

Presidential Advisory Council on HIV/AIDS (PACHA) Seminar U.S. Conference on AIDS

Marriott Marquis Hotel
Washington, DC
September 12, 2015
8:30 a.m.–11:30 a.m.

Council Members Present

Ulysses W. Burley III, M.D., M.P.H.
Vignetta Charles, Ph.D.
Cecilia C. Chung
Grissel Granados, M.S.W.
Robert Greenwald, J.D.
David Holtgrave, Ph.D., Vice Chair,
PACHA
Gabriel Maldonado, M.B.A.
Ligia Peralta, M.D., FAAP, FSAHM,
AAHIVS
Harlan H. Pruden
Scott A. Schoettes, J.D.

Rev. Vanessa D. Sharp, M.Div., MACM,
MATM
Lawrence A. Stallworth II
Mildred Williamson, Ph.D., M.S.W.

Staff

Kaye Hayes, M.P.A., PACHA Executive
Director
Caroline Talev, M.P.A., Public Health
Analyst
Chynna Cole, B.B.A., ORISE Fellow

Welcome and Introduction

Speaking to a standing-room-only crowd, PACHA Executive Director Kaye Hayes, M.P.A., welcomed the participants to the interactive session organized to gather input from the community. PACHA provides advice and recommendations to the Secretary of the U.S. Department of Health and Human Services (HHS) and, through the Secretary, to the President and the director of the White House Office of National AIDS Policy. Its charge is to promote HIV prevention, care, and service delivery and advance a progressive HIV research agenda. PACHA's four Subcommittees reflect the main components of the National HIV/AIDS Strategy (NHAS):

- Increasing access to care
- Reducing HIV incidence
- Reducing HIV-related disparities
- The global agenda.

Ms. Hayes said nominations are being accepted for PACHA as some members reach the end of their terms of service.

Message From the Moderators

David Holtgrave, Ph.D., PACHA Vice Chair, said PACHA is charged with providing advice

and input on the implementation of the NHAS, so the Council is interested in hearing from stakeholders and the public on what is working and what changes are needed. Dr. Holtgrave said each PACHA Subcommittee would briefly describe its recent work and take questions, and then the session would be open for general discussion.

Access to Care Subcommittee

Vignetta Charles, Ph.D., and Robert Greenwald, J.D., Co-Chairs

Dr. Charles said the Subcommittee is focused on four broadly defined priorities for 2015: implementation of the Affordable Care Act (ACA), integration of the ACA and the Ryan White HIV/AIDS program, viral hepatitis treatment, and social determinants of health (SDH). Mr. Greenwald described progress since the ACA was enacted, as well as some new barriers to care faced by people living with HIV (PLHIV). Recommendations made by PACHA (spurred by Access to Care Subcommittee deliberations) over the past year have addressed the following:

- Unfettered access to HIV care and medicine, mental health care, substance abuse services, and specialty care, especially in the Southeast
- Elimination of discrimination against PLHIV in the form of plan designs and formulary structures
- Lack of trained navigation assistance and gaps in coverage provided for PLHIV
- The need for continuous monitoring of plans to ensure that they meet the needs of PLHIV
- Coverage policies for hepatitis C medications that are founded on evidence-based, authoritative guidelines
- The need to address SDH through housing, food and nutrition, behavioral health parity, and trauma-informed care to facilitate access to care and retention for PLHIV.

Questions and Answers (Q&A)

Attention to SDH also should include employment. PACHA's focus on SDH has tremendous implications for access to care for PLHIV and also for reducing disparities in care.

Mr. Greenwald agreed; Dr. Charles noted in her earlier comments that PACHA's Subcommittees sometimes overlap in their topics, and the Disparities Subcommittee also is addressing SDH.

In its 20-year history, PACHA has had only one member who is a veteran of the U.S. Armed Forces. There are 170,000 veterans with HIV, and the U.S. Department of Veterans Affairs (VA) is "a disaster." There has never been a U.S. Conference on AIDS session on veterans. Why do veterans with HIV keep getting overlooked?

Dr. Charles encouraged the speaker and others to submit nominations for PACHA membership, because representation occurs when people step up to serve. She pointed out that the VA is addressing PLHIV. Mr. Greenwald added that PACHA does not recruit

members, so individuals have to nominate people who will represent their interests. Ms. Hayes said the PACHA page of the Web site AIDS.gov offers a link to the *Federal Register* notice about nominations.

Is PACHA monitoring changes in Ryan White and AIDS drug assistance programs such as those in Florida, where PLHIV have found that coverage for some HIV services is limited in certain areas?

Mr. Greenwald said his own organization is taking on discriminatory coverage policies.

Incidence Subcommittee

David Holtgrave, Ph.D., and Ligia Peralta, M.D., FAAP, FSAHM, AAHIVM, Co-Chairs

Dr. Holtgrave said the Subcommittee plans to focus on two areas for the rest of this year: data collection on Native American PLHIV and methods for measuring incidence that get to the heart of the issue. Subcommittee member Harlan H. Pruden is heading the Native Working Group, which is planning a PACHA panel session related to Native American PLHIV that may lead to specific recommendations. Dr. Holtgrave said the updated NHAS replaced the goal of reducing incidence of HIV to decreasing diagnoses of HIV, which could have unintended consequences leading to less or lower-quality testing.

Dr. Peralta added that the Subcommittee is focused on updating and clarifying the Centers for Disease Control and Prevention's (CDC's) guidelines on HIV prevention and testing, especially for vulnerable populations, and working with CDC to provide tools to implement the guidelines. Also, the Subcommittee plans to advocate for comprehensive, universal K–12 sex education as a function of the human right to health. Other areas under discussion by the Subcommittee include the following:

- Development of metrics for schools to assess health and sex education
- Universal testing for HIV and hepatitis C as part of primary care
- Monitoring providers' understanding of HIV prevention
- Dissemination of clear guidelines for providers on billing and reimbursement for preventive care
- Access to rapid HIV and hepatitis C testing technology
- Inclusion of HIV testing in nationally recognized indicators of quality of care.

Q&A

The Real Education for Healthy Youth Act of 2015 (H.R. 1706) calls for comprehensive sex education at all grade levels. Advocates for sex education should look into why the bill has stalled and make their voices heard.

Sex workers are not mentioned in any PACHA recommendations, and they are not recognized by national advocacy organizations. To reduce incidence, it is recommended that policies that criminalize sex work and pose barriers to safer sex practices among sex workers be eliminated.

Mr. Greenwald said PACHA is working on such issues. Dr. Peralta said PACHA is just scratching the surface on the related issue of human trafficking. Rev. Vanessa D. Sharp, M.Div., MACM, MATM, said faith-based organizations have demonstrated a strong interest in dealing with human trafficking but are reluctant to address HIV. Scott A. Schoettes, J.D., said that attention to the issues of human trafficking should not overlook or further criminalize sex work.

Even if there were national legislation requiring mandatory, comprehensive sex education, some States, especially in the Deep South, would push back or opt out, as has been the case with Medicaid expansion. What can we do to hold elected officials accountable?

Dr. Peralta said PACHA is planning a session to address the implementation of sex education as a human right. She said there are opportunities for partnership and for alignment with the NHAS goals. Dr. Holtgrave noted that PACHA led an investigation into a school-based sex education program (included on the Web site of the HHS Office of Adolescent Health's Teen Pregnancy Prevention Resource Center) that lacked a strong evidence base for its claims.

Lawrence A. Stallworth II suggested that young people advocate to their elected officials for sex education in their schools. Personal stories are effective. Efforts should be made to cultivate a group of young people who can talk about these issues. Dr. Charles agreed that advocates must assist those under age 18 to have a voice in policy.

Mr. Pruden said PACHA can shine a light on what works, increasing the visibility of best practices and using them as the basis for solid recommendations. He said more discussion of these issues is needed.

Gabriel Maldonado, M.B.A., agreed that peer models are needed. Also, more models are needed that include parents and how to educate them so they can in turn educate their children.

Disparities Subcommittee

Gabriel Maldonado, M.B.A., and Scott A. Schoettes, J.D., Co-Chairs

Mr. Schoettes noted that many of PACHA's recommendations were reflected in the updated NHAS, including a focus on black men who have sex with men and transgender people. The Subcommittee has prioritized three topics: performance measures, stigma, and SDH. The next PACHA meeting will address appropriate performance measures for holding providers accountable for care of these populations. Specifically, Mr. Schoettes said, the goal is to harmonize performance measures, so that individuals receive the same quality of care no matter what the setting.

Mr. Maldonado said the Subcommittee is reviewing the impact of stigma and discrimination on prevention, treatment, and adherence for PLHIV and those at highest

risk. Mr. Maldonado hoped PACHA would 1) call on CDC and the National Institutes of Health (NIH) to update their guidelines to eliminate outdated practices that perpetuate stigma and 2) recommend that CDC and the NIH integrate stigma reduction into outcomes for funded programs. Much current data on stigma reduction come from global models; more domestic programs are needed.

Mr. Schoettes said the role of SDH is now reflected in the NHAS, but the challenge is determining how to address them effectively. He asked for more public input on what PACHA should do with regard to SDH.

Q&A

As a long-term survivor, I am concerned with the intersection of HIV and aging. Half of PLHIV are more than 50 years old, and by 2020, that figure will rise to 70 percent. Ageism is a form of discrimination that affects a lot of PLHIV.

Mr. Greenwald agreed with the need to focus on older adults with HIV.

There seems to be a drop in HIV prevention efforts. There has been a huge rise in HIV among youth in Florida. PACHA should focus on educating the whole population, not just youth. HIV is so manageable now that young people have a different mindset about it. Comparing HIV/AIDS to diabetes or cancer is “atrocious”; neither of those diseases has a name-based reporting system.

Mr. Schoettes acknowledged that there are differences across generations in the approach to and experience of HIV. He said it is tricky to balance the need for education about the seriousness of HIV against concerns about ramping up fear that contributes to stigma. He added that the Disparities Subcommittee promoted recommendations on disclosure that it hopes will form the basis of a broad information campaign.

Mr. Greenwald noted that the NHAS recognizes the importance of both broad and targeted education. The U.S. Surgeon General has expressed some interest in HIV education.

Mr. Stallworth said that young people are not frivolous in their thinking about HIV. Despite advances in treatment and care of PLHIV, young people on the whole are not complacent, he said. The prevalence of HIV in some communities is so high that young people are at highest risk of contracting HIV with even a single instance of unprotected sex. Moreover, young people face discrimination—for example, being kicked out of their family homes—so it is inappropriate to suggest that they are not concerned about HIV, Mr. Stallworth stated.

I am a young person with HIV, and my social network is made up of older people who are long-term survivors, not my peers.

Mr. Schoettes said it is important to keep the intergenerational conversation going.

About 90 percent of women are infected by heterosexual contact. Efforts always focus on gay men, but how can heterosexual men be engaged?

Entertainment education—spreading a message through music, art, etc.—is very powerful, but is often expensive to produce, and outcomes are hard to measure. How can we fund such education?

Dr. Holtgrave said many lessons can be learned from global efforts about outcome evaluation. Dr. Peralta pointed out that industries other than health care have explored the use of entertainment for messaging. The health care system can consider how to integrate evidence-based tools from other industries to increase knowledge, testing, and adherence.

Mr. Maldonado said advocates can establish relationships with private corporations. However, in places like Los Angeles, talent is abundant, and organizations do not need large funding to produce videos and disseminate them through social media, for example. State and Federal resources are unlikely to go to projects with no evidence base, Mr. Maldonado cautioned.

According to CDC, of new infections diagnosed in 2010, the fifth largest group was heterosexual men. This topic has been brought to PACHA's attention before, to no avail.

Mr. Schoettes agreed that it is important to focus on heterosexual men, because, for example, black and Latina women are disproportionately affected by HIV as a result of infection by heterosexual men. The challenge that PACHA and the HIV community face is that there are many populations suffering disproportionately that lack the numbers to get attention (such as Native Americans). Many populations should be included in education, prevention, and treatment efforts, even if they are not the highest-priority populations.

Cecilia C. Chung said stigma and discrimination may pose barriers to getting good data about the prevalence of HIV among heterosexual men. She wondered how many men give honest answers to questions by health care providers about risky sexual behaviors.

Global Subcommittee

Harlan H. Pruden and Rev. Vanessa D. Sharp, M.Div., MACM, MATM, Co-Chairs

Mr. Pruden said that over the past year, PACHA has had a presentation from the State Department's Deborah Birx, M.D., Ambassador-at-Large, U.S. Global AIDS Coordinator, and U.S. Special Representative for Global Health Diplomacy, on the evolution of the President's Emergency Plan for AIDS Relief (PEPFAR) and another on how some countries funded by PEPFAR developed their HIV strategies. The work of the Global Subcommittee follows two threads: shining a light on work occurring around the world that can inform the domestic conversation (e.g., how data are collected and how access to care is subsidized) and advocating for continued international efforts. Mr. Pruden

noted that the PACHA Subcommittees all work well together, and members see themselves as accountable to the public.

Rev. Sharp described some international media approaches that the United States could adopt to spread the word about HIV/AIDS efforts at all levels. She praised media in Africa and Russia for steps taken to increase sensitivity and combat stigma. Rev. Sharp encouraged attendees to visit the Web site of Emory University's Hope Clinic, which is conducting research on an HIV vaccine. Advancing research and resolving issues require a global effort, she concluded.

Mr. Pruden urged attendees to explore the Allied Media Conference, which spurs dialogue using media of all types (including art and music) and across the spectrum from traditional to new media to affect social change. The conference will change the way advocates embrace their messages, he said.

Q&A

I am an HIV clinician who has seen patients from other countries who need HIV care or even treatment for AIDS within months of their arrival. The United States no longer offers HIV testing to those entering the country, which I think is irresponsible. We should offer testing at the borders (although the results should not affect an individual's ability to enter the country).

Mr. Schoettes noted that only 5 years ago, PLHIV were not allowed to enter the country; testing was offered to identify those prohibited from entering. It may be time to start talking about offering—but not mandating—HIV testing at the borders, he said, but the issue is complicated, not just because of stigma but also because of access and discrimination issues. Ms. Chung added that nonresidents are tested at some entry points. There is no uniform policy on testing; it is a State issue, she said.

Ulysses W. Burley III, M.D., M.P.H., pointed out that from his experience working with refugees, in addition to testing, immigrants need language-appropriate resources and help understanding U.S. culture. Some have suffered extreme violence, and some have a false sense of security about sexuality, for example. There are many layers to address, said Dr. Burley. Only one clinic in his area addresses refugees, and it is understaffed. Mr. Pruden said he would bring the issue of testing incoming immigrants before the Global Subcommittee.

The Stigma Index has been implemented in Africa and other countries and is being piloted in the United States. It is truly global. There also is an accompanying tool that is a framework for dialogue, which has been used by faith-based organizations. I encourage PACHA to get behind the implementation of the Stigma Index and the tool.

Ms. Chung noted that the Stigma Index has to be initiated and implemented by PLHIV. Some States are starting to use it, but it is a gradual process. Mr. Schoettes said the Disparities Subcommittee has a working group that is reviewing various measures of stigma for PACHA. Mr. Pruden added that PACHA had a session about the Stigma Index

in 2013. Rev. Sharp said the Presbyterian AIDS Network has educated Christian universities on how to address stigma and foster conversation about HIV/AIDS; it also has succeeded in changing government policies.

Listening Session

Dr. Holtgrave opened the meeting to questions and comments from the audience.

The more people who are diagnosed, the more people feel differently about getting tested. Getting the “blessing” of faith-based organizations also changes how people feel. The Governor of New York is making HIV testing available in libraries to normalize it. We have thousands of rapid HIV testing mechanisms. How can we establish more focus on diagnosis at the Executive level? An Executive act could put rapid testing in every center, as well as rapid testing of viral load and rapid genome typing, all of which would save funds.

Dr. Peralta said the Incidence and Access Subcommittees are both looking at available new technologies and moving forward with indicators of quality of care.

How can we open a conversation about sexual health and HIV in families? In my South Asian community, young people are open to talking about sexual health with their peers but not with their families. I also see young women who are sexually active but not using health services (e.g., birth control and gynecologic screening) because the services are tied to their families’ insurance.

Mr. Greenwald said he sees protecting family planning services as part of PACHA’s agenda, because it allows young people to get care outside of their parents’ health insurance plans. Congress is focusing on eliminating Title X, which would eliminate all such services. Dr. Charles added that PACHA is focused on the need for medically accurate, comprehensive sex education. Some of the best programs include not only school-based and individual education but also how to engage parents and foster intergenerational and cross-cultural dialogue. (Mr. Greenwald noted that PACHA has made some progress in how sex education programs are labeled; for example, one particular abstinence-only program is now clearly identified as less based in scientific practice and evidence than other programs.)

Mr. Schoettes said one approach is to ensure that policies on privacy and confidentiality are in place for people using their parents’ insurance plans. Once a person reaches legal adulthood, that person’s medical information is confidential.

Ms. Chung said the Family Acceptance Project is an ongoing research project that has gathered a considerable amount of data. It has shown that those who are not accepted by their families at a young age are more likely to develop addiction, attempt suicide, and face other mental health issues. She agreed there is a need to get accurate information to young people, who often get information from their peers and the Internet.

Mildred Williamson, Ph.D., M.S.W., said that for so many young people, family-based education is not an option, which underscores why Title X and safety net health care services are so important as an avenue to information and services for young people. In families that are open and engaged, young people should have access to information and services through the family's medical programs. In States that have not expanded Medicaid for PLHIV, federally qualified health centers (FQHCs) are an important arena for accessing care, she said.

It is important that we not focus only on the medical model for teaching about HIV. South Africa's Grassroot Soccer program uses soccer as the basis for raising HIV awareness. People learn about HIV in a fun forum. I would like to see more of that.

PACHA makes recommendations, but who advises about the consequences when things do not happen? For example, what if FQHCs were penalized for not having inclusive language or addressing stigma? Are there consequences or financial impacts when recommendations are not followed?

Dr. Holtgrave said PACHA's charter allows it to advise, but it cannot impose financial penalties. If an issue is very important, PACHA will revisit it repeatedly as needed. Dr. Holtgrave noted that PACHA's resolution on HIV criminalization has been used by advocates to change State laws. Its resolution on hepatitis C treatment was mentioned in the *New York Times*, so PACHA does have some influence.

Dr. Peralta said PACHA is looking at existing mechanisms, such as Healthcare Effectiveness Data and Information Set (HEDIS) indicators, which are used heavily in the private sector. There are financial incentives to measure certain indicators, which is why PACHA would like to see the private and public sectors using the same indicators. Mr. Greenwald said performance measures of, for example, viral suppression rates could be tied to value-based reimbursement, and thus could identify how successful entities are in getting patients to viral suppression.

Mr. Greenwald added that depending on how measures are set, the health care system can inadvertently incentivize providers to focus on healthier patients, so any measures should account for that. There also should be incentives to address patients with multiple comorbidities.

Rural concerns have not been discussed. We get patients with AIDS who have been in the emergency department multiples times. Is there an opportunity to sue for medical negligence in such cases?

Mr. Schoettes said it is possible to file suit on the basis that an individual's diagnosis was missed multiple times. Such cases are hard to win, however, because the standard of care is hard to prove, and doctors have the latitude to apply "reasonable medical judgment." Despite recommendations, there is no mandate to offer HIV testing. If policies were stronger, it would be easier to hold providers accountable in such cases. However, a

lawyer can always find a doctor who will justify another doctor's care in court.

Rev. Sharp said it is important for hospitals to provide their staff with updated information that is aligned with the hospital's mission. She cited an example of outdated materials and said it is sometimes necessary to speak up when information or practices are incorrect.

We know about the relationships between HIV-related health disparities, rates of transmission, and economic and employment disparities. The National Working Positive Coalition has made recommendations (provided to PACHA). As part of the 2010 NHAS implementation, the Equal Employment Opportunity Commission (EEOC) was asked to 1) provide a plan to reduce employment discrimination against PLHIV and 2) make recommendations on increasing employment opportunities for PLHIV. The EEOC addressed the first question but not the second (which seems to be outside of its scope). Since the 2010 NHAS, there has been discussion about employment as a priority for PLHIV but no change in services and no real action. Also under the 2010 NHAS, the Department of Labor was asked to collaborate with HHS, the Department of Housing and Urban Development, and the Department of Justice on an employment project that never occurred.

Mr. Schoettes said the EEOC is better equipped to address discrimination; he thought PACHA should try to determine who should address the issue of employment opportunities.

No one Federal agency addresses employment for PLHIV. The Labor Department plays a big part, but the biggest employment program for people with disabilities resides in the Department of Education. However, that does not mean the Federal agencies should be off the hook. If we let programs that serve PLHIV ignore employment, we will reinforce the entrapment and poverty in which many PLHIV live.

Ms. Chung said PACHA should consider recommending an interagency task force dealing with employment, as the Administration did following passage of the Violence Against Women Act. Mr. Schoettes said there is still work to be done at the EEOC to ensure that all of its investigators understand the rights of PLHIV.

The updated NHAS demonstrates vision, but how do we translate the vision into reality? I worry that CDC and the Health Resources and Services Administration (HRSA) guidance differs slightly from the NHAS, and now that CDC is re-procuring all the State HIV department prevention programs, the concrete vision of the NHAS will get lost as programs filter down to the State and local levels. What mechanisms are available to prevent that? Also, a partnership between PACHA and the CDC/HRSA Advisory Committee on HIV, Viral Hepatitis, and STD Prevention and Treatment (CHAC) can do a lot. PACHA's support is needed to ensure accountability for the NHAS.

Mr. Stallworth said behavioral interventions are especially important to him, and he is concerned about focus shifting excessively to medical interventions. In reality, just providing medical treatment will not end the epidemic; behavioral interventions are still needed.

Dr. Holtgrave pointed out that PACHA has 60 days to comment on how the updated NHAS should be implemented. He agreed that PACHA and CHAC working together could yield amazing results.

I go to many conferences around the world where investigators present successful research findings on new therapies, but few of those studies are ever published in the top medical journals in the United States. Providers rely on reporters to bring back such news, but the media do not bother to report it. There has to be a way for PACHA and others to translate the data from other countries into U.S. practice. Those studies have been funded and completed. PACHA should establish rapporteurs to go to international conferences and bring back the wealth of information, which would drown us in new innovations for HIV.

Pre-exposure prophylaxis (PrEP) is in the forefront of everything; it is all I hear about—not HIV testing. Even in the testing world, people are asking about PrEP, because it is being publicized. PrEP is a good thing, but we need to talk more about it, and more research needs to be done. Clients are asking service providers questions that we cannot answer. Also, our organization in Texas provides testing and PrEP, and we reach out to communities that are uninsured and undocumented.

Mr. Schoettes noted that people who receive PrEP get tested, so they are engaged in the health care system.

I work for an FQHC in San Francisco that serves the chronically homeless, among others. Most of my clients have suffered from trauma, and there are big links between trauma and behavioral health risks. People with a history of trauma also are hard to engage in care. We need to acknowledge the role of trauma. We also should think about treatment for trauma.

Mr. Schoettes said PACHA has moved the conversation on trauma forward. He would like to expand the conversation to go beyond women who have been victims of trauma and include gay men and others who have been traumatized. Dr. Charles said trauma is a priority for the Access Subcommittee, and PACHA had a presentation from the Substance Abuse and Mental Health Services Administration on its new trauma-informed care guidelines.

A participant provided PACHA members with the *HIV Long-Term Survivors Declaration: A Vision for Our Future* from the organization Let's Kick ASS [AIDS Survivor Syndrome].

Closing Remarks

Mr. Maldonado invited PACHA members to make brief closing comments. Dr. Holtgrave encouraged participants to keep the conversation going by attending PACHA meetings and keeping track of its activities on AIDS.gov. Dr. Charles and Mr. Pruden invited the

public to reach out to PACHA members individually. Rev. Sharp hoped attendees would visit the Hope Clinic's Web site. Dr. Peralta said PACHA is considering a session on various aspects of PrEP. Ms. Williamson said she would like to see the Joint Commission included in efforts to ensure accountability, and she hoped PACHA would look more closely at employment issues, including reentry programs.

Ms. Hayes thanked all the participants. She reiterated that the call for nominations for new members has been published in the *Federal Register*, and a link to the publication will be posted on AIDS.gov. Ms. Hayes thanked all the staff that made the session possible and the PACHA members.