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

### 77<sup>th</sup> Meeting

### Kimpton Hotel Palomar Phoenix 2 E Jefferson St Phoenix, AZ

### **Council Members—Present**

- Marlene McNeese, PACHA Co-Chair, Assistant Director, Houston Health Department, Houston, TX (day 1 only)
- 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
- Raniyah Copeland, M.P.H., Principal, Equity & Impact Solutions, Los Angeles, CA (day 1 only) Alicia Diggs, M.P.H., Manager, Office of Community Engagement, Center for AIDS Research, The University of North Carolina at Chapel Hill, Greensboro, NC (day 2 only)
- Vincent Guilamo-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
- Marc Meachem, M.B.A., Head, External Affairs, ViiV Healthcare North America, Washington, DC (day 2 only)
- Leo Moore, M.D., M.S.H.P.M., Medical Director for Clinic Services, Los Angeles County Department of Public Health, Los Angeles, CA
- Rafaelé Narváez, Co-Founder and Director of Health Programs, Latinos Salud, Wilton Manors, FL
- 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 (day 1 only)
- 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
- Justin C. Smith, M.S., M.P.H., Director, Campaign to End AIDS, Positive Impact Health Centers, Atlanta, GA
- Ada Stewart, M.D., RPh, FAAFP, AAHIVS, HMDC, Lead Provider and HIV Specialist, Eau Claire Cooperative Health Centers (Now Cooperative Health), Columbia, SC

#### **Council Members—Absent**

- 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

Darrell P. Wheeler, Ph.D., M.P.H., M.S.W., President, Status University of New York at New Paltz, New Paltz, New York

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., PACHA Executive Director, Designated Federal Officer; Director, Office of Infectious Disease and HIV/AIDS Policy (OIDP); Deputy Assistant Secretary for Infectious Disease - Office of the Assistant Secretary for Health (OASH), U.S. Department of Health and Human Services (HHS)

#### **Federal Partners**

Sharonda Brown, Deputy Director of Operations, OIDP, OASH, HHS

Laura Cheever, M.D., Sc.M., Associate Administrator, HIV/AIDS Bureau, Health Resources and Services Administration (HRSA)

Demetre Daskalakis, M.D., M.P.H., White House National Monkeypox Response Deputy Coordinator, Director, Division of HIV Prevention, National Center for HIV, Viral Hepatitis, STD, and TB [Tuberculosis] Prevention (NCHHSTP), CDC (day 1 only)

William Dilday, Interdepartmental Liaison, Office of the U.S. Global AIDS Coordinator and Health Diplomacy, U.S. Department of State

Nelly Gazarian, Senior Policy Analyst, OIDP, OASH, HHS

Rita Harcrow, Director, Office of HIV/AIDS and Housing, U.S. Department of Urban Development (HUD)

Timothy Harrison, Ph.D., Principal Deputy Director, OIDP, HHS

Rick Haverkate, M.P.H., National HIV/AIDS & Hepatitis C Program Coordinator, Indian Health Service (IHS)

RDML Timothy H. Holtz, M.D., M.P.H., FACP, FACPM, U.S. Public Health Service (USPHS), Deputy Director, Office of AIDS Research (OAR), National Institutes of Health (NIH)

Ernia P. Hughes, M.B.A., Director, Office of Health Center Investment Oversight, Bureau of Primary Health Care (BPHC), HRSA (day 1 only)

David Johnson, M.P.H., Deputy Assistant Secretary for Health, Office of Regional Health Operations (ORHO), HHS

Jessica Lee, M.D., Medical Officer for Medicaid and Children's Health Insurance Program (CHIP), Centers for Medicare and Medicaid Services (CMS) (day 2 only)

Robyn Neblett-Fanfair, M.D., M.P.H., Principal Deputy Director, NCHHSTP, CDC

CAPT John Oguntomilade, B.D.S., M.P.H., Ph.D., Regional Director, HIV Prevention through Active Community Engagement Program Region 4, HHS

Harold J. Phillips, M.R.P., Director, White House Office of National AIDS Policy (ONAP)

Kristin Roha, M.S., M.P.H., Public Health Advisor for HIV, Substance Abuse and Mental Health Services Administration (SAMHSA)

CDR Michelle Sandoval-Rosario, Dr. P.H., M.P.H., C.P.H., HIV Prevention through Active Community Engagement (PACE) Region 9 Director, OASH, OIDP

Caroline Talev, M.P.A., Alternate Designated Federal Officer for PACHA, Senior Management Analyst, OIDP, OASH, HHS

Andrea Callow, J.D., representing Edwin Walker, J.D., Deputy Assistant Secretary for Aging, Administration for Community Living (ACL), HHS

### Day 1

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

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

Ms. McNeese called the meeting to order at 9:05 am MST. She explained that this PACHA meeting was informed by council and community feedback from prior PACHA meetings to focus on the HIV epidemic as it affects American Indians and Alaska Natives (AI/AN), particularly in the American Southwest. The goal of the meeting was to identify ways that PACHA can influence policy and procedure to expand and sustain ongoing efforts within AI/AN communities.

Ms. McNeese also addressed the nationwide attacks on LGBTQIA+ communities and programs, including drag queen programs and gender affirming care. These challenges to the rights of LGBTQIA+ individuals are threatening the progress made in recent years for LGBTQIA+ rights. As PACHA works to ensure universal access to basic healthcare, the Committee is working to promote rights of racial and ethnic minorities and the LGBTQIA+ community, address HIV stigma, and dismantle systems that perpetuate social and racial injustice.

Ms. McNeese noted that on June 8, 2023, the Department of Health and Human Services (HHS) released the first Sextually Transmitted Infection (STI) Federal Implementation Plan that details roles and responsibilities of federal colleagues and agencies to achieve the goals of reducing adverse outcomes of STIs and accelerating STI research, technology, and innovation. She noted that the plan is timely given the nationwide increase in levels of syphilis infections, particularly among women and babies.

Ms. McNeese concluded her opening remarks by noting the PACHA leadership transition, as Dr. Wiesman's and Mr. Schmid's PACHA terms expired at the end of the meeting. Dr. Wiesman served as a PACHA co-chair, and his replacement will be announced at the 78th Full Council Meeting in September 2023. At the conclusion of the upcoming 78th Full Council Meeting, an additional six members' terms will expire.

Dr. Wiesman shared his experience during his two terms serving as a PACHA member and then as a co-chair during the Trump and Biden administrations. He then summarized the agenda for the meeting. (This meeting was broadcast live online; the recorded broadcast is available <u>online</u>.) PACHA will meet next on September 19–20 in an Appalachian state (exact location to be determined) and December 5–7 in Houston, TX.

Dr. Wiesman concluded by acknowledging the sovereignty of the American Indian tribes throughout the nation and the treaties that outline how the U.S. government interacts with each of those tribes as their own nations. Tribal sovereignty requires careful approaches to the drafting of PACHA's recommendations.

### **Blessing**

Barnaby Lewis, Tribal Elder, Gila River Indian Community

Mr. Lewis, a tribal historic preservation officer and tribal elder for the Gila River Indian Community, provided the blessing for the meeting.

### Roll Call

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

Ms. Hayes called the roll.

### **White House Updates**

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

Mr. Phillips provided an update on the National Pre-Exposure Prophylaxis (PrEP) Program. As part of the administration's FY2024 budget proposal, the White House has requested \$237 million in funding for a National PrEP program, which advances equitable access to PrEP by providing this treatment at no cost, eliminating costs for other prevention services, and establishing a provider network in underserved communities. The Office of National AIDS Policy (ONAP) continues to work with the White House and federal agencies to envision the program as well as solicit feedback from community members. Mr. Phillips noted that ONAP is also seeking to adapt the proposal for a National PrEP program into legislation and will provide further updates about this work in July 2023. The White House budget proposal also requires the state Medicaid and Children's Health Insurance Program (CHIP) to cover PrEP and associated laboratory services with no cost sharing, and places guardrails on utilization management practices, such as prior authorization and step therapy. Both Medicaid and CHIP programs are mandatory budget items and do not impact funding for Ending the HIV Epidemic in the United States (EHE) nor other HIV prevention programs.

In addition to planning a National PrEP program, agency partners have been active in implementing priorities for the National HIV/AIDS Strategy (2022-2025). As part of this implementation, CMS is conducting a national coverage analysis for Medicare coverage of PrEP, which will be completed in the summer of 2023. As the first ONAP director to attend the National Coalition of STD Directors, Mr. Philips was also pleased to see EHE funding used to implement integrated, status-neutral models of care, which utilize a syndemic approach that provides access to PrEP and treatment services. ONAP also continues to conduct EHE listening sessions in Maryland, Louisiana, and Washington D.C.

The United States Business Coalition to End HIV is proceeding as planned. The Coalition released a National HIV Testing Day playbook for employers on June 27. ONAP, The American Public Health Association, the Elton John AIDS Foundation, and other coalition members

convened with representatives from major retail pharmacies, national advocacy organizations, and federal agencies to develop recommendations for expanding the role of pharmacies in providing HIV care and prevention services. The coalition is also launching local innovation hubs in Atlanta and Los Angeles by the end of 2023, which will bring together business chambers, local employers, and local government to discuss unique challenges to businesses' role in addressing HIV.

ONAP continues to work with CDC and community partners on Molecular HIV Surveillance/Cluster Detection and Response (MHS/CDR). Mr. Phillips has attended several meetings with CDC regarding the MHS/CDR resolution released by PACHA, and he confirmed that 80 percent of items in the resolution are either already in place or being considered by CDC and other agencies. Mr. Phillips noted that a minority of items in PACHA's resolution will not be implemented by CDC because the agency determined those items were not in the best interest of public health. ONAP is developing a chart of these items to share with PACHA members. ONAP is also working with the White House Counsel, The Community Health Law Project (CHLP), local health departments, and community partners to strengthen surveillance data protections. Mr. Phillips cited a recently passed Washington, D.C. law as a potential model for HIV surveillance data in other jurisdictions. The legislation is worded as follows:

"The Director shall use the records incident to a case of HIV infection or AIDS reported under this act for statistical and public-health purposes only. Identifying information contained in these records, as well as all identifying information obtained, collected, or created by the Department of Health ("Department") shall be disclosed by the Director only when essential to safeguard the physical health of others. No person shall otherwise disclose such identifying information unless the person about whom the information pertains gives his or her prior written permission. All identifying information obtained, collected, and created by the Department under this act shall not be discoverable or admissible as evidence in a civil or criminal action unless the person about whom the information pertains gives his or her prior written permission."

Mr. Phillips expressed concern about challenges that may obstruct NHAS goals. ONAP is particularly monitoring attacks on LGTQIA+ individuals and programs, including:

- Anti-gender affirming care legislation in many states
- "Drag Queen" bans
- Braidwood case and impact on HIV prevention and other prevention services
- Attacks on U.S. President's Emergency Plan for AIDS Relief (PEPFAR) five-year reauthorization
- Concerns over HIV funding
- Further attacks on reproductive rights access, including abortion and contraception

Mr. Phillips requested PACHA's help in promoting PEPFAR's importance to ending the global HIV epidemic and debunking misinformation about the program, including false claims that it has funded abortion services in Africa. Support from the White House and the Department of Justice has been helpful in supporting the LGBTQI+ community and defending it from discrimination.

ONAP will release new NHAS quality of life indicators, which are being developed in collaboration with the National Working Positive Coalition and the Department of Labor. CDC and HUD have also held a roundtable on HIV housing to highlight the importance of an integrated approach to care, which includes housing and employment. ONAP is also working with agencies to use data to educate the public about the impact of these programs—as well as the continued need to focus on priority populations. The next EHE accomplishment fact sheet will be released in July and the NHAS Progress Update will be released at the end of 2023.

#### **Discussion**

Mr. Phillips noted that he is aware of the rise of mpox cases in Chicago and Los Angeles and has assembled an interagency group to monitor vaccine distribution.

Mr. Carl Schmid expressed doubts about the passage of legislation in Congress for a national PrEP program and asked whether this program would divert resources away from the Ryan White Program. Instead, Mr. Schmid suggested using CDC resources to continue expanding PrEP access. Mr. Phillips noted that a national PrEP program is envisioned to be additive to other programs already in existence, including the Ryan White Program. He also observed that funding for the Ryan White Program has been flat for several years, and national PrEP legislation could actually provide the program additional funding to enhance its services. CDC is set to announce new funding opportunities to help increase PrEP uptake, as well.

Dr. Wiesman encouraged ONAP and CDC to engage the PACHA MHS/CDR subcommittee in discussions of MHS/CDR policy. He noted that during the previous PACHA meeting, participants agreed to increase communication with federal partners to obtain a full understanding of plans for updating MHS/CDR policies. Dr. Weisman implored all those involved with MHS/CDR policy to be careful when characterizing the best interests of public health. Mr. Phillips agreed and intends to seek PACHA's advice on optimal ways to communicate PACHA's recommendations in future Notices of Funding Opportunity (NOFOs). Mr. Justin Smith added that transparency for MHS/CDR policies can be enhanced through community engagement with communities of people living with HIV.

Dr. Vincent Guilamo-Ramos praised the work of pharmacists in the Business Coalition and observed that the nursing health care workforce is another underutilized resource for addressing the HIV epidemic. Dr. Guilamo-Ramos expressed concern about resistance to the reauthorization of PEPFAR, nothing that he recently traveled to Rwanda and witnessed how the program is enabling nurses to increase access to antiretroviral treatment (ART). Dr. Harrison agreed with Dr. Ramos that nurses could be engaged to increase momentum in EHE efforts.

Dr. Portero inquired whether more work can be done to increase awareness of ONAP EHE programs in AI/AN communities. Mr. Phillips responded that such work is in its early stages and plans are being formed to invite AI/AN to the White House for further discussion in August.

### **PACHA Principles: Zero HIV Stigma**

Raniyah Copeland, M.P.H., Principal, Equity, & Impact Solutions; and Leo Moore, M.D., M.S.H.P.M., Medical Director for Clinic Services, Los Angeles County Department of Public Health

Dr. Leo Moore presented a draft resolution for Zero HIV Stigma Day, which was conceived by the PACHA Stigma and Disparities Subcommittee. The goal of the resolution, which is entitled *From Vision to Reality: A Call to End HIV Stigma*, is to eradicate harmful attitudes, behaviors, judgments, and policies toward people living with HIV. The document is meant to be short (one page) and uses plain language to reach broad audiences and communicate best practices for eliminating stigma. Dr. Moore invited PACHA members to provide feedback to optimize the language in the resolution. The feedback involved several themes:

- Adding language about STI stigma
- Specifying federal activities to combat stigma, including policies and legislation
- Including employers in the private sector in EHE efforts
- Referencing health care provider training programs

After a short discussion, PACHA members held a vote to approve the resolution with proposed changes. The vote to approve the resolution was unanimous (see Appendix B).

### **Ending the HIV Epidemic in AI/AN Communities**

### Tribal Sovereignty & HIV/AIDS Work in Native Communities

Laura Platero, J.D., (Navajo), Executive Director, Northwest Portland Area Indian Health Board; and Rick Haverkate (Sault Ste. Marie Tribe of Chippewa Indians), National HIV/HCV/STI Consultant, Indian Health Service; and Nickolaus D Lewis (Lummi), Chairman, Northwest Portland Area Indian Health Board

Dr. Laura Platero welcomed meeting participants and introduced a few key concepts regarding tribal sovereignty and how it relates to HIV/AIDS work in Indian Country. To help familiarize meeting participants with basics of tribal sovereignty, she described the number of federally recognized tribes, their location, and terminology used for Tribal Nations. Dr. Platero then displayed a timeline of major legislative and historical events in health care for AI/AN people throughout U.S. history to demonstrate the complexity of policy changes over time. This timeline is characterized by periods of conquest, treaty-making, assimilation, reorganization, termination, and self-determination.

The bases for tribal sovereignty are treaties, federal trust responsibility, and respect. Treaties are the starting point for AI/AN health care policy, and Dr. Platero observed that health care is one reason (among many) why treaties were formed. The federal trust responsibility, or the unique federal obligation to AI/AN communities as political rather than racial/ethnic communities, is defined by an extensive body of law. The recent 2023 Supreme Court decision *Haaland v. Brackeen* recently affirmed this status as it relates to federal services.

HHS is responsible for health care services for AI/AN people. IHS is the primary HHS agency that funds services to AI/AN communities; however, Dr. Platero pointed out that IHS is chronically underfunded. The current IHS budget for FY2023 is \$6.95 billion, but full finding is estimated at \$49 billion. Other agencies, such as CMS, CDC, HRSA, SAMHSA, and ACF, also fund services for AI/AN people. Government-to-Government relationships between these federal agencies and tribal nations require tribal consultations. These consultations are accomplished

through mechanisms such as various statutory authorities, presidential executive memorandums, and, in particular, the HHS tribal consultation policies.

The HHS Secretary's Tribal Advisory Committee (STAC) meets four times annually to discuss health care policy, which can be a critical resource on HIV/AIDS policy. Dr. Platero pointed out that tribal leaders sit on every STAC committee. National and Regional Tribal Health Organizations and Tribal Epidemiology Centers are also an important resource for HIV/AIDS policy and can help connect federal partners to tribal communities.

Mr. Rick Haverkate presented the <u>Indigenous Syndemic Strategy</u> (Indigi-HAS), which combines the national HIV, HCV, and STI national strategies into one indigenous strategy to address syndemics. Indigi-HAS, which was developed over the last 18 months, is managed by several tribal representatives and is funded through the Minority HIV/AIDS fund. The vision of Indigi-HAS is:

We envision a world in which all Indigenous people are healthy in mind, body, and spirit; the spread of HIV, STIs and viral hepatitis is prevented; every person knows their status and lives free from stigma and discrimination; and every person has access to high quality, holistic care that reflects Indigenous values, promoting relationships with each other, the land and all beings.

Mr. Haverkate identified the core values of Indigi-HAS as those that are perceived as common across many indigenous communities, including honesty, truth, and sharing. Strategy components are composed of a number of interventions such as prevention, treatment, diagnosis, and response—which are implemented at various levels, including individuals, families, communities, and across entire systems.

One example of a program representing the values of Indigi-HAS is *Native Test*, which rapidly distributes HIV self-tests in the mail to individuals, free of charge. This program is funded by the Minority HIV/AIDS fund. Individuals can text "Native Test" to 55251 to receive a free test. The text service also can provide linkages to care and access to PrEP. An additional related testing service, called *I Want the Kit*, provides home tests for chlamydia, gonorrhea, and trichinosis. An in-home syphilis test for this program is in development. To support these programs, Mr. Haverkate highlighted the "PrEP is self-care" public awareness campaign.

#### Discussion

PACHA members inquired about the reach of the *Native Test* campaign. Mr. Haverkate observed that the program was highly successful: it has generated more than 3400 orders and has been utilized by 38 tribal partners in Oklahoma. Of those who contacted the program, 27 were linked to PrEP. The program has also distributed over 27 thousand condoms. In response to a question regarding regional delineation, Dr. Platero noted that the division of administrative regions was a historical decision.

#### Regional Indian Health Board

Maria Dadgar, (Piscataway Tribe of Accokeek), M.B.A., Executive Director, Inter-Tribal Council of Arizona

Ms. Maria Dadgar presented on the Inter-Tribal Council of Arizona, which is a consortium of 21 of the state's 22 tribesThe Council has more than 70 employees, a board of directors composed

of tribal leaders across Arizona, and an annual operating budget of \$30 million. A central goal of the Council is to build public health capacity through health surveillance, research, prevention, and programmatic evaluation. The Council operates more than 60 federal grants and cooperative agreements, which focus on health, research, environmental quality, meeting AI/AN community needs from neonatal to elder care. The Council also operates a local epidemiology center. Its operations in the BIA western region extend beyond Arizona to Nevada and Utah.

Ms. Dadgar shared a short story about public service for AI/AN communities in Arizona. She previously worked for the Center for Native American Economic Development of Mesa, Arizona. At that facility, she worked with the founder Dr. David Lester, who originally encouraged President Carter to create more organizations to serve AI/AN communities. One day, she found Dr. Lester crying and asked him why. He replied that they were tears of joy at the many new AI/AN leaders who had joined the Center to serve the next generation of AI/AN communities, and the fact that she and other leaders had changed the mindset of AI/AN people from one of dependency to development, empowerment, and self-determination.

#### **Discussion**

Ms. McNeese asked Ms. Platero what federal resources are needed to effect change in AI/AN communities and what role PACHA could play in providing assistance. Ms. Platero noted that more funding is always needed for programs and pointed to the success of expedited interagency funding during the COVID-19 pandemic—some of which directly funded IHS, which promoted AI/AN self-determination. Ms. Platero observed that CDC has a tribal advisory committee that could help address HIV in a more robust way. Because of numerous health disparities in AI/AN communities, it is difficult to prioritize HIV. Ms. Dadgar noted that the Council is also made up of elected officials who can make official resolutions, but it has never been approached by PACHA to do so. The Council has also formed an advocacy organization, the Inter-Tribal Association of Arizona, which travels to Washington D.C. annually and it could meet with PACHA during those trips.

Dr. Guilamo-Ramos inquired about reports of chronic underfunding of IHS and expressed concern about the likelihood of success of proposals made during this meeting. Dr. Platero stated that tribal leaders see chronic underfunding as a failure of the federal government to uphold its treaty obligations. She noted that previous administrations have proposed funding increases for IHS, but those proposals are often cut by Congress. Ms. Kelly Vallo underscored the need for AI/AN individuals to be directly involved in creating programs for AI/AN communities, rather than being asked to provide input after programs have already been developed.

#### Addressing HIV in AI/AN Communities

Facilitator: Laura Platero, J.D.; Executive Director, Northwest Portland Area Indian

Health Board

Panelists: Heather Myers Huentelman, Pharm.D., B.C.P.S., CAPT, United States

Public Health Service, HIV Clinical Pharmacist, Phoenix Indian Medical

Center

Jessica Leston, (Tsimshian), MPH, Director, National Center for Clinical

Support and Preventive Health Services, Northwest Portland Area Indian

Health Board

Savannah Gene, (Navajo), M.S., C.H.E.S., Program Director, Community Health Education and Resiliency Program, Albuquerque Area Indian Health Board, Inc.

Rydell J. Curley, HIV Health Technician, Public Health Nursing Department, Chinle Comprehensive Health Care Facility, Indian Health Service

## IHS HIV Center of Excellence for American Indians/Alaska Natives Phoenix Indian Medical Center

The IHS HIV Center of Excellence for American Indians/Alaska Natives Phoenix Indian Medical Center was established in 1996 and provides HIV, PrEP, and PEP services to Arizona AI/AN. Unlike other HIV clinics nationwide, the Center provides a full range of services, including case management, behavioral health, and pharmacy services; Ryan White funding can be used to assist with other health related needs (e.g., housing). The Center services almost 400 AI/AN people living with HIV and approximately 100 additional AI/AN individuals on PrEP. CAPT Huentelman explained that patients often return to the Center because (1) IHS, and by relation the Phoenix Indian Medical Center, is interwoven into the culture of AI/AN individuals; (2) the Center emphasizes cultural and LGBTQ+ representation in its workforce; and (3) the Center demonstrates understanding and inclusion of reservation culture (e.g., nomadic lifestyle, generational trauma) in its prevention and treatment strategies (e.g., providing early refills or larger prescriptions to account for less frequent visits).

CAPT Huentelman shared successes that the Center has experienced during her tenure as Clinical Pharmacist, including the impact of the HIV Undetectable=Untransmittable (U=U) program. She noted that the U=U program has made significant progress toward ending HIV stigma and allaying fear of the disease's spread for those living with HIV in the AI/AN population in Arizona. CAPT Huentelman noted that much of the information included in U=U (e.g., PrEP reduces the risk of transmission by 99 percent with one pill a day) is not commonly known in the general population and the knowledge could greatly assist in reducing stigma nationwide if it were more widely communicated.

Highlighting another success, CAPT Huentelman shared that the Center taught pharmacy students and individuals in the Junior Commissioned Officer Student Training and Extern Program (JRCOSTEP) members how to perform pharmacist-led PrEP in return for the students helping ensure that the Center's data were up to date and that contacts were being followed in a timely manner. The Center also recently opened a walk-in STI clinic, providing patients with an alternative to seeking testing and treatment at an urgent care center, and is implementing universal HIV and STI testing. The Center was also the first to provide Mpox Treatment with Tecovirimat (TPOXX) to a patient in Arizona.

However, the Phoenix Indian Medical Center continues to face challenges. Along with the challenge of stigma, the Center of Excellence struggled greatly during the COVID-19 pandemic. The community of AI/AN people living with HIV was particularly impacted by the pandemic, despite having an immunization rate of 85 percent. Among the Center's population, substance use disorder is the number one comorbidity that limits adherence to prevention and treatment plans. Additionally, the Center has not identified an ideal means of communication with patients that meets Federal Risk and Authorization Management Program (FedRAMP) standards while

also meeting the population's communication needs (i.e., texting or email instead of voicemail). The Center's facility is undersized for the population that it serves and it continues to struggle with understaffing: the Center serves 400 AI/AN people living with HIV, a level that ideally requires 10 case managers, with only 4 case managers. As a result, the Center's workforce often unsustainably work extra hours on a daily and weekly basis to ensure that patients receive the care they need. For example, the Center needs to perform outreach to partners and potential partners (e.g., tribal council, ITCA) to continue providing quality care for patients and attracting additional patients referred via PSAs, marketing, and public relations, but this work takes away hours that the Center's workforce could be using to treat patients. CAPT Huentelman concluded that she was concerned that the program's success may be unsustainable in the long term without additional resources and staffing.

### Applying the Indigenous HIV/AIDS Syndemic Strategy to Rising Public Health Threats

Ms. Leston illustrated how the indigenous HIV/AIDS syndemic strategy can be applied to additional immediate public health threats to AI/AN communities, notably syphilis. CDC recently released an infographic about the syndemic of HIV, STIs such as syphilis, substance use, and viral hepatitis. This syndemic increases the risk for all individuals in an outbreak area to acquire not just one, but multiple conditions. For example, CDC found that individuals who contract syphilis are more vulnerable to HIV, and six percent of sexually acquired HIV infections are attributed to chlamydia, gonorrhea, and syphilis. Additionally, CDC found that young adults who used an illicit drug were 3 times more likely to get an STI. The CDC infographic recommends a holistic (i.e., individual to community level) response and identifies priority populations, including LGBTQIA+, adolescents, pregnant people, and racial and ethnic minorities.

Ms. Leston focused particularly on syphilis cases among AI/AN individuals, citing data showing that between 2017 and 2021, AI/AN populations experienced a dramatic increase in primary and secondary syphilis cases and an 800 percent increase in congenital syphilis cases over the last year. Additionally, among the 15 states with the highest rate of congenital syphilis, 7 have large AI/AN populations that may drive those congenital syphilis rates. While syphilis is more commonly diagnosed in male populations, the largest proportion of females diagnosed with syphilis are AI/AN females (21.3 cases per 100,000 individuals). These rates indicate an issue with women's health care nationwide, but particularly for AI/AN females due to a lack of timely prenatal care and testing and lack of adequate treatments when timely diagnoses occur. Some of the lack of treatment is due to nationwide shortages of penicillin, causing limited or no treatment availability for pregnant women diagnosed with syphilis.

Health care workers can apply the Ending the HIV Epidemic principles and lessons to the syphilis and STI outbreaks nationwide to address the syndemic and create better services for pregnant people. Ending the Epidemic principles makes patients less likely to be lost to follow-up and provides an opportunity for collaboration between medical, social, cultural, and spiritual practices. Often pregnant people who are drug users are lost to follow-up because they fear the repercussions of seeking treatment (e.g., giving birth in jail), and that fear increases the incidence of congenital syphilis and other medical complications, particularly among AI/AN individuals. The issue requires more attention and funding.

#### **National Native HIV Network**

Ms. Gene shared her experience as the program director of the Albuquerque Area Indian Health Board serving the 27 tribes, nations, and pueblos included in the Albuquerque area IHS. Ms. Gene is also a co-creator of the National Native HIV Network (NNHN), which was founded to coordinate individuals working within AI/AN communities on HIV and Hepatitis C prevention. The NNHN is an indigenous-led initiative that mobilizes American Indian, Alaska Native, and Native Hawaiian communities affected by HIV through peer-to-peer and programmatic support, training, and capacity building assistance. The NNHN focuses on culturally sensitive and community-based approaches, hosting bimonthly meetings to hear the challenges faced in individual communities and provide resources to address those challenges.

Within the last year, NNHN has worked with IHS and New York state on a peer worker certification program that offers individuals with lived experience with HIV community-centered training to cultivate the skills needed to help their peers gain access to prevention and treatment. NNHN will begin recruitment and collect feedback from early participants to be more responsive and relevant to individual tribal community needs. This work will help to build a bridge between providers and the community in which they are often unable to adequately participate.

NNHN is currently working with regional representatives on a strategic plan to identify goals for the next 3 to 5 years, including increasing visibility of NNHN and increasing diverse, multigenerational representation. NNHN particularly aims to focus on building relationships with younger and older generations while also addressing barriers to an upstream prevention approach, as opposed to the current downstream, reactive approach. As part of this effort to address barriers, NNHN is working to address the overarching problem that AI/AN and Native Hawaiian populations are often considered statistically insignificant and thus are not considered priority populations. NNHN is also working to tackle stigma surrounding HIV and incorporate indigenous values and practices to help align Western medicine approaches with Native values and practices.

The work NNHN pursues is completed slowly and intentionally to ensure that it can appropriately address community needs and overcome barriers nationally and locally through intentional development of a strong foundation. NNHN ultimately is working to create the foundation for healthier communities and ensure access to the best care possible to maintain overall wellness. This work requires a dedicated workforce that moves above and beyond to build these programs, often doing so because they have a deep connection and commitment to their communities.

#### **Chinle Comprehensive Health Care Facility (CCHCF)**

Mr. Curley shared his experience as an HIV health technician at the CCHCF, an IHS medical center serving 40,000 people within the central portion of the Navajo nation. Most of his work involves correspondence between patients and providers to encourage routine appointments and medication adherence. Mr. Curley emphasized that the most important part of his job is getting to know his patients on a personal level, forging a respectful, unbiased understanding of individuals to help guide them to the best course of care in a way that respects their beliefs, feelings, and needs. To do this work, Mr. Curley has created a multidisciplinary team, including an infectious disease provider, nurse practitioner, pharmacist, and psychiatrist to go into the field

and provide culturally and personally sensitive prevention and screening services. Mr. Curley and his team oversee 24 male patients and are tracking an additional 18 patients. Of these additional patients, 17 do not seek care at the medical facility but live within the service area and are seen by other service units; one does not seek care services but is tracked in case they choose to seek care in the future.

The greatest challenge to care in Chinle, AZ is the persistent stigma of sexual topics (including HIV and STIs), rooted in traditionally conservative values. To address stigma, IHS has bridged the gap between American Indian and Western medicine to create a holistic approach that encompasses and simultaneously utilizes religion, traditional belief, and medicine. This approach integrates elders and religious leaders into healthcare services. Additionally, CCHCF and IHS use less direct approaches to overcome stigma. For example, adults may shy away from HIV education they perceive as unnecessarily directed at them, but these same individuals are more responsive and accepting of HIV education to help them protect the health of their children and grandchildren.

Another major challenge in rural communities, particularly AI/AN communities, is confidentiality. AI/AN communities place great emphasis on extended familial relationships and individuals may be hesitant to admit to HIV or STI exposure in a facility that employs a relative or close friend. A third challenge is the rural and nomadic lifestyle of the patient population. Patients may be unable to travel across poorly maintained dirt roads after heavy rains or lack access to cellphone or internet services to remain in contact. To address this challenge, Mr. Curley seeks out patients who miss appointments to try to bring them to the facility to ensure continued treatment services.

Despite these challenges, CCHCF has also achieved numerous successes. The facility has worked to return patients to their homes of record and reintroduce them to treatment services in a confidential, respectful, and dignified manner. This goal has been achieved by building trust with individuals through culturally sensitive approaches. The facility also recently hired an STI coordinator to help address rising cases of syphilis in the community, including an increased rate of congenital syphilis.

Mr. Curley shared that although AI/AN patients often feel left behind, dedicated workers like his fellow panelists give them hope and PACHA provides the opportunity for them to be seen and heard at a national level. Mr. Curley shared his thanks for the opportunity to participate among these panelists and insisted that his own contributions paled in comparison to the many other providers who go above and beyond to care deeply for their communities. He praised participants as advocates of humanity, patients, and people living with HIV.

### **Discussion**

Ms. Platero emphasized the key cross-cutting themes of culture and tradition, trust, and building relationships. Additionally, she noted that stigma continues to be a universal barrier.

Several PACHA members acknowledged the emotional nature of Mr. Curley's conclusion. Dr. Moore emphasized that navigators, nurses, and other support members of health care teams are critical in connecting patients to providers and the health care system. Dr. Moore specifically highlighted Mr. Curley's commitment to following a single patient not ready for treatment to

ensure they would not be lost to the health care system, which Dr. Moore noted is a critical part of caring for the community.

Dr. Guilamo-Ramos highlighted the importance of CAPT Huentelman's remarks, which illustrate both the structural ways in which IHS receives inadequate resources and the ways in which providers are nonetheless doing critical work to support and care for their communities. Ms. Vallo shared her appreciation that the storytelling of the presenters not only touched on the challenges within Indian Country, but also highlighted the humanity of patients.

Ms. McNeese highlighted that syphilis was a topic both in the meeting and at the site visits that PACHA members attended on June 27. She added that her team at the Department of Health in Houston announced its syphilis outbreak response on June 26, 2023. Syphilis is a rising challenge and threat to communities nationwide that requires an emergency response. Ms. McNeese also applauded Mr. Rydell's comments regarding substance use, noting that substance use is also a priority area for PACHA as it continues to address HIV.

CAPT Oguntomilade asked panelists to describe how they integrate Western medicine, Native religion, and traditional medicine. Mr. Curley explained that the Navajo Wellness Model was designed to bridge traditional medicine, traditional ceremony, and Western medicine to increase adherence to diabetic regimens. At Chinle IHS, the integration of Navajo belief system, cultural sensitivity, and traditional practitioners, alongside Western medicine providers, has increased patient adherence to medications and diet and led them to feel better about themselves. Today, the CCHCF and Indian Health Area hospitals utilize the Navajo Wellness Model for all health care. Several PACHA members appreciated this explanation and supported the practice of bringing culture into health care work, not only in AI/AN communities, but in other communities of color nationwide.

In response to a request for more information about moving toward an entirely Native workforce, CAPT Huentelman shared that her goal is to train AI/AN pharmacists and providers to take over her role over the long term to help make the workforce representative of the communities they are serving. This shift will assist with making care more nuanced and culturally responsive, enabling greater success in prevention and treatment programs. Additionally, this approach creates a workforce well versed in the challenges of the community, which include housing insecurity, employment insecurity, and drug use. For example, about 80 percent of patients at the HIV Center of Excellence for American Indians/Alaska Natives Phoenix Indian Medical Center qualify for Medicaid's annual income cap of \$14,000.

# Ending the HIV Epidemic in AI/AN Communities (continued)

Addressing HIV in AI/AN Youth

Co-Facilitators: Vincent Guilamo-Ramos, Ph.D., M.P.H., L.C.S.W., R.N., A.N.P.-B.C.,

P.M.H.N.P.-B.C., A.A.H.I.V.S., F.A.A.N., Dean and Professor & Vice Chancellor for Nursing Affairs, Duke University School of Nursing Kayla Quimbley, National Youth HIV and AIDS Awareness Day

Ambassador, Advocates for Youth

Panelists: Stephanie Paz, (Ysleta del Sur Pueblo), M.P.H., Ambassador, We R Native

Youth

Kelly Vallo, (Navajo/Acoma Pueblo), Native Youth Coordinator, Inter-Tribal Council in Arizona

### We R Native Program

The Northwest Portland Area Indian Health Board (NPAIHB) was established in 1972 as a nonprofit organization serving the 43 federally recognized tribes of Oregon, Washington, and Idaho. It is located within the traditional and ancestral homelands of the Multnomah, Kathlamet, Clackamas, Tuwater, Tualatin, Kalapuya, Watala bands of the Chinook, and many other indigenous nations of the Willamette and Columbia River regions. NPAIHB has worked to establish evidence-based practices to promote sexual education, and its We R Native (WRN) program is at the forefront of linkages between holistic and modern medicine.

We R Native (WRN) addresses the disproportionate impact of STIs on AI/AN communities and the lack of sexual health curricula focused on AI/AN youth. WRN offers multimedia and multiplatform health education through social media, text messaging campaigns, an "ask your relative" Q&A service, and a "Native Voices" video series. Curriculum topics, which are curated by AI/AN youth and subject matter experts, include relationships, intimate partner violence, substance use disorder, suicide prevention, coming out as LGBTQ+, condom use, STIs, and connections to cultural resources.

We R Native also works with the Washington Youth Sexual Health (WYSH) Project to provide sexual health information to AI/AN youth. WYSH's mission is to improve youth access to and experience with sexual health care in indigenous, tribal, and urban settings, including sexual services for Two-Spirit LGBTQ teens and young adults. WYSH funded the update of the WRN website and provides condoms and other sexual health supplies. WYSH also hires AI/AN youth nationwide to write articles for WRN from a youth perspective.

WYSH has two other campaigns: Loved Here, Safe Here and Get Yourself Tested (GYT). The Loved Here, Safe Here campaign provides materials for tribal clinics and those who engage with Native youth to provide an affirming environment for the 2SLGBTQ community. GYT encourages young people to get tested and treated for STIs and HIV to protect their health and the health of their partners. GYT includes video and graphical campaign materials.

#### **Project Red Talon**

Ms. Vallo works with Project Red Talon (PRT), which is coordinated by NPAIHB in collaboration with ITCA. Since 1988, PRT has worked to disseminate best practices in collaboration, networking, and resource sharing of culturally appropriate sexual health strategies PRT aims to improve the organizational capacity of AI/AN communities and clinics across Indian Country and Alaska, tribal health educators, program managers, and clinicians to provide services to AI/AN communities. One core strategy of PRT is to promote STI, HCV, and HIV prevention in local communities through testing, screening, and reporting. PRT has several partners that work toward EHE goals, including the University of Texas, the Southern Plains Tribal Health Board, and the Indian Health Services.

Ms. Vallo is also the Native Youth Coordinator for the Inter-Tribal Council of Arizona (ITCA), which seeks to leverage and expand HIV testing and prevention by addressing behavioral, social, and structural barriers. To that end, ITCA works with Native Youth programs, such as WRN, on

outreach, with a focus on training and technical assistance, webinars, and curricula for youth and high-risk AI/AN populations. ITCA promotes the Native Test STI self-test and the I Want the Kit (IWTK) HIV self-test programs. The IWTK program is free and available nationwide for those aged 13 and over and has distributed thousands of self-tests to AI/AN communities, and increased access to useful resources, including PrEP. If a test comes back positive, IWTK also links individuals to care through local tribal health agencies.

PRT and ICTA also support the Healthy Native Youth Program, which provides sexual health curricula, training, and technical assistance for educators and health advocates teaching AI/AN youth about HIV, STIs, and teen pregnancy prevention. This program has four main campaigns: Native-It's Your Game (NIYG), Native Stand, Native Voices, and WRN. NIYG is a web-based HIV, STI, and pregnancy prevention curriculum for AI/AN youth. Native Stand provides similar curricula, but also focuses on healthy relationships, substance use, suicide, and intimate partner violence. Native Voices promotes condom use and safer sex. ITCA includes all these resources in an implementation toolbox to provide a variety of culturally-relevant resources. Ms. Vallo encouraged meeting participants to join a Community of Practice which meets regularly to share strengths and experiences in improving the lives of AI/AN youth.

#### **Discussion**

Meeting participants engaged the panelists on various aspects of the presented AI/AN youth programs. Ms. Paz noted that many of the programs presented are consistently updated to remain relevant to young people, and Ms. Vallo added that across updates, messaging consistency is also important to ensure HIV prevention and other programs are effective. Ms. Paz also observed that individual tribal community resources are critical to maintain relevance. In particular, both presenters agreed that peer-to-peer mentoring programs are critical in reaching and establishing trust with AI/AN youth. AI/AN youth face stigma regarding reproductive and sexual health care (including HIV and STI testing), especially in more conservative parts of the country. The panelists both emphasized the importance of promoting communication within families and communities—with storytelling being an important culturally-relevant way of engaging AI/AN communities. Ms. Vallo pointed out that Indigenous people are natural storytellers and storytelling often includes useful information and data, which can be leveraged to improve public health.

Panelists also discussed challenges that PACHA might help address to meet the needs of AI/AN youth. Ms. Paz highlighted the importance of sexual and reproductive health resources in conservative areas of the country where these programs are deemphasized or discouraged. Ms. Vallo noted that too many programs seek to reinvent already existing programs and more efforts should instead be made to build up existing programs. Both panelists also observed that not enough respect is afforded to community workers, like case managers. Likewise, Ms. Vallo promoted the idea of respect through body sovereignty—by ensuring providers include people in their own health care decisions. Ms. Paz implored PACHA to follow through with building connections to AI/AN communities, noting that it is common for organizations to ask for input from AI/AN without that input leading to any progressive change or improvement. The presenters emphasized more funding for not just access to testing, but funding for internet access, rent, food, and substance use disorder services.

Meeting participants were curious about efforts to train the next generation of mentors to continue outreach to AI/AN youth. Ms. Paz confirmed that many professionals are mentoring the next generation. Certain tribal resources, such as the IHS physician training program, also help train new generations of providers. Dr. Platero noted that youth delegates serve on the community health boards of STAC. Meeting participants were impressed with the inclusivity of the presented mentoring programs, particularly for LGBTQI+ youth; Ms. Vallo emphasized that the inclusive nature of these programs are derived from Native laws of respect, relationships, responsibility, reciprocity, and reflection.

### **Public Comment**

Elena Ferguson, Policy Specialist at Positive Women's Network USA, which works with women and transgender persons living with HIV. Elena also works at the Health Not Prisons Collective, which seeks to decarcerate public health. Elena expressed concern about the ongoing HIV/AIDS surveillance that intersects with policing and communities most impacted by HIV. Elena's organization has previously conveyed concerns to PACHA about the lack of privacy protections at a time of rising human rights violations and attacks on transgender and BIPOC communities, although they expressed gratitude to PACHA for passing a resolution regarding MHS/CDR. However, they express outrage and dismay at ONAP for not taking this issue seriously. At the previous PACHA meeting, people living with HIV revoked their consent for data collection and hoped that their concerns would be heard. It is unacceptable that the CDC continues to use MHS/CDR as a core HIV strategy. The consequences of any form of criminalization can be severe. The longstanding harms to those in marginalized communities is neither hypothetical nor overblown. Recent data show that adults seeking abortion care in areas where it is outlawed, people were reported to the police most often by healthcare professionals. Recently, health data involving those seeking transgender care were reported to the Tennessee Attorney General's office. People with HIV face loss of privacy, custody of their children, and employment. The federal government must use every safeguard to protect the data of people, regardless of who they are and where they live. The work of Elena's organization is one part of efforts to dismantle systems of racism and oppression. The lives and dignity of 1.2 million people living with HIV in the U.S. depend on taking these issues seriously. Elena aims to work with PACHA to ensure that federal policy respects and defends people living with HIV.

Michael Blasingame, Director of Data Services at Healthvana, which works on patient engagement and PrEP, particularly Chicanos Por La Causa in Phoenix. Michael recently had his ten-year PrEP anniversary using it as an HIV prevention tool. In 2013, there was little patient advocacy and you had to fight to access PrEP. Ten years later, the environment has changed—but how can we increase access to PrEP when placing burdens on individuals? Michael says he is fortunate to work for a company that identifies HIV patients, helps them get on PrEP, and accompanies them throughout their PrEP journey. The communities he serves stand to gain the most from PrEP, which come from non-white communities of color. In 2017, a study found in Sexually Transmitted Diseases found that people who test positive for rectal gonorrhea or chlamydia have a three-fold risk of contracting HIV. These are ideal candidates for PrEP and Michael's organization runs a pilot program that contacts those diagnosed with these infections within 24 hours of their positive test result. Results of the pilot show that 37 percent of patients indicated they were ready to start PrEP. However, adherence to PrEP is an issue. In 2018, Journal of AIDS published a paper that showed a lack of adherence contributed to the

ineffectiveness of PrEP in many communities. We can address this gap by monitoring adherence by building relationships with patients and providers. This may also identify patients who need other services, such as behavioral and substance use disorder care. Meeting patients where they are does not have to be complicated. Trust and advocacy for patients, leveraged by emerging technologies, will help people living with HIV.

Amir Sadeghi, Policy and Advocacy Manager at CHLP, which works to eliminate stigma, discrimination, and violence for people in our community facing racial oppression, patriarchal violence, and economic divestment. CHLP cofounded the first international collaborative to end HIV criminalization in the U.S., the Positive Justice Project. Amir supports Elena comments. Communities made up of people living with HIV are communicating serious concerns about MHS/CDR. The PACHA resolution was recently blacklisted in a recent convening in Atlanta where CDC, NASTAD, and federal partners discussed lessons learned. How do we learn lessons when people with HIV aren't being engaged in listening sessions? Learning and building trust is difficult when people most likely to face HIV criminal enforcement, such as Black people living with HIV, sex workers, and people who use drugs aren't being centered in the discussion. Bodily autonomy and informed consent do not conflict with public health. Anyone denying this deserves fierce reproach from the advocacy community. According to NASTAD, 33 states allow the release of HIV data in accordance with law enforcement and court requests. 25 states use the general criminal law to target and punish people with HIV. A majority of U.S. states have HIVspecific criminal laws. Thousands of people living with HIV have been criminalized and dehumanized. Arrests are ongoing. Public health agencies, including state and local bodies, need to recognize this situation, which has to be a starting point for any conversation on MHS/CDR. Failing to recognize HIV criminalization endangers public health, undermines the safety of our communities, and will cost lives.

**Douglas Rose, HIV** activist expressed amazement for the work of AI/AN communities to take care of their health despite the low amount of funding for IHS. He thought that the respect inherent in AI/AN approach to public health was more widely applicable to all Americans. Instead, the public health focus is aimed at eradicating disease—which threatens to harm the people carrying it. The Zero Stigma Plan is full of great ideas, but is missing educators as a key component. Douglas said Mr. Phillips' message was disheartening compared to the experiences of local advocates. Messaging on MHS/CDR always seems to be opaque to the public and, despite promises of progress, the same policies that concern advocates continue to remain in effect. Douglas was unsure of exactly how many of PACHA's recommendations regarding MHS/CDR were actually being implemented. As far as PACHA recommendations that are allegedly "not in the interest of public health," Douglas expressed skepticism; he hasn't seen any evidence that MHS/CDR is better than any other type of surveillance.

Terri Wilder, HIV and Aging Policy Advocate at SAGE noted that the CDC recommends that everyone between the ages of 18-64 be tested at least once for HIV. These recommendations have not been revised since 2006. Knowing one's access is vital for prevention and treatment services, but most public health strategies have been focused on younger people. Older people account for approximately 17 percent of new HIV infections, and they are more likely to be diagnosed at later stages of the disease. In New York State, age 50+ counted for 35 percent of simultaneous HIV and AIDS diagnoses. For 60+ individuals it was 37 percent. Older individuals are not undergoing routine HIV testing. Terri contended that preconceived agist views should not

delay care, which can lead to premature death. Studies show that ageism leads to delays in providing ART to older people diagnosed with HIV. Early HIV treatment is essential for older people because of slower recovery rates and more interventions should be tailored specifically for older people. Community organizations, health systems, people with lived experience, and government all need to step up to help. HIV testing is not reaching older people, who are facing increased burdens of disease. Terri noted one story, in which a 79-year-old only discovered their HIV status after changing primary health care providers. It is time to remove the upper age limits from the CDC guidelines.

Jeffrey Kwong Co-director of the American Academy of Medicine HIV and Aging **Initiative** advocated removal of upper age limits for routine opt-out HIV screening. This arbitrary age limit creates barriers for HIV care for older adults and impedes NHAS and EHE. Two key elements of EHE are to diagnose all people to catch HIV infections as quickly as possible, as well as prevent new HIV infections. However, we cannot diagnose all people or connect them to HIV prevention services if we cannot screen them. Jeffrey says he has seen older adults present in hospitals with advanced disease because they were not screened for HIV in a timely manner. One case that stands out was a 69-year-old with pneumonia who underwent an open lung biopsy for a persistent infection and was diagnosed with pneumocystis pneumonia and advanced HIV; had they been screened two years earlier, they could have been spared a lengthy and expensive ICU stay saving this individual and the health care system hundreds of thousands of dollars. Many other cases are similar. STI rates among older adults have doubled or tripled among those over 65; CDC screening guidelines for other STIs do not have an upper age limit. Screening guidelines for HIV have not been updated since 2006, even though other guidelines, such as those for viral hepatitis, have been updated much more recently. Medicare covers HIV screening for older adults "at increased risk." This limits access to care for HIV. One has to ask about sexual health to receive this risk-based screening, and clinicians routinely fail to ask older adults about their sexual health. It is challenging for anyone to ask for an HIV test due to stigma; routine opt-out testing has minimized stigma for those under 65 and should be made available for older individuals. The highest rate of transmission of HIV occurs in people unaware of their HIV status.

Lupe Conchas, Advocate described growing up in Prescott Valley, Arizona in an abandoned trailer his father repaired. When Lupe was 16, his father was deported and he finished high school by himself while briefly living in his car. Lupe attended the University of Arizona and pursued a career in public service in the Arizona Department of Economic Security advocating for treatment of HIV/AIDS and other preventable diseases. While on PrEP, one of Lupe's partners told him it could have negative health consequences, so he ceased taking it. He contracted HIV a few years later through a screening at Native Health. Lupe thought his life was over. Through Native Health he was able to get treatment to become undetectable. Lupe now advocates for PEPFAR. He encouraged PACHA members to use their position to advocate for PEPFAR, which includes aid for food and clean water for the peoples of Africa. PEPFAR aid is important, especially in preventing mother-to-child transmission. PEPFAR is currently under attack and PACHA members need to send a clear message of support.

**Shruti Gurudanti, Co-founder of Televeda** which aims to alleviate social isolation and loneliness among underserved populations, including AI/AN community members, through digital literacy training, broadband access, and socialization training. Shruti often hears that,

although there are many available programs to help community members, people are not aware these programs exist. She worked with members of three different tribes the previous week and in each case, there was a lack of awareness of programs that could help for specific needs. Shruti advocated for a centralized database to share information about available programs based on tribal affiliation, language, and needs. Community-based programs are well aware of what community needs are; federal, state, and local officials need to work directly with communities to develop programs, rather than seeking input after the programs are created. Community-based organizations are trusted messengers in the community, and need to be empowered rather than told what to do by white people.

Ronald Johnson, Chair of US People Living with HIV Caucus, noted that he is an older adult living with HIV. Ronald advocated for removing the upper age limit from the CDC's guidelines for routine HIV testing. There are two reasons he wanted to highlight. The current age limit increases the likelihood of missing HIV infections in older adults. Older adults often have comorbidities associated with HIV. There is growing knowledge on HIV and aging, as well as the impact of other age-related health conditions. Increasing the testing of older adults empowers providers to include HIV care with other health care, as well as monitor the impact on other age-related disease, such as cardiovascular disease. Ronald's second reason is that removing the age limit for HIV testing is a step toward addressing racial and ethnic disparities. According to the CDC, two-thirds of newly reported HIV diagnoses for 65+ were among people of color. Missed diagnoses is having a disproportionate impact on people of color.

Jeff Berry, Executive Director, The Reunion Project which advocates for long-term survivors of HIV. Since 2015, the Reunion Project is the only program dedicated to improving the quality of life for long-term survivors of HIV through local programs designed by, and for, this community. In a few years, almost three-quarters of HIV survivors will be over 50. There are 300,000 such individuals diagnosed before 1996. The Reunion Project is dedicated to long-term survival, including for those who acquired HIV at birth or early in life, who are called long-term survivors. Jeff thought it was great that long-term survivors and older adults are incorporated into the revised NHAS. However, there is no sense of urgency to help these individuals. A piecemeal or patchwork approach does not work. Long-term survivors and older adults must not be an afterthought. The Reunion Project calls for President Biden to appoint a special HIV and Aging official to oversee these efforts, who works closely with ONAP and federal agencies to include long-term survivors and older adults in science research and policymaking. Care for aging people with HIV can serve as a model for care for aging people in the U.S. and throughout the world

Jax Kelly, President of Let's Kick ASS Palm Beach (LKAP), which serves over 400 long-term survivors. Jax estimates that over 2500-5000 individuals live in the area who are over 50 living with HIV. By providing social connections, HIV and aging advocacy seeks to end AIDS Survivor Syndrome and isolation. Jax is a Black, gay man over 60 living with HIV. He advocates updates to the Older Americans Act to include people living with HIV as a community with one of the greatest social needs. The State of California has made this update and he hopes other states do so, as well. It has become necessary for HIV and Aging advocates to seek a seat at the table where policies are made. The Older Americans Act provides delivered meals, job training, senior centers, health benefits enrollment, caregiver support, and transportation. HIV aid service organizations need to be more cognizant of older Americans with HIV. LKAP recently

advocated at a California aging care event for caregivers, mental health, and homelessness—and was the only HIV organization present. More HIV advocates must be present in aging spaces. We must do better.

Wanda Brendle-Moss, Retired Registered Nurse who has been HIV positive since 2002. She is 69 years old and lives with hypertension and atrial fibrillation. Wanda is also a survivor of homelessness and is currently insecurely housed. She is currently food insecure. Wanda is concerned about status neutral policies, but there is a lack of services in general for people living with HIV in North Carolina where she resides. The lack of HIV support services is catastrophic, as there is nobody to guide people to care and local providers do not have cultural competency to fill the gap. If people cannot be connected with services, we are failing as a society.

### "PACHA-to-the-People" Community Engagement Session

The PACHA co-chairs invited all those participating in the meeting (in person and virtually) to speak. Dr. Platero emphasized that PACHA is particularly interested in examples of best practices and effective interventions, challenges in ending the HIV epidemic. Key comments are summarized here according to the main themes.

### **Provider Education**

- Providers who are uncomfortable with HIV care must be comfortable referring people to providers who are able to provide access to care.
- Medicare reauthorization policies have resulted in 150 thousand people being removed from Medicare, which includes HIV preventative care.
  - o Providers and local agencies need to help people get reconnected to care.
  - o A large medical coverage research organization like Kaiser Permanente should conduct a study on how many people have lost care to help inform EHE efforts.
- Fewer medical students are choosing HIV as a specialization.
  - o Advocates need to work with schools to prioritize HIV in curricula and licensing.
  - Omitting HIV from curricula or licensing exams sends the message that HIV does not matter.
- Many HIV experts are retiring.
  - More should be done to retain HIV experts to mentor the next generation of providers.
- Non-physician providers can be enlisted to provide access to HIV care, including nurses and social workers.
  - o Telemedicine should be more widely employed to expand access to HIV care.

#### **HIV and Aging**

- By 2030, 70 percent of people living with HIV will be over the age of 50. There is a shortage of gerontologists in the U.S. already—particularly gerontologists with clinical experience working with aging people with HIV.
- Project ECHO should be utilized as a platform to identify providers who are knowledgeable on HIV and Aging issues.
- HIV prevention is targeted to young people and aging people are often overlooked.

- More providers need training on HIV and aging, particularly training in respect and listening.
- Widespread Viagra use may be associated with increases in STIs in older cohorts; a warning label could be added stating that Viagra does not decrease risk of STIs or HIV.
- Although many people are living longer with HIV, studies should be conducted on those who are not to understand health disparities.
- Older people should be included in national PrEP programs.
- More crossover is needed between aging experts and HIV experts.
  - o Conferences and meetings should be organized to bring these groups of researchers and advocates together.

### **Funding**

- The Ryan White Program needs more funding to provide active training for providers on aging and HIV.
  - o Trainings need to be active; they should not consist just of watching videos.
- Funding for HIV care is often lacking and better mechanisms are needed to pay for services.
  - O People with other chronic conditions, such as diabetes and hypertension, do not have as much access to services as those with a positive HIV test.
  - o Those with negative HIV tests also lack access to services, and should be connected to PrEP and other support services.
- Rural areas often have severe shortages of health care providers.
  - o In Arizona, one southern county health department is not able to provide access to care for those diagnosed with HIV.

### **Cultural Humility**

- Ryan White bans alternative therapies, including AI/AN medicine, which limits access to culturally humble forms of care.
  - o Ryan White should broaden what kinds of culturally relevant care can be reimbursed.
- Medical staff are often not well trained in culturally humble provisions of care.
  - o Integrated care facilities often have high turnover, which makes cultural training important to consistently emphasize.
- Rural populations are often left out of the conversation; more rural points of view should be heard.
- COVID-19 had a major impact on vulnerable communities, which should be acknowledged when providing care.

### **Diagnosis**

- Testing is not lacking only for aging individuals; many people across all age groups are not being tested.
  - o MHS/CDR is not increasing HIV testing.
- Remove the age limit for routine HIV testing in the CDC guidelines.

#### **Data and Data Protection**

- Oklahoma instituted a statewide electronic medical record (EMR) system with an automatic opt-in, which shared individual medical records with all providers in the state.
  - This default system eliminated the ability for individuals to take PrEP anonymously.
- More original data on health equity and social vulnerabilities are needed to understand the HIV syndemic.

During the session, a CDC representative reported to the PACHA to the People participants that the CDC is updating its HIV testing guidelines. The guidelines are undergoing a rigorous update process. Some key topics the CDC is examining include age intervals for screening, revisiting and increasing the upper age limit for screening, screening frequency, and reviewing once-in-a-lifetime screening guidelines. This process includes a systematic literature review, which includes an examination of 13 thousand studies between 2006-2021. Once completed, the CDC will then synthesize evidence and draft recommendations. The CDC representative noted that this is a lengthy process and there is currently no determination yet of how it will affect the guidelines.

After the session, Platero thanked participants and reiterated PACHA's appreciation for community input.

### **Closing Remarks and Recess**

Dr. Wiesman thanked the participants for sharing their lived experiences. He noted that the team is appreciative of those who allowed them to visit their facilities. He recessed the meeting for the day at 5:57 p.m. MST.

### Day 2

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

John Wiesman, Dr.P.H., M.P.H., PACHA Co-Chair and Carl Schmid, M.B.A., Executive Director, HIV+Hepatitis Policy Institute

Dr. Wiesman welcomed the participants at 9 a.m. MST. He reviewed the Day 1 proceedings and the agenda for Day 2.

### Roll Call

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

Ms. Haves called the roll.

### Recommendation to Support and Expand the HIV Workforce

Wendy Armstrong, M.D., F.I.D.S.A., CDC/HRSA Advisory Committee on HIV, Viral Hepatitis and STD Prevention and Treatment (CHAC) Liaison, Professor of Medicine, Emory University, Executive Medical Director, Ponce de Leon Center, Grady Health Center

Dr. Armstrong shared that an aim of both PACHA and CHAC is building and maintaining a sufficient workforce for comprehensive, interdisciplinary, and team-based HIV service delivery. The CHAC Workforce Workgroup worked to draft a series of recommendations to include in a joint letter from PACHA and CHAC to invest in workforce infrastructure for decentralized, differentiated, status-neutral HIV services and incentivization of programs that create pathways for more diversity in professional careers for HIV treatment and prevention services. To that end, Dr. Armstrong presented the four recommendations drafted by the CHAC Workforce Workgroup to the PACHA members for consideration.

#### **Discussion**

Several PACHA members expressed their agreement with the importance of the workforce issue. Dr. Wiesman, speaking on behalf of the EHE Subcommittee, agreed that a joint recommendation with CHAC is a good idea and recommended refining the recommendations at the Subcommittee level. Dr. Wiesman emphasized the need of actionable recommendations that include the perspectives of people with lived experience with HIV. Dr. Cheever emphasized the need to also address the retention issues, specifically the high turnover and resignation of staff due to burnout from unsustainable demand. Dr. Smith added that the prevention workforce should also be considered in the recommendations.

The PACHA members agreed for conversations to continue between CHAC and the EHE Subcommittee at the Subcommittee meetings.

### **Ending the HIV Epidemic in Arizona**

State and County Efforts to Address the HIV Epidemic

Facilitator: John Sapero, M.I.L.; Co-Chair, Ending the HIV Epidemic in the U.S., and

the National HIV/AIDS Subcommittee, Director; ending the HIV

Epidemic; Collaborative Research, LLC

Panelists: Carmen Batista, Division Administrator, Ryan White Program, Maricopa

County Public Health

Ricardo Fernandez, Office Chief, Office of HIV & Hepatitis C Services,

Arizona Department of Health Services

Michael Renee Lopez, Deputy Division Manager, Programs, Clinical

Services Division, Pima County Health Department

Ms. Batista shared that the Ryan White Program in Maricopa County utilizes three main approaches to their work. The first approach is centering their work on people with lived experience, for example by including people living with HIV in their media campaigns. This work also includes finding ways to make data collected by the county accessible to community members. For example, county collected feedback on the best way to communicate survey results of the routine customer satisfaction survey back to the community, and the report was

redesigned to meet community needs. Ms. Batista also noted that the Program received EHE funding, which they utilized to make HIV service navigation seamless for patients. The Program also offers a variety of opportunities for engagement beyond participation in a planning council, such as community ambassadors. Lastly, the program places an importance on relationships. Ms. Batista shared that she often collaborates with Mr. Fernandez to find ways to pursue projects to meet community needs. Additionally, having relationships with state and federal agencies allows the Program to execute projects at the state and county level.

Mr. Fernandez summarized statewide efforts of the Office of HIV & Hepatitis C Services and its community partners and stakeholders. The Office's integrated planning process began in 2021 with a needs assessment of over 100 community engagement groups. Based on the assessment, the Office created a community-driven plan that aligned with EHE pillars and included increased diagnostic testing for HIV, STIs, and Hepatitis C, because these three epidemics are closely correlated in priority populations. The Office is working to decrease stigma around these diseases so individuals can feel safer seeking testing and prevention or treatment and is working to improve programming and outcomes among MSM of color, young adults, gender expansive individuals, and individuals with current or past use of illicit drugs. Treatment protocols and programs, including patient retention elements, are also in development for eventual statewide expansion. Finally, the Office is working to strengthen statewide systems for care, including coordination and interaction between systems to help increase detection, response, and engagement at the community and state levels. Although efforts have been challenged by the COVID-19 pandemic and mpox health emergency, the Office continues to move forward.

Mr. Lopez shared the efforts of the Clinical Services Program in Pima County, Arizona. He echoed other panelists' remarks that Arizona's funding focuses mostly on Maricopa County, but that the counties and communities work collaboratively across jurisdictions to address HIV, STIs, and Hepatitis C. Pima County was the first county in Arizona to initiate a PrEP program through state-community collaborations, with a focus on not only initiating but sustaining preventative services. This program was recently expanded to include PEP through an HIV-status neutral approach. Both PrEP and PEP approaches have succeeded by bridging community and health care services so individuals receive care at a single facility or are referred to additional services at community partner organizations. Pima County is developing a pilot program to leverage Arizona Department of Health surveillance data on individuals previously diagnosed with an STI, particularly less-prioritized STIs, to re-engage these individuals at clinics and connect them with testing, prevention, and treatment services. Mr. Lopez noted that statewide collaborations that create and sustain these types of programs are critical for EHE.

### **Discussion**

### Prevention and Care for AI/AN Communities

Because AI/AN communities tend to receive funding based on HIV incidence levels in communities and not on the prevention and treatment needs of the communities, Dr. Sapero asked the panelists what their organizations are doing to address prevention and care for AI/AN people. All three speakers mentioned successful collaboration and partnerships, but also the challenges of under resourced programs.

Mr. Fernandez noted that the Arizona state departments collaborate with the ITCA and local health departments to monitor rates of HIV diagnosis and coordinates with local public health workers and disease specialists to provide services across fluctuating diagnostic levels. The majority of services provided by the state department are delivered by nonprofit or local county health departments, which have staff and management dedicated to serving their local AI/AN communities. However, efforts are challenged by a lack of dedicated state department funding streams for AI/AN communities.

Ms. Batista noted that the Maricopa County Ryan White Program contracts with the Phoenix Indian Medical Center to provide patients with comprehensive care. Patients travel from hours away to the Center so they can receive dental care, physician care, vaccines, and other services. As Mr. Fernandez mentioned, the work would not be possible without dedicated staff. However, staff are also challenged by having to address several healthcare challenges, including COVID-19 and mpox. The Ryan White Program has also started working with the ITCA to work towards consistent staffing and sustained collaborations.

Mr. Lopez echoed the challenges of workforce and resources, as well as the successes enabled by collaboration. For example, Pima County is offering supplemental support services to a new Indian Health Center in Tuscon to assist them with providing comprehensive support and services but allowing the Health Center to direct the collaboration. Mr. Lopez also emphasized the importance of building support and trust with partners and the community.

### Services for Undocumented Patients

Pima County views its health department as a safety net to ensure that all patients, even patients who are undocumented, have access to care without barriers. This approach is driven by a community health perspective. Additionally, Pima County works to make services culturally accessible, in part by providing bilingual resources and being transparent about uses of collected data. The county also ensures that health care centers are aware of community resources that serve undocumented individuals to allow for secure referrals. Collaboration with these community resources is critical in also ensuring that, should patients be coming from Mexico or elsewhere, they are provided the information they need to maintain their health after services are complete.

### Services for Rural Communities

To make health care visits more accessible to the community, Maricopa County provides patients with Uber rides to their health care appointments—even patients in metropolitan areas who may otherwise have to take a 3-hour bus ride. Additionally, Maricopa County has mapped where their populations served live throughout the county and is working to contract with providers throughout the region. For example, Maricopa County provides dental insurance instead of direct dental services, enabling everyone in their service community to be within a mile or two of a dentist covered by insurance. Ms. Batista noted that the county is still working to better reflect the voices and needs of rural patients, including by moving services into more rural areas.

### Addressing Misclassification of Data

Ms. Platero noted that one reason AI/AN numbers are low in HIV data is misclassification of race and ethnicity in the data collection. For example, linking state data to tribal registry data increased identification of chronic illnesses between 30 and 40 percent. She asked what Arizona is doing to address misclassification of AI/AN data.

Mr. Fernandez noted that the state health department works with the Business Intelligence Office on data sharing agreements with tribal nations to address some misclassification. However, these agreements do not capture any AI/AN individuals who are not enrolled in a tribe. The state is continuing to work towards solutions to help address data deficiencies.

### Organizations Serving Black and Latinx Communities

Dr. Moore noted that the 2021 Arizona Surveillance data showed a high prevalence of HIV among Black and Latinx communities and asked whether the IHS Center of Excellence serve those communities in Phoenix or any other locations. The panelists were not familiar with any Center of Excellence with this service focus; the two closest IHS Centers of Excellence in Phoenix and Gallop, NM, both focus on the AI/AN population. however, other local organizations and agencies, such as the Southwest Center, that do have focus on Black and Latinx populations. These organizations and agencies include Black led organizations, such as Ebony House, Inc., in Arizona that provide services for Black community members, although Ebony House is the only organization that has an HIV-specific focus.

### Ending the HIV Epidemic in Arizona

In response to a question about best practices for ending the HIV epidemic in Arizona, Mr. Fernandez highlighted the importance of bringing people to services, expanding testing, and developing programs responsive to community needs. Mr. Lopez added that mobile health, particularly after the COVID-19 pandemic, has been integral in reaching communities where telehealth is not available due to lack of internet or smart phones. He also noted that building a safe space that is more welcoming than typical clinical facilities can help attract people from the community. He concluded by noting that visibility in the community (e.g., outreach, education, services) is important. Ms. Batista noted that media campaigns, particularly campaigns featuring community members, have decreased health disparities in Maricopa County. Another key tool is case investigations of individual patients to address reasons for inconsistent care or unsuccessful viral suppression, as well as system and process changes to address gaps when possible.

In response to a question about the remaining gaps in ending the HIV epidemic in Arizona, Mr. Fernandez noted that funding remains a major challenge for beginning and maintaining HIV prevention and STI activities. Mr. Lopez added that there are still barriers to paying providers for services rendered, including participating in planning bodies or providing program insights. Stigma also remains a barrier.

### **Remarks from the Assistant Secretary of Health**

Rachel L. Levine, M.D., Assistant Secretary of Health, Admiral, U.S. Public Health Service ADM Levine greeted the Council members and thanked the Council for their dedication to ending the HIV epidemic. ADM Levine also thanked Kaye Hayes for her individual leadership

and dedication. She wished the Council a happy Summer of Pride, noting that HHS is leading important policy initiatives to advance the health and wellbeing of LGBTQIA+ people, including President Biden's National HIV/AIDS Strategy. Pride means hope and an opportunity to catalyze change for communities, states, and the nation. ADM Levine also encouraged Council members and listeners to prioritize their own physical and mental health through tangible actions (e.g., HIV tests, routine cancer screening).

ADM Levine noted that both she and PACHA share the recognition that their power lies within people and that progress can be achieved and sustained only through intentional engagement, empowerment, and support of individuals and communities who bear the burden of public health issues they are working to address. As such, she shared that she is inspired by PACHA-to-the-People and the meetings spanning jurisdictions involved in EHE. These meetings provide impactful insights from communities across the nation, including AI/AN communities. Historically, AI/AN populations have faced discrimination, marginalization, and loss of trust due to mistreatment by the medical system. Engaging AI/AN communities and supporting their efforts is crucial to ending the HIV epidemic for everyone, everywhere.

ADM Levine was glad to report one important form of engagement: through the Minority HIV/AIDS Fund, HHS has supported the IHS and its partners in a review of three relevant national strategies (the National HIV/AIDS Strategic Plan, Viral Hepatitis National Strategic Plan, and Sexually Transmitted Infections National Strategic Plan), which has led to the development of the Indigenous Strategic Plan, also known as INDIGI-HAS. This strategy is complementary to the national strategies and enables Indigenous stakeholders to form their own responses to the syndemic in their communities by incorporating local governments and knowledge. AI/AN communities face barriers to HIV prevention, treatment, and care—including limited access to health care, stigma, and discrimination, cultural and historical trauma, and socioeconomic challenges (e.g., unemployment).

An additional concern for these communities and the nation are higher levels of STIs, which can also increase the vulnerability of affected individuals to contracting HIV. During the past few years, the U.S. has seen increased rates of STIs, particularly chlamydia, gonorrhea, and syphilis. The number of congenital syphilis cases, for example, has increased 701.5 percent over the last decade, and these increases have affected all age groups, genders, and communities. ADM Levine emphasized that addressing this increase is a paramount concern, especially in AI/AN communities.

ADM Levine added that by focusing on Tribal Nations, PACHA has reinforced the idea that to effectively end HIV in AI/AN communities, we must work collectively with cultural humility and appreciation for the unique assets of communities and understanding of the unique challenges they face. She explained that this meeting provided an informative opportunity to learn about the experiences of other partners working to end the HIV epidemic across Arizona, whose stories are vital to understand the successes and challenges of EHE. These partners' strategies in turn can inform nationwide EHE strategies and advance progress toward ending the HIV epidemic.

As part of EHE efforts, ADM Levine shared the concept that treatment is prevention and prevention is treatment. One of the EHE pillars is diagnosis, which enables providers to connect

patients to holistic care to improve their health outcomes and quality of life but also to help reduce HIV transmission. National HIV Testing Day, on June 27, 2023, contributed to these preventive efforts by challenging people to take the test and "take the next step" (i.e., prevention or treatment services), encouraging people towards sexual health and wellness, regardless of their HIV status. Tribal communities in Arizona and beyond have taken innovative approaches to expand availability of HIV testing and connect individuals to HIV prevention or care services.

ADM Levine acknowledged Dr. Wiesman and Mr. Schmid for their contributions to PACHA's work. She bid farewell to both, as their terms ended after the meeting concluded. She acknowledged Dr. Wiesman as a committed leader who led PACHA with a collective and collaborative spirit, championed innovative strategies, and uplifted voices through meaningful community engagement services. She acknowledged Mr. Schmid as an invaluable member of PACHA who was instrumental in the collective efforts to end the HIV epidemic in his role as the co-chair of the EHE and NHAS subcommittee and previously as the PACHA co-chair. She emphasized that Dr. Wiesman's and Mr. Schmid's legacies will continue to inspire everyone to reach higher, strive harder, and keep pushing to end the HIV epidemic.

ADM Levine concluded by thanking the PACHA members for their continued dedication.

# **Resolution Concerning Urgent Action Recommended for Syphilis Syndemic**

John Wiesman, Dr.P.H., M.P.H., PACHA Co-Chair and Carl Schmid, M.B.A., Executive Director, HIV+Hepatitis Policy Institute

Dr. Wiesman presented a resolution for PACHA consideration that addresses the urgent need for action regarding the syphilis syndemic. He summarized the "whereas" clauses of the document, including the rising rates of primary, secondary, and congenital syphilis nationwide; the disparate impact of the syndemic on MSM and AI/AN communities; and the concern raised by the penicillin shortage and by the recently announced recission of funds to support disease intervention specialists. In response to these findings, PACHA drafted five recommendations: create a federal task force to address the syndemic; notify providers and the public of the threat; consider declaring the syndemic a health emergency; rapidly increase production of Bicillin (penicillin) to increase availability of treatment; and evaluate options for retaining disease intervention specialists.

### Discussion

Mr. Schmid proposed an additional "whereas" statement that syphilis can increase the risk of an individual contracting HIV and that having HIV may cause syphilis to progress faster and be more difficult to treat. Ms. Platero proposed adding language to an existing resolution to state that responses by federal, state, and local governments should occur in partnership with tribal organizations. She also proposed to add another recommendation to conduct consultations with Tribal Nations through the HHS Tribal Consultation Policy. She and another PACHA member recommended that the resolution calling for a federal task force include Tribal Nations and community-based organizations in addition to the already stipulated community stakeholders. PACHA members agreed to the previous suggestions and to add a recommendation to further explore the use of doxycycline PEP as a strategy to prevent syphilis cases. Members also agreed

to clarify in the resolution's "whereas" statements that Bicillin supplies are already depleted. Ms. Roha and Dr. Guilamo-Ramos suggested adding a recommendation that substance use care providers should also be notified of the urgent threat to the public.

Mr. Smith and CAPT Oguntomilade provided grammatical and word choice corrections.

#### Vote

The Council voted unanimously in favor of the resolution, as amended (see Appendix C).

### **Ending the HIV Epidemic in Arizona (continued)**

### Community Efforts to Address the HIV Epidemic in Arizona

Facilitator: John Sapero, M.I.L.; Co-Chair, Ending the HIV Epidemic in the U.S., and

the National HIV/AIDS Subcommittee, Director; ending the HIV

Epidemic; Collaborative Research, LLC

Panelists: Grace Ashu, M.S., Regional Director, CAN Community Health

Duvia Lozano, L.M.S.W., Program Director, Chicanos Por La Causa Sheila Soto, Dr.P.H., M.P.H., Director of Community Engagement and Outreach, Mel and Enid Zuckerman College of Public Health, University

of Arizona

Thanes Vanig, M.D., Board Member, City of Phoenix, Fast Track Cities

AdHoc Committee

### **CAN Community Health**

CAN's mission is to provide a continuum of medical, social, and education services essential to the health and well-being of those living with HIV/AIDS, Hepatitis C, sexually transmitted diseases, and other diseases in order to enhance public awareness. CAN utilizes five guiding principles in its work: communicate, advocate, research and innovate, execute, and sustain. Its scope of services include prevention, testing (rapid HIV, rapid Hepatitis C, chlamydia, gonorrhea, syphilis), education, outreach, linkage to care, case management/coordination, medical and dental care, and pharmaceutical services, and its services expand beyond Arizona to clinics in Florida, Virginia, New Jersey, Texas, South Carolina, and soon Las Vegas, NV.

Prevention services available in Arizona include a mobile unit that offers free, rapid HIV and Hepatitis C testing and education in rural counties; engagement with community stakeholders; complementary services, including PrEP; and telehealth. The mobile health unit participates in an average of 15 outreach events per month, including an average of 3 AI/AN events per month, scheduled at various times to engage diverse clients. For outreach events on Native lands, CAN partners with agencies through IHS and other Native health services to provide culturally relevant services.

CAN partners with the Inter-Tribal Council of Arizona, Phoenix Indian Center, Tuba City Regional Health Care, Winslow Indian Health Care, and Navajo Nation Infectious Diseases Control & Prevention Program to provide broader collaborative and complementary services. For example, patients tested at the clinic or mobile health unit receive treatment or PrEP referrals based on HIV status, with PrEP including assistance programs, prescriptions, and adherence services. These connections are made while the patient is still on site, to prevent re-engagement challenges with an often transient community. (Ms. Ashu provided other detailed examples.)

Next steps for CAN include (1) expanding the network and creating more collaboration opportunities and (2) working together to bridge the gaps in services and resources to ensure community needs are met. This work will involve building trust with communities and community organizations. CAN has secured funding to build these capacities.

### Chicanos Por La Causa Latinos Unidos Contra El Sida (CPLC LUCES)

CPLC was founded in 1969 to advocate for equity in education, politics, and labor conditions for Mexican Americans. Today CPLC provides services to people of all backgrounds while honoring its Mexican American roots. CPLC LUCES provides HIV testing through testers or community outreach events as well as STI testing. Individuals who undergo testing are referred to PrEP and PEP navigation services. PrEP and PEP navigators also partner with organizations to provide educational training for the community for HIV, STIs, LGBTQIA+, harm reduction, and barrier methods.

CPLC LUCES's medical case management services include a rapid start initiative, with a goal of care beginning within 5 business days of diagnosis. Once patients achieve undetectable viral load, they are transferred to supportive management case services, where they are followed indefinitely at a minimum 3-month frequency. CPLC LUCES also provides psychosocial support services, including several tailored services for different groups (e.g., Spanish-speaking people living with HIV, English-speaking MSM) within the community. Ninety-six percent of CLPC's patients who attend support groups sustain viral load suppression. CPLC LUCES also provides mental health and substance abuse services for individuals who are 18 years or older and are living with HIV/AIDS, and runs the EHE-funded Fuerza Positiva University. The University is facilitated by bilingual staff providing a 12-week curriculum that includes classes on Ryan White Program services, services navigation, treatment adherence, health relationships, and more.

Finally, Ms. Lozano discussed the work of CPLC LUCES and the Pascua Yaqui tribe. While nearly all Yaqui people are U.S. born citizens, their culture is rooted in Mexico. Due to these traditional roots and because of their predominantly Catholic religious beliefs, the Yaqui have a great deal of ingrained stigma around HIV and STIs. Over several years, CPLC LUCES built a trusting relationship with the Yaqui community to provide access to HIV/STI testing; condom distribution; HIV, STI, and behavioral health interventions and education; linkage to HIV services and STI treatments; access to PrEP and PEP navigation; and community event partnerships. Moving forward, CPLC LUCES is looking to pilot bringing their services to the Cocopah reservation and Mexican Americans living in Yuma, AZ

### Community Efforts to Address the HIV Epidemic in Arizona

Dr. Soto provided an overview of three community and engagement programs to address the HIV epidemic in Arizona: the UArizona Mobile Health Units, Ventanillas de Salud (VDS), and Street Medicine Phoenix. These three programs seek to provide access to health and prevention services and promote healthy lifestyle choices to vulnerable, underserved, rural, and homeless

communities in Arizona. The programs all utilize three models: strategic partnerships, community health workers, and service-learning. Strategic partnerships at the local and state level allow for a comprehensive care program; service-learning enables University of Arizona students to apply their learning in the community setting and gain experience working in rural areas; and community health workers enable the University of Arizona to bring together a bilingual, multicultural workforce that is representative of communities being served.

Two UArizona Mobile Health Units serve the entirety of the state. These Units provide a variety of services, including health screenings, vaccinations (COVID-19, influenza, Hepatitis A), testing (HIV, syphilis, Hepatitis B and C), dental screenings, mammogram referrals, and Narcan/Naloxone distribution. Alternatively, Ventanillas de Salud are one-stop health care facilities located inside Mexican consulates inside the U.S. Ventanillas de Salud enable community members to receive access to health services or be referred to community services.

Dr. Soto shared the process utilized by the University of Arizona to identify which areas to serve and how it establishes a presence in these communities. As part of this process, the university has tracked patient demographics. Between January 2016 and January 2023, University of Arizona programs served 11,533 participants, including more females (68 percent in Phoenix, 63.1 percent in Tucson) than males. Patient ages ranged widely, but most are middle-aged patients (40-49 years old) in Phoenix and older patients (60 years old and older) in Tucson.

Another successful project led by the University of Arizona is the Mobile Outreach Vaccination & Education in Underserved Populations (MOVE-UP), which sought to increase COVID-19 vaccination rates in Southern Arizona, particularly along the Mexican border. Arizona partner organizations provided MOVE-UP with vaccine lots that were expiring soon. The most vaccines administered by the program were at the U.S. Port of Entry, where the program administered 46,176 vaccines between February 3, 2021, and January 31, 2023. These efforts helped reduce rates both in Mexico and in Arizona, protecting Arizona communities as diseases do not respect borders.

#### **Fast-Track Cities Initiative (FTCI)**

In October 2016, former Phoenix mayor Greg Stanton was invited to join the Fast-Track Cities Initiative, a global partnership with the Joint United Nations Program on HIV/AIDs, United Nations Settlement Program, and the International Association of Providers of AIDS Care, in collaboration with the local, national, regional, and international partners and stakeholders. To support the city's work in the initiative, the mayor formed the Phoenix City Council's Fast-Track Cities Ad Hoc Committee, comprised of Maricopa County public health and health care stakeholders, to ensure representation of the community.

The Committee has two subcommittees: Know Your Status and Eliminating Stigma Subcommittee and Virally Suppressed Subcommittee. The Know Your Status and Eliminating Stigma Subcommittee's goal is to increase HIV awareness, HIV testing, and PrEP awareness while reducing HIV stigma within the community. The Subcommittee partners with programs and organizations to help serve key populations, including Black communities, Latinx communities, LGBTQIA+ youth, and drug users.

The Virally Suppressed Subcommittee seeks to (1) launch a rapid start program, (2) increase engagement and retention for people living with HIV, and (3) work with health care providers to integrate routine HIV prevention and testing. To help local providers, the Subcommittee created a single page resource with contact information for HIV-negative patients to be referred to PrEP or PEP services and for HIV-positive patients to be referred to the rapid start program. To accommodate this influx of patients to PrEP and PEP services, FTCI trained providers at Maricopa County's federally qualified health centers on providing PrEP and PEP services.

The FTCI rapid start program, State of Arizona Rapid Treatment (START), seeks to link newly diagnosed patients or patients who fell out of care and are reengaging treatment to HIV treatment services within 5 days. Before the launch of START, patients had to wait an average of 30 days to be linked to care. START patients are connected to treatment within 4 days. Before START, patients took an average of 129 days to reach virally suppressed status after diagnosis. Now, START patients are virally suppressed within about 38 days after diagnosis.

Dr. Vanig shared the following lessons learned from the launch and maintenance of START: (1) requiring HIV testing sites to adjust their practices to a single, unified system for tracking, reporting, and referring patients is complicated; and (2) rapid start clinics exist around the country and start-up can be greatly assisted by existing programs. Dr. Vanig also highlighted the following challenges during the launch process, and how START overcame these challenges. First, programs need a way to cover services for uninsured patients. START was able to work with the Ryan White Program to streamline the application process so patients began services within four hours. Second, programs need a means of effectively communicating with stakeholders. START created a red phone system, which has placed a single, dedicated line at all HIV testing sites, county STD clinics, case management locations, and emergency rooms to rapidly refer patients to care locations. FTCI also added a phone line connecting providers to the Maricopa County Clinic for rapid referrals. Finally, programs need a way track success. The Arizona Department of Health Services partnered with care sites to track progression and retention of patients in START.

Based on the successes of START, FTCI launched a rapid PrEP program utilizing the tools in place for START. FTCI is also looking to use the same system to launch a rapid Hepatitis C program. Dr. Vanig shared that other cities have expressed hesitancy to join FTCI because of existing competitiveness for funds for standing up and maintaining services. He shared that he is grateful that Phoenix was able to bring together FTCI to create a collaborative environment.

### **Discussion**

Ms. Platero asked the panelists to describe how they protect data collected at mobile units. Ms. Ashu explained that CAN program staff are trained to use personal health information (PHI) lock boxes and a strict policy on transporting PHI. For rural overnight trips, PHI must be in the lockbox and additionally locked in another location (e.g., cabinet, bathroom) to ensure security. CAN also uses the encrypted eClinical electronic medical record (EMR) system.

Ms. Platero asked about protocols for program work on reservations. Ms. Ashu noted that CAN respects data sovereignty and defines patient-focused care to include the comfort of the patient

with health care services. CAN must receive permission from a tribal council before holding an event on tribal lands and has been working to increase conversations about tribal visits.

Dr. Moore asked Ms. Ashu how treatment is coordinated for patients with positive HIV tests. For mobile unit events, patients who test positive are transferred either to the CAN clinic for care or a patient care coordinator to arrange transportation for non-local individuals. For more rural communities, CAN connects patients with an organization that is local to them.

Dr. Moore also asked Ms. Ashu to expand on CAN's partnerships with communities of color. CAN has partnered with Gilead as an organization that already had tight bonds within the community and to leverage those bonds to work in a community-centered way and provide services to communities of color.

Dr. Moore asked Ms. Lozano to expound on the work on rental assistance. Ms. Lozano noted that the 340B program was developed several years ago to provide patients receiving PrEP and PEP the opportunity to apply for rent assistance. Housing assistance remains the highest need in the population CPLC serves, and CPLC provides a last resort resource (one-time rental assistance up to \$2,000) so individuals do not lose their homes. CPLC does due diligence research to ensure applicants do not qualify for other programs before considering applications.

### **PACHA Subcommittee Reports**

### EHE and the Updated NHAS

Carl Schmid, M.B.A., Co-Chair

Mr. Schmid reported that, in response to concerns regarding the Ready, Set, PrEP data collection discussed at the March PACHA full committee meeting, the Subcommittee and OASH met with Ready, Set PrEP staff. They clarified that data collection is necessary to distribute drugs to individuals unable to receive PrEP through private insurance, and ultimately the Subcommittee was satisfied with the explanation. The Ready, Set, PrEP team assured the Subcommittee and OASH that the data collected will not be provided to pharmaceutical companies.

The Subcommittee also discussed creating a new, shorter name for itself that better reflects the goal of ending HIV. Mr. Schmid suggested that the new name should reflect the role of federal partners as well as community engagement. The development and finalization of the new subcommittee name will be handled at a future meeting.

In May 2023, the Subcommittee investigated press reports about jurisdictions not spending their EHE funds. OASH staff briefed the Subcommittee regarding the jurisdictions of concern. Often, the spending delay was due to state grant processes, COVID-19 and mpox, and other external factors. To address the barrier of state grant processes, Mr. Schmid suggested that EHE funding be directed to community-based organizations (CBOs), rather than states, in the future. In June, the Subcommittee received a report from Harold Phillips, Director of the HHS HRSA's HIV AIDS Bureau, on the National PrEP Program.

Mr. Schmid concluded by noting priority issues to be considered by the Subcommittee, including the need for a workforce resolution, additional attention for HIV and aging, and a briefing on the America's HIV Epidemic Analysis Dashboard (AHEAD) dashboard.

### The Global Agenda

John Wiesman, Dr. P.H., M.P.H., PACHA Co-Chair

In the absence of the Subcommittee co-chairs, Dr. Wiesman provided the Subcommittee update. The Subcommittee continues to focus on continuing to amplify work led by and focusing on women and girls. Additionally, the Subcommittee has been monitoring the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) reauthorization process. Although the Subcommittee is unable to advocate to Congress, PACHA has a vested interest in the outcome of this process. Finally, with the end of John Wiesman's tenure after this meeting and Greg Alton after the September meeting, the Subcommittee is open for additional members.

### Stigma and Disparities

Justin C. Smith, M.S., M.P.H., and Rafaelé Narváez, Co-Chairs

Dr. Smith reported that the Subcommittee has focused on the Zero HIV Stigma document discussed and approved earlier in the meeting and has continued work on MHS. The Subcommittee is interested in continuing work in several areas, including workforce issues, resourcing CBOs, housing for minority populations and the National PrEP Program. Finally, Dr. Smith announced that both he and Rafaelé Narváez will be leaving PACHA after the September meeting, at which time new Subcommittee co-chairs will be announced.

### Molecular HIV Surveillance/Cluster Detection Response

Justin Smith, M.S., M.P.H., Co-Chair, Stigma and Disparities; and John Wiesman, Dr. P.H., M.P.H., PACHA Co-Chair

Since the last PACHA full committee meeting, PACHA members met with Dr. Jay Butler, senior advisor for infectious diseases and former deputy director for infectious diseases at CDC, to elevate their concerns regarding MHS/CDR and review recommendations presented in PACHA's October 2022 resolution. The CDC has not formally responded to the resolution but informed PACHA to expect more information. Dr. Smith also noted that PACHA will be reviewing new literature on MHS and CDR, particularly on potential additional or alternative directions and on community partner engagement.

Drs. Smith and Wiesman acknowledged the concerns voiced by members of the public and PACHA members regarding MHS and CDR at this and past meetings. They emphasized that they are interested in engaging with the White House and CDC on the resolution, CDC's eventual response, and the transparency of its response to PACHA and the public.

### **PACHA Member Reflections**

Several PACHA members emphasized the need to address work force issues in an upcoming PACHA full committee meeting. Additionally, many PACHA members acknowledged the impressive dedication but also unsustainable efforts of providers in the communities highlighted during the meeting and collectively called for the increase of resources for AI/AN communities and other communities of color. Many PACHA members also shared that they were disappointed to hear about the persistence of stigma among communities but were also encouraged to hear about the work being done to address stigma in AI/AN communities. Finally, many PACHA members expressed their thanks to Drs. Wiesman and Schmid.

A number of members expressed appreciation for the site visits, as well as the particular focus of the meeting on AI/AN communities. Dr. Moore expressed that PACHA has heard about the underservicing and under resourcing of these communities, without understanding the unique needs of the communities. Dr. Moore also emphasized the need to perform a deeper dive into data to investigate the pervasive patterns of stagnation or worsening of HIV and social determinants of health among priority populations.

Ms. Diggs echoed the repeated sentiment of "people trusting people," expounding that the organizations represented at the meeting were successful only because they treated their community members as people and not numbers and worked with trust and compassion. Ms. Diggs also shared a personal reflection that she felt messaging and education regarding HIV has reduced in visibility over the years, and she encouraged a reversal of that trend. Ms. Diggs also voiced support for the revision of the upper age limit for testing to include individuals over the age of 64 and encouraged PACHA members to support the revision.

Ms. Platero shared her key takeaways from PACHA-to-the-People, including (1) the need for providers to have ongoing learning for the care and treatment of older people; (2) increased access to testing, including the removal of the upper age limit; (3) coverage of alternate therapies by Ryan White, Medicare, and Medicaid; and (4) need for increased focus on rural communities. She expressed appreciation for the opportunity to present on tribal sovereignty and encouraged making presentations on tribal sovereignty part of the education for public health workers. Ms. Platero echoed the themes from the meeting of tribal and culturally focused care to support the wellbeing of AI/AN people. She concluded by arguing that tribes should not be forced to prove that their practices are evidence based to be able to have them included in health care.

Dr. Stewart echoed the importance of trust and of providers building trusting relationships with their communities. She also noted the importance of building relationships, encouraging storytelling, expressing cultural humility, ending stigma, and creating safe spaces.

Dr. Moore shared his appreciation of the ability of providers meeting people where they are and never give up on community members, especially individuals not yet ready to seek treatment. He also expressed the importance of the infusion of culture into health care work, including the humanizing aspect of seeing people as people and not numbers. He highlighted moments from the meeting, including passing the ending stigma resolution and syphilis resolution. He concluded with remaining barriers and challenges that still need to be addressed in the field, including housing insecurity, substance use in communities, access for undocumented individuals, and the need to increase the testing for individuals over the age of 64.

Dr. Smith noted the inclusivity of the programs presented, including LGBTQ+ and 2 spirit individuals. He noted that many of the presenters were mentored by Dr. Platero, who modeled a strong way of training next generation providers. He also shared that best practices shared at the meeting should be more broadly shared and replicated in the field, as appropriate. He concluded by highlighting the global health approach, illustrated by partnerships across the United States and Mexican border. Such approaches are crucial as diseases do not respect borders.

Dr. Sapero shared his amazement at the breadth of work conducted in the communities that shared their programs. He highlighted the commentary on advocating for PEPFAR funding and

the difficulty of receiving funding, and the need for PACHA to drive change in that area. Dr. Sapero also commended the ability of PACHA to engage the public during PACHA-to-the-People to address issues of public concern.

Dr. Harrison shared the need to focus on providing cultural humility in health care settings in all communities. He also noted the need for more research to address HIV in an aging population. He expressed appreciation for the elevation and integration of status neutral health care and syndemic into the vocabulary of the meeting, as both concepts have been gaining traction within the government.

Mr. Schmid provided a reflection on his four and half years serving as a PACHA member. He began by reflecting on the difficulties at the beginning of his term balancing the Trump Administration's call for renewed focus on HIV while simultaneously diminishing the Affordable Care Act. Despite early challenges, Mr. Schmid noted the successes of PACHA, most importantly the inclusion of voices from the community. Over the years, PACHA passed several resolutions to address the needs of the community, including national HIV strategies, EHE, and HIV testing. PACHA also worked to address several different issues within the community, including women and aging, HIV in Black communities, and HIV in Latino communities and Puerto Rico. PACHA also was able to engage with CMS as a partner in their efforts. Mr. Schmid concluded that he will continue to be an advocate for HIV, thanked those who he worked with over the years, and wished PACHA well in continuing to carry on their strong work.

Dr. Wiesman echoed the sentiments that Mr. Schmid shared about the challenges and successes of PACHA in the four and half years they served. He expressed his thanks for the providers and advocates on the ground working for the interests of the HIV community. He highlighted the importance of sharing the lived experience and bringing fresh ideas to PACHA. He concluded that he was grateful for the work completed in the time he served, grateful for the people he had a chance to work with and looked forward to the future of the committee's work.

Ms. Hayes presented Mr. Schmid and Dr. Wiesman with a certificate commemorating their time served as members of PACHA.

# **Next Steps and Closing Remarks**

RADM Michael D. Weahkee, M.B.A., M.H.S.A., Assistant Surgeon General, U.S.P.H.S., Deputy Director, Phoenix Area IHS

In closing remarks for the meeting, RADM Weahkee shared that IHS is working to ensure access to quality health care services for AI/AN people living with HIV and those at risk for contracting HIV. This work is being pursued using culturally responsive partnerships with communities. RADM Weahkee shared that as an IHS director, he was among the first federal officials involved in EHE and has been grateful to see EHE funding utilized to make a difference nationwide. IHS supports PACHA efforts to provide advice and recommendations to the Assistant Secretary for Health regarding the development and implementation of EHE and the National HIV/AIDS Strategy.

RADM Weahkee expressed appreciation that during their site visits and meeting, PACHA members witnessed how AI/AN communities are one with their land and culture and how that

relationship influences health care services throughout Arizona. Pheonix IHS is consistently working to expand partnerships between IHS and Native communities to end the HIV epidemic in Indian Country. These partnerships—which include individual tribes; urban Indian Health Organizations; federal, state, and county governments; and academic organizations—address challenges in the community, particularly increasing the Phoenix work force from within the community.

In addition to expanding partnerships, IHS also works to address barriers to health care for AI/AN people living on reservations, in rural communities, and in urban areas. Stigma in Native communities can be a debilitating barrier to receiving disease prevention or health care treatment services people need and deserve. Telehealth and other innovative tools, and implementing the syndemic approach, can help address stigma.

IHS is also training clinicians and the public health work force on PrEP, including clinical guidelines. PrEP was added to the National IHS formulary to reduce the risk of infection among those most at risk, and it is now routinely available. As an agency, IHS engages in tribal consultations and urban conferences to seek input on implementing new programs, such as PrEP, that impact tribes and urban Indian organizations. Phoenix IHS continues to collaborate with Native serving organizations to support and promote HIV screening and connect people living with HIV to appropriate and culturally specific care and treatment. They also continue to expand outreach and education to tribes and tribal organizations to improve their adoption and utilization of HIV prevention best practices and models of care.

RADM Weahkee shared that the Indian Health System of Care has more than 600 hospitals, health centers, and health stations serving 2.6 million AI/AN people from 574 sovereign tribes. In fiscal year 2018 (FY18), IHS received \$3.6 million from the Minority HIV/AIDS Fund; in FY19 it received \$7.9 million; and in FY22 it received over \$11 million. Activities supported through the Minority HIV/AIDS Fund build capacity, promote innovation, enable cross-agency collaboration, integrate best practices in response to HIV among minority communities, and help IHS and communities respond to the National HIV/AIDS Strategy Goal to reduce HIV-related health disparities and inequities. For example, funds allow tribal and Indian health programs around the U.S. to develop and conduct local, state, regional, and national HIV and Hepatitis C education, prevention, and treatment programs. These efforts meet the IHS goal of raising the physical, mental, social, and spiritual health of American Indians and Alaska Natives to the highest level, in part by ensuring communities have tools and information to protect themselves.

RADM Weahkee concluded by thanking IHS employees, facilities, tribal and Indian organizations, and PACHA members.

Dr. Wiesman thanked RADM Weahkee and expressed appreciation for all those who make PACHA meetings possible. He adjourned the meeting at 3:18 p.m. MST.

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

#### June 2023 PWN PACHA Public Comment

Ny name is Elena Ferguson and I currently serve as the Policy Specialist at Positive Women's Network, a national membership body led by and for women and people of trans experience living with HIV. I also coordinate the Health Not Prisons Collective, which seeks to decarcerate public health.

We are here to express concern about the ongoing, dangerous practice of molecular HIV surveillance as it intersects with policing and surveillance of people living with HIV and communities most impacted by HIV. We have previously addressed the Council about our concerns with the lack of informed consent and privacy protections for sensitive HIV data, in the face of rising human rights violations and attacks on queer, trans and BIPOC communities.

We are grateful for the leadership of this Council in passing a resolution to address this important issue. However, we are outraged and disappointed that despite the Council's dedication and hard work to make concrete recommendations that would mitigate the harms of molecular HIV surveillance, the Office of National AIDS Policy appears to be refusing to take this issue seriously

During the March PACHA public comment, people living with HIV went on record to publicly revoke consent for the sharing of health data related to their HIV diagnosis, genotyping, or any other related information. We hope that the Council heard these concerns and took them to heart. It is unacceptable that the CDC continues funding MHS as a core federal HIV strategy while disregarding the concerns and concrete recommendations made by networks of people living with HIV, human rights advocates, privacy advocates, this distinguished Council, and most recently the UN Special Rapporteur on the Right to Health.

The consequences of any form of criminalization can be long-standing and severe. The danger and long-lasting harms of medical information being sharing in the context of criminalized identities or behaviors is neither hypothetical or overblown – recent data shows that, in cases where adults were criminalized for seeking abortion care, people were reported to the police most often by health care professionals, and just last week we found out that the health data of trans patients was released to the TN Attorney General. Survivors of HIV criminalization can experience loss of privacy, custody of children, and employment. The federal government, including CDC, must use every lever of power to ensure consistent and robust data protections regardless of who someone is or where they live and to uphold, or at least stop violating the human right to informed consent for people living with HIV.

Our work to elevate concerns with MHS and HIV criminalization is one, necessary component of our fight to dismantle systems that perpetuate racism, oppression and anti-Black violence

The lives, dignity and safety of the estimated 1.2 million people living with HIV in the US depend on us taking these human rights issues seriously. It's networks of people living with HIV who have been leading the way in making sure these issues are addressed in the federal response. We urge PACHA to ensure meaningful involvement by PLHIV networks in all aspects of decisionmaking about the lives and health of people living with HIV. And we look forward to collaborating with PACHA to demand a federal response that respects, protects, and fulfills the health and human rights of people living with HIV.



Presidential Advisory Council on HIV/AIDS June 28, 2023 - Phoenix, Arizona Public Comment

Hello - my name is Michael Blasingame and I have been the Director of Data Services at Healthvana for the past three years - some of you might recognize Healthvana from our patient engagement and PrEP adherence work with providers from the largest global HIV provider and Chicanos Por La Causa, here in Phoenix, that we've been working with for 3 years, and whose director, Duvia Lozano, is actually speaking tomorrow.

#### My 10-year anniversary on PrEP

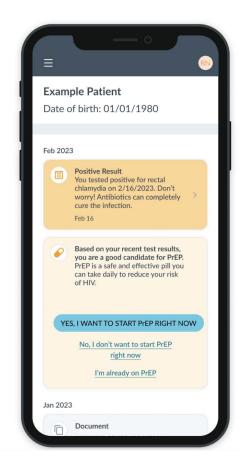
I just hit my 10-year PrEP anniversary starting PrEP as an HIV prevention tool in May of 2013, and a decade ago, there was little patient advocacy—you had to fight for yourself to get on PrEP. My primary care physician, a gay man who likely lost friends and colleagues to the AIDS crisis, initially told me that I did not need to get on PrEP - that I was not a good fit. I had to be my own advocate.

Ten years later, PrEP has undoubtedly changed the HIV landscape, but we still have so much room for improvement. How can we continue to increase access to PrEP without placing the burden of this access on the individual?

I'm proud to work at a company that leverages technology to proactively intervene and advocate for potential PrEP patients and then also accompanies these patients throughout their entire PrEP journey. The communities we serve have the most to gain from increased access to PrEP, as 65% of our patients come from non-White communities of color.

### From Positive Rectal STI to PrEP Education / Telehealth in Hours

Given the work we do in test result delivery, we also have the ability to reach out to the individual. In 2017, a study published in Sexually Transmitted Diseases found that people who test positive for rectal chlamydia or gonorrhea have a three-fold increased chance of acquiring HIV and this persists for up to one year. Because these folks are ideal candidates for PrEP, we are now piloting a program that schedules an initial PrEP appointment within 24 hours of a patient receiving their positive test result, and the initial data on this syndemic approach is really exciting (see real screenshot below). In the first 6 weeks of this pilot, 37% of patients with a positive rectal STI result indicated they were ready to start PrEP right then. This work highlights President Biden's National HIV/AIDS plan, specifically the Leveraging Technology Innovations to Improve HIV Prevention and Treatment.



#### **Engagement** → **Trust** → **Better Adherence and Outcomes**

But just getting people on PrEP is insufficient. We also need to get them to stick with it. In 2018, a paper published in the Journal of AIDS cited a lack of adherence as a significant, contributing factor to PrEP not being as effective for certain communities, including Black and Brown MSM. We can address this gap through adherence monitoring to quantitatively measure PrEP adherence and then communicate this information to patients and their healthcare providers. Building this relationship with both patients and providers may also help identify people who may need additional conversations around PrEP or who may be better suited for different interventions such as injectables.

Although HIV and HIV prevention are complicated, meeting patients where they are at does not need to be. By building patient trust and advocating for our patients, we can increase both access and adherence to PrEP leveraged by emerging technologies, which will ultimately help end the HIV epidemic.

#### Thank you

Michael Blasingame (Healthvana's Director of Data Services)

Good afternoon! Thank you for giving me the opportunity to speak today. My name is Terri Wilder (she/her) and I am the HIV/Aging Policy Advocate at SAGE.

As many of you may know, the CDC currently recommends that everyone between the ages of 13 and 64 get tested for HIV at least once as part of routine health care. These recommendations have not been revised since 2006. Knowing one's HIV status is vital for timely access to essential prevention and treatment services, including HIV medical care. However, most test-and-treat strategies have primarily focused on younger people, leaving older individuals behind. Older people account for around 17% of new HIV diagnoses in the United States, and they are more likely to be diagnosed with HIV at a later stage of the disease compared to younger people.

In New York State, where SAGE is headquartered... in 2021, among individuals aged fifty and above who were diagnosed with HIV, 35% were simultaneously diagnosed with AIDS, indicating a more advanced stage of the disease at the time of HIV diagnosis. Similarly, among individuals aged sixty and above diagnosed with HIV in the same year, 37% of were concurrently diagnosed with AIDS. This data clearly highlights that older individuals are not undergoing routine HIV testing, resulting in more advanced disease at the time of diagnosis and an elevated risk of premature death.

Everyone who acquires HIV benefits from prompt diagnosis and treatment initiation, and preconceived ageist ideas about older adults should not be a barrier to that care. Studies have shown that failure to consider an HIV diagnosis has contributed to delayed initiation of life-saving antiretroviral therapy (ART) in older persons with HIV. Early treatment is particularly important for older people due to **decreased** immune recovery and an increased risk of serious non-AIDS events in this population.

A Lancet journal article highlighted that studies have documented more missed opportunities for diagnosis among older individuals compared to younger ones. Therefore, we need to implement interventions specifically designed for older individuals, with involvement from health systems, community-based organizations, people with lived experience, and the government.

It is clear that routine HIV testing is not reaching older people, leading to delayed diagnoses and increased risk of premature death.

So let me close by sharing a story I was recently told.....A patient diagnosed with HIV at the age of seventy-nine only discovered their HIV status after changing to a new primary care provider who performed an HIV test. This story raises important questions for me: What if this individual had not changed to a new provider? Would they have ever been diagnosed? Would they have gone years without knowing their HIV status, eventually developing advanced disease? The potential consequences could have been devastating and possibly deadly.

Thank you all for your time and consideration. It is time to remove the upper age limit from the CDC HIV testing guidelines. I welcome PACHA members and others in the room in joining efforts to advocate for the removal of the upper age limit of the CDC HIV testing recommendations.



July 6, 2023

Presidential Advisory Council on HIV/AIDS (PACHA)

Pease see below the public comment provided virtually from Jeff Berry of The Reunion Project at the June 28, 2023, 77<sup>th</sup> PACHA meeting. Thank you again for this opportunity, and let me know if you have any questions, I can be reached at (773) 454-5333 or jeff.berry@reunionproject.net.

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Good afternoon, Co-Chairs and members of the Presidential Advisory Council on HIV/AIDS and distinguished guests.

Thank you for the opportunity to provide public comment today. My name is Jeff Berry, my pronouns are he/him, and I'm executive director of The Reunion Project, the national alliance of long-term survivors of HIV. Since 2015, The Reunion Project is the only national network dedicated solely to improving the quality of life for long-term survivors of HIV through local programs that are designed by, and for, people living with HIV and our allies.

In a few years almost three quarters of people living with HIV will be over the age of 50. There are approximately 300,000 long-term survivors of HIV in the U.S., defined as people who were diagnosed before 1996. The Reunion Project holds an expansive view of long-term survival which includes people who acquired HIV around birth or early in life and have been living with HIV for many years, also known as lifetime survivors.

We hear a lot about quality of life, and it's great to now have long-term survivors and older adults with HIV incorporated into the revised National HIV AIDS Strategy, but I ask members of this committee, where is the sense of urgency?

Many organizations have jumped on the HIV and aging bandwagon, but after 40 years of this work, if we've learned anything it's that a piecemeal or patchwork approach never works. We need a concerted, coordinated effort starting at the very highest levels, from the ground up, and infused at every step along the way. People aging with HIV and long-term survivors must not just be an afterthought, a working group, or an add-on to an existing program. We deserve better.

info@reunionproject.net www.reunionproject.net

To that end, we are calling for President Biden to appoint an HIV and Aging Czar to lead these efforts. The HIV and Aging Czar, working closely and in conjunction with ONAP Director Phillips, will coordinate efforts across all federal agencies and with key community partners to prioritize the needs of older adults with HIV and long-term survivors, by meaningfully including us in the design of programs, research, and policies that will allow us all to thrive and age gracefully and with dignity.

Much like people living with HIV transformed healthcare and research in the early days of AIDS through the HIV self-empowerment movement inspired by The Denver Principles, we have an opportunity to create a system that can be replicated and serve as a model for aging in this country, and throughout the world. Let's not squander that opportunity.

Thank you.

Jeff Berry

Executive Director The Reunion Project reunionproject.net

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I am Jax Kelly, President of Let's Kick ASS Palm Springs (LKAPS.org), a 501(c)3 based in Palm Springs, California that serves over 400 long-term survivors of HIV/AIDS and witnesses to the plague years. Our community in the Coachella Valley is estimated to have between 2,500 to 5,000 people living with HIV over the age of 50. By providing social connections, HIV and aging education and advocacy, LKAPS seeks to relieve the stress from AIDS Survivor Syndrome and isolation that impacts our health. I am a Black gay man over the age of 60 living with HIV since 2006 while I have been active in the HIV/AIDS community since 1991.

I support recent efforts by NMAC and its National HIV and Aging Advocacy Network to seek changes in the Older Americans Act to include people aging with HIV as a population of greatest social need. In 2021, California made this change in its version of the Older Americans Act and I encourage advocates to seek similar changes in their own state laws governing their local Area Agencies on Aging.

It has become necessary for HIV and aging advocates to go beyond the usual networks of AIDS service organizations to seek a seat at the table where aging advocates are. Long before HIV impacted our communities, advocates were working on issues concerning our aging population. Medicare and Medicaid served the healthcare needs of older persons in ways similar to Ryan White for people living with HIV. The federal government passed the Older Americans Act to respond to a lack of community social services for older persons such as home-delivered and congregate meals, job training, senior centers, health promotion benefits enrollment, caregiver support, transportation, etc. I will continue to press for changes in Ryan White to support these services for people aging with HIV while I ask our AIDS service organizations to become present in these spaces. I attended a statewide conference last Fall in Sacramento to celebrate the first year of California's Master Plan for Aging. We highlighted three specific needs that cut across the myriad of constituencies represented: caregivers, mental health and homelessness were the top three priorities. I believe out of hundreds of attendees, I was the only representative of an AIDS service organization. This must change. More of us must be present in aging spaces. And please ask any AIDS service organization that addresses HIV and aging whether they are focused on caregivers, mental health and homelessness.

We must and we can do better.

Jax Kelly, JD, MPH, MBA President, Let's Kick ASS Palm Springs JaxKelly@LKAPS.org Dear Presidential Advisory Council,

My name is Rain Garcia, a Latina trans woman who works at the Alamo Area Resource Center in San Antonio, Texas. I am writing to you today to express my deep concern about the HIV epidemic and the challenges faced by HIV advocates, especially within the transgender community.

As a trans woman myself, I have experienced firsthand the discrimination that many of us face daily. HIV has had a profound impact on our community, with transgender individuals being disproportionately affected by the virus. Discrimination against trans individuals not only exacerbates the physical and emotional toll of living with HIV, but it also hinders our ability to provide essential support to those in need.

When we face discrimination from leaders within our line of work, it becomes increasingly difficult to combat bullying and provide comprehensive help to those who require it. Sadly, many people in our field choose to leave their positions due to the mistreatment and prejudice they encounter. This loss of dedicated workers further perpetuates the struggles faced by our clients.

To effectively end the HIV epidemic, we urgently need assistance and support for both our clients and our fellow workers. By addressing the discrimination faced by trans individuals, we can create an inclusive and supportive environment. This will not only empower us to assist those affected by HIV, but it will also ensure that our clients receive the care and attention they deserve. Accessible resources, training programs, and policies that promote inclusivity are crucial steps toward eradicating the barriers faced by our community.

Additionally, it is essential for leaders in our field to recognize the unique challenges faced by transgender individuals. By actively working to eliminate discrimination within our organizations, we can foster an environment where advocates feel supported, courageous, and motivated to make a difference.

Together, through collaboration and empathy, we can amplify our voices and advocate for equitable treatment for all individuals impacted by HIV. By standing united, we can work towards a future where discrimination no longer hinders our ability to help those in need.

Thank you for your time and consideration. I look forward to hearing from you and working together towards a brighter, healthier future for all.

Sincerely, Rain Garcia Michael Morón
CC Morquecho
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210-591-0213
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July 7, 2023

Presidential Advisory Council on HIV/AIDS
Office of the Assistant Secretary for Health
Department of Health and Human Services
Hubert H. Humphrey Building
200 Independence Avenue, SW, Room 443-H
Washington, D.C. 20201

Dear Members of the Presidential Advisory Council on HIV/AIDS,

Subject: Public Comment on Improving Care Coordination, Funding for Agencies in High-Need Communities, and Ending the HIV Epidemic

We are writing to provide public comment and share our concerns regarding the need to enhance care coordination, increase funding for agencies serving people living with HIV in high-need communities, and the urgent goal of ending the HIV epidemic. As concerned citizens and advocates for the rights and wellbeing of those affected by HIV/AIDS, we believe that these issues require immediate attention and concerted efforts.

Firstly, it is imperative to focus on improving care coordination for individuals living with HIV. Care coordination plays a vital role in ensuring that those affected by HIV receive comprehensive and seamless healthcare services. By enhancing coordination and collaboration among healthcare providers, government agencies, and community-based organizations, we can eliminate barriers to care, address health disparities, and improve health outcomes. It is crucial to prioritize the development and implementation of effective care coordination strategies that integrate all aspects of HIV care, including testing, treatment, prevention, and support services.

Furthermore, we urge the Presidential Advisory Council on HIV/AIDS to allocate increased funding specifically for agencies serving people living with HIV in high-need communities. These communities

often face multiple challenges, including limited access to healthcare, stigma, poverty, and disparities in social determinants of health. By providing adequate financial resources to these agencies, we can ensure that they have the capacity to deliver comprehensive services tailored to the unique needs of these communities. This includes funding for testing initiatives, treatment programs, mental health services, community outreach, education, and support programs. Increased funding will enable agencies to expand their reach, enhance their impact, and make a significant difference in the lives of those affected by HIV in high-need communities.

Lastly, we want to emphasize the urgent need to end the HIV epidemic. While progress has been made, it is essential to remain committed to the goal of eradicating new HIV transmissions and achieving an AIDS-free generation. To achieve this, we must prioritize prevention efforts, increase access to pre-exposure prophylaxis (PrEP), expand HIV testing initiatives, and promote comprehensive support for individuals living with HIV. Additionally, investing in research and innovation is crucial to develop new prevention and treatment strategies that will contribute to ending the HIV epidemic once and for all. It is through collaborative efforts, strong leadership, and sufficient resources that we can make significant strides toward this ambitious goal.

In conclusion, we commend the Presidential Advisory Council on HIV/AIDS for its critical work in addressing the challenges faced by individuals living with HIV. We urge the Council to prioritize improving care coordination, allocating increased funding for agencies serving people living with HIV in high-need communities, and continuing the relentless pursuit to end the HIV epidemic. Together, we can create a future where every person affected by HIV receives the care, support, and resources necessary to lead a healthy and fulfilling life.

Thank you for considering our comments. We trust that you will carefully review and incorporate them into your ongoing efforts.

Sincerely,

#### Dear Members of PACHA.

As the Director of Care Coordination at the Alamo Area Resource Center in San Antonio, Texas, I am pleased to provide valuable insights on improving our nation's response to the domestic HIV epidemic. Our organization serves a diverse population, including the LGBTQIA community and a significant number of Latinx individuals.

During the period from January 1st to June 27th, 2023, our programs have demonstrated promising outcomes, and I am proud of the unwavering dedication displayed by our teams. Notably, the ASCEND program has delivered services to 175 unduplicated clients, focusing on newly diagnosed individuals and those who have fallen out of care. Our ASCEND Care Coordinators ensure comprehensive support, encompassing medical care, medication assistance, mental health services, and resource coordination. We have observed an increase in young gay Latinx men aged 18-29, Latinx immigrants, Latina cis-gender women, individuals with substance use disorders, and those experiencing homelessness seeking our services.

Our Medical and Non-Medical Case Management teams, comprised of two Medical Case Managers and one Non-Medical Case Manager, have made a significant impact on care coordination. With a focus on severe cases, they have facilitated medical referrals, benefit enrollment, emergency housing assistance, and medication management for 88 and 84 clients, respectively. In addition, our Client Access Navigators have played a vital role in ensuring medication assistance, resource linkage, and timely updates to Ryan White eligibility for 512 clients.

While our programs have shown success, we have encountered challenges during system transitions. The implementation of Take-Charge Texas, a state program, resulted in delays and training issues that impacted client services. We are diligently adapting to the new system alongside the introduction of the e2SanAntonio record system by our Administrative Agency. Aligning eligibility updates and paperwork remains a challenge due to discrepancies between state and federal guidelines. This creates confusion and additional workload for our staff and clients. We are committed to addressing these challenges and streamlining processes to enhance service utilization.

Furthermore, we have witnessed an increase in the immigrant population from various Latin countries. Hiring bilingual case managers has proven challenging due to low wages, hindering our ability to attract and retain talent. It is imperative that we address salary disparities and provide a livable wage to our dedicated staff. By offering competitive compensation, we can effectively address the needs of diverse populations and contribute to the collective effort of ending the HIV epidemic.

Additionally, we recognize the importance of fostering collaboration and communication among AIDS service organizations. We must work together to ensure seamless referrals, avoid duplication of services, and foster a culture of collaboration. It is essential for agencies to prioritize a collaborative culture, supporting the shared goal of ending HIV.

We also urge administrative agencies to prioritize diversity in leadership roles. This commitment is crucial in combating unconscious bias and better reflecting the populations we serve. Diverse leadership brings different perspectives, broadens decision-making processes, and promotes inclusive policies and practices. By raising awareness of unconscious biases, we can create a culture of accountability and continuous improvement.

One approach that can greatly support the ending of HIV in the United States is the implementation of a status-neutral model. This model ensures that individuals, regardless of their HIV status, have access to comprehensive prevention, testing, treatment, and care services. By removing barriers and stigma associated with HIV status, we can empower individuals to seek the necessary support and engage in effective prevention strategies. The status-neutral model promotes equity, inclusivity, and a person-centered approach, which are key factors in achieving the goal of ending HIV. To fully realize the potential of the status-neutral model, organizations like mine require additional resources to expand our services, enhance community outreach, and provide targeted interventions for populations disproportionately affected by HIV. These resources will enable us to implement innovative prevention strategies, scale up testing initiatives, strengthen care coordination, and offer comprehensive support to individuals living with HIV.

I recognize that PACHA plays a pivotal role in guiding national policies and funding allocations for HIV programs. We kindly request your support and advocacy in securing and creating grants and funding opportunities that align with our mission and vision. By investing in organizations like ours around the nation that are committed to the status-neutral model, we can collectively advance the national response to the domestic HIV epidemic.

In conclusion, I commend the tireless efforts of our staff in providing access to medication, medical services, and resources to our clients. However, there are areas that require attention and improvement. By addressing system challenges, promoting fair wages, fostering collaboration, and prioritizing diversity, we can enhance our response to the domestic HIV epidemic.

Thank you for considering our perspectives, and we eagerly anticipate collaborating with PACHA and other stakeholders to make a lasting impact on the lives of those affected by HIV.

Jake Ledesma, M.S.S.W May May May Director of Care Coordination

Alamo Area Resource Center

jakel@aarcsa.com

## **Appendix B: PACHA Principles: Zero HIV Stigma Resolution**



## PRESIDENTIAL

**ADVISORY COUNCIL ON HIV/AIDS** 

# Zero HIV Stigma Day

From Vision to Reality: A Call to End HIV Stigma

In recognition of Zero HIV Stigma Day, July 21st, the Presidential Advisory Council on HIV/AIDS joins the movement to eradicate harmful attitudes, behaviors, judgments, and policies towards people living with or vulnerable to acquiring HIV. In solidarity with all communities who continue to experience negative consequences of irrational beliefs, myths, and biases, we call for an End to HIV Stigma.

What is HIV stigma? HIV stigma is negative attitudes and beliefs about people living with HIV (PLWH). It is the prejudice that comes with labeling an individual as part of a group that is believed to be socially unacceptable. The HIV stigma that a person experiences can be worsened by their individual characteristics, such as their race/ethnicity, sexual orientation, gender identity, substance use history, and other factors.

How is HIV stigma harmful? HIV affects everyone. Stigma can worsen a person's health conditions and delay or even stop them from getting tested and treated. Stigma can lead to social isolation, depression/anxiety, and impact professional growth and development, trapping a person in a worsening cycle of illness. HIV stigma and misinformation also unfairly shapes systems and policies. For example, the majority of states have an HIV-specific criminal law or use their general criminal laws to unfairly prosecute people living with HIV.

## What can we do to end HIV stigma?

Individuals – Educate yourself about HIV. Check your biases and be conscious of the language you use when discussing PLWH. PLWH on treatment with an undetectable viral load cannot sexually transmit HIV (Undetectable = Untransmittable), which frees them and their sexual partners from the fear of transmitting HIV to their sexual partner(s). This fact has changed what it means for PLWH to live and love with HIV. Talk openly about HIV and sexual health with your sexual partner(s), community, and your health care provider

Communities - Community leaders should learn about HIV and voice their support for HIV testing and treatment, as well as the human right of treating PLWH with dignity and respect. Community settings should post educational material and host events where communities can learn the facts about HIV from PLWH themselves as well as other experts.

Healthcare Settings – Healthcare settings and health professional training programs should provide ongoing HIV-related training and education to the entire staff and future healthcare workforce. In addition, healthcare settings should develop and enforce institutional policies and procedures to protect persons living with HIV from discrimination in their facilities.

Governments – Government organizations should ensure through programming, grants, policies, legislation, and leadership, that ending the HIV epidemic is prioritized and addressed in a non-stigmatizing manner.

Private Sector - Private organizations should use their ability to engage with employees, customers, and communities to support people living with HIV and efforts to end the HIV epidemic.

People Living with HIV – Your very existence is enough. Your ability to thrive in your community is important. Partner with your healthcare provider, family, and friends to benefit from medical innovations and support that ensure you are able to live a long, healthy life.

All of us — We can do our part to end HIV stigma through our individual actions, such as using non-stigmatizing language and knowing the facts about HIV, as well as taking part in collective efforts to ensure policies and systems PLWH to be able to live long and healthy lives. HIV stigma will persist if we fail to recognize the humanity of people living with HIV. To learn more about ending HIV stigma and Zero HIV Stigma Day, visit <a href="https://www.hiv.gov/events/awareness-days/zero-hiv-stigma-day/">https://www.hiv.gov/events/awareness-days/zero-hiv-stigma-day/</a>.

Passed June 28, 2023

# **Appendix C: Resolution Concerning Urgent Action Recommended** for Syphilis Syndemic

Presidential Advisory Council on HIV/AIDS (PACHA)

Resolution Concerning Urgent Action Recommended for Syphilis Syndemic

Whereas, having syphilis can increase a person's risk of acquiring HIV and for those living with HIV, syphilis may progress faster and be harder to treat:1

Whereas, PACHA held its 77th full council meeting in Phoenix, AZ between June 28 - 29, 2023 and visited HIV programs the day prior, PACHA members heard urgent concerns of large and escalating numbers of syphilis and congenital syphilis cases from HIV providers serving American Indian/Alaskan Native and other patients requiring a robust and comprehensive federal, state, and local response in partnership with tribes and tribal organizations;

Whereas, several PACHA members in their usual roles are seeing the same escalating number of syphilis and congenital syphilis cases and some of their jurisdictions are declaring syphilis outbreaks and public health emergencies;

Whereas, in 2021 there were 176,713 cases of syphilis reported in the U.S., which was a 32% increase in the reported rate from the prior year, and of those 176,713 cases, 53,767 of those were primary and secondary cases, the most infectious stages;<sup>2</sup>

Whereas, all regions of the U.S. have had large increases in the rates of primary and secondary syphilis, the West having the highest with a 25% increase from 2020, followed by the South with a 26% increase, then the Midwest with a 48% increase, and the Northeast with a 21% increase;<sup>3</sup>

Whereas, between 2020 and 2021, the rate of primary and secondary syphilis among women increased 55% and 23% in men;4

Whereas, rates of primary and secondary syphilis increased in all racial/Hispanic ethnicity groups, and Non-Hispanic American Indians or Alaska Native persons had the greatest five-year increase of reported primary and secondary syphilis with a 324% increase between 2017 and 2021;5

Whereas, during 2017 to 2021, 46% of primary and secondary syphilis cases were among men who have sex with men, and increased by 7% from 2020 to 2021.5

Passed June 29, 2023

<sup>1</sup> https://www.healthline.com/health/hiv/syphilis-and-hiv#outlook

https://www.cdc.gov/std/statistics/2021/figures.htm (Syphilis slide set, slide 4) all were accessed on June 29, 2023

https://www.cdc.gov/std/statistics/2021/figures.htm (Syphilis slide set, slide 7)

<sup>4</sup> https://www.cdc.gov/std/statistics/2021/figures.htm (Syphilis slide set, slide 6)

https://www.cdc.gov/std/statistics/2021/figures.htm (Syphilis slide set, slide 12)

<sup>6</sup> https://www.cdc.gov/std/statistics/2021/figures.htm (Syphilis slide set, slide 23)

Whereas, in 2020, 9.9% of persons with primary or secondary syphilis reported methamphetamine use, 5.9% reported injection drug use, 3.5% reported cocaine use, 2.4% reported heroin use, and 1.3% reported crack use;<sup>7</sup>

Whereas, in 2021, there was a total of 2,855 babies with congenital syphilis, all of which are preventable with appropriate screening of persons who are pregnant, and this was a 30% increase in the rate from 2020:8

Whereas, tragically, 220 of these babies born with congenital syphilis died (197 stillbirths and 23 infant deaths); which was a 45% increase from 2020 (152 deaths) and a 175% increase from 2017 (80 deaths); 0

Whereas, the FDA listed Bicillin® L-A (penicillin G), the preferred treatment, as in shortage as of April 26, 2023 and estimated recoveries not until second quarter of 2024;<sup>1112</sup>

Whereas, on June 13th, governmental public health jurisdictions received word that as part of H.R. 3746 there was a \$400 million rescission in funds that support disease intervention specialists (DIS), the public health workforce that helps to identify, control, and prevent disease transmission and outbreaks, which will defund 3,000 DIS workers.<sup>13</sup>

Therefore, be it resolved that, the PACHA recommends and advises the Secretary of the United States Department of Health and Human Services (HHS) to:

- Establish, with urgency, a Federal Task Force led by HHS that includes other Federal
  agencies, as appropriate, to coordinate a comprehensive response to limit and
  control this syndemic, and that it be timely and effectively coordinated with state and
  local governmental public health and health care providers and meaningfully
  inclusive of community-based organizations and other community stakeholders, and
  Tribal Nations;
- Notify, with urgency, health care providers, substance use care providers, and the
  public about the urgent threat of syphilis, including congenital syphilis, and work to
  ensure all persons, including pregnant persons, receive the recommended screening
  for syphilis and treatment as appropriate;
- 4. Give full consideration to declaring the syphilis syndemic a public health emergency;

Passed June 29, 2023

<sup>7</sup> https://www.cdc.gov/std/statistics/syphilis-supplement/default.htm (Syphilis Surveillance Supplemental Slide set, slide 4)

<sup>8</sup> https://www.cdc.gov/std/statistics/2021/figures.htm (Syphilis slide set, slide 31)

<sup>9</sup> https://www.cdc.gov/std/statistics/2021/figures.htm (Syphilis slide set, slide 43)

<sup>10</sup> https://www.cdc.gov/std/statistics/2021/figures.htm (Syphilis slide set, slide 91)

https://www.accessdata.fda.gov/scripts/drugshortages/dsp\_ActiveIngredientDetails.cfm?Al=Penicillin %20G%20Benzathine%20Injectable%20Suspension&st=c\_accessed June 29, 2023

<sup>12</sup> https://www.pfizerhospitalus.com/injectables\_availability\_report?cmp=fa99c71c-60f6-4151-bfd5-dd64c7c116e6&ttype=RTE\_accessed\_July 3, 2023

<sup>&</sup>lt;sup>13</sup> https://www.ncsddc.org/ncsd-marks-debt-ceiling-deal-as-a-devastating-blow-to-the-fight-againstrising-sti-rates/ accessed June 29, 2023

- Work with the U.S. Food and Drug Administration, and Administration for Strategic Preparedness and Response, manufacturers, and other appropriate entities to address, as rapidly as possible, the shortage of Bicillin® L-A and evaluate equivalent alternative treatment modalities for syphilis during the shortage;
- Further explore the targeted use of doxycycline post-exposure prophylaxis as a strategy to prevent incident syphilis cases; and
- Work with federal agencies to evaluate all options to retain the DIS workforce who are on the front line addressing this syndemic, and further work to retain, long-term, this vital public health workforce.

Passed June 29, 2023