

**Presidential Advisory Council on HIV/AIDS (PACHA)  
48th Meeting  
Washington Marriott Hotel at Metro Center  
Washington, DC  
October 25–26, 2012**

**Council Members—Present**

Nancy Mahon, J.D., PACHA Chair  
A. Cornelius Baker  
Douglas Brooks, M.S.W.  
Humberto Cruz, M.S.  
Ernest Darkoh-Ampem, M.D., M.P.H., M.B.A.  
Patricia Garcia, M.D., M.P.H. (by telephone)  
Robert Greenwald, J.D. (day 2 only)  
Kathie M. Hiers  
David Holtgrave, Ph.D.  
Michael Horberg, M.D., M.A.S.  
Ejay L. Jack  
Jack C. Jackson, Jr.  
Naina Khanna  
Douglas A. Michels, M.B.A.  
Mario Perez  
Rev. Vanessa D. Sharp, M.Div., M.A.C.M., M.A.T.M.  
Sandra Torres Rivera  
Phill Wilson

**Council Members—Absent**

Praveen Basaviah  
Dawn Averitt Bridge  
Rev. Dr. Calvin Otis Butts III, D.Min., M.Div.  
Kevin Robert Frost  
Anita McBride  
Rosie Perez

**Staff—Present**

Kaye Hayes, M.P.A., PACHA Executive Director

## **Presenters**

Grant Colfax, M.D., Director, White House Office of National AIDS Policy (ONAP)

Nick DeLuca, Ph.D., Chief, Prevention Communication Branch, Division of HIV/AIDS Prevention (DHAP), National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP), Centers for Disease Control and Prevention (CDC)

Antigone Dempsey, CDC/HRSA Advisory Committee on HIV and STD Prevention and Treatment (CHAC) Co-Chair, CHAC Liaison to PACHA

Andrew Forsyth, Ph.D., Senior Science Advisor, Office of HIV/AIDS and Infectious Disease Policy (OHAIDP), U.S. Department of Health and Human Services (HHS)

Catherine Hanssens, J.D., Executive Director, The Center for HIV Law & Policy, Positive Justice Project (PJP)

Deborah Parham Hopson, Ph.D., R.N., FAAN, Assistant Surgeon General, Associate Administrator, Health Resources and Services Administration (HRSA) HIV/AIDS Bureau

Amy Killelea, Senior Manager, Health Care Access, National Alliance of State & Territorial AIDS Directors (NASTAD)

Howard Koh, M.D., M.P.H., Assistant Secretary for Health, HHS

Megan McLemore J.D., L.L.M., Senior Researcher, Human Rights Watch, Health and Human Rights Division

Jonathan Mermin, M.D., M.P.H., Director, DHAP, NCHHSTP, CDC

Scott A. Schoettes, HIV Project Director, Lambda Legal, PACHA/CHAC Safe and Voluntary Disclosure Workgroup Member

Linda Scruggs, M.H.S., AIDS United/Altarum Institute, PACHA/CHAC Safe and Voluntary Disclosure Workgroup Member

Sean Strub, Executive Director, The Sero Project

Ronald O. Valdiserri, M.D., M.P.H., Deputy Assistant Secretary for Health, Infectious Diseases, OHAIDP, Office of the Assistant Secretary for Health, HHS

Andrea Weddle, HIV Medical Association

## **DAY 1**

### **Welcome**

PACHA Chair Nancy Mahon called the meeting to order at 9:35 a.m. She welcomed the members and participants and briefly summarized the agenda. Ms. Mahon called the roll later in the day.

### **Remarks by Howard Koh, M.D., M.P.H., Assistant Secretary for Health, HHS**

Dr. Koh welcomed the PACHA members, praising the expertise and commitment of the members and the chair, PACHA Executive Director Kaye Hayes, and Deputy Assistant Secretary for Health Ronald O. Valdiserri, M.D., M.P.H. He thanked PACHA for its most recent resolutions. The first, highlighting the needs of women with HIV, received a lot of attention from the Director of the HHS Office on Women's Health, among others.

The second, advocating for comprehensive sex education for youth, is key, said Dr. Koh, as another generation grows up vulnerable to HIV/AIDS. Dr. Koh said that Healthy People 2020, the most recent iteration of our public health roadmap, identifies the proportion of people who know their HIV status as a leading indicator of health. About 80 percent of people overall know their status, but among those ages 13–21, fewer than 50 percent do, Dr. Koh pointed out. The PACHA resolution is an important part of the work ahead.

Dr. Koh said the International AIDS Conference in Washington, DC, in July was extraordinary. Thanks to the advocacy of PACHA, the United States ended its discriminatory policy regarding entry of people with HIV, which allowed the international meeting to go forward.

Also thanks to PACHA's advice on implementing the National HIV/AIDS Strategy (NHAS), HHS has developed a common set of metrics for reporting on HIV to reduce the data collection and reporting burden on grantees and agency staff. The core set of seven metrics will allow agencies to share data more easily.

In response to PACHA's input on addressing HIV among the underserved, said Dr. Koh, HHS established a new demonstration grant, coordinated by OHAIDP, to improve HIV diagnosis and linkages to care, especially among minorities and people in the South. Dr. Koh said he looked forward to more insights from PACHA on how to make things better.

## **PACHA/CHAC Safe and Voluntary Disclosure Workgroup**

**Douglas Brooks, M.S.W., and Kathie M. Hiers, Co-Chairs, PACHA Disparities Subcommittee**

**Antigone Dempsey, CHAC Co-Chair, CHAC Liaison to PACHA**

**Scott A. Schoettes, HIV Project Director, Lambda Legal, and Linda Scruggs, M.H.S., AIDS United/Altarum Institute, Workgroup Members**

Mr. Brooks said the PACHA Disparities Subcommittee and CHAC have reached consensus on a set of recommendations about safe and voluntary disclosure, which he hoped PACHA would vote on before the end of the meeting. He explained that the NHAS Implementation Plan directed both PACHA and CHAC to make recommendations for normalizing and promoting safe and voluntary disclosure of HIV status. In January 2011, PACHA assigned the Disparities Subcommittee to draft recommendations.

Mr. Schoettes pointed out that the NHAS directive is biased toward the public health and group benefits of disclosure; it does not sufficiently consider the individual's disclosure process and rights or the potential negative consequences of disclosure. The Disparities Subcommittee held several meetings to discuss the framework of the recommendations, the expertise needed to address the issues, the audience for the recommendations, and the feasibility of broad recommendations given the many contexts in which disclosure might occur, among other things. PACHA and CHAC established liaisons and the Joint Workgroup.

The Joint Workgroup members agreed that safe and voluntary disclosure could not be addressed without also considering the criminalization of HIV, which creates an unsafe environment for disclosure. It was determined that instead of focusing on ways to encourage disclosure, the recommendations should address disclosure within safe contexts. The Joint Workgroup held a summit in June 2012, from which it developed guiding principles to address disclosure in a range of circumstances and situations. People living with HIV/AIDS (PLWHA) directly influenced the guiding principles. In addition, the summit yielded a list of short- and long-term policy recommendations on disclosure.

Ms. Dempsey said that an individual's life involves numerous social networks. She emphasized that disclosure is not a single, discrete event but rather one that the individual faces and makes decisions about within these networks every day.

Mr. Schoettes summarized the benefits and risks of disclosure, which vary with the setting. He pointed out that in some cases, disclosure can help secure legal protections against discrimination. He stressed that individuals must have the option of making an informed decision about disclosure within a given context. The potential for violence around disclosure was an important part of the discussion, said Mr. Schoettes.

Ms. Scruggs outlined the background for the recommendations, which emphasizes the voluntary and personal nature of disclosure as well as the risks. It also notes that disclosure of all sexually transmitted infections (STIs) would enhance communication and improve health. The guiding principles are as follows:

1. Society has an obligation to create a safe environment for disclosure.
2. Discussion of HIV and STI status is important.
3. The circumstances and context of disclosure must be respected.

The draft recommendations are briefly summarized here:

#### **Short-Term Recommendations**

1. Devote a portion of currently funded programs to facilitate campaigns and education on safe and voluntary disclosure.
2. Request that NIH develop a mixed method research agenda/studies on the benefits and challenges of disclosure.
3. Request that the Surgeon General write a letter to the American people containing up-to-date information about HIV/AIDS and the importance of frank discussions about maintaining sexual health.
4. Ask the HHS Secretary to appoint an HHS representative to work with the Associate Attorney General to create a working group to examine laws and policies that discriminate against people with HIV.
5. Establish a dedicated position within the office of the Associate Attorney General for HIV Law and Policy.

#### **Long-Term Recommendations**

6. Prioritize disclosure support as a component of mental health services and include disclosure education, training, and support under the definition of “peer navigation/support.”
7. Develop sex-positive prevention messages rooted in evidence-based research.
8. HRSA should require that States address the intersection between State and local laws that affect HIV status and create barriers to disclosure of HIV status.

#### **Discussion**

Members addressed the tension between the benefits of open dialogue about HIV (including the public health benefits) and the legal ramifications of disclosure, which often focus on the negative aspects. It was suggested that disclosure can be equated with avoiding criminalization and thus should be considered a benefit; on the other hand, it was noted that people who disclose may risk expulsion from their churches, jobs, or housing. The recommendations focus on ways to improve systems so that individuals feel safe disclosing their status in various settings.

The role of States in HIV criminalization was raised, and it was noted that the recommendations aim to focus on disclosure from a national perspective and to promote feasible options. It was suggested that further input be sought from the National Conference of State Legislatures.

Sean Strub of The Sero Project emphasized that stigma is worse now than ever before, making disclosure even harder. Social and support networks, such as the AIDS coalitions that used to exist in the United States, can facilitate disclosure and should be recommended. Several public health practices (e.g., mandatory reporting of contacts) also contribute to reluctance to disclose, said Mr. Strub. He hoped national legislation would eliminate all HIV criminalization statutes.

It was noted that some progress has been made to reduce stigma, and the goal of the recommendations is to create an environment that supports such progress. It was suggested that the recommendations should not only call for review of laws and policies that promote discrimination but also offer suggestions about policies that can help, such as the Americans with Disabilities Act.

The Surgeon General's letter to all Americans in 1988 on AIDS was powerful, so the Joint Workgroup suggested another such letter on HIV to combat stigma and discrimination that arises from misperceptions and inaccurate information. An electronic (e.g., e-mail) version could be disseminated in addition to a printed version.

While HRSA administers the Ryan White CARE Act (RWCA) grants, HHS funds many other public health efforts; it was suggested that Recommendation 8 direct HHS to take action, compelling States to address HIV discrimination. The responsibility should not be placed solely on RWCA grant recipients, who are losing funding (which cannot be spent on advocacy efforts anyway). The intersection between public health statutes and criminal law is complicated and goes well beyond HRSA-funded entities.

It was suggested that the recommendations consider the relationship between trauma (e.g., violence against women) and the diagnosis of HIV and how treatment for trauma can be better integrated with HIV care. These concepts could be incorporated into Recommendation 6 on including disclosure support as part of clinical care. Potential negative reactions to disclosure (going beyond personal violence to such issues as child custody) should be incorporated in the final recommendations.

One way to address the related stigma is to begin using the Stigma Index in the United States.

**Follow-Up Item**

Consider adding to the next PACHA agenda a presentation on the People Living with HIV Stigma Index.

Some members thought that the recommendations should be accompanied by a more detailed document that summarizes issues discussed by the Joint Workgroup (e.g., the range of

potential negative reactions and consequences of disclosure) and considerations that should be addressed in the future (e.g., the implications of over-the-counter HIV test kits).

### **Follow-Up Items**

The Safe and Voluntary Disclosure Workgroup will consider writing a more detailed companion document to the recommendations or compiling the summaries of the Joint Workgroup's meetings.

Members of the Joint Workgroup will revise the recommendations on the basis of discussion and present the revised document to PACHA for review on Friday, October 26.

## **Criminalization Panel**

### **Moderator: Phill Wilson, PACHA Member, Disparities Subcommittee**

Mr. Wilson stressed that we will not reach the NHAS goals without addressing criminalization, which affects disclosure.

### **Criminalization: Where Are We Now?**

#### **Catherine Hanssens, J.D., Executive Director, The Center for HIV Law & Policy, PJP**

Ms. Hanssens said HIV criminalization is inextricably linked with racial justice, social justice, and HIV treatment issues. Since Ms. Hanssens and others presented the issue to PACHA in January 2011, several advocates have spoken out at the State and national levels, and it is time for PACHA and Federal entities to live up to the promise of NHAS, she said.

Ms. Hanssens said she did not believe that more research or information is needed to move forward; she offered a draft resolution for consideration by PACHA. It reiterated four recommendations first proposed at the January 2011 PACHA meeting; three other recommendations mirror the PACHA/CHAC Safe and Voluntary Disclosure Workgroup recommendations but also reinforce the Joint Workgroup's recommendations and therefore merit inclusion in the proposed resolution.

Ms. Hanssens noted that the CDC now has a Web page with information on statistical risks related to sexual contact, which is a step in the right direction.

### **Discussion**

The Disparities Subcommittee agreed to review the resolution and present it to PACHA for consideration on Friday, October 26. There was discussion about whether PACHA can make recommendations to the Department of Justice (DoJ). In response to a question, Ms. Hanssens said that, given the screening mechanisms in place, there is no reason to maintain HIV-specific prohibitions regarding blood, organ, and semen donation; the PJP has a model law addressing the issue. It was noted that the issue is very broad, affecting not just transplantation but also artificial insemination and assisted reproductive technologies.

## **The Sero Project**

### **Sean Strub, Executive Director, The Sero Project**

While the purpose of laws is to ensure stability so that society can function, laws criminalizing HIV undermine stability and create vulnerability because they are arbitrarily drawn and enforced, said Mr. Strub. HIV creates a “viral underclass.” He presented a video featuring testimonials from PLWHA who have been prosecuted and suffered harsh punishment related to HIV disclosure.

Mr. Strub described how criminalization laws result in alienating PLWHA from the justice system, because the laws are unclear, because PLWHA do not feel they will be treated fairly in court, and because they fear they will be falsely accused of and prosecuted for nondisclosure. Many PLWHA believe it is reasonable to avoid testing, disclosure, and treatment because of fear of prosecution.

Mr. Strub pointed out that many people initially agree with the premise of HIV criminalization until they learn more about the inherent discrimination it entails and the risk it poses to public health. He described a robust effort under way in Iowa to repeal that State’s HIV criminalization laws; it involves education through the media; advocacy, education, and leadership from PLWHA in cooperation with service providers; and support from public health leadership.

Inadequate pretest counseling in which HIV testing is routine is likely to lead to more prosecutions. Moreover, posttest counseling is often insufficient; individuals may be in a state of extreme distress or even shock when they are asked to sign a statement saying that they were counseled about State statutes regarding HIV.

The Stigma Index mentioned earlier is a great tool, said Mr. Strub; using it in the United States would have brought the issue of criminalization to light much sooner. Implementing the Stigma Index promotes partnerships and involves training that empowers PLWHA to become leaders.

Mr. Strub supported the resolution presented by Ms. Hanssens and urged PACHA to support it as well. He also asked that PACHA 1) look closely at how the public health system drives criminalization (e.g., through mandatory reporting and pre- and posttest counseling practices), 2) advocate use of the Stigma Index in the United States, 3) urge action to review criminalization convictions, and 4) support legislation proposed by Representative Barbara Lee in the U.S. Congress to repeal State criminalization laws.

Finally, Mr. Strub said we must tell people the truth about HIV treatment, including the risks, which are often downplayed, and the effectiveness. He added that important innovations often come from the grassroots level, so we must listen to the voices of PLWHA.

## **Sex Workers at Risk**

### **Megan McLemore, J.D., L.L.M., Senior Researcher, Human Rights Watch, Health and Human Rights Division**

Ms. McLemore summarized the key issues of a new Human Rights Watch report, *Sex Workers at Risk: Condoms as Evidence of Prostitution in Four U.S. Cities*. It describes police policies in New York, Los Angeles, San Francisco, and Washington, DC, to stop, search, arrest, and prosecute individuals on the premise that carrying condoms is evidence of prostitution. As a result, sex workers carry few or no condoms and have unprotected sex with clients, undermining the goals of the NHAS.

Ms. McLemore presented a video featuring first-person accounts of harassment and arrests, underscoring how the policy hurts transgender women particularly hard. In the video, Ms. McLemore points out that public health providers spend millions to distribute condoms and often target the transgender community, only to find that the condoms make individuals a target for arrest. She pointed out that such approaches pit police action against an individual's right to protect one's own life as well as public health.

While the Human Rights Watch campaign focused on four large cities, other cities have adopted the same policies. Human Rights Watch requests that the DOJ:

- Include the condom issue in its existing mandate on HIV criminalization
- Review law enforcement policies regarding condoms in each of the cities in the 12 Cities Project
- Provide guidance and technical assistance to district attorneys and law enforcement personnel to ensure that policies are consistent with public health and NHAS goals.

Ms. McLemore asked PACHA to promote Federal leadership to eliminate policies that undermine the NHAS goals, recommend implementation of best practices in criminal justice and HIV, and recommend that DOJ address the condom issue.

### **Discussion**

Ms. McLemore said Human Rights Watch is focusing on the condom issue but also advocates more expansive Federal leadership on other criminal justice policies that undermine the NHAS goals, such as those prohibiting syringe exchange. She added that the 12 Cities Project is just a starting point. She noted that the practice of using condoms as evidence of prostitution has been around since at least 1994, when sex workers in San Francisco brought the issue to light.

It was noted that there have been some successes when leaders from public health and the justice system work together to ensure that criminal laws do not conflict with public health laws and goals. Education of the police force about the value of prevention has been successful and should be a key part of the process. Legislators at all levels also should be educated, and the community can bring pressure to bear.

To avoid undermining NHAS goals, States also should look at syringe exchange and drug paraphernalia policies, Ms. McLemore said. Ms. Hanssens noted that broad application of the classification of sex offenders (e.g., for sex workers with HIV) is a significant problem. Another is the use of civil commitment laws to permit indefinite incarceration of PLWHA as sex offenders after they have served their sentences. It is important to consider State laws that may directly or indirectly affect public health policy and HIV criminalization (e.g., a California proposition that addresses sex trafficking that would broaden the sex offender registry).

While Federal guidance and State laws are important components for promoting effective public health policies, the priorities and perspectives of the chief of police dictate the policies of local departments. District attorneys, public health officials, and local police heads should discuss and reach consensus on a common approach. It was suggested that the U.S. Conference of Mayors take up the issue, acting as a national voice to promote progressive public health approaches involving policing at the local level.

It was suggested that the concern about condoms be included in the revised resolutions and recommendations about safe disclosure and criminalization to be reviewed by PACHA on Friday, October 26. PACHA was urged to act swiftly on the criminalization issues raised because they have been under discussion by PACHA for some time.

#### **Follow-Up Item**

Include criminalization on future PACHA agendas to allow continued, thoughtful consideration about ways to address it.

### **Prevention with Positives (PWP) Campaign**

#### **Jonathan Mermin, M.D., M.P.H., Director, DHAP, NCHHSTP, CDC**

Dr. Mermin said the PWP Campaign originally focused on changing sexual behavior but has been expanding into a comprehensive program addressing a range of strategies to integrate prevention into care. It relies on evidence-based, effective, cost-effective, and scalable methods. But the effort faces challenges; if PLWHA who do not have a suppressed viral load cannot access effective treatment and other services, the PWP approach will not work, said Dr. Mermin.

Dr. Mermin summarized the growth and changing face of the HIV/AIDS epidemic, noting that intensive action now to meet the NHAS goals and prevent new infections will save more lives and money in the long term. Dr. Mermin described disparities in HIV care and the social determinants of health that affect HIV prevalence.

To reach prevention goals, clinical care, which focuses on patients receiving treatment, must merge with public health efforts, which address all PLWHA. The scope of responsibility for caring for all PLWHA should be expanded in a sensible, informed way. Recent economic models demonstrate that testing in nonclinical settings yields the best cost-per-infection-averted ratio, while behavioral interventions yield the lowest ratios. Analysis of cost savings per quality-

adjusted life-years (QALY) illustrates that behavioral interventions are either cost-effective or cost-saving in terms of saving QALY.

Examples of the PWP program include funding for health departments in areas of high HIV prevalence to focus on high-impact interventions, an expanded testing initiative among minorities (which yielded a 2:1 return on investment), and efforts to address social determinants of health and link services across the spectrum of prevention, diagnosis, and treatment.

The PWP program is updating its recommendations and working to harmonize them with other Federal guidelines. The CDC provides tools and technical assistance on calculating and reducing community viral load. It also funds electronic laboratory reporting. Dr. Mermin emphasized the importance of data for developing and evaluating plans. The CDC and HRSA are working together on research to improve retention in care.

Dr. Mermin pointed out that attention to health equity is important to eliminating disparities. When antiretroviral therapy (ART) became available, he noted, the racial disparities in HIV mortality rates widened. The combination of a growing number of PLWHA and increasingly restrictive budgets makes it vital to pursue high-impact strategies, and the window of opportunity is closing, Dr. Mermin concluded.

**Nick DeLuca, Ph.D., Chief, Prevention Communication Branch, DHAP, NCHHSTP, CDC**

Dr. DeLuca summarized Act Against AIDS, an umbrella program that seeks to increase knowledge and awareness about HIV through targeted messages to various audiences. It brings together numerous social and civic organizations representing those hardest hit by HIV.

Complacency around HIV is growing. A national awareness campaign is needed to ensure a supportive environment that promotes public health. The Let's Stop HIV Together campaign features real PLWHA representing diverse populations; it aims to increase awareness, reduce stigma, and increase support for PLWHA. Evidence indicates that stigma is higher among those with less knowledge about HIV and less participation in HIV prevention efforts.

Campaign posters, videos, and public service announcements are being distributed through multiple media, including traditional and new media outlets, through billboards and public transportation ads, and in English and Spanish. Dr. DeLuca said the CDC spent a lot of time validating the format and content of the ads upfront through focus groups and interviews; it is also collecting evaluation data through surveys, online metrics, and other mechanisms. So far, the campaign message has been disseminated via more than 300 million media transmissions, including more than \$1.5 million worth of donated media and advertising space.

Another Act Against AIDS campaign is being developed to target the 49 percent of PLWHA who are not in care. It will focus on care linkages, reengagement with care, and sexual risk-taking behavior.

## **Discussion**

Dr. Mermin said he hoped to have preliminary data from the CDC/HRSA joint research effort on retention soon. The cost analysis was not part of the original study and will take place retrospectively; he expects to have some information on the cost-effectiveness of retention strategies next year.

It was noted that the lowest rates of viral suppression appear among heterosexual men apparently infected by women, a population that is particularly difficult to engage in care. Mr. DeLuca said the Act Against AIDS campaigns seek to ensure that health care providers understand effective counseling approaches and can link patients to resources, including social services, but there is no specific focus on subpopulations at the moment. Dr. Mermin said the issue points to the question of how to recognize and bridge gaps along the continuum of care. The CDC has revised its screening guidelines to encourage more heterosexual men to get tested. If the U.S. Preventive Services Task Force upgrades its HIV screening recommendations for heterosexual men to a level-A recommendation, the Affordable Care Act (ACA) would require that such screening be covered by insurers.

It was pointed out that cities like Los Angeles have been the target of numerous social marketing and media campaigns, but they are not well coordinated with each other and they result in mixed messages. It may be appropriate to pause before embarking on new campaigns to consider how to better synchronize these types of efforts. Dr. DeLuca noted that different campaigns have different goals and vary in their reach. The CDC works through partnerships and shares resources to ensure campaigns are coordinated. In terms of impact, it was noted that more analysis is needed to understand the effect of social media impressions on target populations.

Regarding the cost analyses, Dr. Mermin cautioned against placing too much emphasis on any single intervention deemed highly cost-effective. For example, promoting adherence to ART is very cost-effective, but it affects only the 25 percent of PLWHA who are getting ART and thus would not by itself have a major impact on the epidemic. It is necessary to consider which interventions are cost-effective in which populations.

There are differing views about the utility of presenting data regionally. The CDC can provide national estimates but not regional data, although it is possible for other organizations to get data from cities and States. Dr. Mermin said the CDC does have some regional data that it can provide on request.

It was suggested that the new Act Against AIDS campaign involve the medical community and address access issues related to the ACA.

## **NHAS Implementation Report 2011—Update**

### **Ronald O. Valdiserri, M.D., M.P.H., Deputy Assistant Secretary for Health, Infectious Diseases, OHAIDP, Office of the Assistant Secretary for Health, HHS**

Dr. Valdiserri described the 12 Cities Project, which brought the resources of multiple Federal agencies to bear on enhanced planning and prevention efforts in the 12 U.S. cities most heavily affected by HIV/AIDS. Through reviews, interviews, and site visits with health department officials, consumers, and other stakeholders, HHS learned that the project improved communication and collaboration at the local level. The project also brought renewed emphasis to the use of data to drive decision making.

The challenges identified by the project include the following:

- Federal information and resources are siloed by agency.
- The lack of resources hinders collaboration.
- Legislative and other barriers impede integration.
- Data collection terms and processes vary across agencies, creating barriers to collaboration.
- Nongovernmental organizations that have historically provided basic outreach and information services are concerned about their role in the new HIV prevention paradigm.

Two new HHS activities address some of these challenges. For example, HHS is attempting to standardize HIV data collection by requiring all its divisions to reach consensus on a common set of HIV indicators. By 2014, the new indicators will be in place, reducing the reporting burden on grantees and agencies and streamlining data collection.

The Care and Prevention in the United States (CAPUS) project is funded by the Secretary's Minority Initiative Fund and responds to findings from the 12 Cities Project, feedback from PACHA (particularly on the HIV/AIDS epidemic in the South), community input, and concerns of the Office of Management and Budget and the White House. It aims to expand HIV testing and increase linkages to care for minorities by addressing social, economic, and structural barriers. Recipients of the CAPUS grants must direct at least 25 percent of the funding to nongovernmental organizations to integrate them into prevention and treatment and to address social and structural impacts on health.

Eight entities (six in Southern States) received CAPUS grants in September; they will split a total of \$44 million over 3 years. Among the activities they will pursue are a clinical alert system for missed appointments, text messaging for appointment reminders, peer navigators to improve retention, and transportation for rural residents. CAPUS is one way that HHS is incorporating the findings from the 12 Cities Project into its funding initiatives.

## **Discussion**

It was suggested that HHS analyze at the State level what happens to programs when resources are taken out or shifted around. Dr. Valdiserri agreed that PACHA should continue to remind HHS and others about the need for economic analysis of inputs as well as outcomes to measure the impact of programs.

It was observed that substantial changes in Federal funding for RWCA grantees have resulted in some dramatic, devastating cuts to small programs. These cuts fly in the face of efforts to retain PLWHA in care.

Dr. Valdiserri noted that the 12 Cities Project did include some Federal partners outside of HHS but mostly focused on coordination across HHS programs. It was suggested that other departments, such as DoJ, may be appropriate partners for future efforts.

## **Draft PACHA Report, *Achieving an AIDS-Free Generation***

Ms. Mahon asked PACHA to consider the draft report summarizing its achievements since its inception. Recommendations or resolutions passed at this meeting will be added to the final report.

### **Motion**

David Holtgrave, Ph.D., moved to approve the report, and Mr. Cruz seconded the motion. Fifteen members voted in favor of accepting the report. Two members abstained on the basis that they had submitted suggestions for revision that were not yet incorporated into the report.

### **Follow-Up Item**

It was determined that PACHA staff would incorporate the revisions submitted earlier and some recommended wording changes and present a revised report for review by PACHA members on Friday, October 26.

Regarding the future of PACHA, Ms. Mahon noted that the terms of eight of PACHA's 23 members expire in February 2013. The process of filling vacancies is unclear and will not be addressed until after the November presidential election. Ms. Mahon said PACHA should plan to move forward with its work regardless of the outcome of the election.

Ms. Mahon said that once the report is approved, PACHA should consider how best to disseminate it. She urged PACHA members to speak out about PACHA's recommendations, especially those regarding the ACA.

## Public Comments

**Stephanie Arnold Pang** of the National Coalition of STD [sexually transmitted disease] Directors said a growing body of evidence shows that we will never get a handle on the HIV epidemic in our country if we do not also promote aggressive diagnosis and treatment of other STDs. Recent research underscores the importance of addressing all STDs to prevent HIV transmission. A study published in the journal *AIDS* found that in men coinfecting with HIV and another STD, ART did not completely suppress HIV in semen, although it was not clear whether the level of HIV in the semen was infectious. Because HIV transmission by semen is a major factor driving the AIDS epidemic, said Ms. Pang, we cannot overlook the fact that prevention and treatment for all STDs must be a larger part of the conversation about HIV treatment and prevention. She concluded that the National Coalition of STD Directors looks forward to continued cooperation with PACHA.

**Lindsey Dawson** of The AIDS Institute said the full implementation of the ACA will make health care more accessible, robust, equitable, and affordable for millions of people. How the essential health benefits (EHBs) are defined—which will largely be determined by the States—will directly affect health coverage. Ms. Dawson hoped that HHS would ensure that EHBs provide PLWHA with access to quality health plans and services that meet their needs.

HHS has provided some guidance on the prescription drug benefit, signaling that it will allow plan formularies to limit coverage to just one drug per class. Such limited coverage will not meet the needs of PLWHA and does not appear to provide the protections against discrimination outlined in the law. Limiting formularies to one drug per class would be catastrophic to PLWHA who use ART and must have the option of switching drugs should they develop resistance. Furthermore, it is critical that patients not be denied access to treatment through utilization management techniques that limit access. The AIDS Institute strongly urges PACHA to express to the HHS Secretary its concerns about the one-drug-per-class proposal and support strong and protective application of the nondiscrimination requirements mandated by the ACA. The notice of proposed rulemaking for EHBs is expected to come out soon.

**Sarah Audelo** of Advocates for Youth thanked PACHA for its resolution supporting comprehensive sexual education. Advocates for Youth remains concerned that the Heritage Keepers abstinence-only curriculum remains on HHS' list of evidence-based interventions. Previous iterations of this curriculum were fear- and shame-based; reinforced gender stereotypes; and ignored lesbian, gay, bisexual, and transgender (LGBT) youth. Any HHS-endorsed curriculum should undergo a review of the supporting evidence, medical accuracy, and content. Ms. Audelo requested that PACHA invite representatives from the Office of Adolescent Health, the Assistant Secretary for Planning and Evaluation, and the Administration on Children and Families to the next PACHA meeting to discuss the content of federally funded programs. She asked that the writers of the Heritage Keepers curriculum be invited as well.

Finally, Ms. Audelo requested that young people be represented in future PACHA membership. Their voices are needed on issues such as health department HIV testing after school hours, adapting evidence-based programs to local communities, and the need for national or statewide campaigns on HIV and youth.

**Amanda Lugg** of the African Services Committee of Harlem, New York, said that the number of African-born U.S. residents is increasing dramatically. They are diagnosed with HIV at a rate six times higher than that of the general population but have a lower rate of mortality after diagnosis. Rates of HIV among African-born U.S. residents are higher among women than men, and HIV is less likely to be transmitted by drugs than sex. Despite their distinct profile, African-born U.S. residents are grouped with U.S.-born Blacks in data. More accurate data are needed to address and reduce disparities in HIV care. Demographic data should look at individuals' country of origin to highlight the populations that are now invisible. Ms. Lugg asked for PACHA's support in moving forward with efforts to improve data collection.

**Athena Moore** of the National Black Leadership Commission on AIDS and founding member of the 30 for 30 Campaign said she had requested that PACHA include on its agenda an update from the Federal workgroup focused on HIV/AIDS, violence against women, and gender-related health disparities. The workgroup was formed 6 months ago; an update on its progress and the inventory is appropriate.

Ms. Moore thanked PACHA for its resolution on the needs of women living with HIV. Because the NHAS has been in place for 2 years, she expects to see women's issues incorporated into the evaluation of its implementation. She stressed the importance of keeping women's issues on the front burner and hoped to see progress reports.

**Anna Forbes**, an independent consultant, raised similar concerns about the lack of transparency of the Federal workgroup on HIV/AIDS, violence against women, and gender-related health disparities. Grant Colfax, M.D., White House ONAP director, has provided some updates in private settings but there has been no public account of the workgroup's progress. The 30 for 30 Campaign was advised that stakeholder meetings would be held in November to gather input on the inventory, but no information has been provided on how the stakeholders would be selected. While she was encouraged by the focus on stakeholder engagement, Ms. Forbes said she strongly prefers transparency and information-sharing, especially in the face of major political shifts. We must form an armature to keep going despite those who wish we would disappear quietly, said Ms. Forbes. Resolutions need to thrive in sunshine, she concluded.

#### **PACHA Response**

Ms. Mahon noted that she passed on the request to the Federal workgroup for an update and that Dr. Colfax would provide an update on the stakeholder engagement plans at the PACHA meeting on Friday, October 26. She pointed out that PACHA has no control over that workgroup's agenda.

**Robert Suttle** of The Sero Project (who was featured in The Sero Project video describing his conviction for exposing his partner to HIV) said he does not believe he is a criminal or a sex offender, but the State of Louisiana does. Louisiana has the highest rates of incarceration in the Nation, as well as a high rate of HIV infection. People who do not live in the South probably cannot imagine what it is like. HIV criminalization is real and very much alive, and we must do something about it, said Mr. Suttle. You cannot look out for the welfare of PLWHA and allow those prosecuted to fall by the wayside. We cannot afford to forget those people. He asked that PACHA consider his and others' testimony and do something about HIV criminalization.

**Rashida Richardson** of The Center for HIV Law & Policy read aloud the comments of **Marvelyn Brown** of Marvelous Connections and **Michelle Lopez** of Sel Medical Group, women who have been living with HIV for a long time. They offered their comments on behalf of the many women who cannot or do not live openly about their HIV status and all the women who have been in custody battles, experienced the criminal justice system, and who live in fear of abuse and abandonment because of their status. Ms. Brown's comments described the stigma and prejudice she faces as an activist who has disclosed her HIV status—even from friends and boyfriends. Ms. Lopez's comments described the harassment her child suffered because Ms. Lopez disclosed her status. She noted that some believe that HIV criminalization laws are needed to protect women from men with HIV.

Questions remain as to whether HIV criminalization reduces the chances that women will get HIV, protects women from other STIs, or empowers women to control and protect their sexual health. Is there a better way to address the harm and anger that result from being exposed to HIV and other STIs? Betrayal in an intimate relationship can lead to disease, illness, pregnancy, and violence, but only in the case of HIV do policymakers see criminal charges and jail as a solution. Most people agree that PLWHA have an ethical obligation to reveal their HIV status to a partner. However, the same obligations apply to other STIs. Doesn't everyone have an ethical responsibility to use protection when having sex to protect themselves and their partners from disease or pregnancies they are not ready for?

In the United States, many women with HIV are women of color who are already dealing with stigma and discrimination. Arresting and incarcerating partners for HIV nondisclosure or exposure in consensual relationships does not do anything to end the social inequities that make women and girls more vulnerable to HIV, such as gender-based violence or the lack of financial independence. In fact, HIV criminalization laws increase women's risk of violence and further promote fear and stigma.

Ms. Brown and Ms. Lopez asked that PACHA take action and support a resolution that calls for an end to the injustice of HIV criminalization and the harm that such policies cause women like them.

**Faith Hunter** of the Dr. Michael A. Hunter Foundation read a statement on behalf of her brother, Mark A. Hunter, who is on parole and cannot travel. A hemophiliac who became infected with HIV at age 7, Mr. Hunter faced charges brought by his ex-fiancé under HIV

criminalization laws, although she had been aware of his status since the time they were dating. The Hunter family fought the charges for 18 months until reaching a plea. Mr. Hunter served “2 years, 10 months, 21 days, 11 hours, and 52 minutes as an involuntary resident of the State of Arkansas.” While in prison, Mr. Hunter was required to enroll in a sex offender class and made to feel like “the lowest type of person in life.” While incarcerated, he founded the Dr. Michael A. Hunter Foundation to help PLWHA in Louisiana. He speaks at events and universities about his ordeal around the criminalization of HIV. In the statement, Mr. Hunter asked PACHA members, “What if I were your child, and what if you were in my shoes?” In addition to reading her brother’s written testimony, Ms. Hunter added that the intent to infect is not the same as the failure to disclose.

**Nick Rhoades**, a volunteer for Positive Iowans Taking Charge (who was among those featured in The Sero Project video describing his conviction for exposing his partner to HIV), said that despite the fact that he had an undetectable viral load and used a condom, he was sentenced to 25 years in prison in Iowa for nondisclosure of his HIV status. He described the conditions of his first 6 weeks in solitary confinement and the restrictive terms of his probation. Because he is considered a sex offender, he is required to take lie detector tests every 6 months that involve demeaning, humiliating questions. Lambda Legal is representing Mr. Rhoades’ appeal to the Iowa Supreme Court, but he will never get his old life back. He said people are shocked at his situation and sympathize with him, but they do not speak out or exercise their influence, and they do not make it a priority to correct the terrible injustice. He hoped that members of the influential PACHA would be different.

**Monique Moore**, founder of Monique’s Hope for Cure Outreach Services, explained that she was diagnosed while pregnant and serving in the Army. She received almost no counseling following her diagnosis, and she was afraid to disclose her status. Charges against her were eventually dropped, but she felt like a criminal and spent time in psychiatric wards because she wanted to give up on life. Women living with HIV go through a lot, but the stigma leads to depression, loneliness, broken homes, and ruined friendships. Stigma causes people to avoid testing and treatment because society treats PLWHA as though they are monsters. You will not get more people to disclose their HIV status by passing laws, telling them they should disclose, or wagging your finger at them. More people will disclose when it is safe and free of stigma. Ms. Moore referred to the case of Cicely Bolden, who was murdered by her boyfriend when she revealed her HIV status. If you don’t say criminalization is wrong, you are making stigma worse, said Ms. Moore.

**Edward Casto** of Spokane, Washington, said he was born with HIV. At 21, he is starting college late because he served 2 years in prison for not disclosing his HIV status before having sex, although he had an undetectable viral load and did not infect anyone. Prison was hell, especially as a teenager, but Mr. Casto has support from a loving family, close friends, and a great pastor. People say HIV criminalization is complicated, but Mr. Casto posed a simple question, “Why did I go to prison for fear of something that no one has proven has ever happened?” Mr. Casto said the Declaration of Independence states that all men are created equal, but he was not born equal. He was born as a threat to society, so dangerous that special

laws are created to protect HIV-negative people from him. Making different laws for people based on things they cannot change, like their skin color, sex, or genetics, is wrong. Mr. Casto said he cannot change his HIV status, and yet he has fewer rights than others. Every day that these laws remain on the books, every day that PACHA and other powerful leaders remain silent, and every day that PLWHA live in fear of unfair prosecution is a day of shame for our country.

**Hazel Hunter** said her son Mark Hunter was incarcerated by the State of Arkansas for potentially exposing someone to HIV. She described her family's traumatic journey: both of her sons received tainted blood products during treatment for hemophilia and became infected with HIV. In 1994, Ms. Hunter's eldest son, Dr. Michael Hunter, died from complications related to AIDS. Her son Mark was imprisoned, betrayed by his ex-fiancé, the media, and even the attorneys who were supposed to protect him. Ms. Hunter said her family lost trust in the government when her boys received contaminated blood in the 1980s, but she still had hope. After the years of her son's incarceration under harsh and unfair HIV laws, the financial and emotional strain on her family, and the lack of hope in her son's eyes, Ms. Hunter said, she no longer trusts the government or the judicial system. She sought to shed light on injustice with her story and stop the criminalization of HIV. She said that her faith and trust in God leads her to believe that all is possible.

**Donald Bogardus** of the Sero Advisory Committee, the youngest of 17 siblings, said he is on pretrial release awaiting sentencing in Iowa for not disclosing his HIV status, although he had an undetectable viral load and did not transmit HIV. Mr. Bogardus said he thought he knew what stigma was as a gay, African American man with cerebral palsy, but that was nothing compared with the stigma he experienced—including from other gay men—when he disclosed his HIV status. He was charged with criminal transmission of HIV in 2009 and is awaiting the decision of a judge. Mr. Bogardus worked as a certified nursing assistant caring for elderly and ill people. If convicted, he will likely be classified as a sex offender and will lose his license, his income, his passion (his work), and his pride. He said that if PACHA can say something about how wrong HIV criminalization is, the judge in his case might read it. He asked that PACHA write to the judge that Mr. Bogardus is not a bad person or a threat to society and that he did not hurt anyone; he just wants to be loved, like everyone else.

**Oscar Mairena** summarized NASTAD's efforts to eliminate stigma and encourage safe and voluntary disclosure practices, including its 2011 HIV Criminalization Policy Statement. Many criminalization laws do not consider public health advances in suppressing viral loads, promoting effective condom use, and communicating the actual risks of transmission based on exposure. The laws are based on stigma, not science, and are just one of the barriers faced. The first 2 years of NHAS implementation focused on HIV prevention and access to care and treatment. Mr. Mairena said that in year 3, reducing stigma and discrimination must be a priority at the Federal, State, and local levels. NASTAD is encouraged by PACHA's recognition that HIV disclosure and criminalization must be addressed in a way that does not increase stigma against PLWHA. NASTAD looks forward to working with PACHA to further reduce stigma and discrimination and ensure the health and human rights of PLWHA.

**Christine Campbell** of the DC Community Coalition called on PACHA to use its influence to obtain strong State implementation of the NHAS and annual reporting. Many at the community level do not know what their region is doing in response to the NHAS, and there does not appear to be a comprehensive approach. For example, Washington, DC, still has no cross-agency plan for coordination. Instead, Federal funding drives local planning and decisions, and reports are written only to meet Federal requirements. The DC Community Coalition is calling for the creation of a city-wide strategy that is based on community need and not funding silos and that would give the District the ability to work with regional partners. Ms. Campbell asked that PACHA formally request regular reporting on programs charged with NHAS implementation, advocate a cross-agency approach to implementation, affirm the value of collaboration, and urge local governments to collaborate and develop regional strategies.

**Rashida Richardson** of The Center for HIV Law & Policy spoke on behalf of the more than 1,000 HIV-positive women, children, and young adults in Brooklyn, New York, who have been affected by a HRSA decision to cut Ryan White Part D funding. HRSA said that the Kings County Hospital and the FACES Network of Brooklyn were previously funded to serve Brooklyn with a combined total of \$2.05 million; now Kings County Hospital has been designated the sole provider for the borough, with funding of \$350,000—an 83 percent drop. Ms. Richardson said most patients will not travel to the hospital for treatment, and the hospital could not absorb an additional 1,000 patients within 3 months. Reducing funding to Brooklyn, which has very high rates of HIV/AIDS, is reprehensible and irresponsible, as some of the most vulnerable people in the HIV community will not receive service. Resolutions such as those passed by PACHA to address the needs of women living with HIV are obsolete if HRSA makes such irresponsible cuts. On behalf of those in Brooklyn affected, Ms. Richardson asked that PACHA review HRSA's decision to cut Ryan White Part D funding in Brooklyn.

**Nathan Danskey** of the HIV Medicine Association offered the perspective of 5,000 health care providers who practice on the front lines. He urged PACHA to advocate for the repeal of laws that target HIV-positive people. They are not based on evidence. Criminalization discourages individuals from learning or disclosing their status and thus places more people at risk. It also fuels the stigma associated with HIV that slows efforts to combat the epidemic. Mr. Danskey urged PACHA to join HIV health care providers, the PJP, and others working to end punitive laws that single out HIV and ensure that all State and Federal policies are based on scientifically accurate information about transmission and risk. He called for review of Federal policies on prosecution to identify harmful policies and take action to mitigate them, including repeal. He asked that PACHA and others promote public education and understanding of the impact of stigma and the negative public health impacts of HIV criminalization and prosecution. In closing, Mr. Danskey said his organization hopes to be a resource to PACHA as it moves forward.

**Jenny Collier** of the Ryan White Medical Providers Coalition said that her organization wrote to the HHS Secretary to request that the annual conference for Ryan White providers be reinstated. Ms. Collier was told that the conference was canceled this year because of the scrutiny on conferences resulting from the U.S. General Services Administration scandal. In past

years, the conference has been a valuable opportunity for clinical providers to learn about new research in a time-effective, cost-effective way. Providers then translate that information into practice and communicate it to local colleagues, multiplying the effect. Ms. Collier said clinical providers face a lot of stress. She asked that PACHA support efforts to reinstate the conference early next year so that providers have the opportunity to get information, especially as they plan for full implementation of the ACA in 2014.

#### **PACHA Response**

Ms. Mahon said that PACHA would let HHS know that it supports reinstatement of the conference.

Mr. Alfaro of Casa Ruby said his organization is one of only a few Latino LGBT organizations in Washington, DC. Many of its clients do not have food or stable housing, and some are homeless. How can we stop the epidemic if PLWHA do not have access to these basic resources? These people need to worry about feeding themselves before they can think about getting treatment for HIV. Mr. Alfaro asked that PACHA express support for more resources. If the United States is a world superpower with immense technological capacity, why isn't it studying HIV at a higher level? Mr. Alfaro concluded that he has taken part in many studies and is willing to participate in any clinical trial because he recognizes how treatment can help.

#### **Public Comments Conclusion and Closing Remarks**

Ms. Mahon thanked the commenters for their moving testimony and assured them that their voices had been heard. She appreciated the time and effort of the commenters, especially those who had traveled a long distance, and she said PACHA's work is influenced by the advice that public citizens provide.

Mr. Brooks hoped PACHA members would consider what PACHA can do immediately in response to some of the comments, such as asking CDC Director Thomas R. Frieden, M.D., M.P.H., or Surgeon General Regina Benjamin, M.D., M.B.A., to weigh in on the court cases in Iowa. Alternatively, advocates should advise PACHA on what entities are in the best position to provide input to State judges.

#### **Conclusion**

Ms. Mahon concluded the meeting for the day at approximately 5:10 p.m.

## DAY 2

### Welcome

Ms. Mahon welcomed PACHA members, presenters, and the public. She called the roll later in the morning.

### Remarks from Grant Colfax, M.D., Director, White House ONAP

Dr. Colfax expressed his appreciation to PACHA members for their work, noting that the legacy of HIV is that of the HIV and scientific community coming together to do the right thing. The NHAS implementation report released at the International AIDS Conference reinforced the commitment to meeting the goals of the NHAS.

Dr. Colfax promised to provide a comprehensive update on the Federal workgroup focused on HIV/AIDS, violence against women, and gender-related health disparities at the January 2013 PACHA meeting. The workgroup is compiling an inventory of programs to identify areas of potential synergy. On November 16, it will hold a half-day meeting to identify research gaps and catalogue existing research. PACHA members are invited to attend. The workgroup is committed to stakeholder input and is planning several opportunities for input in November and December.

ONAP is collaborating with the CDC and others on an NHAS implementation tool to help local jurisdictions prioritize HIV interventions according to local needs and evidence-based approaches.

Dr. Colfax said he would follow up with Ms. Mahon and Dr. Valdiserri about PACHA's input to ensure that the promise of the ACA is recognized and that the RWCA program continues to serve PLWHA. Traditionally, the first PACHA meeting of the calendar year is held in the White House, and Dr. Colfax hoped to see PACHA members then.

#### Follow-Up Item

The January 2013 PACHA meeting agenda will include a comprehensive update on the Federal workgroup focused on HIV/AIDS, violence against women, and gender-related health disparities from ONAP.

### ACA Update

#### Robert Greenwald, J.D., PACHA Member, Co-Chair, Access to Care Subcommittee

Mr. Greenwald explained the various factors contributing to the status quo in which as many as 59 percent of low-income PLWHA do not have regular access to care. The RWCA program is a lifesaver but is not keeping up with increased need. Implementation of the ACA holds great promise, but key decisions about Medicaid expansion, health exchanges, and EHBs will determine whether the ACA works for PLWHA.

Massachusetts' health care reform efforts are the model for the ACA. By expanding Medicaid, subsidizing private insurance coverage, and retooling RWCA programs, the State now has 99 percent of PLWHA in care, compared with 37 percent nationwide. It also has much higher rates of PLWHA taking HIV medication, achieving viral suppression, and in good health. By the end of 2011, Massachusetts saw a 46 percent reduction in new HIV diagnoses. Between 2002 and 2008, the State's AIDS mortality rate dropped by 44 percent, compared with 33 percent nationally. Hospital costs and per-patient costs have decreased. It is estimated that Massachusetts saved about \$1.5 billion in HIV health care expenditures over the past 10 years, largely thanks to early diagnosis and intervention.

Mr. Greenwald pointed out that Massachusetts uses all of its RWCA funding to offset the premiums and copays for low-income PLWHA, which allows the State to serve more people despite level funding. It costs about \$3,000 per person per year to ensure coverage—an incredibly smart investment, said Mr. Greenwald, and a key point for the future of the RWCA. He added that planning is vital. To address its health care issues, California created an approach that failed to take PLWHA into consideration. PLWHA then enrolled in Medicaid programs and lost their RWCA eligibility.

**Amy Killelea, Senior Manager, Health Care Access, NASTAD**

Ms. Killelea said the U.S. Supreme Court upheld the entire ACA, including Medicaid expansion, but removed the Federal government's ability to cut a State's Medicaid funding if it fails to comply in 2014. States with the most restrictive Medicaid programs have the most to gain from expansion. Advocates should speak out for Medicaid expansion in all States by 2014; at present, States have a lot of flexibility, and the rules and regulations will not be finalized until after the election.

Without State compliance, many PLWHA will not qualify for Medicaid and will not be eligible for Federal subsidies to purchase insurance. Advocates and planners must anticipate the gaps and how to fill them (e.g., through RWCA programs).

**Andrea Weddle, HIV Medical Association**

Ms. Weddle said that the Medicaid Home Health option supports comprehensive care management for beneficiaries with two or more chronic conditions, including HIV. It appears to leverage Medicaid funding using a RWCA model. States will develop their own models to pay for coordinated care, but the Federal government will support these programs for the first 2 years.

Ms. Weddle emphasized the important role of State health exchanges. The exchanges will certify the health plans offered and so directly influence the quality of coverage. State exchanges can be active purchasers who leverage the State's buying power and negotiate for the best possible plans or passive players who set minimum standards and allow any plan that meets those standards to offer coverage. Plans will be required to report quality measures.

Federal regulations for insurance exchanges have been published and set important standards for consumer education (e.g., requiring patient navigators and out-of-pocket cost calculators), but benefits will be determined by the States. The Federal regulations require a “no wrong door” policy; that is, anyone eligible for Medicaid will be enrolled no matter where he or she enters the system. Because of the California experience, Federal policies define RWCA providers as essential community providers, but States will set their own standards for provider networks. States are required to make decisions about their 2014 exchanges by mid-November, and many States remain undecided about the option they will pursue.

Ms. Killelea added that it is important to ensure that access to insurance translates into access to care by ensuring that the State-defined EHBs include coverage sufficient to meet the needs of PLWHA. Only about half of the States have met the deadline to select a benchmark plan on which to base their EHBs, and there has been no Federal guidance on how EHBs map onto existing requirements. Without robust Federal standards, States could limit coverage. The one-drug-per-class policy demonstrates that a weak benchmark plan can hinder access to care for PLWHA. Plans may meet the minimum EHB standards yet include other utilization management approaches that limit access to benefits. We need strong Federal regulations that mandate an HIV standard of care for EHBs.

Medicaid also has a benchmark requirement, but States could design packages that do not help PLWHA and others with chronic diseases. Even with full implementation of the ACA, gaps will remain, and RWCA programs will be needed.

Ms. Killelea said HHS is responsible for providing Federal guidance on implementation of the ACA. PACHA should advocate for regulations that incorporate HIV providers and programs. Federal oversight and enforcement are needed to ensure the protections promised by the ACA. Definition of EHBs is the most significant issue of immediate concern. Currently, Medicaid programs will be required to cover all those with incomes below 133 percent of the Federal poverty level.

Ms. Weddle called for HHS to establish a point person for HIV health care reform to help connect all the moving pieces and minimize gaps. Mr. Greenwald said someone at CMS should be identified as responsible for ensuring that PLWHA, their providers, and their programs are integrated into the ACA. (PACHA members differed on whether responsibility should lie within an office at HHS or specifically within CMS to ensure that Medicaid programs address HIV needs.)

Ms. Weddle said RWCA programs and providers need education and technical assistance, including regular updates on ACA implementation and ongoing support for forums that bring grantees together (e.g., the canceled annual conference). She also called for increased investment in Medicaid programs, noting that 50 percent of PLWHA are on Medicaid now, and reduced funding to States will cut programs. The RWCA program model works for various and complex patient populations, and it should be leveraged to ensure stability. A sample of eight

RWCA sites demonstrated the effectiveness of the programs in retention and treatment. Ms. Weddle also called for ongoing assessment beyond 2014 of access to HIV care and treatment.

### **Discussion**

It was noted that HIV programs must be part of the overall health care structure and that they must be represented in State-level discussions about reform. Advocates should form State coalitions and get involved at the highest levels to emphasize the EHBS needed for PLWHA.

Technical assistance is crucial to ensure a smooth transition and address the anguish, uncertainty, and fear of systemic changes. It is important not only to maintain the RWCA program but to recognize that it works in tandem with and not in place of the ACA. Strong information about the benefits and cost-savings of HIV treatment should be highlighted for decision-makers.

The ACA recommends an overhaul of health information technology (HIT) systems, and most States are revamping Medicaid HIT. Efforts should be made to ensure that State and Federal HIT systems talk to each other, said Ms. Killelea.

Ms. Weddle agreed to provide some straightforward language that advocates can use to describe the gaps in care that PLWHA face.

It was noted that the HHS Secretary has delegated responsibility for a lot of the ACA provisions, such as the EHBS needed for PLWHA. PACHA should recommend that the Secretary take back the authority to dictate the minimum benefits required to support PLWHA, among other issues.

### **Follow-Up Item**

The Access to Care Subcommittee will draft a resolution describing several areas in which the HHS Secretary should directly exercise her decision-making authority for ACA implementation.

## **RWCA Reauthorization Update**

### **Deborah Parham Hopson, Ph.D., R.N., FAAN, Assistant Surgeon General, Associate Administrator, HRSA HIV/AIDS Bureau**

Dr. Hopson said HRSA is more focused on the interaction between the RWCA program and the ACA than on the specifics of RWCA reauthorization. HRSA and CMS are cooperating. For example, because State Medicaid and HIV/AIDS directors do not always work together in the same State organization, HRSA and CMS are encouraging collaboration and have developed a toolkit to provide training materials, technical assistance, and Web links on the rollout of State health plans.

Already, many States have enrolled a lot of PLWHA in preexisting condition insurance plans. Because the AIDS Drug Assistance Program (ADAP) counts toward Medicare out-of-pocket drug expenses, fewer people are relying entirely on ADAP. Medicaid expansion, insurance subsidies,

private market reforms, and support of medical homes all have positive implications for PLWHA.

HRSA conducted a qualitative study of seven States about ACA provisions that immediately affect RWCA programs. It revealed the need for education, technical assistance, and collaboration within States and across sectors. The study also underscored the need for EHBs that meet HIV health care needs.

Another study is evaluating who will need RWCA programs once the ACA is fully implemented. The California experience already has shown the need to ensure continuity of care and allow for flexibility within RWCA programs. Massachusetts demonstrated significant decreases in new HIV diagnoses by ensuring comprehensive care with no gaps and keeping its RWCA programs. Colorado found that case management is important to maintain people in care throughout a transition, but it is expensive.

Dr. Hopson said the ACA will not eliminate the need for the RWCA program, but it is not yet clear what the next iteration of the RWCA will look like. From stakeholders, she has heard strong support for reauthorization and much focus on continuity of care, retention, support services beyond medical care, and reaching viral suppression. Linkages to care and retention remain key to addressing the cascade, and the RWCA program is a model of successful retention with good outcomes. There have been many requests for increased flexibility within RWCA programs (e.g., grace period, waivers, allowable uses of funds).

Dr. Hopson pointed out that Massachusetts' reform would not have been as successful if HRSA had pulled out all the RWCA program funding. She recognized the need to monitor the implementation of the ACA and to educate RWCA providers and PLWHA about the ACA and about the effectiveness of the RWCA program.

### **Discussion**

HRSA was urged to reinstate the annual clinical conference for RWCA providers. The restrictiveness of the RWCA legislation was challenged, and Dr. Hopson maintained that the RWCA pays for care only when there is no other reasonable expectation that payment will be made. She said legislative change is needed to enable more flexibility.

### **New PACHA Subcommittee Update: Expanding Access to HIV Care**

#### **Humberto Cruz and Mario Perez, PACHA Members, Co-Chairs, Expanding Access to HIV Care Subcommittee**

Mr. Cruz noted that the new Subcommittee was charged with providing advice and recommendations on revising the RWCA program in light of the ACA. Mr. Perez said that the Subcommittee agreed to delay its deliberations for a few weeks to get a better sense of the shifting political landscape and to digest the growing body of findings and reports on issues of concern. The Subcommittee will meet in November during the RWCA grantees meeting.

## **HIV/AIDS Core Indicators Update**

### **Andrew Forsyth, Ph.D., Senior Science Advisor, OHAIDP**

Dr. Forsyth said that to ensure consistent metrics are available to measure progress and to reduce reporting burdens on grantees, HHS is developing a core set of indicators for HIV programs. The indicators will be fully deployed by the beginning of fiscal year 2014. They are consistent with the Institute of Medicine's recommendations. OHAIDP also aims to standardize demographic variables to allow for comparison of subgroups as they progress along the continuum of diagnosis and care. The indicators are as follows:

- HIV positivity (proportion of all HIV tests that are positive)
- Late HIV diagnosis
- Linkage to HIV medical care
- Retention in HIV medical care
- ART among persons in HIV medical care
- Viral load suppression among persons in HIV medical care
- Housing status

OHAIDP is working with the various agencies within HHS to finalize the list; at the same time discussion is under way about standardizing other measurements, streamlining data collection, and sharing data. Dr. Forsyth said his office is thinking about potential next steps—for example, a dashboard of indicators; a dedicated HIV program data system; enhanced integration of electronic health records and Federal data systems; and alignment of indicators, reporting processes, and reporting deadlines.

Dr. Forsyth asked for PACHA input on the fact that no behavioral or prevention metrics are included among the seven core indicators and on ways to harmonize data collection across agencies to improve standardization.

### **Discussion**

It was noted that HHS has developed a good site that helps gay people select the best health plans to meet their needs, but more efforts are needed to help consumers identify the best local services and providers according to provider quality data. Dr. Forsyth said LGBT health issues are important to HHS, and work is under way to develop common indicators for sexual orientation and gender identity, but the long-term issue of using data to help individuals select providers has not yet been considered.

It was suggested that HHS look outside of government systems for models of interoperability. Regarding the dashboard concept, the San Francisco Department of Health has a model that gives insight, for example, on progress in linking care.

Reporting data is sometimes conflated with measurement and evaluation, which can be daunting. Targeted studies may provide as much useful information as broad efforts that

require the entire system to collect data that no one uses. Dr. Forsyth reiterated the goal of reducing the data collection burden on grantees by 25 percent.

### **Draft PACHA Report, *Achieving an AIDS-Free Generation***

Ms. Hayes summarized changes made to the report overnight, including the following content issues:

- Information added on HIV and Native Americans with corresponding citation to CDC data
- Language added from PACHA's resolution on the needs of women with HIV
- Some discussion of PACHA's future work

Members offered a number of suggestions for editing (for grammar, style, and format), particularly on the charts and tables.

#### **Motion**

Mr. Perez moved to approve the report with the changes, and Naina Khanna seconded the motion. The PACHA members voted unanimously in favor of the motion.

#### **Follow-Up Item**

PACHA staff will incorporate the suggested changes to the PACHA report, *Achieving an AIDS-Free Generation*, ensure that the report is professionally edited, and submit the charts and tables to the Subcommittee chairs for final approval.

### **Safe and Voluntary Disclosure Recommendations**

Mr. Brooks highlighted the following changes made to the document in response to PACHA comments:

- In the background, noted the importance of contextualizing the recommendations within the larger NHAS goals.
- In Recommendation 2, replaced "mixed method research" with "qualitative and quantitative research."
- In Recommendation 4, added a statement that the working group should make recommendations to eliminate HIV criminalization laws and promote laws and policies that would support people living with and vulnerable to HIV.
- In Recommendation 6, indicated that disclosure support should be a component of mental health services within clinical settings and highlighted that it should take trauma into account.
- In Recommendation 8, shifted the responsibility for working with States from HRSA to HHS more broadly and removed references to RWCA Part B.

There was much discussion about the intention of the revised Recommendation 6. Members agreed with emphasizing the need for trauma-informed services. They unanimously agreed to

revise the recommendation to clarify that approaches to disclosure in clinical settings that *only* involve informing the newly diagnosed of the existence of a law mandating disclosure and/or advising and admonishing the person to disclose to all sexual partners should be discouraged. Recommendation 2 was revised to target all Federal research agencies, not just NIH. Ms. Hayes pointed out that the document will be edited to ensure it reflects a single, consistent voice. Mr. Brooks added that CHAC must also review and approve the final document.

#### **Motion**

Ms. Hiers moved to accept the document with the suggested changes, and Mr. Wilson seconded the motion. PACHA members voted unanimously in favor of the motion.

#### **Follow-Up Item**

The PACHA staff will incorporate the suggested changes to the summary document and recommendations of the PACHA/CHAC Safe and Voluntary Disclosure Workgroup. The document will then be sent to CHAC for review and approval.

### **HIV Criminalization Recommendations**

The Disparities Subcommittee revised the PJP's proposed resolution on HIV criminalization. Ms. Hiers noted that the document is intended to stand alone and therefore overlaps with the Safe and Voluntary Disclosure Workgroup recommendations in some areas. The following concerns were raised:

- Some of the recommendations contain declaratory statements that would be better suited to the rationale (i.e., "whereas" statements).
- The terms used to describe the risk of transmission from individuals with an undetectable viral load should be precise, accurate, and scientifically defensible.
- The document does not state clearly enough that HIV criminalization laws undermine public health and public safety.
- The concerns and experiences of those who may support HIV criminalization (e.g., those infected by a partner who deliberately withheld his or her HIV status) have not been presented to PACHA, and the proposed resolution does not speak to their concerns.
- Language about how HIV infection should be addressed within the justice system requires more consideration and discussion with legal experts.
- In cases of intentional and actual harm, laws specific to HIV are unnecessary.
- The title of the resolution refers to Federal and State laws. PACHA can speak only to Federal laws.
- References to communities of color who are disproportionately affected by HIV should be removed because HIV criminalization is not exclusive to communities of color.

Members agreed to delete the section referencing intended and actual transmission of an STI. Although the need for swift action is pressing, so is more careful deliberation within the Disparities Subcommittee. Input from those with legal expertise and those with other perceptions on the issue should be sought. Key statements from the proposed resolution

should be incorporated into PACHA's final report, *Achieving an AIDS-Free Generation*, along with a statement that PACHA is addressing HIV criminalization with a more in-depth resolution.

**Follow-Up Item**

The PACHA staff will add to the PACHA report, *Achieving an AIDS-Free Generation*, the following in a description of PACHA's ongoing efforts to address HIV criminalization:

The NHAS includes a statement on the problem and public health consequences of HIV criminalization and notes that many State HIV-specific criminal laws reflect long-outdated misperceptions of HIV's modes and relative risks of transmission.

The PACHA Disparities Subcommittee will revise the proposed resolution on HIV criminalization, with input from others as needed, and present it to PACHA for consideration.

**Adjournment**

Ms. Mahon adjourned the meeting at approximately 12:45 p.m.