

**Presidential Advisory Council on HIV/AIDS (PACHA)**  
**53rd Meeting**

**Hubert H. Humphrey Building**  
**U.S. Department of Health and Human Services (HHS)**  
**Washington, DC**

**February 27–28, 2014**

**Council Members—Present**

Nancy Mahon, J.D., PACHA Chair  
Ada A. Adimora, M.D., M.P.H.  
Dawn Averitt  
A. Cornelius Baker (day 2 only)  
Praveen Basaviah (by telephone)  
Douglas Brooks, M.S.W.  
Cecilia C. Chung  
Ernest Darkoh, M.D., M.P.H., M.B.A.  
Kevin Robert Frost  
Patricia Garcia, M.D., M.P.H. (by telephone)  
Robert Greenwald, J.D.  
David Holtgrave, Ph.D.  
Michael Horberg, M.D., M.A.S.  
Ejay L. Jack, M.S.W., M.P.A.  
Naina Khanna  
Douglas A. Michels, M.B.A.  
Mario Pérez, M.P.H.  
Rev. Vanessa D. Sharp, M.Div., M.A.C.M., M.A.T.M.  
Elizabeth Styffe  
Phill Wilson

**Council Members—Absent**

Humberto Cruz, M.S.  
Kathie M. Hiers  
Alton B. Pollard III, Ph.D.  
Sandra Torres-Rivera

**Federal Liaisons**

Antigone Dempsey, M.Ed., Centers for Disease Control and Prevention (CDC)/Health Resources and Services Administration (HRSA) Advisory Committee for HIV and STD Prevention and Treatment (CHAC) Co-Chair, CHAC Liaison to PACHA  
Eva Margolies, M.P.A., Associate Director for Planning and Policy Coordination, National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, CDC

Ronald O. Valdiserri, M.D., M.P.H., Deputy Assistant Secretary for Health, Infectious Diseases;  
Office of HIV/AIDS and Infectious Disease Policy, Office of the Assistant Secretary for Health,  
HHS

## **Staff**

Kaye Hayes, M.P.A., PACHA Executive Director  
Caroline Talev, PACHA Public Health Assistant

## **Presenters**

Gary Cohen, Director, Center for Consumer Information and Insurance Oversight (CCIIO),  
Centers for Medicare and Medicaid Services (CMS)

Liza Conyers, Ph.D., C.R.C., Associate Professor of Education, Rehabilitation and Human  
Services, Department of Educational Psychology, Counseling, and Special Education,  
Pennsylvania State University

Leonardo Cuello, Director, Health Reform, National Health Law Program

CAPT Eugene Freund, M.D., M.S.P.H., Medical Officer, CCIIO, CMS

RADM Deborah Parham Hopson, Ph.D., RN, FAAN, Senior Advisor for HIV/AIDS Policy, HRSA  
Jennifer Kates, Ph.D., Vice President/Director, Global Health and HIV Policy, Kaiser  
Family Foundation

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

Ann Lefert, M.P.P., Director, Policy and Health Care Access, National Alliance of State and  
Territorial AIDS Directors (NASTAD)

Tommy Luckett

Cindy Mann, Deputy Administrator Director/Director, Center for Medicaid and CHIP [Children's  
Health Insurance Program] Services, CMS

Mark Misrok, M.S.Ed., C.R.C., President, Board of Directors, National Working Positive Coalition  
(NWPC)

Claudia Schlosberg, J.D., Director, Health Care Policy and Research Administration, District of  
Columbia Department of Health Care Finance

Hon. Kathleen Sebelius, Secretary, HHS

Matt Sharp

Melanie Thompson, M.D., Principal Investigator, AIDS Research Consortium of Atlanta

April Watkins, Assistant Director, Workforce Development, Gay Men's Health Crisis (GMHC)

## **Day 1**

### **Welcome and Introduction**

PACHA Executive Director Kaye Hayes called the meeting to order at 9:11 a.m. and called the roll. PACHA Chair Nancy Mahon welcomed the participants. Ms. Mahon credited the Obama Administration, HHS Secretary Kathleen Sebelius, and Assistant Secretary for Health Howard Koh, M.D., M.P.H., for having the “determination, guts, and ferocity” to change our health care laws, ensuring that all people have access to high-quality health care through the Affordable Care Act (ACA). The ACA represents an extraordinary shift in the lives of people with chronic conditions, such as people living with HIV (PLHIV), she said. The goal of this meeting is to assess the effects of the ACA so far and discuss how to improve it.

Ms. Mahon noted that the terms of 13 PACHA members will expire soon. She believes that all those members who wish to remain on the Council can renew for another term.

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

Dr. Koh welcomed PACHA members and said he is always inspired by their dedication and perseverance. He enthusiastically praised Ms. Mahon’s leadership of PACHA; he called Ms. Hayes “a true star of HHS,” and proudly described the accomplishments of Deputy Assistant Secretary for Health Ronald O. Valdiserri, M.D., M.P.H.

Dr. Koh summarized some of the accomplishments of the past 5 years, including developing the first National HIV/AIDS Strategy (NHAS); hosting the first International AIDS Conference in the United States in 20 years, including HIV screening as a Level A recommendation of the U.S. Preventive Services Task Force; making scientific advancements related to treatment as prevention (TasP); and providing new HHS treatment guidelines for PLHIV. He also cited efforts to improve HIV/AIDS data reporting and collection and address HIV/AIDS in high-risk regions. Dr. Koh said he could see all these efforts coming together at the 2013 World AIDS Day in December when President Obama, Secretary Sebelius, Secretary of State John Kerry, Bill Gates, and others gathered to address HIV/AIDS.

Dr. Koh expressed his appreciation for the input of PACHA members and their colleagues, because they have their fingers on the pulse of the nation and know what it will take to make a difference “on the ground.” The agenda for this PACHA meeting addresses topics on the cutting edge that are moving quickly, he said, so he looks forward to the Council’s advice and insight. Finally, he urged members and participants to continue encouraging each other, to take the long view, and to celebrate their successes so far.

## **Federal Interagency Working Group on the Intersection of HIV/AIDS, Violence Against Women and Girls, and Gender-Related Health Disparities**

### **Naina Khanna, PACHA Liaison to the Working Group**

Ms. Khanna said that since the working group was created by Presidential Memorandum in March 2012, it has conducted an inventory of relevant Federal programs, reviewed the literature, consulted with experts in research, and gathered stakeholder input. These efforts culminated in a report released in September 2013, [Addressing the Intersection of HIV/AIDS, Violence against Women and Girls, & Gender-Related Health Disparities](#).

Ms. Khanna provided some data that reveal how these three issues affect one another and contribute to worse outcomes for women. Violence and trauma affect women at every stage of the HIV care continuum (from diagnosis through viral suppression), and HIV perpetuates the risk of violence and trauma against women, she stated. Ms. Khanna summarized the working group's core objectives and highlighted some recommended actions:

- 1. Improve health and wellness for women by screening for intimate partner violence (IPV) and HIV:** The ACA offers many opportunities to expand screening for both conditions at no cost to patients. Efforts could focus on federally qualified health centers (FQHCs), prenatal clinics, and violence and rape crisis centers. More work is needed to train providers on screening for both and linking patients to care.
- 2. Improve outcomes for women in HIV care by addressing violence and trauma:** Increase models and capacity for trauma-informed care and services for women with HIV that also could benefit other populations.
- 3. Address certain contributing factors that increase the risk of violence for women and girls living with HIV:** Address the criminalization of HIV and laws that perpetuate a climate of violence for PLHIV, especially women; address housing insecurity; and evaluate how the use of hate crime statutes can protect PLHIV.
- 4. Expand public outreach, education, and prevention efforts regarding HIV and violence against women and girls:** Enhance violence prevention programs and engage men and boys in preventing IPV.
- 5. Support research to better understand the scope of the intersection of HIV/AIDS and violence against women and girls and develop effective interventions:** CDC and the National Institutes of Health (NIH) have already committed to specific research goals. The working group identified some areas for further research, including microfinance and economic empowerment.

The working group will report on progress toward these goals in December 2014. Ms. Khanna encouraged PACHA to think about how to move the work forward, because it has great potential to improve care for PLHIV.

### **Discussion**

A participant asked whether the working group has evaluated the percentage of women of color who fall into this intersection. Ms. Khanna said the working group report recommended

creating a Subcommittee to look specifically at the issue for black women and Latinas. The report cites considerable data on HIV, violence, and trauma among women of color, she added.

Phill Wilson pointed out that although he supports disclosure of HIV-positive status, laws that require disclosure are problematic, as women who disclose are more vulnerable to violence. Criminalization laws undermine efforts at every step of the cascade, he emphasized, and Ms. Khanna added that there is considerable data demonstrating that criminalization deters testing. Receiving HIV care or having HIV medication in your home can be forms of disclosure that put a person at risk of violence, and so women in particular have a disincentive for treatment.

Most laws about HIV were created when less was known about transmission, said Ms. Khanna; laws have not been updated, nor are they applied in ways that reflect current science and knowledge. Judges and prosecutors may not have access to updated information, she added. She called for eliminating laws that create a hostile environment and for recognizing that under such laws, individuals cannot be prosecuted if they do not know their HIV status, which is counterproductive. Ms. Khanna said a bill before Congress [H.R. 1843/S.B. 1790] would address this issue.

## **Message From the Secretary**

### **Hon. Kathleen Sebelius**

Secretary Sebelius thanked Dr. Koh and Ms. Mahon for their amazing work with PACHA and a broad array of domestic HIV/AIDS initiatives. She assured PACHA members that their voices are heard and that the efforts of the Council inform HHS policy.

Among this Administration's accomplishments related to HIV/AIDS so far, HHS eliminated the waiting lists for the AIDS Drug Assistance Program (ADAP) last fall, and PACHA played a role, said Secretary Sebelius. She also pointed to NIH-funded efforts to develop new treatments and services, Food and Drug Administration approval of a new diagnostic test, and public-private partnerships to facilitate access to treatment. These steps were due in no small part to the people at this meeting, said Secretary Sebelius. She thanked PACHA for providing guidance on vulnerable populations, noting that PACHA recommendations inform the dialogue and budget considerations at HHS and the White House, keeping the focus on implementation of the NHAS.

Secretary Sebelius said she is heartened by this meeting's attention to implementation of the ACA as it intersects with the lives of PLHIV. The ACA is the most significant thing to happen to the HIV/AIDS community since HIV was first diagnosed and treated, and PLHIV will never again be locked out of treatment because they have HIV. There will be affordable health care coverage for people who do not have such coverage through work. Secretary Sebelius emphasized that efforts by PACHA members and their colleagues are incredibly important to encourage enrollment in health plans. (She noted that the Web site Healthcare.gov is now working very well in both English and Spanish, and telephone and in-person assistance also are available.)

Moreover, advocates must keep the pressure on Governors to expand their Medicaid programs, which are critical for PLHIV, especially those who are uninsured, said Secretary Sebelius. She said about two-thirds of States either have already expanded their Medicaid programs or intend to do so, but way too many States have not stepped up. She encouraged advocates to make the case for return on investment. Medicaid expansion to cover the uninsured will be entirely federally funded for the first 3 years; over the next 7 years, the proportion of Federal funding will gradually decline but will never fall below 90 percent.

Secretary Sebelius said chambers of commerce are leading the battle for Medicaid expansion because they see it as a good business proposition. Taxpayer dollars now spent on uncompensated care, on taking care of people in jails because they did not have access to mental health or substance abuse treatment, on helping people who live under bridges because they do not have access to health care or mental health care—those are taxpayer dollars that could be redirected if money were provided for health services. There is not only a moral case to be made for helping people get healthy, stay healthy, and take care of their families and communities, but also a business case, said Secretary Sebelius.

Regarding the court case in Louisiana against insurers who have refused to accept third-party payments for insurance premiums from the Ryan White HIV/AIDS program, Secretary Sebelius emphasized that use of Ryan White funds for premium support is not new; it has been underway for at least 10 years. The litigants in the Louisiana case have succeeded so far in getting the insurance companies to accept Ryan White payment through the end of open enrollment.

Secretary Sebelius stressed that HHS is monitoring the case. She said CMS has already issued guidance stating that Federal rules do not prevent the use of Ryan White funds to pay for health plans, and HHS wants to make that point clearly.

As of February 27, 4 million people had signed up for health insurance in the marketplace; 6.3 million more people qualified for Medicaid as of the end of January. However, a huge need remains, and many people do not realize they are running out of time, said Secretary Sebelius. She welcomed the advice of PACHA members and their colleagues. She stressed that once people enroll, they still will need help understanding their plans and how to access care. HHS intends to conduct a large educational initiative to help people navigate their new policies. Secretary Sebelius requested input from PACHA on how best to help newly insured PLHIV. In closing, she thanked PACHA members and colleagues for the work they do every day for their constituents and as part of PACHA.

## **Panel: Medicaid Under Health Reform: An Overview of the Diverse Experiences of PLHIV**

**Moderators: Robert Greenwald, J.D., and Phill Wilson, PACHA Members**

In PACHA's ongoing effort to assess progress toward fulfilling the promise of the ACA for PLHIV, panelists were invited to describe immediate concerns about Medicaid expansion, said Mr.

Greenwald. Mr. Wilson added that while there is talk about ending the AIDS epidemic, there is no pathway to fulfilling that promise without the ACA and Medicaid expansion. He noted that PLHIV have already gained a great deal more access to health insurance under the ACA, but there are still vulnerabilities and unknowns ahead.

### **Medicaid and Vulnerable Populations**

*Leonardo Cuello, Director, Health Reform, National Health Law Program*

Mr. Cuello stressed the importance of Medicaid expansion in covering vulnerable populations. In addition to providing access to health care for the uninsured, Medicaid programs include many consumer protections designed to ensure access to low-income beneficiaries and generous benefits for children. Mr. Cuello pointed out some key issues. For example, CMS requires that Medicaid expansion program benefits actually meet the needs of the covered population. CMS also could declare that anyone who is HIV-positive meets the definition of "medically frail" and is thus eligible for traditional Medicaid.

Some States have negotiated with the Federal Government regarding Medicaid expansion. Arkansas negotiated successfully to use its expansion funding to allow individuals to buy private health insurance. Once approved, Iowa requested the same deal, but also negotiated waivers that remove some of the benefits intended under the ACA. Pennsylvania is pushing to go even further, adding a significant number of restrictions. Mr. Cuello said HHS is under great pressure to get States to expand their Medicaid programs, but advocates must insist that HHS draw some clear boundaries.

New case management programs offer a great opportunity to improve coordination of care, but some are untested. Mr. Cuello argued in favor of determining what works and providing adequate supports during any transition. Finally, HHS is working on final guidance about how the ACA will interact with nondiscrimination laws. Mr. Cuello concluded that we cannot go back to "the dark ages" of health coverage, when individuals had to become disabled before qualifying for care.

### **Medicaid Expansion—Washington, DC: A Case Study**

*Claudia Schlosberg, J.D., Director, Health Care Policy and Research Administration, District of Columbia Department of Health Care Finance*

Ms. Schlosberg described the successful Medicaid expansion in Washington, DC, and its impact on PLHIV. In 2010, the city already had a local program and two small demonstration projects that covered some of those not eligible for Medicaid or Medicare. By expanding Medicaid early (2012), Washington now covers 50,000 residents who would not otherwise have coverage.

The 100 percent Federal funding for Medicaid expansion is a tremendous opportunity for States, said Ms. Schlosberg, and a real economic driver. She pointed out that the average monthly cost to Medicaid has been significantly higher for PLHIV, and Washington has had to make some adjustments, such as instituting a citywide network and pricing for HIV drugs and improving care coordination models.

Ms. Schlosberg illustrated the need to eliminate the stigma of Medicaid. She urged advocates to help people, especially PLHIV, understand the Medicaid benefits package. For example, Medicaid provides substantially better HIV drug coverage than private insurers, she noted. Ms. Schlosberg said there remains a need to explore differences in coverage levels that may affect PLHIV, particularly those subject to churn.<sup>1</sup>

### **Consumer Perspective: Medicaid Expansion in Arkansas**

#### *Tommy Luckett*

Ms. Luckett explained that she was diagnosed with HIV in September 2012. She did not have insurance as a child and had never been able to afford insurance through her employers. When she was diagnosed, she was linked to the local Ryan White program and ARcare, a private, nonprofit community health center. Through ARcare, she was linked to an HIV specialist and enrolled in a research protocol that pays for her HIV medications. Now, under the ACA, Ms. Luckett has access to private insurance (through Arkansas' unique approach to Medicaid expansion) that addresses her other health care needs.

Ms. Luckett said it took all of November to determine that she would be eligible for Medicaid, but then it was easy to sign up. She had several options to choose from. She was enthusiastic, but notes that HIV medications are not even listed on her insurer's Web site, and she is not sure whether her drugs will be covered when the study no longer pays for them. Ms. Luckett described the stress of not knowing and having to track down information about her coverage. She hoped her story would resonate with PACHA members.

### **Medicaid Expansion and the Ryan White Program**

*RADM Deborah Parham Hopson, Ph.D., RN, FAAN, Senior Advisor for HIV/AIDS Policy, HRSA*

Dr. Parham Hopson emphasized that the Ryan White program is HRSA's main focal point in its efforts to achieve the NHAS goals of reducing new HIV infections, increasing access to care, improving the health of PLHIV, and reducing health disparities. In 2011, the Ryan White program served more than half a million PLHIV, 72 percent of whom were insured. A 2012 NASTAD study found that 65 percent of those who used ADAP were insured.

Dr. Parham Hopson estimated that 70,000 PLHIV are uninsured and receiving medical care. About 18,000 of them live in States that are not expanding their Medicaid programs; they will remain eligible for services through the Ryan White program. Approximately 26,000 PLHIV are in States that are expanding Medicaid, and the remaining 25,000 will be eligible for subsidized coverage in the private insurance market.

Most uninsured PLHIV have incomes below the Federal poverty level (FPL), said Dr. Parham Hopson. The Ryan White program will continue to provide coverage for people who have no other access and to pay for care completion for those who do have public or private insurance, she stressed. The Ryan White program will continue to fill the gaps.

---

<sup>1</sup> Churn has been introduced as a framework for describing the continuous movement of individuals entering, reentering, and exiting clinical care at any given point in time.

Dr. Parham Hopson pointed out that the Ryan White program covers core services that may be covered by public or private insurance under the ACA, but, as Ms. Luckett pointed out, there is great variability within and across States. The Ryan White program also pays for support services critical to PLHIV, such as oral health care and transportation, that other insurance usually does not cover. HRSA is working with grantees to ensure that they understand the available plans so they can help PLHIV enroll in the plan that best meets their needs. HRSA offers more information on its own Web site and Web sites of partners.

### **Federal Perspective**

*Cindy Mann, Deputy Administrator Director/Director, Center for Medicaid and CHIP Services, CMS*

Ms. Mann said the decision by States not to expand Medicaid is “unconscionable” and “fiscally irresponsible.” She stressed the importance of working toward Medicaid expansion in every State. Getting more people eligible for insurance is the most important thing we can do under the ACA, said Ms. Mann.

Next, we must simplify the determination of eligibility and ensure that everyone who is eligible is enrolled through outreach, education, and community-based efforts. Ms. Mann pointed out that open enrollment in the marketplace is coming to a close, but Medicaid enrollment is always open. With good design, communication, and enrollment assistance, States can come close to full participation. In addition, said Ms. Mann, advocates should be thinking now about renewing policies for next year.

Third, CMS is focusing on getting beneficiaries the services they need. Ms. Mann said the best option for States is to incorporate the essential health benefits (EHBs) required under the ACA into their basic Medicaid package. It avoids the need to determine who is “medically frail” or whose benefits will change in response to a life change. Ms. Mann said CMS is working with HRSA and the Substance Abuse and Mental Health Services Administration on modernizing Medicaid to ensure access to the most appropriate services.

Fourth, Medicaid, like other programs, is focused on how to deliver care to people with chronic conditions, especially PLHIV, who have the most to gain from an integrated approach (and the most to lose without it). The Innovation Center at CMS is proposing various models to achieving high-quality, integrated care.

### **Questions and Answers (Q&A)**

***What is HHS doing to ensure that insurers (in Louisiana and elsewhere) accept Ryan White funds to pay for premiums?***

In her remarks, Secretary Sebelius said she was very aware of the litigation and that HHS is currently engaged in understanding how to make sure people have access to care, said Ms. Mann.

***Will CMS do research with established metrics to evaluate the effects of Medicaid expansion on improving the treatment cascade?***

Ms. Mann responded that CMS does not have funding for such research. However, CMS is partnering with the Office of the Assistant Secretary for Planning and Evaluation (ASPE) to look at the impact of the ACA on insurance coverage and outcomes, and there is a focus on PLHIV.

***Is there a shortage of resources for outreach around Medicaid? Are there targeted resources to address HIV prevalence among young people?***

Ms. Mann responded that CHIP reauthorization included some money to grantees for outreach to families. Some new efforts will focus on Tribal entities. Every State has access to Federal matching funds under Medicaid that can be used for outreach, she noted. Some States have leveraged foundation dollars for the non-Federal portion. Ms. Mann said CMS is happy to offer technical assistance. She agreed that targeted enrollment is very important, and CCIIO is working with community assisters and others on reaching hard-to-reach communities.

***Which States have not yet committed to Medicaid expansion?***

Mr. Cuello responded that the number is hard to pinpoint. Only 25 States are fully on board, he said; several others are in negotiations. Most of those States that are not expanding are in the Southeast and have Republican Governors, he noted.

***Ryan White services will continue to be necessary even under full ACA implementation. What is HRSA doing to document the effectiveness of Ryan White services, and how will such services be prioritized in the future?***

Dr. Parham Hopson said HRSA is working with the ASPE to evaluate Ryan White services. It has been proven that some support services are needed to link PLHIV to care and retain them. Such services will continue to be funded under the Ryan White program even with the transition to the ACA, said Dr. Parham Hopson.

***What are the best talking points to make the case for Medicaid expansion in “nonsupportive” States?***

Mr. Cuello suggested making the financial case. In “red States,” people are heavily influenced by dollars. While the Federal funding drops to 90 percent after a few years, he noted, most States get only about 50 percent Federal funding for their existing Medicaid programs, so the deal is extremely generous.

Hospitals are the most powerful partners in making the case for expansion, Mr. Cuello continued. Hospital emergency departments are required to treat uninsured patients and often do not get paid for it. If those patients had insurance, hospitals would benefit. Hospitals often are big players within communities, especially in rural counties where the hospital may be the only major employer. Hospitals are the top allies in Medicaid expansion.

***With the pressure on HHS and CMS to get all States to expand Medicaid, what can be done to ensure that all States embark on meaningful expansion?***

Mr. Cuello pointed out that Medicaid was established in 1965, but Arizona did not establish its program until the 1980s. It is important to consider both the short-term gains and the long-term ramifications of negotiated expansions, he said. For example, Mr. Cuello posited, if Arizona had agreed to join Medicaid earlier but without covering children's health, would we be better off today? As recent history shows, once one State successfully negotiates a waiver, another State will ask for that waiver and then some. We have to identify which lines we will not cross—that is, what exceptions alter the program for all of history, Mr. Cuello said.

Asked to provide examples of requests that go over the line, Mr. Cuello pointed to Pennsylvania, which has requested 24 waivers from current Medicaid expansion rules (compared with Arkansas' 3 and Iowa's 6). One such request is a work requirement that allows for termination from the program for noncompliance and a lockout period for nonpayment of premiums. The requests represent categorical changes to the program, which would cease to be a program that meets the needs of low-income people, said Mr. Cuello. HHS is under a lot of pressure, he reiterated; the agency needs to hear from advocates that Medicaid expansion must care for vulnerable people.

***Medicaid expansion in Arkansas is provided through private coverage; it is optional to the State, and the State could rescind its coverage. What could the Federal Government do if the State did rescind coverage?***

Ms. Luckett said she recently learned that the Arkansas Congress is discussing rescinding coverage. Without the Medicaid expansion, she would not have health care coverage, she said. It would be "heart-wrenching" if it were taken away, she added. Mr. Greenwald said the Governor of Arkansas supports Medicaid expansion and has vowed to keep it. Also, the Ryan White program would provide treatment and services for PLHIV if the State rescinded its coverage.

***How can we help a person with HIV who is enrolled in Medicaid and has a great doctor but cannot get his medications?***

Ms. Schlosberg said Medicaid has strong mechanisms in place to ensure due process. If a beneficiary is denied medications, he can request a hearing, and his benefits will continue until the hearing reaches a resolution. In the hypothetical case posed, it is important to determine why an individual is unable to obtain medications. In some cases, the issue can be resolved by working with the health plan, the State Medicaid program, or the pharmacy benefits manager.

Dr. Parham Hopson said that the Ryan White program and ADAP are available in every State and the District. Online, a user can type in his zip code, find the closest Ryan White program, and get medications through that program.

Mr. Cuello said that appealing a denial is never a wrong decision. There is confusion about what falls under Medicaid, and Medicaid does have cost protections, but cost is usually less of an issue in Medicaid than in other programs. Within Medicaid, beneficiaries still must jump

through some hoops, such as prior authorization, step therapy, tiered formularies, etc., said Mr. Cuello, and knowledgeable advocates are needed to help people navigate the benefits. There should always be a smart exception process so that doctors can help people meet their needs, and we should all be working toward that, said Mr. Cuello.

## **Panel: Private Health Insurance Expansion: An Overview of the Diverse Experiences of PLHIV**

**Moderators: Ada Adimora, M.D., M.P.H., and Michael Horberg, M.D., M.A.S., PACHA Members**

Dr. Horberg acknowledged that health insurance is complicated and sought input on how to make the system easier to navigate for PLHIV. The ideal system combines access to care with high-quality outcomes at a reasonable cost, he noted.

### **The Health Insurance Marketplace**

*Gary Cohen, Director, CCIIO, CMS*

Mr. Cohen said CCIIO is currently focusing on improving the consumer experience on Healthcare.gov and ensuring that people can enroll outside of the open enrollment period if they experience certain life changes. Of the 6.5 million people newly enrolled in either a public or private insurance program through the marketplace, one-fourth were young adults (ages 18–24). About 82 percent of those who signed up through the marketplace have received some type of financial assistance (subsidy), either through advance credits or cost-sharing reduction. More than one-half (61 percent) chose a silver (or mid-level) plan, and only 1 percent chose a high-deductible catastrophic plan.

For the newly insured, CCIIO has a robust process for managing enrollment issues as they arise (such as verification of coverage). Each of CMS' regional offices has employees trained to address complex problems through the CMS casework system. CCIIO staff are tracking cases to allow States to exchange information about related issues. Mr. Cohen encouraged PACHA to let CCIIO know what is working and what issues are coming up.

CCIO is looking ahead to 2015. It is reviewing comments received about a draft letter to issuers that addressed, among other topics:

- The availability of essential community providers (ECPs)
- Enhanced review of potentially discriminatory benefit designs
- The adequacy of provider networks
- Consumer access to up-to-date drug formularies
- Allowable use of Ryan White program funds for premium payment.

Mr. Cohen reiterated that outreach is crucial as the end of open enrollment nears. More than 45,000 agents and brokers have been trained to help people navigate enrollment, along with 26,000 assisters and 12,000 call center operators. The public will soon see more paid media and outreach efforts emphasizing the urgency of enrollment, he concluded.

## **Private Health Insurance Expansion and PLHIV**

*Ann Lefert, M.P.P., Director, Policy and Health Care Access, NASTAD*

Ms. Lefert said enrollment got off to a slow start for everyone, but especially for PLHIV in Ryan White programs, because it took a long time to sort out provider network and formulary requirements. On top of the barriers posed by Louisiana's insurers, PLHIV experienced delays getting third-party payments to insurers because insurance is tricky. A NASTAD survey of ADAP recipients showed that they are enrolling in both public and private plans in all States. NASTAD plans a larger survey in the future, and Ms. Lefert expects the number of insured ADAP clients to spike.

Ms. Lefert summarized some key concerns and potential solutions:

- Qualified health plans in Louisiana and North Dakota are refusing to accept payment from ADAP.
  - NASTAD recommends that HHS require all qualified health plans to accept third-party payment from Ryan White and ADAP programs.
- Questions have been raised about the adequacy of drug formularies, restrictive tiering structures, and the lack of a U.S. Pharmacopeia (USP) classification for combination antiretroviral (ARV) regimens.
  - NASTAD recommends that CMS assess plans' compliance with ACA requirements using the latest version of USP classification (which includes combination and single-tablet regimens)
  - NASTAD recommends that CMS require all plans to provide complete formulary information, including the actual out-of-pocket costs, in a standard format.
- Some plans use confusing or unpublished formulas and specialty tiers to determine drug costs, resulting in higher-than-expected cost-sharing for beneficiaries.
  - NASTAD recommends that HHS limit coinsurance for drugs on specialty tiers to at least 25 percent.
- The availability of ECPs and the inclusion of sufficient access to pharmacies are questionable.
  - NASTAD recommends that HHS require all plans to provide detailed lists of ECPs (in a standardized, searchable format) and detailed pharmacy information, including requirements for specific drugs or tiers.

## **ACA Marketplace Challenges: A View From Georgia**

*Melanie Thompson, M.D., Principal Investigator, AIDS Research Consortium of Atlanta*

Dr. Thompson described the disheartening state of health care options for PLHIV in Georgia, which has the fourth highest rate of HIV in the United States. Enrollment of PLHIV who receive Ryan White services in insurance plans has been slow, and Ryan White program funding to assist with premiums, copays, etc., for private insurance is essentially on hold in Georgia.

Dr. Thompson provided numerous quotes and anecdotes from Ryan White administrators and providers that paint a picture of the significant barriers to implementation of the ACA, which include the following:

- Patients' lack of awareness about the basics of insurance (e.g., copays, deductibles)
- Providers' refusal to accept certain insurance
- High medication copayments, confusing formularies, and barriers to obtaining medications
- Lack of navigation assistance to select appropriate plans
- Lack of patient education
- Unaffordable coinsurance costs.

Georgia requires health insurance navigators to acquire special certification (at a cost of \$300), intended to prevent community providers from counseling patients or helping them enroll in plans. The State insurance commissioner believes it is his job to obstruct the ACA. The Department of Public Health is under an informal gag order from the Governor and has been unable to address any ACA-related issues. As a result, Georgia has lost 5 months of open enrollment, said Dr. Thompson.

The Ryan White administrators and providers identified some steps to remove these barriers, which Dr. Thompson incorporated into a list of key recommendations:

- Address restrictive provider networks, increase the percentage of ECPs required, and allow out-of-network providers when HIV specialty care is not available.
- Provide technical assistance to clinics for insurance billing.
- Create regulations to eliminate prior authorization and high copays/coinsurance for ARVs (which discriminate against PLHIV), and ensure that all medications are covered.
- Help States design workable systems for subsidizing medications and out-of-pocket expenses for those who otherwise cannot afford private insurance.
- Take action to eliminate obstructive State laws.
- Provide transparency and clear tools for estimating out-of-pocket costs. Require transparency of insurers.
- Improve the quantity and quality of navigation efforts.
- Extend the open enrollment window for Ryan White patients (to compensate for structural challenges in transitioning to the ACA).
- Begin immediate data collection and analysis to troubleshoot problems and maintain quality.
- Maintain the Ryan White safety net and easy ADAP access, because people will be passing in and out of Ryan White programs in an effort to maintain continuity of care and medications.

## **Consumer Perspective: Private Insurance in California**

*Matt Sharp*

Mr. Sharp described himself as a long-term AIDS survivor; he is 57 years old and was diagnosed 26 years ago. Thanks to the ACA, he has insurance coverage through Covered California. As an independent consultant for the past few years, he juggles multiple contracts and therefore has an erratic income. The California Office of AIDS premium assistance program, which uses Ryan White funds, allows Mr. Sharp to purchase a better insurance plan than he could on his own, but his plan still does not include dental, oral, or visual health benefits. Moreover, Mr. Sharp says that as a well-educated, highly aware professional HIV/AIDS educator, he still found it very challenging to make informed decisions about plans under the ACA.

For example, said Mr. Sharp, insurers' Web sites contain inaccurate provider network details and no formulary information. Formularies, once obtained, are impossible to decipher, so one cannot anticipate likely costs of medications. Insurers have denied drugs even when they are listed on the formulary. It has been extremely difficult to get information, resolve problems, and address coverage denials, said Mr. Sharp. There appear to be problems with the application of premium tax credits and subsidies, and the guidance on these issues is written in language intended to assist tax preparers. The appeals process is not clear even to providers. Efforts to reach insurers for answers result in long telephone wait times and unanswered messages. For some PLHIV, ADAP covers HIV drug costs, but it is not a long-term fix, said Mr. Sharp.

Problems implementing the ACA were expected, Mr. Sharp noted, but these issues point to discrimination and decreased quality of care for PLHIV and those with other chronic conditions. Many in California are refusing coverage because there are just too many unknowns. Mr. Sharp's recommendations echoed those of other speakers:

- Require all qualified health plans to accept premium payments from Government payers.
- Require plans to provide complete, accurate drug formulary and provider information to consumers in a standard, usable format.
- Ensure that there are clear processes to assist with enrollment, appeals, grievances, and measurement of client satisfaction.
- Facilitate much more assistance with navigation, including more frequently asked questions on Web sites, timelines, statements of rights and responsibilities, avenues for problem-solving, and accurate and complete information. Telephone waiting times and response times for those seeking answers must be reduced.

Mr. Sharp regretted that so many who advocated for high-quality, universal health care for PLHIV are not here to benefit from the ACA. It is a critical victory, but in memory of those already lost and in honor of those still fighting to stay alive, Mr. Sharp said he will continue to advocate for single-payer universal health care in the United States, a statement that was met with applause. He concluded that he is thankful for the ACA, but he wants care that benefits the people, not the industry and its lobbyists.

## **Message From CClIO**

*CAPT Eugene Freund, M.D., M.S.P.H., Medical Officer, CClIO, CMS*

Dr. Freund said people with chronic conditions understand how expensive and even bankrupting these conditions can be. The system works when everyone is insured, so it is important to make the case to the uninsured and healthy that they need to be insured. PLHIV are in a good position to deliver that message, said Dr. Freund.

Dr. Freund acknowledged that there are a lot of “gut-wrenching” stories, and CClIO is working to address the causes. As Mr. Cohen explained, CClIO expects to make progress on the formulary and transparency issues soon. Dr. Freund said PACHA’s role is important and its input very helpful.

## **Q&A**

Dr. Horberg said that a joint statement from the HIV Medicine Association and the American Academy of HIV Medicine comments on many of the issues raised in the presentation and the questions submitted.

### ***How should insurance companies be integrated into the Ryan White program?***

Dr. Freund said that it is clear that private insurers should accept Ryan White program payments, and that is the HHS position, but HHS does not have the authority to make that happen. He said that although the insurance industry wants an unregulated formulary so that its beneficiaries do not end up in the hospital, CClIO hears stories about pharmacy denials.

### ***Should it have been mandated that Ryan White clinics be listed as required ECPs for plans that cannot provide evidence that they have truly qualified HIV specialists available?***

Dr. Freund agreed that if plans cannot provide qualified care, they are not providing essential access to their clients. However, from an operational standpoint, the appropriate care structure is hard to implement and requires people to go through an appeals process. Dr. Freund expressed the hope that clients are making those appeals, because insurers will recognize that it is not good business to be spending a lot of time on the telephone [arguing] with people who have legitimate needs. He acknowledged that his response was “not the best answer for people who need care now.”

### ***Many practices described are discriminatory, but State oversight bodies are not responding.***

#### ***When will CClIO enforce the ACA laws?***

Dr. Freund said CMS makes the regulations, but States are in charge of enforcement. In some cases, CClIO can work with the States, but private insurers are subject to State enforcement alone.

Dr. Adimora stressed that some States, such as Georgia and North Carolina, are actively obstructing implementation of the ACA. Dr. Horberg said the HHS Secretary has the authority under the ACA to demand compliance, decertify plans, and demand coverage.

Dr. Thompson praised the antidiscrimination statutes within the ACA, but stated that it still needs to be determined how to use them. Some States are proudly obstructing Federal law with no consequences, she said. If no effort is made to act against the discriminating practices, States will continue to ignore the law, she added.

***HIV-positive pregnant women and their exposed infants should be eligible to see a provider without a referral to avoid delays that could compromise their care. How can we address delays caused by referral requirements for these populations?***

Dr. Thompson agreed that such referral delays are unacceptable. Other PLHIV also may suffer from the delays caused by referral requirements if they are not directed to a specialty provider at the time of diagnosis. She suggested that HIV specialists be recognized as primary care providers for PLHIV.

***Is Truvada for pre-exposure prophylaxis (PrEP) covered by Medicaid or ACA plans?***

Ms. Lefert said some plans do cover it, and Dr. Thompson said there is no prohibition against the regimen. Eva Margolies, M.P.A., of CDC said that if the drug is covered under the formulary, the insurer will pay for it without bothering to identify the beneficiary's HIV status.

***Hepatitis C is a common comorbidity for PLHIV. Medications for hepatitis C that cost \$100,000 for a 12-week curative course of therapy will soon be available. How can we increase the pie to cover hepatitis C treatment without negatively affecting PLHIV?***

Dr. Freund pointed out that most plans limit the beneficiary's maximum out-of-pocket costs. Therefore, the burden of such an expensive drug would fall on insurers, both public and private. Dr. Thompson wondered whether plans will avoid adding the drugs to their formularies or place them in specialty tiers that are not subject to cost-sharing limits. The issue warrants close attention, she said.

***People in low-income areas in Georgia believe that the State is rejecting Medicaid expansion because it does not want the "loan" that the Federal Government is offering. What is holding up Medicaid expansion in Georgia?***

Dr. Thompson confirmed that some in Georgia have framed the Federal funding for expansion as a "loan," because the Federal portion declines from 100 percent to 90 percent over time. Thus, the State will have to take on 10 percent of the costs of expansion, and the Federal Government cannot be trusted to pay its portion. Ms. Lefert said the Governor is twisting the funding support into the idea of a loan to make refusal of expansion more appealing to his base. Mr. Greenwald emphasized that the funding does not constitute a loan in any way.

Rev. Vanessa D. Sharp, M.Div., M.A.C.M., M.A.T.M., confirmed that communication in Georgia is very twisted. Dr. Thompson stressed the importance of educating constituents and even legislators who do not understand how the ACA and Medicaid expansion work.

Mr. Greenwald added that States are free to withdraw from Medicaid expansion at any time, so refusing the full funding offered now is just refusing to accept free money. Mr. Wilson added

that the decrease in Federal funding (from 100 to 90 percent) is gradual; it will take 13 years. Rev. Sharp agreed that people need to know the facts; she hears misinformation daily, and it is outweighing the facts.

***If the HHS secretary has power over Governors who have refused to expand Medicaid, why should individual citizens be penalized for not buying insurance?***

Dr. Thompson emphasized that the Secretary does not have authority over Governors. In Georgia, a bill is circulating that would give the State legislature the power to accept or refuse Medicaid expansion.

### **Conclusion**

Ms. Mahon thanked all the participants for an incredible day during which she had learned a lot about how Medicaid works. She reiterated the importance of destigmatizing Medicaid and taking every opportunity over the next 5 weeks to encourage enrollment in both private insurance options and Medicaid. Ms. Mahon concluded the meeting for the day at 2:30 p.m.

## **Day 2**

### **Welcome and Roll Call**

Ms. Mahon welcomed the participants and called the meeting to order at approximately 9:00 a.m. Ms. Hayes called the roll.

### **HIV Knowledge and Attitudes of the HIV/AIDS Workforce on the Treatment Cascade**

#### **Phill Wilson, President and CEO, the Black AIDS Institute; PACHA Member**

Mr. Wilson described preliminary findings from a survey assessing knowledge and attitudes about HIV/AIDS treatment and clinical and biomedical interventions among workers (other than clinical providers) at AIDS service organizations, local health departments, and other community-based organizations. (The survey data are embargoed and will be released this summer.)

The preliminary results suggest a solid understanding of the basic tenets of HIV (e.g., modes of transmission), but knowledge clearly declines on more complicated topics, such as current biomedical interventions. Mr. Wilson pointed out that ending the AIDS epidemic will require more extensive use of high-impact interventions, yet the preliminary survey data suggest that even those working in the field do not have a good grasp of what is available and what works.

Mr. Wilson explained that respondents were first asked to assess their level of familiarity with certain topics and then tested on their actual knowledge of those topics. Researchers then compared those data with the respondents' answers about their confidence in their knowledge and their belief in the efficacy of certain interventions. Familiarity with biomedical interventions (e.g., TasP, microbicides, vaccine research, PrEP) was not very high among any of the respondents, said Mr. Wilson, but familiarity did correlate with knowledge, which, in turn, correlated with stronger belief in the efficacy of interventions.

The preliminary findings point to a need for more education and better scientific literacy among the HIV workforce. Increasing knowledge about effective biomedical interventions could help increase retention and medication use and contribute to viral suppression. Appropriate interventions also can contribute to decreasing resistance to ARVs. Mr. Wilson said the Black AIDS Institute and its partners have used the preliminary survey findings to develop training programs. Evaluation of the programs suggests that trainees are retaining what they learn over time and putting it to work on the job.

### **Discussion**

Mr. Wilson said the data suggest that PLHIV who work in the field have more knowledge than those who do not have HIV, and the type of work also affected the scores. He expressed concern that among those scoring lowest on the survey were people responsible for linking PLHIV to care (e.g., treatment educators, social workers, and case managers). The survey was not designed to identify the cause of the lack of knowledge, but Mr. Wilson noted that those

responsible for linkages tended to be the least tenured in their organizations and thus least likely to attend national conferences or networking events where current information is disseminated.

## **Employment Panel**

**Moderator: Douglas Brooks, M.S.W.**

Mr. Brooks thanked PACHA staff member Caroline Talev for proposing and organizing the panel on employment issues.

### **Research Findings on NHAS Implementation and Employment**

*Liza Conyers, Ph.D., C.R.C., Associate Professor of Education, Rehabilitation and Human Services, Department of Educational Psychology, Counseling, and Special Education, Pennsylvania State University*

Through the NWPC, Dr. Conyers and others are focusing on the role of employment in achieving the NHAS goals. She summarized results of the NWPC Vocational Development and Employment Needs Survey. An HIV diagnosis has a devastating impact on employment and economic well-being, the survey found. Other research indicates that those who lose their jobs may be especially vulnerable to dropping out of health care. There are no data or reports of interventions related to reducing unnecessary job loss among PLHIV.

The NWPC survey found that employment has a positive impact on health and on behavior that contributes to HIV transmission. A review of the literature on work and health found that in the general population, health improves with a return to employment and declines with continued unemployment. Dr. Conyers emphasized that positive outcomes cannot be expected for everyone who returns to work. The type of work, setting, and psychosocial aspects affect health outcomes.

Among PLHIV, there is little knowledge about available employment resources, such as work incentives for Social Security disability payment recipients, vocational rehabilitation services, and the Department of Labor's (DoL's) American Job Centers. Few know about the Family Medical Leave Act (FMLA) or the reasonable accommodation provisions of the Americans with Disabilities Act that could help an individual retain his or her job. Providers generally did not know about these services, either.

Dr. Conyers explained that rehabilitation counseling is a growing profession that incorporates efforts to achieve successful employment for clients. However, rehabilitation counseling is not promoted in the HIV field because neither Medicare nor Medicaid reimburses for such services. Furthermore, PLHIV often do not qualify for State rehabilitation services until their conditions deteriorate to include serious physical disability.

The only study that specifically examined the relationship between use of State vocational rehabilitation services and health outcomes related to the NHAS found a positive link.

Unfortunately, vocational training falls under the Department of Education (ED), which is not mentioned in the NHAS. Dr. Conyers stressed that there is considerable evidence that employment interventions are effective, and interventions designed for people with disabilities can be adapted for PLHIV and others. Many PLHIV can work but do not for reasons other than health status.

Dr. Conyers called for more focus on addressing the barriers to employment for PLHIV, including discrimination. Like others with disabilities, PLHIV do not know their rights or the resources available to them. Dr. Conyers hoped PACHA would consider how PLHIV can align on employment issues with others with disabilities and chronic medical conditions.

#### *Discussion*

Mr. Greenwald said the availability of insurance through the ACA means that PLHIV do not necessarily have to choose between working and being poor enough to qualify for Medicaid. Medicaid expansion is key to providing options for low-income people who want to work. Those who are working at jobs that do not provide health insurance can buy their own. The disability framework is changing because of the ACA, he noted.

#### **Making the Transition to Employment**

*April Watkins, Assistant Director, Workforce Development, GMHC*

Ms. Watkins described her transition from minimally educated drug addict and felon to mother of healthy twins with a good professional job who is working on a master's degree. She explained how her journey gives her empathy and insight into the barriers that clients at GMHC are facing. However, over the years, she has seen few systemic changes regarding employment and PLHIV. Ms. Watkins said employment saved her life. Employment is not for everyone, she said, but we need to do better for people who want to work.

To start, PLHIV need a firm safety net so they do not have to fear losing housing and other benefits because they work. We should not be discouraging people from working, as Ms. Watkins said her doctor discouraged her. Rather, we should allow for some flexibility, so that people can try working and move back into benefits programs if necessary—an approach Ms. Watkins was not aware she could take for herself at first. She said that over time she has learned to meet clients where they are, focusing on their current abilities and how to get back to work.

To meet the goals of the NHAS, Ms. Watkins said, we should put a higher priority on employment (e.g., at professional conferences, where sessions on employment are usually relegated to the end of the last day). More people should recognize that employment is the next step, allowing individuals to earn more money and move into private insurance plans. The restraints that have been in place for years must be removed, Ms. Watkins concluded.

## **Proposed Roadmap for Promoting Employment To Achieve NHAS Goals**

*Mark Misrok, M.S.Ed., C.R.C., President, Board of Directors, NWPC*

Mr. Misrok said that as someone living with HIV for 30 years and AIDS for 18 years, he is convinced his survival is largely related to the critical employment assistance he received. The NWPC aims to partner with PACHA to promote employment as a mechanism to achieve the NHAS goals. It is time to augment our extraordinary medical tools with interventions that target economic stability, said Mr. Misrok.

Economic empowerment of PLHIV is imperative and achievable, said Mr. Misrok. The attention to employment in the NHAS provides an opening. It tasked DoL with increasing support for employers to hire and retain PLHIV and integrating PLHIV into broader employment initiatives for people with disabilities, and the Office of Disability Employment Policy has taken the lead. The Department of Housing and Urban Development (HUD) also has created employment initiatives through its Office of HIV/AIDS Housing.

The NHAS also called for development of recommendations on increasing employment opportunities for PLHIV, which are still needed. Mr. Misrok called for a Federal interagency task force that includes DoL, HUD, and ED, which oversees vocational rehabilitation services at the State and Federal levels.

Communities disproportionately affected by and at risk for HIV/AIDS also have high rates of poverty and unemployment and unequal access to education and employment protections. As we improve HIV/AIDS health and prevention outcomes, we should commit to addressing employment for PLHIV, said Mr. Misrok. He implored PACHA to intervene in the economic and social marginalization of PLHIV that has for decades impeded efforts to end HIV.

### **Q&A**

#### ***Where can we find more information about the profession of rehabilitation counseling?***

Dr. Conyers said the Web sites of the National Council on Rehabilitation Education and the Council on Rehabilitation Education can identify relevant programs. She said more trained rehabilitation counselors are needed, but many candidates choose mental health or social work education because those professions provide billable services and thus have higher pay. The inability to bill for rehabilitation counseling is critical, she noted.

#### ***Vocational rehabilitation can be effective for those at high risk for HIV and could translate to reduced transmission. How would a young transgender person at high risk or a high-school dropout working on the streets, for example, be linked to GMHC for help?***

Ms. Watkins noted that GMHC just initiated a transgender work group to improve its services for transgender people. She said that transgender people looking for work—and the people trying to help them—face unique challenges, such as what information can and should be divulged and when. Ms. Watkins said GMHC currently refers transgender clients to other services with better knowledge of issues facing transgender people.

Ms. Watkins added that GMHC primarily focuses on HIV-positive people, although services are available for those at high risk. She hoped Congress would consider policy changes that allow more people to get services based on need.

***Why does employment for PLHIV drop substantially following diagnosis, as identified by the NWPC survey?***

Dr. Conyers replied that the data are difficult to interpret, because the survey took place in HIV treatment programs. She believed that some PLHIV drop out of work early because they believe they will die soon. Others leave as a result of the trauma of diagnosis or subsequent depression. For them, early intervention and the use of the FMLA, for example, could help them stay employed. Dr. Conyers said the question demonstrates the need for more research as well as initiation of a needs assessment to help track an individual's progress over time.

Douglas A. Michels, M.B.A., agreed the issue merits more research.

Ms. Watkins added that in her experience, many of the PLHIV that GMHC serves had low-paying, labor-intensive jobs at the time of diagnosis. Others seeking to qualify for disability payments may choose only to work for cash until they qualify. Those who have been unemployed for a long time require many supports in place before they can find and hold a job. Some only find jobs that are unfulfilling and not worth the effort. Ms. Watkins reasoned that the NWPC survey results are predictable given that the survey targeted people with low literacy and low employment skills.

Ms. Khanna agreed that employment issues are urgent, as the NHAS timeline aims to achieve goals by 2015. Employment and economic justice are top priorities for the women she works with, Ms. Khanna explained. She hoped others would recognize that employment is part of a good quality of life and key to engaging in health care. Ms. Khanna suggested that PACHA dedicate more time to exploring the employment issues and proposals raised.

***Are there examples of model programs or suggestions for making vocational rehabilitation part of health service delivery?***

Mr. Misrok responded that some very specific steps can be taken that do not require new resources. Well-funded systems exist, but PLHIV are not getting their share of those resources. Service providers must increase their knowledge of existing resources for workforce development and vocational rehabilitation. These services should be part of the health care system, because health outcomes are tied to economic health. Mr. Misrok called for integrating employment assessment and support through service provision.

Dr. Adimora agreed with the call for a Federal interagency task force and recommended that it include a representative of the Department of Justice. Addressing the barriers that felons face in obtaining work would help PLHIV and people at risk. Dr. Adimora appreciated the speakers' recognition that work is problematic for some people. Mr. Misrok pointed to the absurdity of releasing individuals with HIV/AIDS from prison with no assistance or support toward employment. He stressed that a felony conviction does not necessarily exclude one from employment.

***How can we address employment for PLHIV in cities with high costs of living, such as New York and San Francisco?***

Mr. Misrok reiterated that PLHIV are being left out, even though there are services in their communities that could help if more people knew about them. He pointed out that community colleges are under pressure to provide meaningful training for good jobs, and PLHIV could benefit from their innovative approaches.

Mr. Brooks concluded that the Disparities Subcommittee will discuss employment and bring its findings to the full PACHA.

**Public Comments**

**Lindsey Dawson of The AIDS Institute** focused on two issues affecting drug access for PLHIV. First, an analysis of silver health plans in the Florida marketplace revealed that about one-half of the plans place drugs for HIV and hepatitis into specialty tiers that require a 50 percent copay. As a result, each of these drugs can cost an individual as much as \$1,000 per month. Even with the cost-sharing protections and out-of-pocket caps in the law, these costs are unthinkable for many PLHIV.

The same tiering structure is occurring across the country and across a range of products. However, not all issuers engage in this practice, suggesting it is not a market norm or a necessity to balance costs within a plan. Rather, this practice serves to deter those living with HIV and hepatitis from selecting certain plans and amounts to discriminatory benefit design, which is a gross violation of the ACA.

Further, many plans are using utilization management techniques that require excessive preauthorization for all HIV and hepatitis drugs, which amounts to discrimination. The AIDS Institute urges the Administration to issue further guidance to implement the ACA's antidiscrimination protections and to enforce them. It is concerned that leaving enforcement to State insurance commissioners passes the buck on these critical protections under Federal law.

Second, The AIDS Institute is troubled by the proposed rule from CMS that would restrict access under Medicare Part D to immunosuppressants, antidepressants, and antipsychotics. There is significant concern that ARVs will be the next class of drugs to lose protection. About one-half of PLHIV have comorbid mental health or substance use conditions. The proposal's attack on immunosuppressants may pose significant barriers for the 25 percent of PLHIV who also have hepatitis C and may need liver transplants. The AIDS Institute urges CMS not to finalize the proposed rule as written. Ms. Dawson concluded that progress made to advance health care for all Americans could be undone unless action is taken to ensure essential drug access.

**Rebekah Horowitz of the National AIDS Housing Coalition** said that as we move forward with ACA implementation, the role of housing within health care will need to increase to ensure that PLHIV are able to fully benefit under the new law. The evidence is clear that housing insecurity is a formidable barrier to effective ARV therapy and HIV risk reduction, even when access to

health care is readily available. As fewer people depend on Ryan White funding for their medical care, those funds should become available to provide services essential to PLHIV leading healthy lives, such as housing.

Ms. Horowitz gave some examples from the large body of evidence demonstrating that housing status has a direct and powerful impact on HIV incidence and on the health of PLHIV. For example, housing assistance for PLHIV contributes to a dramatic reduction in the use of expensive emergency and in-patient services, generating savings in public health care spending that more than offset the cost of providing housing.

Based on this evidence, Ms. Horowitz called for a reconsideration of the definition of core and non-core services under the Ryan White program. A larger proportion of resources should be available for support services that help complete coverage. Although Ryan White funding can already be used to support short-term, emergency housing services, the National AIDS Housing Coalition recommends that the Ryan White housing policy be expanded to include longer-term housing as well. PACHA should examine the efforts by HRSA and HUD to integrate Ryan White and Housing Opportunities for Persons With AIDS services more directly. The National AIDS Housing Coalition looks forward to PACHA's continued attention to the structural drivers of the epidemic and its support for responses that reduce viral load, improve access to care, and save taxpayer dollars.

**Felicia Carroll of Housing Works** explained that she has been infected and affected by HIV for 23 years and has seen so many people suffer from the effects of HIV/AIDS because of a lack of services to support health, prevention, and retention in care. Medicaid expansion is the most important component of the ACA and will provide coverage for thousands of PLHIV who do not have it. It will fill gaps, address disparities in services, and provide high-quality medical care to people who have been receiving substandard care.

About one-half of PLHIV will need housing assistance at some point. For PLHIV, housing is health care. For people struggling with the disabling and impoverishing effects of HIV/AIDS, housing is an essential cornerstone of health and stability, facilitating access and adherence to care. Ms. Carroll cited steps taken by New York State to increasing housing services for high-cost Medicaid beneficiaries. By ensuring stable housing for PLHIV, New York is improving outcomes across the treatment cascade.

Each new HIV infection prevented through more stable housing saves countless life-years and more than \$400,000 in lifetime medical costs. The ACA provides an unparalleled chance to meet the greatest unmet need of PLHIV and the goals of the NHAS. Meeting these objectives is critical to realizing the end of AIDS, Ms. Carroll concluded.

PACHA members also received written comments from the American Dental Education Association in support of continued funding for dental care under the Ryan White program.

## **Kaiser Family Foundation Update: New Analysis Estimates of the Number of People With HIV Who Could Gain New Coverage Under the ACA**

**Jennifer Kates, Ph.D., Vice President/Director, Global Health and HIV Policy, Kaiser Family Foundation**

While many PLHIV were expected to gain health coverage through Medicaid expansion programs or private insurance plans, the Kaiser Family Foundation and CDC were the first to develop estimates of the numbers. Dr. Kates summarized the methodology behind the study, which relied on CDC's Medical Monitoring Project from 2009.

As initially designed, the ACA would have facilitated coverage (through either Medicaid eligibility or subsidies) for most PLHIV who were not already covered by either public or private insurance—in the Kaiser study, about 17 percent of adult PLHIV under age 65. A small number (approximately 4 percent) of those above 400 percent of the FPL would not be eligible for either Medicaid or subsidies. The Supreme Court decision allowing States to opt out of Medicaid expansion complicated matters.

In 2009, the Ryan White program provided assistance to 40 percent of PLHIV, including a good portion of insured people, and Dr. Kates expected that such assistance would continue. The policy challenge, she noted, lies in the 25 States that have not yet expanded Medicaid; 43 percent of PLHIV live in those States.

The study found that the ACA could provide new health coverage for the approximately 70,000 uninsured PLHIV in care today and may also provide new options to some with coverage. Extrapolating the findings to all PLHIV (not just those in care), almost 200,000 could gain new coverage. However, State decisions regarding Medicaid expansion matter. If only 26 States expand, the number of uninsured PLHIV who are newly eligible for Medicaid is reduced by more than 40 percent. Most of these individuals will not be able to obtain subsidized coverage in the marketplace because their incomes are above 100 percent of the FPL. Dr. Kates concluded that Ryan White funding will play a key role for those in States that do not expand as well as for those who gain new coverage or already have coverage.

### **Discussion**

Dr. Kates said the study highlights two major points. First, PLHIV in half of the country are not eligible for Medicaid, and many do not have access to subsidized coverage, so Ryan White funding will be especially important in those States. Second, the share of PLHIV in care who are low-income is high, and that contributes to structural barriers that affect their ability to stay engaged in care. Dr. Kates asked, how do we reach people who are not engaged in care?

Mr. Wilson pointed out that if all States expanded Medicaid, the concept of being “too poor” to benefit from the ACA would be resolved. Dr. Kates clarified that in some States, childless adults are not eligible for Medicaid, even if they earn below 100 percent of the FPL. Furthermore, ACA subsidies were not designed to cover people below 100 percent of the FPL. For PLHIV, Ryan White funding can be used to pay the premiums for private insurance, but without Ryan White

support, insurance coverage is unaffordable. The Kaiser study estimated the number of PLHIV who fall into that gap (below 100 percent of FPL in States that do not expand Medicaid) to be about 15,000 (or 22 percent) of the 70,000 PLHIV in care.

## **Heritage Keepers Abstinence Education Follow-Up**

### **Robert Greenwald, J.D., PACHA Member**

Mr. Greenwald explained that PACHA has been trying to better understand why the Heritage Keepers abstinence-only education curriculum is listed on the HHS Web site as an effective, proven sexual health and education criteria, despite limited data on effectiveness, questions about medical accuracy, and complaints that it allegedly promotes sexist and offensive stereotypes, among other concerns. Mr. Greenwald and PACHA member Kathie Hiers met with HHS staff, and the Office of Adolescent Health (OAH) maintained that the Heritage Keepers curriculum meets the criteria of effectiveness.

OAH staff said that inclusion on the Web site does not imply HHS endorsement. The Web site disclaimer indicates that a curriculum can be designated effective if it has sufficient data to demonstrate effectiveness for a single outcome. Mr. Greenwald said that HHS evaluates curricula by statistical analysis and not by holistic review of the program. To compound the problem, the Heritage Keepers Web site promotes its curriculum as the only abstinence-only program approved by HHS on the basis of medical accuracy, results, and other elements.

Mr. Greenwald said neither he nor others have been able to obtain a copy of the current Heritage Keepers curriculum. OAH says it now has the curriculum, and Mr. Greenwald and colleagues may review it on site at HHS but may not make copies. Mr. Greenwald offered some examples from the student manual he obtained and from others' reports. The curriculum describes cohabitation relationships as "weak" and "morally violent." Reportedly, it states that because boys and men are more aroused by visual stimulation, girls and women are responsible for wearing modest clothing that does not invite lustful thoughts. Mr. Greenwald said that on the basis of such statements, HHS should decline to review the curriculum for effectiveness.

Mr. Greenwald and Ms. Hiers proposed to HHS that curricula be screened for medical accuracy and for stereotypical and discriminatory language and images before they are reviewed for effectiveness. He called for categories of effectiveness (e.g., low, moderate, and high), as well as description of how a curriculum performed on each outcome. Such a system would at least identify to potential users that Heritage Keepers achieved only a moderate rating of effectiveness on a single outcome and was proven ineffective for all other outcomes. Also, HHS should monitor the Web sites of approved curricula to identify misleading promotional copy.

Mr. Greenwald said he and Ms. Hiers would report back to PACHA on their findings. If HHS does not take sufficient action, he hoped PACHA would address the issue further. Ms. Mahon thanked Mr. Greenwald and colleagues for persevering in their efforts.

## **Subcommittee Updates**

### **Moderators: David Holtgrave, Ph.D., and Mario Pérez, M.P.H., PACHA Members**

Ms. Mahon introduced the session by asking PACHA to consider whether it could develop some organizing principles that would help in prioritizing the topics addressed by the Subcommittees and that focus on achieving the NHAS goals. Mr. Pérez added that PACHA had made some progress through its resolutions and letters to the President and the HHS Secretary. However, 2014 must be the year of action to meet the 2015 NHAS goals. Each Subcommittee presented a summary of the issues it hoped to address in 2014.

### **Access to Care Subcommittee**

- Continued surveillance and discussion of the intersection of the ACA implementation and Ryan White programs, including 1) promoting success stories; 2) evaluating EHBs, especially drug formulary issues; 3) requesting more metrics on enrollment, receipt of care, and other issues; and 4) integration of FQHCs and HIV care
- Workforce issues, including increasing capacity and continuing to define quality
- Women's issues, including the intersection of HIV, sexual and reproductive health, and IPV
- Social determinants of health, specifically food as medicine and other social determinants that affect access and quality of care for PLHIV
- Hepatitis C, including costs and the impact on HIV as the treatment paradigm changes
- “NHAS 2.0”

### **Incidence Subcommittee**

- Innovative process(es) to improve PACHA’s relevance, visibility, and credibility
- A dashboard of timely and critical information to evaluate NHAS and improve progress
- Elements of a core prevention package on the basis of emerging science, implementation research, opportunities afforded by ACA implementation, and structural and social determinants of health
- The status of 2015 NHAS goals and beyond (e.g., 2020 goals)
- National accountability (immediate and ongoing), recognizing the crisis of HIV among black gay men in the United States

### **Global Subcommittee**

- Immediate priorities:
  - U.S. Government funding for the global AIDS response (in light of worrisome proposals to decrease contributions to the U.S. President’s Emergency Plan for AIDS Relief [PEPFAR] despite past promises and the ripple effect of decreased contributions to The Global Fund)
  - Criminalization of lesbian, gay, bisexual, and transgender people (LGBT), given recent developments overseas that are morally unacceptable
- Potential longer-term issues:

- Best practices (PACHA role in facilitating information exchange or other mechanisms)
- Barriers to HIV/AIDS programming and effectiveness (including discrimination against women and girls)
- HIV in children

### **Disparities Subcommittee**

- Increasing health insurance enrollment and supporting Medicaid expansion
- Raising awareness of geographic disparities (and relationship to Medicaid expansion and ACA implementation)
- The contribution of criminalization to disparities
- The status and results of past resolutions
- Workplace and employment issues

### **Discussion: Prioritization and Next Steps**

Dr. Adimora asked the Global Subcommittee to consider how LGBT discrimination and criminalization are intertwined with international funding for HIV/AIDS. She was aware of at least one organization funded by PEPFAR that actively discriminates against LGBT people.

Discussion turned to the mechanisms for addressing urgent matters. Ms. Hayes said PACHA can hold a public meeting by telephone on relatively short notice to review and approve resolutions, which are then forwarded immediately to either the Secretary or the President, whichever PACHA chooses. She added that PACHA is not required to submit reports to HHS for clearance, but PACHA staff sometimes seek HHS review of the scientific data in reports.

Dr. Holtgrave proposed developing a report over the next few months that identifies changes that can be made immediately to help achieve NHAS 2015 goals and a second report by the end of the year addressing the next reiteration of the NHAS and strategic goals after 2016. There was some pushback on the utility of reports, which may have recommendations but often do not include specific requests for action as resolutions and letters do.

### ***Follow-Up Items***

Ms. Mahon will work with the Subcommittee Co-Chairs to consider how to move forward on process improvements, such as the dashboard and the next iteration of the NHAS.

Ms. Mahon will 1) draft letters that express PACHA's position on the following issues, 2) work with PACHA staff to circulate the letters to PACHA for approval, and 3) send them to the Secretary and the President.

- The positions of director of the Office of National AIDS Policy and U.S. Global AIDS Coordinator remain vacant. At this critical moment for addressing HIV/AIDS, PACHA urges the Secretary and President to fill the positions.
- The landscape of the HIV/AIDS epidemic has changed, and black gay men are now the population with the highest rate of HIV infection. Given that the President is launching an initiative focused on young men of color, PACHA should let the President know how the face of HIV/AIDS is changing and request that the data be updated to focus on the current direction of the epidemic.
- International LGBT criminalization efforts should be addressed. (The Global Subcommittee Co-Chairs will draft a letter describing the concerns and request for action.)

PACHA staff will work with Ms. Mahon to create a grid of the topical issues raised by each Subcommittee to identify overlap and will share it with the Subcommittee Co-Chairs for discussion.

Ms. Mahon noted that PACHA can request help from partner organizations, such as the Kaiser Family Foundation. She asked PACHA members to consider within their Subcommittees how to further prioritize issues and what to address at the next full PACHA meeting. The Subcommittee Co-Chairs should narrow down the topics so that PACHA can focus on a few key issues (no more than four).

## **Adjournment**

Ms. Mahon thanked PACHA members, participants, and PACHA staff and adjourned the meeting at 12:24 p.m.