrant camps and detention centers.
- Engage more young people with lived experience in policymaking.

### **Interventions**

- Reach the community through pop-up or mobile clinics, as was done for monkeypox and COVID-19.
- Ensure equitable distribution of long-acting injectables.
- Pair HIV testing with counseling and education, particularly for those who test positive.
- Seek ways to leverage existing technology and tools to boost the workforce and increase individual adherence to treatment, for example.
- See the Connect to Protect program, which promotes sexual health among young people.
- Support trauma-informed HIV care, prevention, and advocacy.
- Empower young people with prevention education, harm reduction strategies. The Los Angeles Unified School District has a comprehensive health program that includes sex education with medically accurate, current, unbiased, and inclusive information.
- Identify and expand creative strategies for increasing mental and spiritual health among PWH.
- Address the HIV workforce:
  - o Fix the broken pipeline of health care providers.
  - Address education debt for health care providers.

#### Research

- Increase Federal support for clinical trials on what works to combat medical mistrust (e.g., around PrEP, long-acting injectables, and HIV care).
- Conduct more research on aging in women with HIV and those who were infected perinatally.
- Assess barriers to uptake beyond access and medical mistrust, such as cultural norms and perceptions of wellness.
- Evaluate whether primary care providers are delivering the message of U=U consistently among PWH; if they are not, determine why not.

## **Aging PWH**

- Provide behavioral and mental health support for older PWH.
- Increase HIV testing among people over 50 years by offering testing in novel places.
- Reach out to older PWH who are not in care.
- Support the needs of aging PWH through flexible funding and by bolstering the capacity of community health centers.

## **Discrimination and HIV Criminalization**

 Prevent discrimination. See the Williams Institute's report, <u>Enforcement of HIV</u> Criminalization in Tennessee.

## **Closing Remarks and Recess**

Dr. Wiesman explained that PACHA uses the public's input to determine where to invest its energy as it advises HHS and key Federal personnel. Mr. Schmid observed that the Federal government funds programs narrowly, and officials must determine how to address complex and interrelated problems within the funding restrictions. Mr. Phillips added that the NHAS Implementation Plan is an important step toward doing what needs to be done to end HIV. He quoted Secretary Becerra, who said the moment is now, despite setbacks from COVID-19 and monkeypox. Mr. Phillips said the HIV response must accelerate to meet goals. Dr. Wiesman recessed the meeting for the day at 7 p.m. PT.

## Day 2

## **Opening Remarks from the PACHA Co-Chairs**

Marlene McNeese and John Wiesman, Dr.P.H., M.P.H., PACHA Co-Chairs

Ms. McNeese welcomed the participants at 12:30 p.m. PT. She reviewed the proceedings of Day 1 and the agenda for Day 2.

## Roll Call

B. Kaye Hayes, M.P.A., Deputy Assistant Secretary for Infectious Disease, Director, OIDP; PACHA Executive Director; OASH, HHS

Ms. Hayes called the roll.

## White House Updates

Harold J. Phillips, M.R.P., Director, ONAP

The NHAS Federal Implementation Plan reflects contributions from 10 Federal departments and focuses on actions thought to be transformative. It includes some new partners, most notably the Department of the Interior. At least one PACHA meeting will review the progress of Federal agencies and non-Federal stakeholders toward NHAS implementation. The plan describes five new indicators to address quality of life (QOL) for PWH that will capture self-reported perception of health, mental health needs, food insecurity, unemployment, and housing instability and will inform policymaking, program development, and the research agenda. Together, these indicators increase understanding about whether a person gets care and stays in care. Addressing QOL will move the country toward a more holistic approach to care for PWH. The NHAS goes beyond the Federal government and involves academia, community- and faith-based organizations, philanthropists, and the private sector. The NHAS overlaps with other Federal strategies to address STIs, viral hepatitis, and substance use.

The White House convened a meeting in May to educate prosecutors at the State, county, and local levels about HIV criminalization laws and their impact. The meeting provided an opportunity for prosecutors to meet with their State HIV/AIDS coordinators, some for the first time. Many of the prosecutors were not aware of U=U or that HIV cannot be transmitted through saliva from biting or spitting, two important facts that raise questions about the basis for some current State laws. Mr. Philips said the White House has limited capacity to address HIV criminalization laws, so it is using available channels to advocate for change at the local level.

Mr. Philips recognized a number of new Federal programs, such as new HRSA projects to improve outcomes for aging PWH, use telehealth strategies to maximize HIV care, replicate successful housing interventions, and increase the uptake of long-acting injectable ART. Some of these projects leverage the Minority HIV/AIDS Fund, demonstrating a commitment to increase flexibility and create new partnerships. CDC is pursuing work on status-neutral HIV prevention and care services for transgender persons. The Indian Health Service received EHE funding to eliminate HIV and hepatitis C in Indian country. The Substance Abuse and Mental Health Services Administration is incorporating PrEP and HIV testing in substance use disorder projects that it funds in EHE jurisdictions. A number of publications have disseminated new findings and best practices to professional audiences.

### **Discussion**

Mr. Philips noted that the COVID-19 pandemic forced policymakers to be more innovative and collaborative. Similar efforts can be taken to end HIV. Mr. Philips sought insight on how to engage with current and new stakeholder partners around implementation and how to ensure that the NHAS and the Federal Implementation Plan are useful to communities.

Regarding pressing HIV workforce issues, Mr. Philips said more work can be done to improve workflow through technology, as was demonstrated by a clinic in Montreal that was almost completely digitized. Michael Saag, M.D., suggested working with CMS on mechanisms to improve workflow, which could benefit all health care providers and their patients.

Mr. Philips said the budget request for fiscal year 2023 included a proposal for a national PrEP program, but it did not have enough support in Congress. It remains an important priority. Several countries are beginning to bring the HIV epidemic under control through massive testing initiatives, immediate linkage to care, and national PrEP programs.

Dr. Saag noted that many factors affecting aging PWH are universal, so engaging specialists in geriatric care in the NHAS implementation could benefit the HIV community.

Guillermo Chacón requested that ONAP report to PACHA in one year on the status of NHAS implementation and progress toward the goal of ending HIV by 2030. Dr. Phillips said ONAP would describe some work underway on World AIDS Day this year and provide a full progress report on December 1, 2023.

## **PACHA Subcommittee Reports**

Ms. McNeese said that PACHA needs an inventory of all of its work to demonstrate how it has influenced HIV policy. Plans are underway to write a progress report demonstrating the real-world impact of PACHA's efforts. Most of that work begins in PACHA's subcommittees, which gather information and craft proposals for the full Council's consideration.

## **EHE and the Updated National HIV Strategy**

Carl Schmid, M.B.A., and John Sapero, Co-Chairs

Mr. Sapero reported that the Subcommittee organized the upcoming panel discussion on aging and HIV. It is interested in bringing the whole weight of the Federal government to bear on ending HIV, so it is seeking nontraditional Federal partners to join the fight. The Subcommittee is discussing a resolution to propose a national PrEP program that would address minimizing disparities in access to injectable PrEP and overall disparities in PrEP uptake. The group is also looking at the impact of COVID-19 on PWH and the HIV workforce. It would like to re-energize the HIV workforce to increase the quality of care and services.

Mr. Schmid added that the Subcommittee would like to hear more from communities in EHE jurisdictions about the status of efforts. At a meeting in May, the PACHA subcommittee cochairs agreed that CMS should be integrated in the EHE initiative, so PACHA is requesting a meeting with CMS leadership. In response to an ONAP request, work is underway to delve into findings from Emory University research on disparities in PrEP uptake. The Subcommittee will also look closely at the NHAS Federal Implementation Plan. Mr. Schmid emphasized that implementing the EHE initiative requires funding.

### The Global Agenda

Jen Kates, Ph.D., Co-Chair

Dr. Kates said the domestic and global HIV response exist on the same continuum. The Subcommittee is working to ensure that global issues are integrated into the agenda at every PACHA meeting. In May, John N. Nkengasong, Ph.D., was sworn in as the PEPFAR Ambassador-at-Large and U.S. Global AIDS Coordinator. He is pursuing a new strategy for the agency, which must be reauthorized by Congress next year. Dr. Kates said the Subcommittee seeks input on how to facilitate bidirectional flow of best practices between PEPFAR and U.S. programs. The Subcommittee is particularly interested in PEPFAR's efforts to prevent HIV by

reaching out to young women and girls, address stigma and discrimination, and foster community engagement.

## Stigma and Disparities

Justin C. Smith, M.S., M.P.H., Co-Chair

Mr. Smith said the Subcommittee is bringing forth a resolution on Federal policies around blood donation deferral among MSM. It works with the other subcommittees to ensure that PACHA applies an equity lens to all of its efforts. The Subcommittee is also discussing molecular HIV cluster detection and response and will put forth a resolution for the Council's consideration at a public PACHA meeting on October 17, 2022. Mr. Smith said the Subcommittee's process involves Federal partners and the community in all of its work.

## Older Adults with HIV and Long-Term Survivors

Alicia Diggs, M.P.H., and John Sapero, PACHA Members

Ms. Diggs and Mr. Sapero described their personal experiences of aging with HIV, highlighting some of the challenges PWH face to their physical and mental health as they get older.

## **Clinical Interventions on Aging and HIV**

Michelle Floris-Moore, M.D., M.S., FIDSA, Associate Professor of Medicine, Division of Infectious Diseases, Chapel Hill School of Medicine, University of North Carolina

Dr. Floris-Moore summarized the demographic data, pointing out that the population of older PWH is increasing. Aging is associated with comorbidity, regardless of HIV status. A study of found that more than 75 percent of women with HIV age 60 and over had four or more comorbidities not related to HIV. Women with HIV have higher rates of diabetes than those who do not have HIV across the lifespan, with a significant spike after age 65. Men with HIV have a much higher risk of cardiovascular disease (CVD) as they age when compared with counterparts who do not have HIV. Older PWH can also suffer from frailty resulting from a combination of environmental determinants, including use of multiple medications, multiple comorbidities, smoking, social isolation, and stigma that prevents access to diagnosis and treatment. Use of multiple medications also increases the risk of falls and subsequent injury.

A model of the impact of interventions for CVD found several effective approaches:

- Early HIV diagnosis, treatment, and viral suppression
- Avoidance of older ART regimens that are associated with a high risk of CVD
- Smoking cessation
- Standard treatment for atherosclerosis (i.e., treatment of hypertension and dyslipidemia)

Combining all four interventions resulted in a 30-percent reduction in CVD.

For general health of PWH, Dr. Floris-Moore noted that viral suppression decreases the incidence of all types of morbidity. Earlier HIV diagnosis and initiation of ART lowers the risk of severe immunosuppression. Managing metabolic and CVD risk is important for all older PWH. Addressing stigma and social isolation also play a role in long-term health outcomes of PWH. Dr. Floris-Moore outlined programs at Weill Cornell Medicine and the University of

California, San Francisco, that take a multidisciplinary approach to care for older PWH, incorporating health screenings and emphasizing functional fitness, wellness, and community support.

## **HRSA Programs for Older PWH**

Laura Cheever, M.D., Sc.M., Associate Administrator for the HIV/AIDS Bureau, HRSA, HHS Of the 560,000 PWH in the United States served by the Ryan White program, about 48 percent are over age 50. With the increase in survival, the age distribution of PWH served by the Ryan White program has shifted; in 2010, the largest cohort was those ages 45 to 54 years, while in 2020, it was those ages 55 to 64 years. Dr. Cheever said HRSA has been working with stakeholders through listening sessions to determine the needs of older PWH who had achieved viral suppression but were not fully served by the Ryan White program.

In response, HRSA funded a SPNS that is launching 10 demonstration sites that will implement interventions for comprehensive screening and management of comorbidities, geriatric conditions, behavioral health, and psychosocial needs. The results of successful interventions will be captured in a toolkit and disseminated across the entire Ryan White program. Dr. Cheever noted that aging PWH will be part of the teams that implement and document the demonstration projects.

HRSA is also collaborating with the HHS Administration for Community Living, which has funded community-based services for older people for many years. The agencies share information about services and funding and seek out areas of mutual benefit. For example, the Administration for Community Living encourages State agencies on aging to include PWH as a priority population in their planning, and HRSA requires its SPNS recipients to work with their area agencies on aging. Dr. Cheever appreciated the inclusion of QOL indicators in the NHAS Federal Implementation Plan, pointing out that the Ryan White program has been dedicated to improving QOL from inception with wraparound services to address health, financial, and psychosocial needs. HRSA aims to identify and address the gaps in services to aging PWH.

## **Community Perspective**

Moisés Agosto-Rosario, Director of Treatment, NMAC

Mr. Agosto-Rosario emphasized the importance of hearing from aging PWH who bring their real-world experience and community perspective to the table. Many older PWH did not expect to live so long. Like their counterparts who do not have HIV, they experience multiple comorbidities related to aging, but they experience them earlier in life (e.g., beginning in their 50s), and those conditions become more complicated with time. Mr. Agosto-Rosario said some of his friends resent the impact of comorbidities on their QOL, including the need for constant management of multiple health conditions, which can be physically and emotionally draining.

Mr. Agosto-Rosario called for a comprehensive care model that recognizes the key role of maintaining viral suppression, which prevents inflammation, and the needs of older PWH for specialty care. He applauded the model programs described by Dr. Floris-Moore but asked how to create a comprehensive geriatric care model for PWH that works for many more people and addresses the following:

- Mental health, with trauma-informed care integrated into all care services, recognition of stigma and social isolation, and attention to depression
- Health disparities, recognizing the disproportionate burden of HIV on people of color, which is exacerbated with aging, and addressing barriers to access and medical mistrust
- Socioeconomic services to tackle critical SDH that force people to choose between health care and food, for example
- Biomedical research on accelerated aging among PWH, new drug development, and the effects of inflammation on health
- Coordination across agencies to ensure collaboration to meet the needs of PWH
- Increased funding for HIV programs and services

#### The Role of Socialization

Jeff C. Bailey, M.P.H., Director of HIV Access, APLA Health

Mr. Bailey elaborated on the social needs of older PWH. His organization's efforts grew out of a 2017 Statewide project on healthy living for multiple populations affected by HIV, which informed an educational initiative on HIV and aging. It addresses the needs already recognized by other presenters: the importance of housing and the role of HOPWA in ending HIV, the need for employment and financial security, and the crucial role of social support and engagement. On this last item, APLA Health organizes opportunities for social networking around areas of shared interest. The COVID-19 pandemic lockdown increased interest in gathering face-to-face to take part in events, so the organization plans trips to concerts, games, and events.

APLA Health has launched new programs for women with HIV (because so few programs exist for them in Los Angeles) and for transgender people. It recognizes that in Los Angeles, HIV is predominately an epidemic among men, especially single gay men who lack family and may find themselves aging and dying alone. All of these populations need social structures for support, said Mr. Bailey. The COVID-19 pandemic triggered a great deal of trauma for PWH who were already dealing with stigma and isolation. The HIV workforce would benefit from more training in trauma-informed care in clinical and case management.

Mr. Bailey called on the HIV care community to become more involved with other providers, such as the geriatric care community, to leverage available resources and opportunities. In California, PWH are part of the planning team for the State's master plan on aging.

#### **Discussion**

Adrian Shanker proposed that CDC and HRSA update their HIV screening guidelines to recommend annual testing for most people and more frequent testing for those at high risk. Dr. Floris-Moore agreed, noting that providers miss a lot of people who should be screened. Dr. Saag advocated for focused research on the unique aspects of aging with HIV. Research on accelerated biological aging among PWH could offer valuable insights into aging in general.

## **Public Comments**

**Deondre Moore of the Prevention Access Campaign** was grateful that the Federal government formally adopted the U=U message across all agencies. The U.S. government collaborated with the government of Canada on a multinational call to action that urges all nations to support and

leverage U=U in efforts to end HIV. At AIDS 2022, Federal partners committed to centering U=U in Federal activities and have taken every opportunity to demonstrate that commitment. While U=U is not yet featured in the NHAS Federal Implementation Plan, it is being prominently featured by Federal leaders. Mr. Moore celebrated the time and effort put into centering QOL for PWH in the most recent NHAS update, which demonstrate that Federal partners are listening and acknowledge that PWH are more than their viral loads. However, U=U cannot be fully celebrated until barriers are dismantled and all PWH can access care, treatment, and services that make U=U possible. That starts with prioritizing the whole person: mental health, housing, employment, the HIV workforce, linkage to care practices, and decreasing stigma among PWH. Mr. Moore and his colleagues looked forward to continued collaboration to fully integrate U=U into Federal HIV prevention and care activities, programs, funding announcements, and future NHAS updates, including its rightful place across the continuum of care. Together, Mr. Moore concluded, we can all improve the QOL of PWH and ensure that all are able to enjoy the hope and freedom, reduced stigma, improved mental health, and all the other benefits that U=U brings.

Kelly Flannery said the Positive Women's Network is pleased to see that the NHAS Federal Implementation Plan made progress toward recommendations made by networks of PWH, such as the five new QOL indicators. However, the work of crafting a future where every PWH has high-quality care and treatment, free from stigma and discrimination, and can achieve their full potential for health and well-being across the lifespan requires more concrete actions than were laid out in the Federal Implementation Plan. More meaningful action is needed to involve PWH networks in the Federal response; further the sexual and reproductive health and rights of PWH; promote the wellness of long-term survivors and older PWH; use all levers available to end the criminalization of HIV, sex work, and substance use; and halt dangerous data practices that target PWH, such as cluster detection and response. The Federal Implementation Plan lists community engagement among strategies and actions without a clear definition, process, or accountability mechanism. Networks of PWH are key and necessary partners for a robust Federal HIV response. These networks are created by, led by, and accountable to the estimated 1.2 million PWH in the United States and have mechanisms for taking input from and supporting PWH to advocate on behalf of constituency rather than just as individuals. PACHA should be rechartered to include a minimum of two designated seats for the U.S. People Living with HIV Caucus to fill with representatives of its own choosing, who will consult with a larger constituency of PWH.

Furthermore, Ms. Flannery continued, many PWH networks, HIV organizations, and human rights advocates have raised deep concerns about incorporating molecular HIV surveillance as a cornerstone in the Federal EHE initiative for years and have provided PACHA, CDC, and ONAP with concrete recommendations. The Positive Women's Network continues to be disappointed and troubled by the lack of attention to these concerns. PACHA should pass a resolution requiring CDC, HRSA, and NIH to partner with PWH networks to develop strong guidance on HIV data collection, sharing, and use; community engagement standards for the development of future HIV-related data collection, usage, sharing, and storage; and guidelines that require EHE to integrate data privacy. PACHA should also demand national standards for HIV data protection, including prohibiting law enforcement and immigration enforcement from accessing data, firewalls to protect public health data from improper use, and limitations on the length of

time data may be stored. Finally, PACHA should call for a moratorium on HIV cluster detection and response activities until data privacy standards are addressed.

Mark Misrok of the National Working Positive Coalition said CDC's annual HIV surveillance data show that more than 40 percent of PWH are unemployed and 35 percent live in poverty. The NHAS Federal Implementation Plan contains little to no action anywhere to improve access to employment-related information, services, or resources for PWH, so there is little hope for changing this continuing extreme and entrenched high rate of unemployment and poverty among PWH. Many PWH are angry that they have never had access to information on how to avoid impacts on their income, health care access, and housing benefits related to employment or help with pursuing goals for employment had they understood how they could work and maintain access to health coverage, care and treatment, and income and housing supports. The HIV/AIDS Bureau at HRSA maintains a decade's-old ban on employment services or job readiness among Ryan White-funded supportive services. It provides no training or incentives to grantees to develop knowledge of and partnerships with local employment programs. Neither the CDC's Division of HIV prevention, the Department of Housing and Urban Development's Office of HIV/AIDS Housing, the Department of Labor, nor the Department of Education are likely to bring about change in the unemployment rate among PWH. Mr. Misrok encouraged PACHA to use its voice and influence to help end the abdication of responsibility in HIV care and prevention for addressing employment needs of communities confronting social, economic, and health inequities that have always driven this epidemic.

Aaron Tax said SAGE USA appreciated the discussion around older PWH and long-term survivors, which has been an area of focus for SAGE dating back to its creation of the first support group in the country for older PWH. Mr. Tax drew attention to laws, known as bills of rights, that bar discrimination on the basis of sexual orientation, gender identity, and HIV status in long-term care settings and spell out the steps that long-term care institutions must take to ensure that all people are treated with respect. For example, a long-term care bill of rights can make it illegal for a long-term care facility or its staff to deny admission to someone based on sexual orientation, gender identity, or HIV status. It could require staff who interact with residents to be trained on best practices of caring for lesbian, gay, bisexual, transgender, and queer (LGBTQ)+ older folks and residents living with HIV. San Francisco passed the first longterm care bill of rights in 2015, and other States, cities, and counties have followed. The President's Pride Executive Order talked about creating an administrative long-term care bill of rights at HHS. Sage looks forward to working with the administration on that proposal and making sure that older PWH are explicitly included. Such laws and policies are important because many older people still confront fear, stigma, and discrimination, especially in long-term care settings. SAGE is working with advocates across the country to pass these measures. Older PWH deserve to know that when they go into long-term care facilities, that they will be treated with respect and receive the best care possible.

**Hedda Fay of Northland Cares**, a rural HIV and hepatitis health care clinic, called for national changes to advance care and prevention. Limiting when people can enroll in insurance plans under the Affordable Care Act does not make for a healthier society. Having to wait for as much as 11 months to access health insurance can cause people to disengage and avoid preventative services. Health insurance companies should be prohibited from denying prescriptions that people want or choose with their providers, such as Truvada versus Descovy. Insurance

companies expect people to experience an adverse health condition before switching to the patient-preferred prescription. The people paying for their own health care should be allowed to make these decisions with their providers. PWH and PrEP patients should be able to receive and self-administer their injectable medications, as is the case for other temperature-controlled injectable prescriptions. For hepatitis C treatment, do away with the prior authorization quagmire needed for curative treatment. Insurance companies continue to deny treatment repeatedly for the cure, which prevents people from accessing care. These barriers are killing people and perpetuating the spread of hepatitis C throughout the country. A positive laboratory result and a physician referral should be the only requirements for access to the cure. People are experiencing negative and costly health complications because they cannot access the cure. Do away with prior authorizations for postexposure prophylaxis (PEP) meds. Insurance companies that deny PEP meds should be fined or sanctioned for potentially causing someone to become HIVpositive. Time-sensitive medications should be approved with a referral from a provider. Allow people to get treatment for certain STIs over the counter at a pharmacy. In rural areas with limited providers, people can wait for weeks, which leads to further health complications. Anyone who is sexually active should be screened for STIs at their annual health care examination. Most providers, including obstetrician-gynecologists, do not discuss sexual health risk with patients. Initiating discussion can reduce stigma nationwide around STIs, including HIV. It would also assist in finding not only the one in seven people who do not know they have HIV but also those experiencing other undiagnosed STIs.

Benjamin Brooks of Whitman-Walker Health appreciated the importance of a holistic approach to ending the HIV epidemic. Vulnerability to HIV infection, like COVID and tuberculosis, is an indicator of social and economic marginalization. Without serious investment in the reformation of a social safety net, the difficulties that mire the delivery of HIV care and prevention will continue. The QOL indicators in the Federal Implementation Plan are an implicit acknowledgment of this. Mr. Brooks pointed to the lagging progress on the HIV goals already set. Meeting the challenge requires meeting people where they are at. Members of the communities most impacted are those best equipped to reach those communities. Whitman-Walker supports the movement to invest in organizations and programs that are designed and led by communities most impacted by HIV. It supports the ongoing training of the HIV care and prevention workforce to improve capacity to offer dignified and respectful care in the presence of difference. Mr. Brooks emphasized the value of cultural competency in creating accessible and acceptable care modalities for people at risk for or living with HIV. Although there are calls for community involvement and engagement, in particular in molecular HIV surveillance and cluster detection and response activities, Mr. Brooks suggested that investments in SDH and engaging marginalized communities that are disproportionately impacted by HIV will help reach the goal of ending the HIV epidemic, without relying on technologies that endanger the privacy, dignity, and safety of marginalized and criminalized people.

Noah Raper, a member of the Tennessee HIV Modernization Coalition, who has been living with HIV for 30 years, explained that in August 2014, he was accused of criminal exposure to HIV and aggravated assault with a deadly weapon and jailed. In Tennessee, those offenses are class C felonies that carry up to a 15-year sentence and result in being labeled as a violent sex offender permanently. Through SeroProject, Mr. Raper found a lawyer who challenged these false charges until a judge dismissed them and expunged them from his record. Mr. Raper hoped that sharing his story would create awareness and compassion for the many innocent PWH who

are and continue to be unjustly criminalized. There are documented race, class, and gender disparities in who is charged under these laws, and most of those arrested represent multiple minority communities. In Tennessee, African Americans represent 17 percent of the State population, 56 percent of PWH, and a whopping 75 percent of those arrested for HIV-related crime. HIV criminal laws are used as legal tools of discrimination and used disproportionately against minority communities. Tennessee is one of six States with legislation that places people convicted of HIV-related crimes on the sex offender registry. This is an exceptionally punitive punishment, because there is no scientific evidence to support that these policies are effective, nor is there any Federal law that requires PWH to be on the sex offender registry unless their crime involved a sexual offense with the use of coercion or force or if the victim is a child. Registration as a sex offender makes it extremely difficult for a PWH to meet their basic needs after incarceration, like finding housing or work, especially given the public nature of sex offender registries. Sex offender status becomes a relentless and ongoing punishment that deprives PWH of the ability to maintain health and be self-supportive. Mr. Raper said that people, including PWH, may be surprised to hear that the sex offender registry is mandated in some States for people convicted with HIV. Defendants are often not even informed that the sex offender registry is a collateral consequence to pleading guilty to an HIV-related crime. PACHA should take a stand, make this a priority, and help stop innocent people from being arrested and having their HIV status used as a tool to label and brand them as a violent sex offender. People on the sex offender registry need to be freed.

Ramin Bastani, CEO of Healthvana, advocated for leveraging technology to address the many challenges around HIV. The private sector uses technology to reach specific niche markets, yet health care providers cannot identify and reach out to people at risk for HIV or monkeypox and offer them PrEP or vaccines. Healthvana seeks to empower patients through their mobile phones, connecting 50 million people since 2015, primarily around HIV and STIs, most recently with monkeypox and COVID-19. Healthvana has worked with organizations large and small across the country and has demonstrated how software can help, such as improving workflow, which Mr. Philips mentioned. More can be done through basic technology using email and text messaging. Mr. Bastani stressed the need to start with the most basic stuff that will get to people and have immediate impact tomorrow, not 2 or 3 years from now. For example, during a meningitis outbreak in Los Angeles, Healthvana messaged tens of thousands of people who met criteria, and thousands got vaccinated within a few days. With monkeypox across 10 States, the company notified people at risk, as determined by their local jurisdiction or health care provider, about eligibility for a vaccine. When Johnson & Johnson announced a pause in their COVID-19 vaccine delivery, Healthvana targeted information directly to people who had received that vaccine. Mr. Bastani asked that PACHA advocate for and include technology in every conversation, because it seems to be missing.

Jules Levin of the National AIDS Treatment Advocacy Project, who is 72 years old and has had HIV for 40 years, said he is stuck at home, walks with a cane, and has seven comorbidities, some of them very serious. He said he did not want to live, nor did he want to die, and there are many people just like him. The HIV care system is broken. It is not meeting the needs of the aging and elderly, particularly those over 65. He called for a better care system and better care now. People over 65 have multiple comorbidities, suffer from poor physical and mental health, have cognitive impairment, and cannot perform normal daily living activities. Many of them are pre-frail or frail and they need urgent help. The NHAS Federal Implementation Plan does not

mention care at all, especially for the elderly and the aging, except HRSA's SPNS project. The \$10 million project is a drop in the bucket that does nothing to help the elderly now. It opens 10 clinics around the country, but that does not affect the 200,000 people now who are over 60 all over the country— and that number will double by 2030. They need better care now. People are dying. Mr. Levin pointed to the number of PWH who die prematurely from stroke, illustrating that PWH face accelerated aging by 10 years. Older PWH have double the rates of heart disease, mental disorder, recurrent falls and fractures, CVD, kidney disease, and cancers. Older PWH need better care, and they need it now.

Natalie Sanchez of the Los Angeles Family AIDS Network, which focuses on preventing mother-to-child HIV transmission, said more HIV programs are needed, specifically programs that focus on women and families. Typically, prevention of mother-to-child transmission centers on the medications to prevent the transmission to children, but little attention is paid to the complexities of the mothers who are giving birth to these children. For example, some women have had their children taken away from them by Child Protective Services, so that when they are pregnant again, they do not trust the health care system. These are the kinds of challenges that providers face with mothers who are not compliant with their HIV medications or who fear coming in for prenatal services. As a result, pregnant women with HIV come into care late and have high viral loads on delivery. Given the lack of funding and resources that focus on women, providers might be able to care for women during pregnancy but not help them with rehabilitation or reuniting their families, because there is no program specific to supporting the women who are experiencing substance use or homelessness or to providing housing for families. During the initial outbreak of COVID-19, Los Angeles County did a great rollout of emergency financial assistance, recognizing the urgent needs of those facing job loss or receiving disability or other subsidies, who may have to choose between housing, utilities, and food. To retain clients in care and support them along their journey of HIV care, programs need to provide the emergency financial assistance that can stabilize clients.

Ms. Hayes noted that anyone can provide public comment up until Tuesday, September 27, via email to <a href="PACHA@hhs.gov">PACHA@hhs.gov</a>. See Appendix A for all written public comments submitted.

## **PACHA Recommendations**

## Molecular HIV Surveillance and Cluster Detection and Response

Justin Smith, M.S., M.P.H., Co-Chair, PACHA Stigma and Disparities Subcommittee

The Stigma and Disparities Subcommittee convened a special working group on molecular HIV surveillance and cluster detection and response. In May 2022, the working group convened academics, researchers, clinicians, advocates, Federal partners, and community members with HIV to discuss data protection, surveillance, consent, and HIV criminalization, among other topics. The working group has followed up with senior leaders from CDC and networks of PWH that have made recommendations on this topic. The Subcommittee will summarize the efforts of the working group at a public PACHA meeting on October 17. Once draft recommendations are formulated, they will be shared with community partners for feedback and presented to the full PACHA for consideration.

Ms. McNeese added that HIV criminalization continues to be a significant concern that is affected by implementation of molecular HIV surveillance and cluster detection and response

activities. Participants at the May convening heard about all the protections around HIV data in this country but also the disparities in how protections are applied at the State and local level. Thus, Ms. McNeese said, there is confidence in CDC assurances that HIV data will be protected, but concerns persist about the ability of individual States and jurisdictions to do so. The Subcommittee is awaiting evaluation data from CDC about the impact of work implemented so far. At present, there is a mandate for all health departments to have implementation plans for molecular HIV surveillance and cluster detection and response, and health departments are asking for flexibility to work through the implications of such plans.

## **MSM Blood Donation Deferral Policy**

Adrian Shanker, PACHA Member

Mr. Shanker explained that the U.S. government has long limited the ability of MSM to donate blood in an effort to ensure the nation's blood supply is safe. The Stigma and Disparities Subcommittee met with FDA representatives, scientific experts, and community representatives for insights that informed the draft resolution. It calls on FDA to update its screening questions to ensure they are gender-inclusive and based on sexual behavior risks and that FDA harness the latest biomedical advances to screen blood for HIV and other bloodborne pathogens. The resolution also calls for swift completion of related ongoing research and updated fact sheets to help decrease stigma against PWH and LGBTQ+ people.

#### **Discussion**

PACHA members offered changes to clarify the wording of the resolution, noting, for example, that the current screening questions are discriminatory in nature because they are not applied equally and clarifying why the current questions are unclear. Some discussion centered on the inclusion of Canada's approach to screening as a model. There was agreement that the model is imperfect but still worth consideration because FDA has identified it as a potential model and because Canada has not faced blood supply challenges since implementing it.

Mr. Sapero noted that some jurisdictions identify PWH through blood donation screening and send a letter of notification but do not facilitate referral to care. Although not related to the intent of the recommendation under discussion, Mr. Sapero highlighted the need to take advantage of the opportunity to link newly diagnosed PWH with care providers.

#### Vote

The Council voted unanimously in favor of the resolution, as amended.

See Appendix B for the finalized resolution.

## **PACHA Member Reflections**

Ms. McNeese invited PACHA members to offer their reflections on the proceedings. Numerous members thanked the hosts, the organizers, the presenters, and the Federal partners who took part. Mr. Chacón appreciated the attention to innovation, collaboration, providing services with dignity, considering the future of the HIV workforce, and beginning the discussion on aging PWH and long-term survivors. Dr. Kates echoed the appreciation for service with dignity, highlighted by the organizations that PACHA visited in Los Angeles. She applauded the

community's use of partnerships to expand their reach, and she was impressed by the efforts to address SDH and treat the whole person.

Ms. Copeland thanked Ms. Hayes and colleagues for restarting the PACHA to the People community engagement effort, which embodies PACHA's guiding concept of "Nothing for us without us." The site visits showed the value of centering and empowering people of color in leadership roles, demonstrating what can be achieved with resources and support. Ms. Copeland emphasized that collaboration is critical to response.

Mr. Smith noted that cash transfer programs are difficult to implement, especially with Federal funds, but PACHA should discuss the approach. He also highlighted the role of culture in creating and amplifying messages.

Dr. Saag said the first decades of HIV revolved around understanding the science and translating that into care. Now, as effective treatments are available, providers and others need a better understanding of effective implementation in communities. PACHA can help identify the kind of expertise the field needs for the years to come.

Tori Cooper appreciated that the concerns of transgender people are finally being acknowledged. She emphasized that people know what they need, and PACHA plays a role in making sure they get what they need. Dr. Moore added that he was inspired to see how the organizations in Los Angeles have shaped lives and how they approach clients with dignity and respect. The site visits also demonstrated the value of investing in the workforce.

## **Next Steps and Closing Remarks from the PACHA Co-Chairs**

Marlene McNeese and John Wiesman, Dr.P.H., M.P.H., PACHA Co-Chairs

Dr. Wiesman said PACHA takes all of the materials, presentations, and discussions into consideration as it prioritizes its next steps. He appreciated the contributions of all participants. Ms. McNeese thanked all those involved and adjourned the meeting at 4:57 p.m. PT.

## **Appendix A: Written Public Comments**

Hello, my name is Noah, my pronouns are he/him. I am speaking from my hometown of Nashville, TN. I would like to thank PACHA for the opportunity to discuss the issue of HIV Criminalization. I have been living with HIV for 30 years and in August 2014 I found myself in a jail cell accused of criminal exposure to HIV, and aggravated assault with a deadly weapon, class C felonies in Tennessee which carries up to a 15 year sentence and being labeled as a violent sex offender permanently. I knew that I was not guilty of this charge. Fortunately, I was connected to SeroProject who referred me to Abby Rubenfeld, who took me on as a client. She challenged the false charge until the judge eventually dismissed and expunged my case. If not for her guidance I would have been given a public defender and my story would have ended very differently.

I am speaking out today in hopes that sharing my story today will create awareness and compassion for the many innocent people living with HIV who are and continue to be unjustly criminalized.

There is documented race, class, and gender disparities in who is charged under these laws with the majority of people arrested often representing multiple minority communities. This is the situation in Tennessee, where African Americans represent only 17 percent of the State population, 56 percent of people living with HIV, yet a whopping 75 percent of people who have been arrested for an HIV related crime. HIV criminal laws are used as legal tools of discrimination, disproportionally used against minority communities.

Tennessee is one of six states with legislation that places people convicted of an HIV crime on the sex offender registry (CHLP, 2020). This is an exceptionally punitive punishment because there is no scientific evidence to support that these policies are effective, nor is there any federal law that requires people living with HIV to be on the sex offender registry unless their crime involved a sexual offense with the use of coercion, force, or if the victim is a child. Registration as a sex offender makes it extremely difficult for a person living with HIV to meet their basic needs post-incarceration, like finding housing or work, especially given the public nature of sex offender registries. Sex offender status becomes a relentless and ongoing punishment that deprives a person living with HIV of the ability to maintain good health be self-supporting and independent.

If you are surprised to hear that sex offender registry is mandated in some states for people convicted of HIV crimes, you are not alone, so are the people living with HIV. Defendants are NOT informed that sex offender registry is a collateral consequence to pleading guilty to an HIV crime. This comes as a complete shock to each person after they take a plea. It ensures their life will be a constant struggle for survival.

We need PACHA to take a stand and help stop innocent people being arrested and having their HIV status used a tool to label and brand them as Violent Sex Offenders. We need those on the Sex Offender Registry to be freed.

U.S. laws should be consistent across the nation with current medical and scientific knowledge. I would like to ask PACHA to make the issue of HIV Criminalization a priority. We will never be

able to end the HIV epidemic as long as there are outdated and discriminatory HIV laws on the books. HIV laws need to be modernized or repealed. And, We MUST demand the termination of the sex offender registry and insist those currently imprisoned by the sex offender registry to be freed.

My name is Noah Raper from Nashville Tennessee. Thank you.

From: Noah Raper

Sent: Tuesday, September 20, 2022 12:51 PM

To: Presidential Advisory Council on HIV/AIDS (HHS/OASH) PACHA@hhs.gov

Subject: Public comment pacha sept.2022

Hi,

I have another comment for pacha. It would be nice if there was a website for people with HIV living on disability that want to go to work part time. The website would help connect them to available part and full time jobs in the HIV industry.

I went on disability several years back and it's the hardest job I've ever had. I never anticipated how much of my own self worth was connected to my job. My mental health has suffered greatly, not having a purpose in life. Not having the financial ability to live a social life has been challenging.

I went to work part time for three months and my mental health immediately improved. Unfortunately it was for only three months. During that time I felt alive again. I hada reason to get out of bed, a reason to shower and leave my apartment. If I didn't have advocacy to give me a purpose I don't know know what I would do to feel like I have a reason for being on this earth.

There is so much talk about hiring people who are HIV+. There are no tools in place that I'm aware of that helps connect those who want to go back to work with jobs in the HIV industry.

I believe many on us on disability would love to have a part time job. For me I'm ready to go back to work full time but can't do it because I fear losing my insurance, I fear not being able to find a job that will pay me enough to support myself. I would love to go back to school and finish up a few classes to get my bachelor but there are no programs that I'm aware of that will help me return to the work force successfully.

Thank you pacha for making pacha to the people available. I know people have a lot to say about everything y'all do. I remember a time when there was no support from the government. Now we have great support from the government. We have funding that saves lives. I've been pos for 30+ years. I would not be alive today if we didn't have support from the government. Ryan White has made it possible for me to live all these years, have an undetectable viral load, and tcells consistently greater than 1,000. I never planned to live this long and wouldn't have lived this long without the help of Ryan White.

Thank you all for your service!

Noah Raper he/him HIV Law & Policy Advocate #HIVisNOTaCRIME Good afternoon and thank you for the opportunity to provide public comment. My name is Aaron Tax and I'm the Managing Director of Government Affairs and Policy Advocacy at SAGE. Unfortunately, our HIV/Aging Policy Advocate Terri Wilder could not be here today.

First, I want to thank PACHA for including a discussion around older people living with HIV and Long-Term Survivors on the agenda. This is has been an area of focus for SAGE dating back to when we created the first support group in the country for older people with HIV.

Today I would like to speak about a need concerning the quality of life of older people living with HIV in long term care settings.

In particular, I want to talk about Long Term Care Bills of Rights, which are laws that bar discrimination on the basis of SOGI and HIV status in LTC settings, and in a granular way, spell out the various steps that LTC institutions need to take to ensure that all people are treated with respect.

For example a Long-Term Care Bill of Rights can make it illegal for a long-term care facility or its staff to deny admission to someone based on SOGI or HIV status. Additionally, it could require staff who interact with residents to be trained on the best practices of caring for LGBTQ+ people and residents living with HIV.

San Francisco passed the first one in 2015. California followed in 2017. Washington DC passed its law in 2020, as did Montgomery, Maryland. New Jersey passed its law in 2021.

In the President's pride executive order, he talked about creating an administrative long term care bill of rights at HHS. We look forward to working with the administration on getting that done and making sure that older people living with HIV are explicitly included.

So ,why are these laws and policies so important?

Many older people with HIV still confront fear and stigma. Some still face discrimination and many still fear discrimination, especially in long-term care settings.

So, in addition to working with the administration, we are working with advocates across the country to follow the lead of SF and CA and to pass these measures in their states and in their communities.

If you are interested in working on advancing a Bill of Rights in your state, SAGE wants to work with you to make that happen. Older people with HIV deserve to know that when they go into a long-term care facility that they will be treated with respect and receive the best care possible.

And, we look forward to work together with all of you to ensure that the administration moves forward on advancing the LTC Bill of Rights that the President referenced in his Executive Order.

From: Eldonna Beal

Sent: Wednesday, September 21, 2022 7:03 PM

To: Presidential Advisory Council on HIV/AIDS (HHS/OASH) < PACHA@hhs.gov>

**Subject:** Public Comment

Incentives should be offered to medical students who are willing to go into Geriatric care. I have been looking for a geriatric provider In the Tacoma area. I prefer a woman doctor. There are only 2 listed in my area, on my insurance plan and neith are taking new patients. We are going to have a medical crisis if we don't get more geriatric providers.

Also, I have been diagnosed with short term memory loss due to long term HIV (37 years) but I never would have known that if I had not gotten a baseline test done. It is important that if PLWHIV are complaining of forgetfulness that we don't just assume it is "getting older.". We must make recommendations that Folx have baseline testing at about age 50 or when they start to realize changes. My base line proved nothing but 10 years later there was a marked difference. Thank you

## Eldonna Beal, BS, Peer

WICY Medical Case Manager (she/her)



Comments to the Presidential Advisory Council on HIV/AIDS

Mark Misrok, Executive Director, National Working Positive Coalition and Member, Steering Committee, U.S. People Living with HIV Caucus

September 20, 2022

I'm Mark Misrok, Executive Director for the National Working Positive Coalition, a person living with HIV, and a member of the Steering Committee for the U.S. People Living with HIV Caucus.

The National Working Positive Coalition is focused to strengthen responses to the long-ignored employment needs of people living with or at greater vulnerability to HIV. Just this past July, the CDC released their latest annual HIV surveillance data report from their MMP, or Medical Monitoring Project, reporting on their data collection for 2020. For the second annual report in a row, the data showed over 40 percent of people living with HIV as unemployed, with 35 percent reported as living in poverty in the new 2020 report.

This continuing extreme and entrenched high rate of unemployment and poverty among people living with HIV cannot be hoped to change based on review of the recently released Federal Implementation Plan for the National HIV/AIDS Strategy, which describes 350 actions across multiple Federal agencies. The Implementation Plan contains little to no action anywhere to improve access to employment related information, services, and resources for people living with HIV.

In my work, I am regularly met with an intense reaction from many people living with HIV who are angry they've never had access to information that could either have helped them avoid impacts on their income, healthcare access, and housing related to employment, or helped them to pursue goals for employment had they understood how they could work and maintain access to health coverage, care and treatment, and income and housing supports.

But how would they have a chance to learn this information, or how they could access employment services, training, education, and vocational resources? The HIV/AIDS Bureau at HRSA maintains a decades-old ban on employment services or job readiness among Ryan White-funded supportive services. They provide no training or incentives to their grantees to develop knowledge of and partnerships with local employment programs. Neither the CDC's Division of HIV Prevention, HUD's Office of HIV/AIDS Housing, nor the minimal appearances of the Department of Labor or the Department of Education in the Implementation Plan are possible to see as likely to change future MMP data reports from an over 40 percent unemployment rate among people living with HIV – who we know need currently unprovided employment-related information, services, and resources.

I'm here today to encourage PACHA to utilize its voice and influence to help end the abdication of responsibility in HIV care and prevention for addressing employment needs of communities confronting social, economic, and health inequities that we know have always driven this epidemic.

From: Kevin Donnelly

Sent: Tuesday, September 20, 2022 10:55 PM

To: Presidential Advisory Council on HIV/AIDS (HHS/OASH) PACHA@hhs.gov

**Subject:** Public Comment

Dear PACHA members,

Thank you for coming to Los Angeles and sharing the experience of your full council meeting.

One of your members shared about the trips that you have made in the past. Jackson, Miss. is the destination I remember. The comment was on the differences in their HIV response from what you witnessed in Los Angeles County. This highlights the foresite of the Ryan White Legislation. The program empowers local jurisdictions to craft the kind of programming that is tailored to the needs of the individual community.

At the recent RWP conference the EHE was spoken of as the dominant model of the Federal HIV response. Ryan White was a program in service of the EHE. The robust range of services in Los Angeles County has been championed, crafted and created by the Planning Council. In Los Angeles that body is the County Commission on HIV. The strongest voices in this council have always been the unaligned consumer. We have a strong consumer caucus that assists with the planning process. We also have recommendations that unaligned consumers serve in positions of leadership. Currently we have a consumer co chair in three of our four committees and the full body. We strive to center the voice of the consumer and especially consumers of marginalized communities. This is our greatest strength as a planning body.

My concern is that the model of the EHE has no mandate to empower those with lived experience. The voice of the consumer has been marginalized. The funds connected with the EHE do not have the restrictions of RW. And they have greater flexibility in the programs they can fund. In the PLWH listening session of the recent conference, I asked Dr. Laura Cheever what EHE can do to amplify the voice of those with lived experience. She responded that without a mandate, local jurisdictions have no incentive to do so.

Los Angeles County residents in the Ryan White system of care have consistently superior health outcomes to those in other systems. Please re-examine the model of EHE so that the persons served also help to craft the programs. The locally crafted response and the voice of the consumer are a proven model of success. Please do not abandon what we know to be effective.

Thank you all for your commitment. I truly appreciate the work that you do. Please make a place at the table for the unaligned consumer and permit us to see through the work that we have started together.

With respect, Kevin Donnelly From: Hedda Fay <fay.h@northlandcares.org> Sent: Tuesday, September 20, 2022 6:40 PM

To: Presidential Advisory Council on HIV/AIDS (HHS/OASH) < PACHA@hhs.gov>

**Subject:** Recommendations

Good afternoon,

Thank you so much for allowing for public discussion. I wanted to send to you my recommendations to further prevention, harm reduction and remove barriers to care.

As a community outreach worker, in HIV Care, prevention, testing and stigma reduction there are several things I would like to see occur to move care and prevention forward for our country.

- 1: I believe changes need to be made to ACA enrollment. Limiting when people can be engaged with the ACA, does not make for a healthier society. People having to wait for as much as 11 months to start treatment can cause them to disengage and avoid preventative services. people are falling in the proverbial healthcare cracks.
- **2.** Do away with health insurance companies, being able to deny prescriptions that people want or choose over others such as Truvada v Descovy. insurance companies expect people to experience an adverse health condition such as kidney issues prior to patient preferred prescription. If we are paying for healthcare, we should be allowed to make these decisions with our providers.
- **3**. Allow HIV and PrEP patients to receive their injectable medications to self-administer as we do with other temperature controlled injectable prescriptions.
- **4.** For Hepatitis C treatment, we need to do away with the prior authorization quagmire needed for the Hepatitis C cure. We continue to experience insurance company denials for the cure, with the multiple hoops required for a person to access care. These barriers are killing people and perpetuating the spread of Hepatitis C throughout the county. The only thing that should be required for a person to access the cure for this virus is a positive lab result and a physician referral. People are experiencing negative and costly health complications due to not being able to access the cure.
- **5.** Do away with the prior authorizations for PEP medications. It is common for people seeking PEP medications to get a text from their insurance, prior to them leaving our office, advising them that their medications are not approved. I believe insurance companies denying PEP medications, should be fined/sanctioned for potentially causing someone to become HIV+ due to their prior authorization shenanigans. Time sensitive medications should be approved with a referral from a doctor. This prior authorization game that is levied against the insured must stop.
- **6:** Allow people to get treatment for certain STI's over the counter at a pharmacy. In rural areas, we have limited number of providers, and people can wait for weeks which leads to further health complications.

7: recommend STI panels as a part of sexually active individuals annual healthcare examination. Most providers including OBGYNs do not do a sexual health risk discussion with patients, and

they need to. By doing this we can reduce stigma nationwide about STI's including HIV. This will assist us in finding not only the 1 in 7 who are living with HIV and do not know they have it and we will find people experiencing undiagnosed STI's as well.

Why do we pay for insurance, why do we have health plans if the insurance companies can deny treatment recommended by our medical professionals.

Insurance companies are allowed to deny care and services people need with no regard to the health outcomes of their decisions. We pay for care, and need be allowed to have autonomy and the ability to make decisions with our provider and not be at the mercy of unelected bureaucrats.

## Best,

Hedda Fay Community Outreach Manager

**Northland Cares** 

**Pronouns: She**| **Her** | **Hers** 

Email: fay.h@northlandcares.org

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Whitman-Walker at LIZ 1377 R Street, NW, Suite 200 Washington, DC 20009

Good afternoon PACHA members, co-chairs, government partners, and assembled community members. I am Benjamin Brooks, the Associate Director of Policy and Education at Whitman-Walker Institute. It is an honor to speak with you on issues of such importance to the health and wellbeing of our communities.

Throughout these meetings, I have had the pleasure of hearing about the importance of a holistic approach to ending the HIV epidemic; it thus seems appropriate to co-sign all of these efforts and express wholeheartedly that vulnerability to HIV infection – like COVID-19 and monkeypox – is an indicator of social and economic marginalization present in our society. It seems to me this group has arrived at a consensus that without serious investment in the reformation of the social safety net, the difficulties that mire the delivery of HIV care and prevention will continue. The quality-of-life indicators, which are a major accomplishment of the National HIV/AIDS Strategy Implementation plan, are an implicit acknowledgement of this and I am glad to see them!

Data presented during this meeting also highlights our lagging progress on the HIV care and prevention goals that we have set. Reaching these goals requires meeting people where they are at. As we have heard from many speakers, the community members most impacted are the ones best equipped to reach their communities. We support the movement we have seen to invest in organizations and programs that are designed and led by communities most affected by HIV.

We also support the ongoing training of the HIV care and prevention workforce to improve our capacity to offer dignified and respectful care in the presence of difference. As such, we cannot emphasize enough the role of culturally competent care in HIV treatment and prevention. Cultural competence and cultural humility are a set of skills that cultivate the ability to put aside learned biases and provide services that respond to patients' needs. Building workforce capacity to address implicit bias and stigma is central to providing non-discriminatory care. Towards that end, we ask for PACHA to approve a resolution in support of robust non-discrimination requirements for participants in federally funded and administered health services. This includes, but is not limited to, those addressing the needs of people living with or at risk of acquiring HIV.

Robust community involvement in molecular HIV surveillance and cluster detection and response activities is critical. However, it is also my opinion that investments in the social determinants of health, and investment and engagement in marginalized communities that are disproportionately impacted by HIV, will help us achieve the goal of Ending the HIV Epidemic without unnecessarily endangering the privacy, dignity, and safety of marginalized and criminalized people.

My thanks for your time,

Buch

Benjamin Brooks, JD, MPH bbrooks@whitman-walker.org

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Sept. 20, 2022

Co-Chairs and Members of the Presidential Advisory Council on HIV/AIDS (PACHA):

The HIV Medicine Association (HIVMA) is pleased to have the opportunity to offer public comment during the PACHA-to-the-People session that will focus on the 2022-2025 National HIV/AIDS Strategy's (NHAS) Federal Implementation Plan. HIVMA represents nearly 6,000 physicians, researchers and other health care professionals who provide HIV prevention, care and treatment and conduct research in communities across the United States.

While our comments will primarily focus on the workforce components of the NHAS implementation plan, given the impact of the monkeypox virus (MPV) outbreak on people with HIV, we also want to highlight the urgent need for emergency supplemental funding to support the MPV response. We support the Administration's recent request for emergency supplemental funding and have urged Congress to provide additional funding for the MPV outbreak and COVID-19 pandemic responses.

While critical work is being done to strengthen the MPV response, additional actions and resources are urgently needed to control the outbreak. Resources are necessary to ensure affordable access to services for uninsured and underinsured individuals and to support a multifaceted public education campaign to reduce the stigma associated with MPV. In addition, resources are needed to increase provider education, given the lack of MPV experience among most health care providers in the U.S., and to support the workforce, given the intensity of service delivery required for MPV diagnosis/testing, vaccination and treatment.

#### National HIV/AIDS Strategy Federal Implementation Plan

HIVMA applauded the release of the comprehensive NHAS Federal Implementation Plan as an important roadmap for dramatically reducing new HIV infections. In August 2022, HIVMA published a paper outlining 10 broad policy reforms with specific policy recommendations necessary to make progress toward ending HIV as an epidemic in the U.S. We were pleased to see that the NHAS Implementation Plan would take steps to advance many of the policy reforms, including incorporating new strategies in the plan for addressing HIV and LGBTQ+ -related stigma and discrimination and reducing HIV-related disparities by focusing more on the social determinants of health in critical federal programs.

We appreciate the attention to the HIV workforce woven throughout the NHAS plan, including recognizing the value and importance of community health workers and peer navigators, increasing the use of telehealth and supporting partnerships with historically Black colleges and universities to foster the next generation of investigators. As previously shared, a <u>study</u> of the infectious diseases workforce published in 2020 estimated that nearly 80% of counties in the U.S. did not have an ID specialist. Another <u>study</u> that evaluated the HIV workforce in 14

southern states found that more than 80% of counties had no experienced HIV clinicians, with the disparities being greatest in rural communities. Addressing HIV-related disparities and achieving the goals of NHAS will require an adequate, diverse and culturally responsive HIV workforce that reflects the populations disproportionately impacted by HIV. With this in mind, we hope there will be opportunities to enhance the NHAS implementation plan by including more actions to sustain the current workforce and to develop the clinical workforce pipeline to ensure a future generation of HIV providers.

We appreciated that PACHA's convening of the 73rd full council meeting on March 15 dedicated a session to the HIV workforce and highlighted education and training issues and strategies for reimagining the workforce. In conjunction with that meeting, HIVMA submitted recommendations for strengthening the workforce, which included urging the Administration to convene an HIV and infectious diseases (ID) workforce summit. The summit could bring together the Department of Health and Human Services, the Centers for Medicare and Medicaid Services, the Health Resources and Services Administration and other relevant agencies. The purpose of the summit would be to evaluate HIV and ID workforce needs and the novel strategies and policies, including health care financing, required to address them. Now just six months later, the need for novel strategies and policies to support and bolster the ID and HIV workforce is even greater, with the HIV workforce being further strained by its role in the response to the MPV outbreak. We also strongly urge the Administration to consider (or support where the action is not within their purview) the recommendations included in HIVMA's recent policy paper highlighted in the table below.

Policy Principle: Ensure a strong and culturally responsive ID and HIV clinical and research workforce that better reflects the populations heavily impacted by HIV.

#### **HIVMA** recommends:

- States and institutions allow health care providers, including physicians, advanced practice providers and pharmacists, to work at the fullest extent of their training and expertise with the appropriate clinical guidance and consultation.
- Congress provide incentives, such as loan repayment, for providing care and treatment to
  people with HIV in underserved communities through passage of the Bolstering Infectious
  Outbreaks (BIO) Preparedness Workforce Act (S. 3244/H.R. 5602), the BIO Preparedness
  Workforce Pilot Program included in the PREVENT Pandemics Act, or similar legislation.
- CMS revalue the initial inpatient E/M codes (hospital visit and observation codes) to reflect the complexity of care provided and the historic relativity between these codes and the office and outpatient visit codes, which were revalued in 2021.
- Enhanced support for teaching and training the clinical workforce to deliver culturally competent care to diverse populations throughout the duration of their education and training, e.g., requiring completion of courses such as the Accreditation Council for Graduate Medical Education's Equity Matters CME Learning Path.
- Improving grant pay lines for those involved in HIV-related research to promote and sustain their commitment to this field.
- Supporting more diverse areas of research that are critical to ending the HIV epidemic, such as implementation science and health disparities related to HIV.
- Expanding the number of J1 visas available and allowing physicians on H1B and J1 visas to be eligible for T32 training grants and NIH career development awards.

Source: Anna K. Person, MD, FIDSA, et al., <u>Principles for Ending HIV as an Epidemic in the United States:</u>
A Policy Paper of IDSA and HIVMA, *Clinical Infectious Diseases*, 2022.

Thank you for your important work and for the opportunity to provide additional comments on the NHAS Federal Implementation Plan. Please contact HIVMA Senior Policy & Advocacy Manager Jose A. Rodriguez at JRodriguez@hivma.org to schedule a meeting to discuss our recommendations.

Sincerely,

Marwan Haddad, MD, MPH

## Chair, HIVMA

Attachments:

- 1. <u>Recommendations</u> for Strengthening & Diversifying the HIV Workforce, U.S. National HIV/AIDS Strategy (2022 to 2025), Version: February 2022.
- 2. Anna K. Person, MD, FIDSA, et al., <u>Principles for Ending HIV as an Epidemic in the United States: A Policy Paper of IDSA and HIVMA</u>, *Clinical Infectious Diseases*, 2022.

## **Appendix B: PACHA Resolution**

## Presidential Advisory Council on HIV/AIDS Resolution on MSM Blood Donation Deferral Policy & Screening Questions

**Whereas**, the current Food and Drug Administration (FDA) Blood Donation Deferral Policy for men who have sex with men (MSM) requires a three-month period of sexual abstinence to be eligible to donate blood, and previous iterations of this policy had required a one-year period of sexual abstinence, and a lifetime ban;

Whereas, the current MSM Blood Donation Deferral Policy and associated screening questions are discriminatory in nature because they are not applied equally to all groups, including those not subject to any deferral. Further, they do not consider protective factors, such as the number of recent sexual partners and/or adherence to PrEP, the current policy and screening questions increase stigma for people living with HIV (PLWH) and to MSM populations as a whole;

**Whereas**, the current screening questions utilized to implement the Blood Donation Deferral Policy for MSM are unclear and do not consider transgender and non-binary blood donors;

Whereas, the Administration's Ending the HIV Epidemic (EHE) initiative has a goal of reducing stigma, the initiative will be more successful if stigma against people who are gay, bisexual and other MSM, transgender, non-binary, and PLWH is decreased; Whereas, the FDA is currently administering the ADVANCE Study that could potentially lead to a change in blood donor eligibility for MSM populations and that enrollment in the study has been extremely slow;

**Whereas,** Canada has approved and implemented a universal sexual behavior screening tool by which everyone will be asked questions about sexual behavior. During screening, everyone will be asked if they have had new and/or multiple sexual partners in the last three months, and if they have, will be asked a follow-up question about whether they have had anal sex with any partner in the last three months. Although this approach is imperfect, it is less stigmatizing and more inclusive of transgender and non-binary individuals than the current FDA process;

**Whereas**, HIV is not the only blood-borne pathogen but is the only one that is still subject to screening questions based upon one's identity;

**Whereas**, technology today exists to screen blood in an identity and behavior-neutral method. These technologies can identify traces of HIV in the blood supply and can significantly shorten the waiting period. This is a safer method to protect the blood supply than identity or behavior-based screening questions;

**Be it resolved,** PACHA urges the FDA to swiftly update the screening questions ensuring that they are based on sexual behavior risk, not gender or sexual orientation; **Be it further resolved,** that PACHA urges the FDA to harness the latest biomedical advances to appropriately screen all blood donations for HIV and other blood-borne pathogens, and to then consider if a period of sexual abstinence for certain populations and screening questions continue to be necessary;

**Be it further resolved,** that PACHA urges a timely completion of the ADVANCE study and the implementation of a new policy based on the scientific data collected in the study;

**Be it further resolved,** that upon a change in the MSM Blood Donation Deferral Policy and associated screening questions, that the FDA publish a fact sheet for community-based blood donation agencies to help decrease stigma against LGBTQ+ individuals and PLWH.