

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

## **41st Meeting**

**Hubert Humphrey Building**

**Washington, DC**

**January 27–28, 2011**

### **Council Members—Present**

Helene D. Gayle, M.D., M.P.H., PACHA Chair

A. Cornelius Baker

Praveen Basaviah.

Dawn Averitt Bridge

Douglas Brooks, M.S.W.

Humberto Cruz, M. S.

Ernest Darkoh-Ampem, M.D. , M.P.H., M.B.A.

Kevin Robert Frost

Patricia Garcia, M.D., M.P.H.

Robert Greenwald, J.D.

Kathie M. Hiers

David R. Holtgrave, Ph.D.

Michael Horberg, M.D., M.A.S.

Ejay L. Jack

Jack C. Jackson, Jr., J.D.

Naina Khanna

Anita McBride

Douglas A. Michels, M.B.A.

Mario J. Perez

Rosie Perez

Malika Saada Saar, M.Ed., J.D. (by telephone)

Sandra Torres Rivera

Phill Wilson

### **Council Members—Absent**

Rev. Dr. Calvin Otis Butts, III, D.Min., M.Div.

Jim Kim, M. D., Ph.D.

## **Staff—Present**

Christopher Bates, M.P.A., Executive Director, Presidential Advisory Council on HIV/AIDS, U.S. Department of Health and Human Services (HHS)

Melvin Joppy, Committee Manager

## **Presenters**

Chris A. Bina, Pharm.D., Captain, U.S. Public Health Service, and Director, Pharmacy Program, Federal Bureau of Prisons (BOP), Health Services Division, U.S. Department of Justice (DOJ)

Jeffrey Crowley, M.P.H., Director, Office of National HIV/AIDS Policy (ONAP), The White House

Maggie Czarnogorski, M.D., Deputy Director, National Clinical Public Health Program, U.S. Department of Veterans Affairs (VA)

Laura Hanen, Director, Government Relations, National Association of State and Territorial AIDS Directors (NASTAD)

Catherine Hanssens, Executive Director, Center for HIV Law and Policy

David W. Knight, Trial Attorney, Disability Rights Section, Civil Rights Division, DOJ

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

Allison Nichol, Deputy Chief, Disability Rights Section, Civil Rights Division, DOJ

Ronald Valdiserri, M.D., M.P.H., Deputy Assistant Secretary for Health, Infectious Diseases, HHS

David Vos, Director, Housing Opportunities for People With AIDS (HOPWA) Program, Office of Community Planning and Development, U.S. Department of Housing and Urban Development (HUD)

Andrea Weddle, Executive Director, HIV Medicine Association

Sheryll Ziporkin, Associate Commissioner, Office of Public Inquiries, Social Security Administration (SSA)

## **Other Participants**

James Albino, Senior Program Manager, ONAP

Gretchen Stiers, Branch Chief, Office of Policy and Program Innovation, Substance Abuse and Mental Health Services Administration (SAMHSA)

## Day 1

### MORNING SESSION

#### Welcome

PACHA Chair Helene D. Gayle welcomed everyone; noted delays due to weather; thanked those attending for their flexibility, including members attending by phone; and indicated that some rearranging of agenda items would be necessary.

Dr. Gayle predicted that 2011 will be an interesting year in Washington, for much change has occurred. There is much support “for our issues,” she added, “So our ability to keep the agenda moving will be very important.” She noted that on Day 2, the Council would engage in a retrospective, including an assessment of where it stands and what it wants to tackle.

Dr. Gayle then turned the meeting over to Howard Koh, Assistant Secretary for Health, and Jeffrey Crowley, ONAP Director, for opening remarks on the status of HIV/AIDS issues from the perspective of HHS and the White House.

#### Opening Remarks by Howard Koh, Assistant Secretary for Health

Dr. Koh thanked PACHA members and colleagues for their dedication and continued commitment to the National HIV/AIDS Strategy (NHAS) and its implementation, which Mr. Crowley, Dr. Ronald Valdiserri, and the Office for Health, Infectious Disease have been working on with particular diligence this past year, sometimes 24/7.

It is essential for this commitment to remain high, for it is one thing to announce a strategy and another to make it come alive, an effort that Dr. Valdiserri is helping lead at HHS.

Dr. Koh noted the leadership of Secretary Kathleen Sebelius in taking specific steps to improve coordination across Agencies and for adoption of common metrics. In coming weeks, the public will be hearing more from the White House on specifics of implementation of the NHAS by HHS, as well as HUD, the VA, the DOJ, the Department of Labor (DOL), and the SSA.

At this moment, many are working on numerous fronts in the domestic fight against HIV/AIDS, and, therefore, “we have to maximize that opportunity.” This includes the need for continuing efforts by experts, such as PACHA members, community groups, and advocacy organizations, and “many presentations at various conferences here and abroad, continuing to be as transparent as possible” about the NHAS and its implementation.

Dr. Koh noted that PACHA members would hear more during this meeting about the 12 cities which HHS “has now embraced” as representing some 44 percent of the AIDS burden in the United States today. Dr. Koh looks forward to members’ reactions to this concept of modeling how to work better and smarter “and really turn this epidemic around.”

Dr. Koh noted a recent meeting with the five lead Agencies mentioned earlier and a “very good discussion on housing issues for those living with HIV/AIDS and how that is a common thread, a challenge we need to confront together, across the board.” While David Vos from HUD and Dr. Valdiserri will say more later, Dr. Koh would like to note now that we have a National strategy to end homelessness that can be woven into the needs of those living with HIV/AIDS as well as the needs, for example, of veterans.

Dr. Koh noted the recent news regarding successful pre-exposure prophylaxis (PrEP) trials, adding that he could not recall another time when there was more of an engaged, aligned commitment of people and resources in HIV/AIDS than “right now.”

Concluding, he said he was eager to hear what Council members say during this meeting and to take their advice moving forward. He ended by pledging to “convey your recommendations directly to the Secretary.”

### **Opening Remarks by Jeffrey Crowley, ONAP Director**

Mr. Crowley thanked Dr. Koh for his kind words, adding that he has been a strong partner in this Administration’s efforts, personally and as part of the new leadership at HHS.

Mr. Crowley said that although the NHAS has been out for some time now, “we still have momentum at the Federal level and with the community.” The recent positive PrEP trial results are an additional sign that “sometimes the stars do align.”

During this meeting, PACHA members will have an opportunity to hear about plans for making the NHAS operational. It is the White House’s intent to release these plans publicly in the near future. At present, Mr. Crowley’s office is working on an overview report of how these plans fit together, so “we will look for input from PACHA all along the way.” He assured members that senior leadership in all the Agencies involved is being held to account and is driving change. “There is something new in the level of energy coming from these Agencies, not just HHS but HUD, the VA, and others. The reports they are delivering are not the same they would have produced a few years ago. They see the potential for doing some great things.”

Reflecting on the course of the NHAS so far, Mr. Crowley noted that 2009 was “all about public input,” then 2010 marked many events, including convening the interagency group, releasing the NHAS, beginning implementation, and drafting agency operational plans about how to achieve systemic change. In 2011, the plan is to continue the interagency process, which Dr. Valdiserri’s office helps coordinate. Meanwhile, the President has directed Mr. Crowley to report annually on progress, and the focus of the report will be what the Nation is doing to respond to the epidemic.

In addition, Mr. Crowley and his office are entertaining process measures; for example, “how we will measure whether a given agency is doing something, year after year.” When the White House releases the NHAS implementation plan, PACHA members will notice activities conducted in 2010 and planned for 2011 as well as thoughts about 2012.

## **Discussion/Comments/Question and Answer Period**

### **Highlights**

- Responding to a query about the 12-cities model, Mr. Crowley said these Metropolitan Statistical Areas (MSAs) were chosen because they are high-prevalence jurisdictions, but the plan is not just to improve response there but to employ these MSAs as models for innovation. “If we knew everything, we wouldn’t need this model. We hope to learn both positive lessons and mistakes about planning prevention and care. It will evolve.”
- Responding to Mr. Crowley, Humberto Cruz said that like many other PACHA members, he too supports the 12-cities concept and that “new money is a good idea.” He feels, however, that the Administration “also should consider the States, because we need resources to continue the fight outside of those cities.” Additionally, while the idea of using a model as a learning process is a good one, “many of us have been doing this a long time and have had great successes, so these should not be ignored.”
- Responding to Mr. Cruz, Dr. Gayle said he made good points and that “PACHA can play a role in capturing lessons learned that could then be transferred to the 12-cities model.”

### **Operational Plan Updates From Federal Agencies**

#### **Presentation by David Vos, Director, HOPWA Program, Office of Community Planning and Development, HUD**

Mr. Vos said that as the Director of HOPWA, he is working with his colleagues in an “unprecedented” manner to address cases of HIV. At HUD in general, “we are looking at outcomes for programs in a way that we have not before, in terms of health outcomes, and working across divisions to bring health issues to the table across the board.” This is reflected in HUD’s operational plan.

In its operational plan, HUD also tried to address targeting AIDS resources in a better manner. This follows HUD consultations with cities and grantees on how to make preexisting program tools work better. HUD also plans a broader meeting with stakeholders to consider any necessary legislative changes.

“We know housing as a base for receiving care is an essential way to address the epidemic. HUD is excited about being more broadly involved in this and considering what kinds of services are needed.” Already, for example, HUD has discussed opportunities to coordinate with the DOL in terms of employment opportunities for people living with HIV/AIDS (PLWHA).

In conclusion, the NHAS Implementation Plan is an opportunity for HOPWA to work with HUD leadership “on issues we care about, do that more efficiently, and get results.” In the near future, HOPWA will be looking at data and the planning and technical assistance (TA) that “supports good results in our communities.”

**Presentation by Maggie Czarnogorski, M.D., Deputy Director, National Clinical Public Health Program, VA**

The VA is the largest provider of HIV care in the Nation. Currently, more than 24,000 veterans diagnosed with HIV are in VA care. The Administration prides itself on providing high-quality, comprehensive, integrated care and has electronic medical records (EMRs) and a separate database of all known HIV-positive veterans with which to monitor care and outcomes.

In its operational plan, the VA was identified in several action items and was able to respond to 90 percent of them. Many of the action items are not necessarily new initiatives for the VA but, rather, involve programs or plans already in progress. The VA will place more emphasis on these items in FY 2011 because they were identified as goals for the NHAS.

In terms of the NHAS goal to reduce incidence and focus on testing, the VA made two major policy changes in 2009: first, the VA eliminated the need for written informed consent (although it still requires verbal consent documented in an EMR); second, the VA moved away from its risk-based HIV testing policy to one of routine testing of all veterans. Specifically, in terms of routinized testing, the current policy is to test at least once in a lifetime all veterans who consent and test at least annually those with ongoing risk factors, but because the VA realizes that policy alone will not change practices, it is in the process of implementing several initiatives to improve HIV testing rates, including:

- Developing a large social marketing campaign about routine HIV testing within a policy to test all veterans, regardless of age, gender, race, or ethnicity
- Due to the NHAS focus on high-risk populations, developing a plan to conduct focus groups with target populations to help tailor marketing messages
- Funding eight large pilot projects in high-risk populations and geographic areas of high prevalence and low screening rates to increase HIV testing rates and develop models/best practices that can be disseminated nationally throughout the VA
- Working with mental health providers, substance use disorder (SUD) providers, homeless programs, jail reentry programs, and other support services to improve HIV testing rates in these programs
- Partnering with the Centers for Disease Control and Prevention's (CDC) to update the VA HIV Prevention Handbook to include/update sexually transmitted infection screening guidelines (although the VA may wait until the CDC develops updated prevention materials so as to provide a consistent message across the Federal Government).

In terms of the NHAS goal to improve access to care and health outcomes:

- In 2009, 95 percent of newly diagnosed veterans were linked to care within 3 months of diagnosis. Of veterans in care, 84 percent are virally suppressed.
- The VA's Public Health Strategic Health Care Group will be working with the VA's homeless program, incarcerated veterans' programs, women's health programs, and mental health and SUD programs to ensure that diagnosed veterans are linked to appropriate specialty and subspecialty care within 3 months of diagnosis as well as to support programs, as needed.

- The VA will continue to educate its providers about HHS treatment guidelines and hold its providers accountable to those guidelines. The VA also plans to increase educational opportunities related to how to best manage HIV and comorbidities, particularly as it is seeing an increasing rate of comorbidities among diagnosed veterans.
- Due to its extensive database, the VA has a systematic way to measure health outcomes and is very willing to work with other Agencies to develop standardized quality measures.
- The VA also is exploring opportunities to use technologies such as telehealth to improve HIV care in remote locations and will consider supporting pilot programs to improve health care to rural veterans with HIV.

In terms of the NHAS goal to reduce health disparities:

- The VA already routinely collects data on viral load and CD4 counts for all veterans with HIV who receive VA health care, and has the capability to report annually on viral load suppression rates.
- The VA also is “working hard” to reduce stigma by reaching out to faith-based communities to develop community outreach programs and also hopes that routinizing HIV testing will reduce some of the stigma associated with the virus.

Dr. Czarnogorski concluded by noting that the VA is willing to participate with other Federal Agencies as needed “to ensure coordination, consistency in reporting, and collaboration across the Federal Government.”

### **Discussion/Comments/Questions and Answers**

- Dr. Gayle said it is useful to get this background.

### **Presentation by CAPT Chris Bina, Pharm.D., Director, Pharmacy Program, Federal BOP, Health Services Division, DOJ**

CAPT Bina introduced himself as the chief pharmacist for the Federal prison system.

Correctional health is public health. Many offenders incarcerated in the Federal system will return to society. Approximately 14 percent of persons with HIV in the United States pass through the correctional system each year. Prevalence in prison is 1.6 percent, or some two-and-a-half to three times higher than that of the general population.

There are some 5,000 correctional facilities in the United States—that is, about 3,000 local jails and 1,800 State/Federal correctional institutions. Some 211,000 individuals are now incarcerated within the Federal BOP system, 173,000 within 116 BOP-managed institutions. (The BOP is the largest correctional jurisdiction.) Well over 700,000 inmates are released from correctional jurisdictions each year.

Within the BOP, HIV screening is offered to everyone. “We take the CDC approach to universal testing.” Testing is mandated for inmates with risk factors. The 2009 BOP Preventive Health

Guidelines encourage routine HIV testing for all sentenced inmates who have not been previously tested in the BOP. At present, the BOP is working with a major university to evaluate its testing and screening programs. CAPT Bina is not at liberty to say which university.

The BOP has many clinical practice guidelines, including for sexually transmitted disease (STD) screening, prevention, and treatment, and for Hepatitis A and C screening. The BOP is currently working on a guideline for Hepatitis B screening.

The BOP has EMRs, which have advanced its ability to look at data across the country. Six years ago, “we knew we could do a better job of HIV/AIDS treatment, so we instituted a regional HIV clinical pharmacists consultant program, so that today there are HIV-credentialed pharmacists available even to rural institutions, including through virtual technology.”

The medical records of all inmates with HIV are reviewed quarterly. The BOP has partnered with the VA for viral load and CD4 lab testing, and if there are “any red flags,” inmate-specific recommendations are made to the clinical provider at the institution in question. Additional training is available to these clinicians through Johns Hopkins University. In addition, the BOP has an agreement with the University of California, San Francisco, through the Health Resources and Services Administration (HRSA) to discuss particularly hard-to-treat cases, and partners with the Mayo Clinic for assistance as well.

The BOP employs national performance measures, one of which is HIV viral load. As of June 10, 2010, performance data indicate that a median of 81 percent of patients who have been on treatment for at least 6 months in a BOP-managed facility are virally suppressed. The BOP works with many other correctional organizations to share best practices and intends to incorporate academia into this sharing as well.

Linkage to care post-incarceration is “logistically challenging.” At present, the BOP is working with Brown University via a National Institute on Drug Abuse (NIDA) grant to uncover how long it takes for discharged inmates to access care upon their release. The research is using an algorithm developed by the National Security Administration that prevents backtracking to uncover individual identities. The BOP also is collaborating with the VA to link released veterans from Federal prisons to VA assistance. Although the BOP has had case managers at each institution to help with links to care, it recently took the additional step of hiring reentry affairs coordinators to handle that on a broader level, including coordination with the VA and many other Federal Agencies that can provide support, such as assistance with employment opportunities.

**Presentation by David W. Knight, Trial Attorney, Disability Rights Section, Civil Rights Division, DOJ**

Substituting for Allison Nichol today, Mr. Knight noted that his last PACHA meeting was 11 years ago when he was an ONAP intern.



The Disability Rights Section of the DOJ's Civil Rights Division has a straightforward mission: to reduce stigma and eliminate discrimination, including in partnership with HHS, the DOL, HUD, and the Equal Employment Opportunities Commission.

A first goal is to frame discrimination against PLWHA as a civil rights issue and as illegal disability-based discrimination. In 2008, Congress passed amendments to the Americans with Disabilities Act (ADA) that confirmed that PLWHA are covered by the act, whether they are symptomatic or asymptomatic, including for many of the side effects of treatment.

As a result, Mr. Knight's office is now prioritizing and fast-tracking cases involving PLWHA, including a recent investigation of a hair-styling institute in Puerto Rico that refused to enroll a young woman because she was HIV-positive. As a result of his office's investigation, a settlement was reached in which the young woman was enrolled and received financial compensation, a penalty was paid to the Federal Government, and publicity was gained for the Federal Government's intention to pursue such cases.

Mr. Knight characterized the case as based on misunderstanding about transmission but also "overly broad statutes" regarding communicable diseases in trade schools and in the licensing of certain professions, which presents a challenge in many States and territories. However, "we're working on that" and to remove any vestiges of exclusion, including through joint efforts with HHS, training, education, and outreach. In addition, his office is working on a study of how to resolve issues involving HIV criminalization statutes, a subject others will address tomorrow.

Mr. Knight emphasized that his office is looking for referrals as well as more opportunities to do research and to educate the American public about ADA across the board. He suggested that PACHA members invite members of his office to speak. He concluded by noting that not every case involves a lawsuit.

#### **Presentation by Sheryll Ziporkin, Associate Commissioner, Office of Public Inquiries, SSA**

Ms. Ziporkin is standing in for David Rust, Deputy Commissioner, Retirement and Disability Policy.

The SSA estimates that 190,000 PLWHA are on Social Security disability and received some \$2 billion in Federal benefits last year. The SSA's current three-part strategy for PLWHA is to improve the economic well-being of these individuals, to make faster and more accurate disability decisions, and to assist return-to-work programs and outreach in communities. "We understand the key role we play in providing economic relief and, in many cases, health care, so we have begun targeted outreach on the types of assistance available through our programs."

At present, the SSA is collaborating with the CDC on the Acts Against AIDS campaign, working with African American AIDS organizations to disseminate information on SSA programs, and seeking opportunities to present to groups such as the National Action Network and the National Organization of Black County Officials. The SSA also is making kits available to managers and labor leaders to help them build comprehensive HIV/AIDS programs. In addition,

it is working to disseminate its factsheets and provide other outreach through Mac Aids Fund grantees.

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

Dr. Valdiserri said that today he would provide an overview of the contents of the HHS operational plan, emphasizing important elements and focusing on the question of what “do we at HHS consider to be new and innovative in the plan.”

First, the plan, which is 44 pages long without appendices, contains a very detailed description of the HHS domestic HIV/AIDS budget. Dr. Valdiserri’s office knows that PACHA is very interested in the budget, and most Subcommittees have asked for presentations on this, so PACHA has some information on the agency level, but this is the first time an across-the-board description has been attempted. This is important because of the NHAS’s “strong message that everyone—not just HHS but all the lead Agencies—need to look seriously at where they have invested resources and determine if these need to be realigned to better serve the Strategy.”

HHS’s operational plan contains data both on entitlement funding—such as Medicare and Medicaid—and discretionary funding, primarily domestic. One thing PACHA members will note when they review the plan is that “while we were able to achieve a heretofore unavailable level of detail, we were unable to describe at the client level every dollar spent because there is no common way, at the program level, across HHS programs, that program managers collect data and information.” Also, in prevention, and in many instances, the CDC, for example, makes funds available to State and local health departments and “it is not the easiest thing to capture and collect all the information back at the client level.”

PACHA members will find much useful information, however, including a valuable examination of investment of HIV/AIDS dollars that more broadly service the population, like microbicides research. And “we commit to try to improve the level of detail in the next cycle of data collection.”

Dr. Valdiserri went on to note that although the plan contains a pie chart to show the total budget, which is about \$16 billion, “thinking about that as a whole is not very realistic, as those funds, excluding entitlement funds, come in on separate budget lines and have their own advocates and champions.”

Having said that, Dr. Valdiserri concluded that “we think this was an important first step.” It “lays the groundwork in a transparent way to inform any discussion about realignment, and that is definitely new.”

**The 12-Cities Project**

Also new is the 12-cities project, which has sparked several questions.

First, Dr. Valdiserri said, the project “is not everything we are doing as a department to achieve the goals of the Strategy.” However, the department does consider the project to be extremely important as a proving ground to demonstrate that HHS programs can work across vertical program lines, that it is possible to do a better job of determining unmet needs, and that it is possible to realign these unmet needs from highest to lower priorities.

In addition, the project provides important opportunity to move forward the discussion of common metrics, which is a 20-year-old discussion, and see if it is possible not only to reduce the number of program measures but also to have some that are consistent across various HHS programs.

In short, with this project, “we have a real opportunity to see if we can do some of the things it will be necessary to do to achieve the HHS goals.”

### **Genesis of the Project**

The genesis of the 12-cities project is that the CDC received monies from the HHS Secretary and the Prevention and Wellness Fund last year and determined that one way to use these funds was to work more specifically with the 12 Metropolitan Statistical Areas (MSAs) that account for about 44 percent of those living with HIV/AIDS.

In its funding announcement, the CDC took steps forward that it had not taken before. For example, instead of basically stating that all prevention is good, the funding announcement asked for interventions based on science and most likely to have maximum impact. The announcement also informed jurisdictions that they would need to enhance their planning and “figure out where the gaps are.” In addition, the announcement looked beyond the prevention agenda and stated, essentially, how important it is to interface prevention with treatment.

Then the funding announcement became public, and when key HHS staff read it in light of the NHAS, they recognized that implementation of the NHAS at HHS could entail, in part, building on the CDC program, which is formally called ECHPP for Enhanced Comprehensive HIV Prevention Plan and Implementation for MSAs Most Affected by HIV/AIDS. Specifically, “we thought how much more powerful it would be if we pulled HRSA and SAMHSA into this.”

When members read the HHS operational plan, they will see that it spells out a number of specific responsibilities for HRSA, SAMHSA, the Center for Medicare and Medicaid Services (CMS), and the Indian Health Service (IHS), without additional funding. These entities and their leadership have committed to supporting the 12-cities project in specific ways. For example, HHS has heard many times from States and localities that they cannot find out who is being funded in their jurisdictions, so one thing that has happened is that HRSA offices that administer the Ryan White CARE Act (RCWA); the Bureau of Primary Care; and other SAMSHA, IHS, and NIH offices have committed to sharing with CDC who they are funding and in what amount to help develop a comprehensive picture. “This is about planning and coordination to try to develop an enhanced response, and the proof of it will be if anything has changed or changes in terms of response.”

In addition, as relates to the 12-cities project, Dr. Valdiserri's office now has a steering group that includes the CDC and the CMS and that is meeting monthly to oversee a smaller working group that includes HRSA and SAMHSA "to begin to grapple with metrics and report to the larger group." The intention "is to make recommendations on needed changes."

### **The Rest of the HHS Operational Plan**

The rest of the HHS plan lays out the most important activities "we can continue and implement within the Strategy's major goals," as follows.

**Reducing new infections:** Highlights here include several references in the plan to the CDC in terms of its interactions with State and local health departments. Under "active discussion" in the CDC is what changes it can make within its large cooperative agreements to provide opportunities to health departments to address the use of prevention funds in different ways. "We're talking about looking at how monies are allocated, as well as what kinds of activities will be supported to address scale-up once the money hits a State or local department."

Dr. Valdiserri then introduced Gretchen Stiers (Branch Chief, Office of Policy and Program Innovation, SAMHSA) as "the point person in this process." Part of the process will be discussion of the block grant set-aside. Current statutory language "indicates that at a certain level—10 living AIDS cases per 100,000 population—it is mandated that up to 5 percent of the set-aside be spent on HIV/AIDS early intervention." At present, "we're having internal discussions about whether we need to change this trigger, how we look at this, and actively exploring ways to do a better job with the resources available."

**Access to care:** Highlights here include that the Secretary's Office has had recent discussions about the AIDS Drug Assistance Program (ADAP) situation, "and has asked our office to continue to convene across the department to explore that issue." At present, "we're thinking about what options we might be able to put in place." In addition, HRSA has committed to increasing testing and treatment capacity at community health centers. In addition to anticipated participation in the 12-cities project, HRSA and the CMS have committed to actively support States to maximize use of Medicaid programs to serve the needs of those with HIV/AIDS.

**Disparities and reducing health inequities:** Here, "we are in the process of developing a large consultation with the leadership across various communities that represent the lesbian, gay, bisexual, and transgender (LGBT) populations to hear about how the U.S. Government can do a better job partnering with them in terms of health and HIV/AIDS but also broader issues." This is an area where public/private partnerships might work well. Also under consideration is how "we might reconfigure our use of the Secretary's Minority AIDS funds to better serve the Strategy." In addition, the NIH has a number of studies underway on how stigma affects access to testing.

## Discussion/Comments/Questions and Answers

### Highlights: HUD

- Responding to a question about what proportion of PLWHA with housing support also are consistently in care, Mr. Vos said there are opportunities for those involved with HOPWA to be engaged in testing and care, and HUD wants to encourage that. In addition, many health departments across the country are engaged in a robust planning process to assist in development of more integrated services, including access to HOPWA and RCWA programs.
- Responding to a query about prioritizing HIV-positive and pregnant women's access to housing to help reduce perinatal transmission, Mr. Vos said in terms of populations with pressing needs, "sometimes it's a matter of knowing how to access these populations." HOPWA "can do a better job of outreach, and perhaps we can learn from the communities around the PACHA table, for example."
- Responding to a query about when the CDC will make living HIV/AIDS case data available, Mr. Vos said that he expects the CDC "to make the process available to HOPWA soon." He said it is important "to get and use quality data on the epidemic as it is." He further observed that service delivery silos are a problem, so HOPWA and others are thinking about how to effect integration. "We're thinking about changing planning and how we use data, not just in the housing program that uses vouchers, but others. We already track access to care. Going forward, the rest is HUD is looking at that too, in terms of health outcomes." Mr. Vos added that HOPWA relies on the community to be creative, "so ideas and models are welcome."
- Responding to a query about the most vulnerable and about inefficiencies that result from lack of integration, Mr. Vos noted that HUD and all Federal departments are part of a strategic plan to prevent homelessness as well as HIV/AIDS. A goal of this strategy is to stabilize the most vulnerable as quickly as possible and also assist in access to care.
- Responding to a query about how HOPWA is addressing young people, Mr. Vos said that query "speaks directly to those on the streets." Here, "there are models of successful intervention, but we need to work more with the community to take advantage of knowledge gained. And we want to make sure that health is addressed."
- Responding to a query about housing authorities, Mr. Vos said that HOPWA does not have as high a profile with housing authorities as it should and needs to explore "how we can work with every community's housing authorities so that it is understood that PLWHA can be there."

### Highlights: VA

- Responding to queries about the VA's plans to work with LGBT populations with "don't ask, don't tell," the VA's plans to address the need to increase the HIV workforce and to pay more attention to comorbidities, the VA's new social marketing campaign, and how the VA assists female partners of veterans with disclosure and prevention of sexual transmission and perinatal transmission, Dr. Czarnogorski said:

- In terms of “don’t ask, don’t tell” and the impact on the VA, the VA is not the Department of Defense and it “does not discriminate in any risk factors.” All veterans are eligible for HIV care and services, and that information is in all VA materials. While in the past, “we have done a lousy job of testing on a risk basis, we think our focus on routine testing is a way to address the epidemic in a better way and, if the diagnosis is positive, to link the individual to excellent care.” That “is the key focus for us.”
- In terms of increasing the HIV workforce, “workforce as a general issue is huge for us.” At present, there is “a push in our system to move away from face-to-face interaction and to better leverage the resources we do have across the system.”
- HIV, aging, and comorbidities “are of significant concern for us, as about 66 percent of our population is over the age of 50, and this number is growing.” At present, the VA is focusing a great deal of its education of providers on comorbidities. This education is taking place through Webinars, face-to-face training, materials, and dissemination of a general handbook on HIV. In addition, the VA was included in a recent meeting at the White House on HIV and aging.
- With regard to its new social marketing campaign, the VA is currently working with a Government contractor on conducting focus groups in five cities, some of which are high prevalence/low testing rates, some of which are rural, and some of which have successful testing rates. The five cities are geographically dispersed. Dr. Czarnogorski will report back on which five cities are involved.
- At present, in terms of the social marketing campaign, the VA is in Phase 1, which is costing \$2 million. The VA is contacting the CDC for materials but also wants to develop specific target messages for veterans. Dr. Czarnogorski emphasized once again that addressing older veterans is very important to the VA; thus, while the CDC recommends routine testing for everyone up to age 64, “this doesn’t necessarily apply to the VA, because we want to make sure all vets are screened.”
- In terms of prevention materials, the VA is in the process of updating a 2001 handbook on approaches to prevention because there have been many changes over the past decade, not only in VA policies but in resources. Dr. Czarnogorski noted that the CDC also is updating its materials, so she may postpone release of the VA’s handbook to 2012 to utilize any new CDC information.
- Disclosure to female partners and reducing sexual transmission “are challenging in the VA system because we provide care to veterans, and partners can’t necessarily receive services at VA hospitals.” That being said, the VA encourages all the 153 VA medical centers and approximately 1,000 outpatient clinics to work with State and local health departments “to have a plan in place for disclosure and reducing transmission.”
- Last, “we encourage each individual facility to work with local health departments wherever they are located, including on tribal lands. But proper channels need to be in place. And there is no one method by which we do that.”

- Responding to a query about the number of unidentified or undiagnosed veterans, Dr. Czarnogorski said “we wish we knew.” The VA “could use CDC projections and models.” In 2009, the VA conducted its first systematic assessment of the number of those tested, “and what we found, based on risk-based testing policy, was that we had only 9.2 percent, so we have a long way to go,” although there “are many vets who may be accessing sources in the community.” The VA’s current goal is to increase its rates significantly in the next few years. “This is a huge priority, and hopefully we will be tracking CD4 counts for earlier intervention.”
- Responding to a query about VA facilities with veterans most highly affected by HIV/AIDS and opportunities to embed partner services, Dr. Czarnogorski said the VA can break its statistics and numbers down by medical center and that the VA “works closely with those most affected to ensure that they have all the support services they need. Individuals are encouraged to work with their communities.” Some communities, such as DC and a few other major cities, make this easier than others do.
- In discussing embeddedness, Dr. Czarnogorski said this varies by facility per determination by a given facility and that “it is not impossible to do that.” Dr. Valdiserri, who once worked for the VA, added that “there are models that could be tried. The way some VA facilities have addressed this during flu season is that they’ll work with the local health department to come on site as a way to get around prohibitions against using veteran monies for the family. That, however, would be difficult to do on a regular basis in terms of partners.”
- Dr. Czarnogorski added that sometimes the VA is invited to local community events and that there are great models for cooperation in DC.
- Responding to a query about how clearly the VA is addressing the issues of stigma and whether there are big barriers to getting tested through the VA system, Dr. Czarnogorski said that the VA’s latest social marketing campaign is focused not only on veterans but providers as well. “We need a culture change so that testing is not a big deal, like you’ve done something bad.” The VA is trying to take some of that stigma out of the process by making testing routine and also by strategizing with focus groups, consisting not only of veterans but also providers, and not just doctors but administrative staff. The main messages of the campaign will be available by World AIDS Day 2011.
- Dr. Czarnogorski continued that clinical reminders of routine testing emanating from EMRs will help, and that has been instituted. She also pointed out that part of what makes routine testing possible right now is the change in policy that allows for verbal consent—a change from the barrier of written consent. She added that the change to verbal consent was assisted by Dr. Valdiserri. Having eliminated the written consent barrier, “we’re now trying to educate providers about how offering testing can be simple, that they can say it is VA policy to test everyone and also that it takes only 5 seconds.”
- Responding to a query about how the VA is reaching out to the parts of the veterans’ community that are not actively interacting with providers at the moment, Dr. Czarnogorski said, “last year, we had 5.6 million veterans in care, so we’re reaching out not just to those who come into the system, but we’re trying to interact with all the

## Highlights: BOP

- Responding to queries about whether the Federal prisons system has routine testing for HIV and STIs and whether inmates have access to HIV specialists, CAPT Bina said HIV testing is mandatory for risk-based inmates, and these inmates also must have a physical within 14 days. Testing and a physical are offered to all inmates. That is policy. For STDs, the BOP has preventive health guidelines for clinical practice.
- Responding to a query about whether inmates have access to HIV specialists, CAPT Bina said each Federal institution has a hospital contract with the local community for acute care and, through those contracts, often has access to specialists. However, because some Federal institutions are in very remote places where there is limited clinical competence, the BOP is trying to create a remedy that could be used across the country. In addition, “we have six medical referral centers within the system based on acuity level, regardless of the disease.”
- Responding to a query about arranging for care and/or appointments post release, CAPT Bina said HIV-positive inmates on antiretroviral therapy (ART) are currently provided with a 30-day supply of medication. He added that there is much controversy and dialogue on how many days “that should be.” However, once an inmate is released, the patient/provider relationship ceases to exist, and “if you don’t have someone to monitor, there’s a liability issue there.” If “you’re not monitoring, and you give an inmate 90 days’ worth of medication, things can go south quickly.”
- CAPT Bina added that at the Federal level, an inmate might be released from California, for example, and then go to New York. There “have been some issues there where we tried to get an appointment for an inmate like that and the physician’s office will refuse until the inmate is actually in the State because there are a lot of no-shows.”
- Responding to a query about the NIDA study and when data will be available, CAPT Bina said he does not know. He does know that the study is looking at three States right now and plans to incorporate Federal data into that portion of the study, “but I don’t know where we are in that process.”
- Responding to a query about percentage of viral suppression among inmates on a national level, CAPT Bina reiterated that the percentage is 81 percent for inmates who have been at a BOP-managed institution for at least 6 months. He added that “this rate wasn’t that good when we started 10 years ago.” Pharmacists at the institutions have been trained to be experts in this care, but sometimes there is not “an appropriate followup.” We “are trying to hold clinicians accountable as part of this system.”
- Responding to a query about patterns and access to prevention services as well as access to condoms, CAPT Bina said the subject of prevention within the walls themselves was raised several times during NHAS workgroup meetings, adding that



- Responding to queries about partners and also about pregnant inmates and the importance of uninterrupted linkage to care as they make prison-to-community transitions, CAPT Bina said that the BOP does not have access to partners who are not incarcerated. “We know nothing about them.” In terms of pregnant inmates and linkage to care, the Federal prison system does not have many pregnant inmates, but they receive assistance in linkage to care just like other inmates. There is a mothers, infants, and toddlers program where inmates have access to their children to do breastfeeding and bonding. When they are about to be released, they have a reentry coordinator and a case manager like anyone else, but once they go into the community “we lose touch with them.”
- Responding to a query regarding prevention of stigma and discrimination and also about the existence of counseling options for inmates who are men who have sex with men (MSM), CAPT Bina said every inmate goes through an admissions and orientation process, which includes watching a video entitled “Staying Alive” produced by inmates “basically as a prevention tool to educate other inmates.” The video shares the producers’ experiences and challenges while they were in the prison. Staff also has access to an infectious disease manual.
- Responding to the observation that other inmates and staff have been known to discriminate against certain inmates and the question whether psychiatric assistance is available in Federal prisons, CAPT Bina said “all Federal institution have psychologists in place, and some have a psychiatrist, while others will get them via contract or telemedicine.” Some of the things we do, he said, include not labeling bottles and also providing separate rooms where HIV-positive individuals are treated. “That’s where I think our focus should be,” CAPT Bina said, adding that “once an inmate’s status is known, it is going to be just like it is in the general community.”
- Responding to a query about remote clinical pharmacy programs and where they are located, CAPT Bina said that because the BOP has EMRs, these programs can be anywhere. There are six regions in the BOP, and there is one clinical pharmacy program for each. Participating in the program “is collateral duty.” Once a quarter, the pharmacists involved look at red flags in the VA records and then coordinate with the VA through a variety of mechanisms.
- Responding to a query about whether there is any thought of bringing the BOP into the 12-cities project, Dr. Valdiserri responded, “Not yet.”

### Highlights: DOJ

- Mr. Knight said that “every discrimination case in the department is mine, so if you know of one, e-mail me directly at david.w.knight@usdoj.gov.” Mr. Knight added that the DOJ gets the message out through outreach, such as going to PACHA meetings and as many other different venues as possible. In terms of the DOJ, the ADA has its own Web site, as mentioned earlier, which will be updated shortly. Mr. Knight added that a number of aspects of the DOJ’s implementation plan address outreach. Current thinking is that faith-based organizations “will be the educators in the South particularly.”
- Responding to concerns expressed about discrimination against safe conceptions, Mr. Knight said “if there is a known denial to couples trying to conceive, I’d like to know.” In addition, he wants to make clear that adoption discrimination “is a thing of the past.”
- Responding to a query about how the DOJ chooses to intervene in a discrimination case and how sexual identity can be protected, Mr. Knight said the DOJ is the enforcer and is endeavoring make an impact by reminding each industry, whatever it might be, that “we’re paying attention.” That includes employment discrimination related to HIV, even when another reason has been used as “pretext.” We are “very familiar with pretext, and we are happy to look at underlying causes of discrimination,” including under Title IX, which protects against gender stereotyping.

### Highlights: HHS

- Responding to a statement of support for the 12-cities project but also a statement of concern that emergent cities/MSAs are not included, Dr. Valdiserri said that the CDC project and the project envisioned in the HHS implementation plan “are very different.” If the HHS “was pulled off the planet, it would be gone, but CDC’s ECHPP would not be.” Specifically, the 12-cities project in the HHS implementation plan is anchored on and builds on top of ECHPP.
- Dr. Valdiserri added that the issue of looking at incidence rates and emergent communities “is a very good one” and “that’s the rest of the HHS operational plan,” because “if we’re not able to decrease incidence, we will have difficulty in treating our way out of the epidemic.”
- In terms of additional resources for the 12-cities project, the only additional resource that has currently been allocated to the project is the money the Secretary designated for CDC use from the Prevention and Public Health Fund. The Secretary designated \$30 million for the CDC’s use, \$12 million of which is supporting ECHPP. PACHA members should remember that the CDC’s project is still in a gestation period. “While everyone is hoping for the best, it is not yet a full-blown project to point toward.”
- Responding to another statement of support for the 12-cities project but also a statement of concern that the initiative is already taking money away from SAMHSA grants, Dr. Valdiserri asked Ms. Stiers to respond. Ms. Stiers stated that SAMHSA has no prevention funds available in 2011 and has some mental health and treatment funds. Meanwhile, “all the current grants that are not ending are continuing.” As part of SAMHSA’s involvement in the NHAS and in working with Dr. Valdiserri, “it seemed we could use the dollars we do have available to support the ECHPP initiative and direct

- Continuing, Ms. Stiers explained that “next year, we have less than \$2 million that won’t be tied to current grants. We will have more in 2013, maybe. A lot depends on what happens with Congress.” Meanwhile, as far as the SAMSHA Administrator is concerned, “mental health and substance abuse are equally important, and it is important to provide behavioral health services.”
- Ms. Stiers added that she is excited about looking at best practices for integration of mental health and substance abuse services with the primary care system, which is a SAMSHA goal in the 12-cities initiative and, indeed, “one of our priorities.”
- Dr. Valdiserri added that, in the HHS operational plan, it is clear that what SAMSHA has committed to as part of its support for the 12-cities project is giving priority to infected individuals with substance abuse treatment needs. What “we’re trying to do at the Federal level,” he added, “is pull what levers we need to pull, and push not only in getting individuals into testing but then those who need it into care in a way that doesn’t ignore their mental health needs.”
- Responding to the suggestion that metrics developed under the HHS implementation plan be applied beyond the 12-cities project, Dr. Valdiserri noted that there are specific ongoing activities at the HHS level to coordinate the project, including a steering committee that he chairs, which meets each month. This steering committee is currently focused on the issue of metrics.
- Responding to a query about how the 12-cities project model would be used to assess unmet needs and provide new opportunities to meet them, Dr. Valdiserri said he continues to have specific followup conversations with the CDC, focused, in part, on the challenge of showing “there’s some output from all this, that things are happening differently and more positively in those 12 MSAs.”
- Continuing, Dr. Valdiserri said that there are a number of other coordinating activities being conducted in relation to the 12-cities project, including a smaller group coordinated directly by the CDC that includes members from all the relevant parts of HHS and that is reviewing implementation of the NHAS, including metrics. The CDC also has incorporated other HHS partners into its review of plans it originated.
- Dr. Valdiserri further explained that, sometime in February, the first draft of a plan is due to the CDC, with a final plan expected sometime in March.
- Dr. Valdiserri said that David Purcell at the CDC is managing ECHPP on a day-to-day basis and that Dr. Purcell understands “we need to look for evidence at the implementation level that things are different, like a new program effort in Los Angeles, where the community health center and the CDC have decided they want to do something differently.”
- Returning to metrics, Dr. Valdiserri said that a pitfall to avoid is limiting this discussion to the Federal level. It is “great that we’re talking about application of metrics across the Federal Government, but we have to pull in State and local health departments.” That is, “we can’t just dream up this scale of metrics and then tell those guys to measure this.” At this time, “we have not expanded the discussion beyond the Federal

- Dr. Valdiserri added that there is an issue involving denominator data. That is, under the NHAS, we “have to bring to scale programs that are effective.” Yet, “if we don’t know how many sexually active gay men we are trying to reach or how many were recently released, for example, if we don’t have those denominators, there is no way to know whether you are at scale or not.” In short, “when cutting across boundaries, one tends to define needs differently.”
- It was noted that the entire Prevention and Wellness Fund is at risk in Congress.
- Dr. Gayle said that PACHA will focus more on that, including how to protect some of these resources, not just for the 12-cities project “but for other things, too.”

### **Final Questions and Responses**

- It was suggested that more research is needed on rectal microbicides.
- A pending question is the role of the private sector and how systematic engagement with the private sector is being addressed.
- Another pending question is what systems are in place to ensure that 5 percent set-asides from block grants are actually being set aside and used.
- A third pending question is whether, in regions that lack providers, such as the South, there is a challenge in terms of spending Federal dollars on subcontracted providers.
- Dr. Valdiserri said that HHS has taken the first step to provide more detail in terms of programs than ever before, but “we have to do a better job.” Also, his understanding is that not much information is available about the use of block grant funds, so that is an issue to be explored as “part of the delicate dance between the Federal and State Governments.”
- In terms of the private sector, there will be many recommendations for its role and, in fact, Dr. Valdiserri is convening a meeting to discuss the steps needed to explore this further in light of the recent positive PrEP trial results, such as whether it might be possible to get private sector support to help with demonstration projects.
- Last, in terms of the issue of subcontracting, Dr. Valdiserri said that while it is important for community health centers to expand their activities, they should make sure “they have the resources they need to do this well.”

### **Administrative Roll Call**

Christopher Bates announced that at least one roll call of members would be conducted during every full Council meeting. He conducted such a roll call of those physically present at the meeting and present by phone, then announced that “we do have a quorum” of members for the purposes of voting.

## Lunch

### AFTERNOON SESSION

#### **Access to Care Subcommittee Report by Co-Chairs Michael Horberg and Robert Greenwald**

Monitoring health care reform implementation is a primary priority of this Subcommittee. Therefore, the Subcommittee asked Health Care Access Working Group members Laura Hanen, Director, Government Relations, NASTAD, and Andrea Weddle, Executive Director, HIV Medicine Association, to provide a presentation on this subject. More than 100 national community-based AIDS organizations support the working group. PACHA Access to Care Subcommittee Co-Chair Robert Greenwald is one of the working group Co-Chairs, and Ms. Weddle and Ms. Hanen share the other Co-Chair position.

#### **Health Care Reform Implementation Update by Laura Hanen, Director, Government Relations, NASTAD, and Andrea Weddle, Executive Director, HIV Medicine Association**

##### **Highlights:**

- Ms. Hanen began with the impact of health care reform on Medicaid, as it is the Nation's largest provider of care for PLWHA. She noted that the essential health benefits package would be discussed later.
- Medicaid reforms include:
  - Beginning in 2014, Medicaid's categorical eligibility requirements will be eliminated (i. e., disability).
  - Most low-income, uninsured people will automatically be eligible for Medicaid. (Low income equals 133 percent of the Federal Poverty Level, or an approximate annual income of \$14,000 for individuals and \$29,000 for a family of four.)
  - A 100 percent Federal matching rate will be made available to States. This will drop to 90 percent in 2019.
- The impact on Medicaid includes:
  - Comprehensive health coverage will be available for most uninsured, low-income PLWHA, including most RWCA clients (and most people on AIDS ADAP waiting lists), but will not be available to undocumented immigrants. In addition, the current 5-year ban on Medicaid for legal immigrants continues.
- Medicaid and implementation:
  - In terms of defining new essential health benefits, the Institute of Medicine will not conduct its Essential Health Benefits Survey until late 2011. Meanwhile, DOL plans an Employer Benefits Survey this March.
  - There is advocacy at the Federal and State levels to maximize these new benefits for both newly eligible and already eligible beneficiaries.

- In addition, the Medicare Part D “donut hole” will be phased out by 2020. As of this past January, ADAP contributions have begun to count toward true-out-of-pocket (TrOOP), and there is a 50 percent discount on all brand-name prescription drugs.
  - Most Part D beneficiaries with HIV and AIDS will have their donut hole reduced from \$4,500 to \$2,100.
  - HRSA and the CMS are providing guidance for State implementation of ADAP as TrOOP. Some States are behind in implementation.
  - The crisis in ADAP continues, so ongoing Congressional funding support is needed.
- Private insurance reforms include:
  - As of July 2009, the formation of preexisting condition insurance pools was allowed, and enrollment is beginning to pick up.
  - Beginning in 2014, the formation of State-based exchanges will be allowed.
  - Beginning in 2014, all plans offered through exchanges will be prohibited from charging higher premiums based on gender or health status.
  - As of September 2009, individual and group health plans cannot place lifetime limits on coverage or rescind coverage because a person gets sick. In addition, beginning in 2014, no annual limits on coverage will be allowed.
  - As of September 2009, prevention services must be available without cost-sharing (for new plans).
- Ms. Hanen emphasized the importance of changes to private insurance for PLWHA because, at present, it is virtually impossible for PLWHA to obtain individual insurance policies, and only 17 percent of PLWA have access to employer-based private coverage.
- In terms of implementation, HRSA’s HIV/AIDS Bureau (HAB) issued guidance on Pre-Existing Condition Insurance Plans (PCIPs) in December. Grants have been issued to States to help in the design of exchanges.
- Clinical preventive services reforms include:
  - As of September 2009, many preventive services will be delivered with no cost-sharing under Medicare and new private plans.
  - Eligible services are those with an A or B rating by the U.S. Preventive Services Task Force (USPSTF), services listed by Bright Futures, those listed by the Advisory Committee on Immunization Practices, and those listed by HRSA for women. Only at-risk HIV testing is covered by these reforms.
  - In 2013, there will be a 1 percent increase in Medicaid Federal matching funds for those providing these services.
  - With regard to clinical preventive services and implementation, HHS has issued regulations on prevention services for Medicare and private insurance that cover only those services with an A or B USPSTF rating.
    - USPSTF needs to reevaluate its HIV testing recommendation.
  - New investments include the Prevention and Public Health Fund and the Administration’s allocations of funding for workforce education under the Affordable Care Act.

- The Prevention and Public Health Fund funds State and community-based prevention initiatives and programs that could support HIV prevention and wellness efforts (e. g., Community Transformation Grants).
  - The investments program could help address growing HIV provider shortages.
- With regard to implementation, only \$30 million was allocated to the Prevention and Public Health Fund for HIV in 2010; there is HIV representation on the HRSA committee evaluating criteria for medically underserved areas and health professions shortage areas; and the National Health Service Corps has been expanded.
- Under the law, \$11 billion has been authorized for operation, expansion, and construction of community health centers over the next 5 years.
  - The impact of this on HIV care is that this expansion provides an opportunity to build HIV capacity in Federally Qualified Community Health Centers (FQHCs), and some RWCA-funded clinics are pursuing FQHC status.
- FQHC expansion implementation updates include:
  - An AIDS Education and Training Center (AETC) grant has been awarded to HealthHIV and the National Association of Community Health Centers, Inc., to provide TA to 30 Community Health Centers (CHCs) per year for 3 years to build HIV capacity.
  - CHC planning grants are due March 2011.
  - The first HRSA/Bureau of Primary Health Care (BPHC/HAB) TA call on FQHC 101 was conducted in December, and another is planned for January 31 on the NHAS and improving HIV/AIDS care in health centers.
- Care delivery improvements include:
  - Creation of the Center for Medicare and Medicaid Innovation (CMMI), which will evaluate delivery systems and payment mechanisms that promote high-quality, cost-effective care and which has launched demonstration projects testing payment and delivery models. It is hoped that the projects document RWCA as a good model of care to inform payment reform ([innovations.cms.gov](http://innovations.cms.gov)).
  - As of January, the availability of a new Medicaid Health Home benefit for beneficiaries with two or more chronic medical conditions, which gives States the option to develop enhanced and coordinated care for such individuals. The latest is that CMS's letter to State Medicaid Directors identified HIV as "a chronic condition" for this program.
- Challenges ahead for health care reform include threats from Congress, such as full repeal and elimination or reduction of funding for key provisions (e.g., the Prevention and Public Health Fund, CHC funding, and CMMI), even though the Congressional Budget Office has pointed out that it would be costly to repeal the act (Slide 14). Advocates are being alert to threats against the discretionary spending provisions listed on Slide 14, as they are subject to the annual appropriations process.
- Health care reform also faces major legal threats from cases brought against health care reform by the Commonwealth of Virginia and the State of Florida, joined by other States

- Meanwhile, building a bridge to 2014, when major elements of the reform act take effect, presents challenges:
  - The current Federal and State funding environment is creating difficulties for many programs, particularly HIV programs. At present, HIV/AIDS advocates face a multiyear freeze (or cuts) in Federal spending, State budgets are severely constrained, and ADAP waiting lists are growing.
  - In addition, HIV clinics across the country are at or over capacity.
  - While early Medicaid expansion is a viable option for a few States, unfortunately, the required waiver process is complex and challenging.
  - In addition, the Early Treatment for HIV Act long favored by the advocacy community still lingers on the sidelines.
- The advocacy community's work plan for advancing health care reform and the HIV advocacy agenda includes:
  - Responding to implementation guidance and regulations
  - Educating Federal and State policymakers and communities on the importance of health care reform to PLWHA
  - Building coalitions with other low-income and chronic disease advocates, organizations, and movements
  - Strengthening connections between national HIV coalitions and grassroots partners
  - Connecting to the NHAS.

## **Discussion/Comments/Questions and Answers**

### **Highlights:**

- Responding to a query about how to ensure under the new health reform rubric that high-quality care standards win out and that there are consequences for unacceptable care outcomes, Ms. Weddle said fewer than one-third of the current Ryan White Part-C-funded clinics are FQHCs and that she and Ms. Hanen share others' concern about wanting to retain high quality and access to care under Ryan White. For the exchanges to come, advocacy groups have been weighing in on standards for provider networks and how to measure quality and outcomes. Medicaid indicators are out for comment and, more recently, Medicare measures. HRSA also has put its measures out for comment. It is hoped there will be an effort to get all these measures "in line."

### **Access to Care Subcommittee Draft Resolution Regarding HIV Testing**

Access to Care Subcommittee Co-Chair Michael Horberg noted that the Subcommittee has drafted a resolution for the full Council's consideration regarding the need for reconsideration of the USPSTF position/rating on routine testing in clinical settings. He asked members to review the printout before them and make comments.



Dr. Gayle noted Subcommittee discussion of changes, and Dr. Horberg assured her that these changes had been incorporated in the draft that follows.

**Presidential Advisory Council on HIV/AIDS**  
**Access to Care Subcommittee**  
**Draft Motion**  
**PACHA Resolution Regarding HIV Testing**

Background: An individual’s ability to benefit from the great strides that have been made in the treatment and care of HIV largely depends upon timely diagnosis, effective treatment, and attention to comorbidities and co-conditions (including mental health, substance use, and housing). Further, reducing the potential for HIV transmission in our communities through reduced viral load and behavior change, also depends upon timely diagnosis and effective treatment. The benefits of early diagnosis and linkage to care are only realized if individuals know their status through HIV testing.

The United States Preventive Services Task Force (USPSTF) recommends routine HIV screening for those persons at “increased risk” of HIV infection (a Grade “A” recommendation). USPSTF also recommends testing of all pregnant women (Grade “A”), which should continue and be promoted. The USPSTF recommendation is important because coverage and reimbursement for preventive services under Medicare, Medicaid, and most private insurance under the Affordable Care Act depend on an “A” or “B” level USPSTF recommendation, and adequate reimbursement supports clinicians’ efforts to increase health screening.

WHEREAS, the USPSTF clinical considerations defining “increased risk” for HIV infection include: (1) one or more individual risk factors; (2) receipt of health care in a high-risk clinical setting; or (3) receipt of health care in a high-prevalence clinical setting (defined by the Centers for Disease Control and Prevention as those with a 1 percent or greater prevalence of infection among the patient population being served);

WHEREAS, “increased risk” covered under the Grade A USPSTF recommendation includes: 1) men who have sex with men after 1975; men and women having unprotected sex with multiple partners; past or present injection drug users; men and women who exchange sex for money or drugs or who have sex partners who do; individuals whose past or present sex partners were HIV-infected, bisexual, or injection drug users; individuals being treated for sexually transmitted diseases; individuals with a history of blood transfusion between 1978 and 1985; individuals who request an HIV test; 2) high-risk clinical settings, including clinics serving men who have sex with men, and adolescent health clinics with high prevalence of STDs; and 3) high prevalence settings, including those with 1 percent or greater prevalence of infection among the patient population being served;

WHEREAS, even with the broad definition of “increased risk” under current Grade A USPSTF recommendations, there are still people who fall outside of the “increased risk” category who

will benefit from testing, and numerous studies document that risk-based HIV screening in health care settings fails to identify up to half the patients infected with HIV;

WHEREAS, many health care providers often do not have time to take detailed sexual or substance use history or may simply assume their patients are not at risk for HIV disease and/or are unaware of the broad definition of “increased risk”;

WHEREAS, numerous studies also document that routine screening of patients without specific risk factors is well accepted by patients;

WHEREAS, the USPSTF last considered HIV routine testing in 2007, updating a 2005 evidence review; and the evidence model that led to their “C” level recommendation for routine HIV testing was based on preventing clinical progression or death within 3 years, assuming treatment would be initiated only at CD4 T-cell counts less than 200/uL, but subsequent evidence of increased survival and improved health outcomes with earlier treatment and decreased infectiousness among horizontal transmissions with effective antiretroviral treatment has accumulated; and, the DHHS and other professional societies recommend initiation of antiretroviral therapy at CD4 levels of 350-500 /uL (A/B II), if not sooner;

WHEREAS, both public and private insurance reimbursement often relies on health care providers’ full understanding of the definition of “at increased risk,” but many health care providers are unaware of the scope of this definition;

Therefore:

BE IT RESOLVED that the President’s Advisory Council on HIV/AIDS recommends that the U.S. Preventive Services Task Force immediately launch a new review regarding its rating for routine population-based screening for adults and adolescents in clinical care settings; and the Department of Health and Human Services convene the Centers for Medicare and Medicaid Services and the Health Resources and Services Administration to undertake a joint HIV testing initiative and provider education campaign to ensure that providers understand the breadth of the already existing Grade A recommendation and to ease reimbursement difficulties for increased risk HIV testing.

## **Discussion/Comments/Questions and Answers**

### **Highlights:**

- Dr. Horberg said the resolution’s two key points are contained in the “be it resolved” section, the Access to Care Subcommittee unanimously approved the resolution as it appears above, and the Subcommittee requests full Council approval of the resolution as it appears above.
- Responding to a comment about individual risk factors leaving many out, including women at structural risk, Dr. Horberg said that is precisely why we need routine testing.
- Responding, Naina Khanna indicated that she would be interested in another resolution in the future that addresses structural risk.

- It was agreed that adding the verb “convene” in the “be it resolved” section would solve a few people’s concerns, and this was accepted as a change in the draft without further comment.
- Responding to Douglas Brooks’ concern about the language in the fourth “whereas,” Dr. Horberg made an adjustment that appeared in the next version of the draft.
- Responding to continued concerns about women at structural risk, Dr. Horberg said that assuming that PACHA passes this resolution and sends it on, the cover letter could address structural risk issues.

### **Administrative Matter**

Mr. Bates said a PACHA member had requested that the public have an opportunity to comment on draft resolutions before they are voted on. Therefore, he asked for members to indicate whether all the resolutions could be acted on during Day 2, near the end of the meeting and before the Executive Session, which could allow for public comments and reaction today and tomorrow.

There were no objections from members.

### **Continued Presentation/Discussion of Access to Care Subcommittee Report**

#### **Women and Youth HIV/AIDS Strategy**

Discussed next was whether the NHAS could more explicitly address women and youth, as advocated by PACHA member Patricia Garcia and other Subcommittee members.

### **Discussion/Comments/Questions and Answers**

#### **Highlights:**

- Praveen Basaviah suggested that this topic deserved a dedicated session with presentations, which seemed to be agreed to by other members.
- It was suggested that others who are interested in addressing this make their interest known to Dr. Gayle; other members seemed to agree with this.
- Mr. Bates indicated that he may want to address this topic at the next meeting of the Access to Care Subcommittee.
- Dr. Gayle asked how all Subcommittees could get involved.
- It was suggested that an ad hoc working group be formed on youth and women.
- Dr. Gayle suggested that Subcommittee Co-Chairs discuss how to do this, as she is concerned about working group overload.
- Dr. Garcia suggested that the subject matter deserves input from all the Subcommittees and, if they work individually in parallel, the result will be less than coherent.
- Dr. Gayle said she is suggesting that when the Subcommittee Co-Chairs next get together, she would make sure this issue is on the table so that what is going on related to youth and women “could stay organized.” She said she is not opposed to a working group, and that is “up to this body.”

- Dr. Horberg suggested that a cross-representative group help plan to address this for the next meeting, with the charge going back to the Subcommittees.
- Responding, Dr. Gayle asked Dr. Horberg to make sure that the group has representation from all the Subcommittees.
- Dr. Garcia commented that youth and women need to be focused on as subpopulations with specific needs with regard to access to care and access to care measurement. A recent NIH Office of AIDS Research (OAR) meeting that focused on adolescents struck her in this regard, in particular, although both youth and women are distinct subpopulations. She too advocated that the NHAS as it impacts youth and women must be examined across all Subcommittees, as these populations and their needs crosscut all Subcommittees.

## **Public Comments**

After indicating that public comments would be split into two 15-minute sessions on Days 1 and 2, Dr. Gayle and Mr. Bates asked for Day 1 public comments.

**Carl Schmid**, Deputy Executive Director of The AIDS Institute, made the first comments. Mr. Schmid noted that The AIDS Institute has approached PACHA and the Obama Administration many times during the past year to ask for consideration of the crisis in ADAP. PACHA did pass a resolution in support of \$126 million in emergency funding, the \$25 million in emergency funding identified by the Secretary, and the President's \$30 million midyear budget request. Unfortunately, none of those steps was adequate, and NASTAD now reports an ADAP waiting list of 5,550 people in 10 States.

Today, the ADAP waiting list is three times larger than it was when PACHA met in June 2010. The situation is so severe that the State of Florida is planning to remove 6,400 participants from that State's ADAP program beginning February 1. The plan is for patients to receive their medications from a pharmaceutical-sponsored charity. Virginia is in the process of removing 760 people from its program, and Washington State is removing 500 people.

At present, the entire country is operating on a continuing resolution at current funding levels until March 4. A new Congress has been constituted, and many members are calling for significantly less Federal spending. The ADAP program cannot be cut, however. Can you imagine how long the waiting list would be or how many patients would be disenrolled from the program if funding were cut? A 20 percent cut would equal \$172 million and would translate into dropping more than 19,100 people from the program. Even with level funding, the situation would continue to be grave, given that ADAP utilization continues to skyrocket.

Congress needs to protect ADAP from any cuts and actually increase funding by at least the \$65 million proposed by the Senate for FY 2011. The Obama Administration needs to insist forcefully on these increases as it works with the Congress and also to propose adequate increases in FY 2012.

**Jenny Collier**, Coalition Convener, Ryan White Medical Providers Coalition, said she represents mainly Part C providers. A recent survey of these providers indicated that their top three concerns are funding cuts and shortfalls, how health reform will affect Part C, and program and clinic management issues, including HIV workforce recruitment and retention.

Increasingly, the Coalition is seeing an increasing number of pressures in the HIV care world, including access to medication. Clinics are diverting resources and spending staff and clinical resources to obtain medications for HIV-positive individuals. The ADAP crisis has affected the clinics, which have increasing patient loads, patients with loss of health insurance coverage, and cuts in funding of other programs. In addition, these clinics have fewer people to work on all these challenges due to cuts and problems with recruitment and retention.

Many Part C clinic staff are worried about cuts to Federal funding, as many clinics have already experienced cuts to State funding. The majority surveyed have made cuts to or changes in programs due to funding shortfalls. The types of cuts or changes include 32 percent cuts in services, 22 percent cuts by freezing or laying off staff, and 80 percent cuts in drug assistance. Specific comments from these clinics include concern about unsustainable provider workloads and reductions in laboratory monitoring.

In sum, the current situation is truly perilous and cannot continue if we want to preserve what we have learned from the RWCA and RWCA programs. Providers are facing fairly serious Federal cuts now and cannot wait 36 months for relief from health reform.

**Sarah Audelo**, Senior Manager, Domestic Policy, Advocates for Youth, said she wants to encourage PACHA to have young people present and speaking to its members at its next full Council meeting. Ms. Audelo added that she would like PACHA to consider a resolution focused on its concern for young people and also to invite more young people (ages 14–24) to sit on the Council. “We may not have your depth of experience, but we know what is or is not working for us.”

Last, Ms. Audelo asked for an explanation of the differences between PACHA resolutions and recommendations. In the meantime, the President’s proposed FY 2012 budget is due out soon, and Ms. Audelo’s organization would like to go on record that it does not like “the abstinence program, which, at \$50 million per year, is a waste of money.” Specifically, Ms. Audelo asked if PACHA could recommend that the Administration “say that it doesn’t want to fund this program but it has to, and also that it supports comprehensive sexuality education programs.”

**Anna Ford**, Director, Urban Coalition for HIV/AIDS Prevention Services (UCHAPS), a coalition of the seven CDC directly funded jurisdictions that shoulder one-third of America’s HIV burden, said UCHAPS remains committed to successful, aggressive implementation of the NHAS. She stressed that targeted investment of resources is necessary to meet HIV prevention goals, particularly given that 50 MSAs in the United States shoulder 70 percent of the domestic HIV/AIDS epidemic.

Ms. Ford focused on two areas: domestic HIV prevention funding and the 12-cities initiative. Uncertainty remains concerning FY 2011 investments in HIV prevention. Secretary Sebelius must exercise her authority to ensure that the Prevention and Public Health Fund continues to fund HIV prevention programs. Under her leadership last year, \$30 million in new HIV prevention resources were programmed through the fund and have allowed for dramatic expansion of HIV testing across the country and launch of the exciting 12-cities project. PACHA should send a statement to the President and the Secretary that calls for continued HIV prevention investment through the fund.

Current HIV prevention investment is woefully inadequate, and any further erosion in prevention funding will cripple chances of achieving NHAS goals. The Administration must not prematurely relent in 2011 and must strive for full funding of HIV prevention programs in 2012. There are opportunities for thoughtful redistribution of funds, one of which is through the CDC's cooperative agreements with State and local health departments. UCHAPS understand that release of this announcement, the flagship of the CDC's HIV prevention program, is imminent, and UCHAPS has appealed to the CDC to align its focus and investment strategy with NHAS principles. UCHAPS urges PACHA to work with the Administration to review and monitor this critical HIV prevention investment and set the tone for other HHS Agencies.

In the spirit of accountability, UCHAPS applauds PACHA's ambition to inventory all Federal prevention budgets (particularly those of SAMHSA, NIH, and HRSA) and encourages PACHA to recommend strongly to the Secretary and to Dr. Koh that they fully support maximum accountability and redirection where necessary across several HHS Agencies.

Last, UCHAPS is fully supportive of the 12-cities project, particularly as described by Dr. Valdiserri as an effort in broad cross-agency coordination and engagement. Over the past several months, it has become clear to local jurisdictions making progress with ECHPP deliverables that success will depend on the following:

- Uninterrupted funding
- Increased capacity to measure change and local level incidence and transmission rates
- Integration of data systems
- Bringing necessary interventions to scale
- True engagement from local, care, housing, substance abuse, and mental health providers and administrators.

Ms. Ford concluded by saying that UCHAPS looks forward to continuation of the meaningful progress in the first quarter of 2011.

### **Access to Care Subcommittee Draft Resolution: Full Council Vote**

Presented with a draft resolution, the substance of which was little changed during discussion but for the fourth "whereas," which now reads "WHEREAS, many health care providers often do not take detailed sexual or substance use history or may simply assume their patients are

not at risk for HIV disease and/or are unaware of the broad definition of ‘increased risk,’” PACHA members in the room and on the phone were asked to vote.

By a show of hands in the room and by a roll call of those on the phone and saying “aye,” the resolution passed by 17 votes.

### **Pre-Adjournment Discussion/Comments/Questions and Answers**

- In response to a member’s request, it was noted that the full Council would address the resolution process on Day 2. Dr. Gayle invited members to be thinking about how the Council wants to use its resolution power, adding that if it uses a resolution to address everything, “we lose some of our power.” This will be discussed more tomorrow.
- Cornelius Baker said that letters could come from the Chair if the full Council has already passed a resolution on any given matter.
- Responding, Dr. Gayle said as useful as a specific resolution might be, direct contact, such as with the White House, might be just as useful.
- Observing that PACHA has now heard from some of the Federal Agencies about their operational plans, Jack Jackson asked how PACHA will go about working with the various State, local, and tribal authorities.
- Responding, Dr. Gayle said this is one of those issues the full Council will discuss further during this meeting because “this is one of the gaps in our charge as a Federally constituted body, and the question is how we want to fill that gap in terms of recommendations to Agencies and departments.”
- Ms. Hanen noted that her office and others plan to have conversations with HHS about that topic in the near future, particularly related to metrics and benchmarks.
- Responding, Dr. Valdiserri observed that one of Dr. Koh’s specific responsibilities is to track Federal resources at State levels, and this leads into the discussion of metrics. How measurement should occur, including how to get detail from States without adding a burden to State health departments and their resources, is under discussion. Many non-governmental organizations, as well as his office, are exploring options for tools that could be used by State and local authorities as well as CBOs and others to “empower them to see what they can do to help with the Strategy.”

### **Day 2 Agenda Preview**

Dr. Gayle said the full Council meeting on Day 2 would begin with a report on the Incidence Subcommittee by Co-Chairs David Holtgrave and Mario Perez, followed by a report on the Global Subcommittee by Co-Chairs Kevin Frost and Dawn Averitt Bridge and a report on the Disparities Subcommittee by Co-Chairs Kathie Hiers and Phill Wilson.

Two draft resolutions will be on the table: one from the Incidence Subcommittee and one from the Global Subcommittee.

Subcommittee reports will be followed by a presentation on HIV criminalization, another brief public comments period, general discussion, and an executive session, which will be closed to the public.

## **Day 2**

### **MORNING SESSION**

#### **Welcome and Call to Order**

Dr. Gayle called Day 2 of the full Council meeting to order at 9:15 a.m.

Dr. Gayle thanked the Council for the lively and useful input on Day 1. She believes that the group is coming together a bit more and starting to get to know each other. While there are issues that different members feel strongly about, differences in opinion are being expressed in constructive ways. This is something she looks forward to again today as well as the public's perspective during a second session of public comments.

Dr. Gayle noted that Committee Manager Melvin Joppy would be making all PowerPoint presentations from yesterday and today available to those who are present by phone.

#### **Roll Call**

Mr. Bates conducted a roll call of members. It was established that 21 members were present at this time, either in the room or by phone.

#### **Incidence Subcommittee Report by Subcommittee Co-Chairs David Holtgrave, Ph.D., and Mario Perez**

##### **Members and Overview**

It was noted that Subcommittee members in addition to the Co-Chairs are A. Cornelius Baker, Naina Khanna, Douglas Michels, and Rosie Perez.

The Subcommittee's focus has been prevention funding, prevention metrics, and issues related to stigma. In looking at the potential for public/private partnerships, the Subcommittee concluded there may be opportunities to work with private partners and private funding, not only in terms of research but possibly in terms of metrics.

With regard to metrics, the Subcommittee is eager to identify the best benchmarks to gauge our national progress, most particularly our "ambitious" prevention goals. The Nation cannot really rely on transmission rates and incidence, given the time it takes, so there is motivation to develop proxies. The Subcommittee has had presentations and robust discussion about education or school-based prevention. It has postponed its conversation on stigma and is looking forward to some joint work on that with the Disparities Subcommittee.



## **Incidence Subcommittee Draft Resolution on Prevention Funding**

The Subcommittee's draft resolution on prevention funding rose out of its focus on the budget and utilization. Subcommittee members concluded that it was important to address two major components: the scope of prevention investment because "we're not at the scale we need to be" and the need to make best use of current and future resources.

As introduced to the full Council, the draft resolution read as follows:

### **Presidential Advisory Council on HIV/AIDS Incidence Subcommittee Draft Motion**

WHEREAS, the HIV prevention funding investment is far too small in the U.S. to truly change the course of the epidemic according to the 2008 sworn testimony of the Director of the Centers for Disease Control and Prevention and other witnesses, as well as according to peer-reviewed published articles;

WHEREAS, the current level of investment continues to shrink when adjusted for inflation (dropping over 20 percent since FY 2002), and the purchasing power of the HIV prevention investment in the U.S. is now approximately only what it was in 1993;

WHEREAS, the HIV prevention funding in the U.S. only accounts for about 3 percent of the total U.S. investment in HIV/AIDS;\*

WHEREAS, all HIV prevention funding (be it current or future) must be subjected to the highest standards of transparency, effectiveness, and efficiency so as to be fully accountable, maximally impact the epidemic in the U.S., and assure attainment of the goals of the President's National HIV/AIDS Strategy;

BE IT RESOLVED that PACHA urges the Administration and Congress to achieve the following:

- (a) In FY 2012 fully fund the HIV prevention efforts in the U.S. at levels previously described as necessary in Congressional testimony and peer-reviewed publications so as to assure attainment of the goal of the National HIV/AIDS Strategy;
- (b) By March 2011, develop a system of annual reporting whereby all HIV prevention funding in the Federal Government is described in a publicly available document containing all funding amounts, uses, and measured or estimated outcomes; and
- (c) Work closely with PACHA by July 2011 to develop and implement a set of recommendations for any necessary redirection of current Federal HIV prevention funding from its existing use to more impactful utilization.

\*Original wording: "WHEREAS, the HIV prevention funding in the U.S. only accounts for about 3 percent of the total HIV/AIDS investment in the U.S.;"

## Discussion/Comments/Questions and Answers

- Mr. Perez said friendly amendments are welcome, particularly as pertains to the “be it resolved” section.
- Dr. Holtgrave said that this resolution or some version of it is urgently needed because of the importance of implementing programs at the right scale. He added that leaving prevention at its current investment level “is the most expensive thing to do,” and fully funding prevention efforts “the least expensive thing to do.” It must be recognized, he concluded, that we have a unique, historic chance here to try to bend the curve of the epidemic in the United States.
- Responding to a query about the discrepancy between where we are now in prevention funding and what is being proposed in part (a), Dr. Holtgrave said “right now, all prevention efforts at the CDC total \$750 million and, beyond that, about \$850 million.” CDC testimony in 2008 indicated that the level of investment should be 1.6 times that, or nearly double. Other testimony and the literature indicate the right sizing would be about 1.3 times that. The Subcommittee did not propose an exact dollar amount because there are differences, but it did want to tag or cite testimony that is publically available.
- Mr. Perez added that recommendations could be made related to the FY 2011 budget, such as on the level of funding for the Prevention and Public Health Fund.
- It was proposed that part (a) reflect a recommendation that the FY 2011 budget include at least \$30 million for HIV prevention initiatives.
- It was proposed that part (c) address redirection of “current Federal funding,” because there are places other than the Federal HIV prevention budget where one could look for more funding, including some of the TA the Federal Government provides.
- Responding, Dr. Holtgrave said this was a good point.

## Further Resolutions Discussion

Dr. Gayle redirected the discussion by noting that all the headlines these days are about deficit spending, and clearly there will be cuts to everything discretionary. Because full funding for prevention is unlikely, she wondered if there is another way to construct the resolution “that doesn’t make us seem naive and that takes into consideration the budgetary realities.” Possibly the way to go, she said, is along the lines of greater priorities and also stating that full funding is the best and cheapest way.

Dr. Gayle said she does not want to be seen as giving in too early on funding, “but if we don’t put something forward that has a reasonable chance of success, it will seem like there is nothing we can do.” She then proposed addressing full funding as ideal, while recognizing tough decisions and suggesting that there are places one could look to get additional resources for prevention where dollars being spent do not have as much impact.

Responding, Dr. Holtgrave suggested that part (a) begin “As rapidly as possible, fully fund...” Dr. Gayle agreed, adding that cost-effectiveness also needs to be addressed.

Responding, Mr. Greenwald suggested that could be a new “whereas” statement, which the Subcommittee will submit for the Council’s consideration before the vote.

Drs. Horberg and Holtgrave also discussed part (b) and moving the March 2011 date back to the end of the second quarter.

Further discussion indicated various opinions about the wording of part (c) related to redirection.

### **Resolution Changes/Decision Points**

At the end of discussion, it seemed to be decided that a new “whereas” would be added; part (a) would begin “As rapidly as possible”; part (b) would call for a deadline at the end of the second quarter of 2011; and part (c) would address either redirection of “Federal HIV prevention and other Federal funding” or “Federal HIV prevention and other HIV funding.”

After further brief discussion, it was decided that Dr. Holtgrave and Mr. Perez would edit the draft resolution, including its title, and submit the edited document for a vote following public comments.

### **Subcommittee Report**

#### **NHAS Prevention Goals and Metrics**

Mr. Perez noted the NHAS Prevention Goals for reducing new HIV infections, as follow:

- By 2015, lower the annual number of new infections by 25 percent (from 56,300 to 42,225).
- Reduce the HIV transmission rate, which is a measure of annual transmissions in relation to the number of PLWHA, by 30 percent (from 5 persons infected per 100 people with HIV to 3.5 persons infected per 100 people with HIV).
- By 2015, increase from 79 percent to 90 percent the percentage of PLWHA who know their sero status (from 948,000 to 1,080,000 people).

Mr. Perez said measuring these goals comprehensively throughout the country is “a significant task, so in the spirit of making progress and laying out some interim markers,” the Subcommittee has four recommendations for the Council’s consideration regarding outcome and impact metrics related to HIV prevention, as follows:

1. It is recommended that the CDC issue HIV incidence, prevalence, transmission rate, and death rate estimates for a given year no later than 18 months after that year has ended. (Even if the levels of confidence in said estimates must be quite broad initially and narrow over time, that is better than waiting for information that has ceased to be timely and useful for program and policy planning purposes.)

2. It is recommended that, as a proxy to national HIV incidence, there be utilization of the best available assays for real-time monitoring of trends in new HIV infections in the CDC-sponsored ECHPP (12-cities) project.
3. It is recommended that, as a proxy to national awareness of HIV seropositivity, there be utilization of real-time monitoring of knowledge of HIV seropositivity in the CDC's National Health Behavior Survey.
4. It is recommended that the peer-reviewed paper by the CDC's Michael Campsmith on the characteristics of PLWHA who are unaware of their sero status be updated annually, using the most timely and best information available.

### **Discussion/Comments/Questions and Answers**

- Elaborating, Mr. Perez said the Subcommittee's understanding is that the first recommendation is doable. Even if the confidence intervals are too broad or too narrow, estimates could be an important tool for policy planning and programming. He said that doing what the second recommendation suggests is overdue, particularly as technology is evolving at a rapid pace. He noted that in terms of the third recommendation, "we want to lean on the CDC's survey to help glean what may be happening on the ground." Last, he observed that many PACHA members are familiar with Dr. Campsmith's paper and want to urge the CDC to update this report annually using the best information possible, particularly as the last report was in 2006.
- Responding to Dr. Gayle's query about the budget implications of these recommendations, Dr. Holtgrave agreed that it would be useful to talk with CDC colleagues about this. While the Subcommittee tried to keep in mind the practicality of the recommendations, he added that Dr. Gayle's point is extremely well taken and that the Subcommittee should do as she suggests.
- Dr. Valdiserri said that for most of these recommendations, there are "systems in place." He then asked if the Subcommittee discussed the value of community viral load.
- Responding, Dr. Holtgrave said the Subcommittee did not talk much about community viral load, as it was trying to hone as closely as possible to the three major prevention goals in the NHAS and "how close we could get to those in a certain time period." Dr. Holtgrave added that while he supports exploring community viral load, "we won't know what that is for some time with existing systems and in terms of a report card in real time."
- Subcommittee members asked that other PACHA members provide feedback and take these recommendations up at the next full Council meeting so that they can be discussed more fully, including with regard to CDC funding and implementation plans.
- After a brief discussion of how some metrics are related to promulgation of prevention science, such as giving people access to PrEP and other pre- and postexposure resources, Dr. Valdiserri said it is important to hone in on the most important metrics, and, as he mentioned yesterday, "these could be process, not

- Dr. Holtgrave noted that the Subcommittee also reviewed 2010 and 2020 Healthy People metrics, of which there are several related to HIV, one of which is incidence, “so all the problems we ran into with the Strategy in terms of time frame, we confronted there, too.”
- Dr. Horberg commented that PACHA will “have to be parsimonious” about its metrics recommendations, for as each Subcommittee tackles this, “we could be developing a very long system.” In addition, these have to be metrics that can apply to the non-Federal sector.
- Dr. Horberg then proposed that the Council as a whole should discuss metrics, including stigma, and in alignment with the 12-cities project.
- Responding, Dr. Gayle suggested that the Council get a list from all the Subcommittees of what metrics are feasible for all four Subcommittee areas of interest.

### **Proceeding With Metrics**

There seemed to be general agreement with Dr. Gayle’s suggestion that the Council get a list from all the Subcommittees of what metrics their members think are feasible.

Dr. Gayle asked all the Subcommittees to consider this as a charge for their next conference calls. She urged members not to wait until their next face-to-face meetings. She will then convene the Subcommittee Co-Chairs to get the complete list to all PACHA members before the next full Council meeting.

Responding, Mr. Perez said it is clear that the capacity to measure things consistently across the country is very mixed and, even after a benchmark is set, it will take several years to develop the capacity to measure progress consistently. Therefore, he would like consideration of the cost of any continued delay in making up for 10 years of limited progress, with expanding the testing initiative one example and community viral load another.

Continuing, Mr. Perez said setting more aggressive timelines knowing that there will be slippage “is important. We should all know the percentage of those with undetected viral load in our system. That’s core. In fact, I think there are a handful of core measures we can all agree to.” The bottom line, he concluded, is that he favors increased urgency “in all our work.”

Responding, Dr. Gayle said “let’s make sure the other Subcommittees don’t pull you back by making sure they convene rapidly.”

### **Reframing the Incidence Subcommittee’s Draft Resolution**

Dr. Gayle said the Council may want to “reframe” the Incidence Subcommittee’s draft resolution toward “increasing impact in HIV prevention.” Increased funding “is part of it, but not all of it, so can this be called something other than a funding resolution?”

After brief discussion, Dr. Holtgrave suggested that the resolution be renamed an HIV prevention impact resolution, and members seemed to agree.

### **Report on the Global Subcommittee by Subcommittee Co-Chairs Kevin Frost and Dawn Averitt Bridge**

Mr. Frost noted that other members of the Subcommittee include Ernest Darkoh-Ampem, Praveen Basaviah, and Anita McBride, who could not be on the call today.

### **Global Subcommittee Draft Resolution on Continued Scale-Up of AIDS Programming Internationally**

#### **Introduction and Background**

Mr. Frost introduced the Subcommittee’s draft resolution by noting that Subcommittee members approved it while being mindful of the current fiscal environment. The title of the resolution can be changed. The substance is a revision of a draft the Subcommittee put forward at the last full Council meeting. With this draft, the Subcommittee “tried to focus on what we perceive to be the central focus, which is increasing our investment in global AIDS spending.”

Factors to consider that differentiate the global from the domestic epidemic are contained in the resolution’s “whereas” clauses, which are based in part on Subcommittee meetings since the last full Council meeting with several global AIDS entities, including but not limited to the United Nations Children’s Fund, the United Nations Development Program, and the Joint United Nations Programme on HIV and AIDS (UNAIDS).

The draft resolution as introduced is as follows:

**Presidential Advisory Council on HIV/AIDS  
Draft Motion  
Global Subcommittee**

WHEREAS, the President’s Emergency Plan for AIDS Relief (PEPFAR) has been among the world’s most successful health and development programs and is moving in important directions of country ownership and more effective prevention strategies, but requires the resources to effectively hand off to host countries while maintaining the momentum achieved thus far; and

WHEREAS, according to PEPFAR estimates, the annual cost of AIDS treatment to PEPFAR is approximately \$436 per individual—thus each investment of \$100 million has the potential to save and improve the lives of 230,000 people; and

WHEREAS, more than 9 million people in low- and middle-income countries, including nearly 1 million children, are in need of HIV/AIDS treatment but still do not have access to it; and

WHEREAS, PEPFAR-funded programs had enabled more than 450,000 babies to be born without HIV as of September 2010; and

WHEREAS, investments in global response to HIV/AIDS have far-reaching consequences that include building and strengthening health care infrastructure and advancing America's humanitarian, diplomatic, and security goals; therefore

BE IT RESOLVED that the Presidential Advisory Council on HIV/AIDS strongly recommends that the President seek an increase in the 2012 budget request on global AIDS programming and with the Secretary of State work closely with Congress to support the continued scale-up of AIDS programming globally, including the increased provision of treatment and care, as well as access to prevention services for all those at risk of HIV infection.

Concluding his introduction and background, Mr. Frost said that, without sugarcoating it, what this resolution would do is continue the scale-up of AIDS programming internationally, "not retreat from it." It is a funding resolution, but it is important to recognize that global funding for AIDS and PEPFAR have enjoyed bipartisan support from their inception. Therefore, "the changed environment in Washington doesn't necessarily bode negatively. We are seeing retreat on some global commitments, but even the United Kingdom, which has made drastic cuts elsewhere, is not retreating from global AIDS and is in fact making increased investments." In sum, "this is our best advice."

Ms. Averitt Bridge urged PACHA not to see this as an "either global or domestic" discussion because "this is not about more and better, it's about whether to continue the momentum." Inertia "is not just stopping, it is creating enormous problems." It is imperative to continue to move forward, and helping define the U.S. leadership role is an important part of that.

### **Discussion/Comments/Questions and Answers**

- It was noted that the resolution is in the present tense except for "had" in the fourth "whereas," which the Subcommittee agreed to change.
- Dr. Gayle said she agreed with Ms. Averitt Bridge that the conversation is not "either/or." Domestic and global programs use different funds. Also, "we should continue to support evidence-based programs that we know have an impact."
- Dr. Gayle noted that PACHA did weigh in on Global Fund funding but not through a resolution. She noted, too, that PEPFAR is now rolled into the Global Health Initiative (GHI) and, therefore, "we need context, the context of these different initiatives and how we see this funding in light of that."
- Dr. Gayle added that if all PACHA does is weigh in every time a budget matter arises, "we risk not being taken seriously."
- Dr. Gayle concluded that while she has "no problem with the major points" of the resolution, there is a need to "step back on how this intersects with GHI and with GHI funding—show awareness of that and context that gives a sense of where this Council sits in the context of the overall global picture."

- Responding, Mr. Frost said that the Subcommittee did not address how global AIDS funding is distributed because, as part of its work, it met with many Government Agencies, all of whom have a piece of the epidemic, such as the Department of Defense. Therefore, the resolution speaks only broadly to the overall program.
- Mr. Frost said he would support contextualizing the resolution in the way Dr. Gayle suggests, but the Subcommittee understood that the timing of this meeting and of consideration of this resolution would be fortuitous due to the expectation that the Administration will come out in a matter of weeks with its FY 2012 budget request. Therefore, there is not much opportunity to make changes to the resolution here if PACHA wants to make a statement at this critical time.
- Mr. Frost added that the Subcommittee would like to reach a consensus on the matter, if possible.
- Noting that PACHA would be voting on resolutions later in the day, Dr. Gayle said this can be discussed further then. She added that she has spent the last week on the Hill, so she now knows what the different fights will be. “Most international folks are hoping to hold steady and not have a rollback to 2008. The idea that we would get an increase is unlikely versus making the case that rolling back to 2008 levels is unacceptable. So we may want to think about that a bit.”
- Responding to Mr. Baker’s query about whether the intention of funding resolutions is to try to influence administrative decisionmaking, and to the suggestion that PACHA consider fashioning a comprehensive resolution that addresses not only moving the NHAS forward but U.S. leadership globally as well, Dr. Gayle said she was thinking along those lines, particularly as with the FY 2012 budget request, no decisions will be made before summer and the next full Council meeting.
- Dr. Holtgrave added that there is some urgency about acting more quickly in certain areas. For example, Baltimore is one of the 12 cities in the 12-cities project, but there is no way, without some help, that it is going to meet the NHAS goals, much less awareness goals. That is but one example of a reason to move for funding, “whether global or domestic.”
- Dr. Darkoh-Ampem addressed the urgency associated with the issues highlighted by the Global Subcommittee resolution because, in many cases abroad, “things are just beginning to...stop.”
- Mr. Baker said he appreciated that comment and that “the context is a compelling case.” However, his underlying frustration is with the resolution process and not making broad statements that the American public can understand. “If you read this resolution, it states none of what was just explained.” So, how does PACHA move to make broader reports/statements, including to the public, so that they can see the various elements of the epidemic that we are talking about and convey them?
- Brief discussion ensued, with more to come later in the day, about what the Council wants as a legacy and how it is going to make changes. Some of the questions that need to be asked are what kind of difference the Council is trying to make and how it can effectively make that difference.



- Returning to the resolution, Dr. Darkoh-Ampem said, “Ideally, we do need increased funding.” Keeping in mind that PEPFAR was designed as a ramp-up program predicated on operational and guidance pressure to scale up and ramp up, in the last 2 years, programs “have been flat-lined if not decreased, and we’ve been told cuts are on the way.”
- Continuing, Dr. Darkoh-Ampem said the result has been “pulling people off treatment, and no new enrollments in many countries.” In terms of the U.S. geopolitical position in the world, “this has a very big impact.” The message being sent is related to “how the United States actually deals with these countries, particularly in Africa.”
- What is likely to happen, Dr. Darkoh-Ampem continued, is “off treatment.” That is, countries are being pressed to use regimens “none of us could recommend, including in terms of side effects.” In sum, “the situation on the ground is quite dire. The message coming through is how to do more with less, and all the partners on the ground are trying to do that, but there is only so much you will get from efficiency.”
- Concluding, Dr. Darkoh-Ampem stated that “some type of message, such as hold at current levels and increase if possible, does need to get out quite urgently.” Also, “if the United States rolls back globally, others will too.”
- Responding, Dr. Gayle said “that huge message doesn’t come across.” “The knives are out for the Global Fund,” she added, “which won’t help PEPFAR.”
- Continuing, Dr. Gayle said PACHA must give guidance “in a broader sense”; for example, “what is the reason we can’t roll PEPFAR back?” In addition, PACHA needs to think about ways to get points across, such as in Op Eds.
- Dr. Gayle added that, in deference to the Global Subcommittee’s work, the resolution before the Council today is a good start, “but people are expressing concern that this doesn’t give us the language needed to put it in the context it deserves.” Therefore, the Subcommittee may want to think about stepping back.
- In terms of urgency, Dr. Gayle added, “I think this resolution as currently drafted won’t influence the current funding situation and will impact it less favorably if it doesn’t put it in context. Make the case!”
- Mr. Wilson said this discussion raises confusion for him about PACHA’s work. “Part of our role is to advise the President on what he should be doing. Part of our role is to advise on how HIV/AIDS should be dealt with in the context of the larger budget and larger issues. So, I’m curious about the timing of our work. How do we communicate and serve our role as an advisor, in addition to being an advisory body?”
- Mr. Frost said the Subcommittee did consider the points being made, and it was the group’s understanding that the best way to provide advice was through the resolution process; this is an effort to advise the President and even members of Congress.
- Regarding broader, contextual language, Mr. Frost said, much of that work “is already being done, and we didn’t see it as our charge to provide the large picture.” For example, the National Academy of Sciences conducted a study noting that U.S. Government funding has the power to save lives and enhance the U.S. position and calling for a doubling of global funds, a position the Foundation for AIDS Research has taken as well.

- Responding, Dr. Gayle said it is up to PACHA to decide whether for every issue, “this is the best way to do it or not.” The perspective that this Council “does not have the mandate nor resources to take on all the issues is correct, but referring to some of the things that have been done and pulling those in for broader context puts what we do in a light that shows we’re thinking about the overall alignment.”
- Ms. Averitt Bridge said that the conversation about how best to serve in our advisory capacity is an important one. “We all struggle daily with how we can communicate more effectively out there to the mainstream about HIV/AIDS, but I did not perceive that our role in this capacity was specifically that.” Meanwhile, “we have a responsibility to make recommendations along the way, and if the best way to do that is a resolution, fine, and if there is a better way, we would love to hear it.” We “do have to be careful not to miss opportunities to state what needs to be stated.”

### **General Discussion of Mechanisms Available to PACHA**

- Noting that this discussion has evolved and is public, Mr. Cruz said there is no question that resolutions are a mechanism. Reports are as well. PACHA members are also advocates, and, thus, “we have mechanisms for providing input that way.” We “have incredible power and opportunity, and I never put limits on my input unless it is made explicitly clear to me that I should not. The sky is the limit.”
- Ms. Perez said that “what we have to grasp and remember and allow the White House to be aware of is that we all started as advocates with fire in our bellies, we created new rules, and we kept moving forward.” She commented further that she feels restricted with respect to PACHA. She felt that she could not clearly contribute to the stigma discussion during the Incidence Subcommittee’s presentation. “We need to recapture the fire. Let’s bring it all out and go forward and say these are the rules, and we don’t like them. This is our shot.”
- Responding, Dr. Gayle said we “always need to be reminded to keep the fire in the belly.”
- Dr. Gayle added that she is not thinking of an entire white paper. For the Global Subcommittee resolution, she was thinking of a few contextual statements in the “whereas” section.
- Dr. Gayle said she is not necessarily suggesting that the Subcommittee engage in a “major long effort that would push this back further.” Rather, what she is wondering about is a way “to come out with a statement on an annual basis, a consolidated statement around the budget.” Given the four goals, “here are the things we suggest for the Secretary and President to consider in terms of using the resources to have the most impact.”
- Dr. Gayle then asked members to “put that off to the side, and we can talk about if that is a good recommendation.”
- Dr. Gayle added that PACHA could look into commissioning a white paper on, for example, AIDS during the times of a budgetary crisis, with the theme being “what we need to maintain and not move backwards.” If “we don’t talk about what needs to be done to maintain alignment with the Strategy and get the greatest impact, who is going

- Mr. Basaviah indicated his appreciation for the statement about “fire in the belly,” adding that, after many years of lack of faith in previous PACHAs, “folks are coming to our meetings.” The fact that “the public has a stronger eye on us than in the past,” and the fact that PACHA members have expectations of their service, lead to questions such as “what is our potential, what are our expectations, and how do we manage those expectations.” The answers to these questions could come from some sharing of knowledge with PACHA by others. For one thing, “it would be useful to understand how previous PACHAs have operated.”
- Responding, Dr. Gayle said these kinds of questions are “very much part of the discussions we will have later.” She added that if the Council did do a white paper, it could become “the basis for advocacy.” Whatever the Council does, it needs to be something it can work on and use in our advocacy and in consistent messaging.
- Ms. Khanna commented that “we keep finding ourselves in the same place, meeting after meeting. A lot of work is done in these Subcommittees, and then we wait to see how it fits in the context.” Therefore, “let’s take time to get on the same page in our vision.” Also, “we need to make sure that the work of the Subcommittees is streamlined because we don’t have much time.” In “the spirit of honoring the work that has already been done, let’s move through our agenda quickly, honor our presenters, and get to the discussion of legacy, because we have a mandate to monitor the Strategy and expectations.”
- Responding, Dr. Gayle agreed and said when the Council returns to discussion, “we’ll see where we’ll go with the Global Subcommittee resolution.” We “want to make sure we are being strategic in our use of resolutions.”

### **Report of the Disparities Subcommittee by Subcommittee Co-Chairs Kathie Hiers and Phill Wilson**

Mr. Wilson noted that the Subcommittee is not bringing forth a resolution. In addition, much of what the Subcommittee has been discussing has already been addressed during this meeting or will be during the Council’s later “legacy conversation.”

A few issues the Subcommittee does want to talk about include, first, what mechanisms will help us move forward with the objectives of the NHAS.

#### **Use of Medicare Performance Indicators**

Here, as relates to HIV testing, the Subcommittee wants to bring to the Council’s attention that utilization of Medicare performance indicators in hospital admissions and emergency rooms (ERs) would encourage those facilities to improve HIV testing. Reasons why this is “a good idea” include that it is simple, it does not have significant cost implications, and hospitals and ERs “take these indicators very seriously.” Therefore, the Subcommittee would like to open the concept to larger discussion by the Council.

Mr. Wilson then turned the Subcommittee report over to Subcommittee member Ejay Jack for an update on use of existing technology for moving the Strategy forward. After Mr. Jack's update, Mr. Brooks will discuss implementation of safe disclosure.

### **VA Use of Geographic Information System (GIS) Mapping**

Mr. Jack has been exploring the VA's use of GIS mapping to enhance delivery of its services. In interviews with VA officials, Mr. Jack found out that VA has been using GIS mapping for some time and has implemented a Web-based portal at all the main VA facilities around the country, where certain staff can access a mapping tool "to look at metrics similar to those we were discussing, such as drive times." That the VA has this in place "could be pertinent to community viral load, which is a goal spelled out in the disparities section of the NHAS implementation plan." For example, such technology could help the CDC and HRSA work together to calculate viral load "in addition to other metrics."

If HRSA could implement something similar to what the VA has implemented, possibly through the Ryan White Program, "this could begin to give us a baseline of data," Mr. Jack said. While there will be implementation issues, Mr. Jack said he has seen GIS technologies in use in San Francisco as well as at the VA.

Concluding, Mr. Jack said he is working with the VA to get more information, and VA officials are expected to present at the next Disparities Subcommittee meeting. The CDC and HRSA also will be invited to discuss how this can inform PACHA's work.

### **Reducing Stigma**

Mr. Brooks began by noting that PACHA is named as the lead group to work within the NHAS framework to reduce stigma. Because this charge falls under the disparities section of the NHAS, the Disparities Subcommittee has discussed how to deliver on it this year.

The Subcommittee has taken note that reducing stigma "cuts across all the NHAS goals and therefore is something we all should be talking about and working on." Now, some discussion is needed on whether the Disparities Subcommittee takes the lead on this or whether the Council should create a crosscutting working group.

Mr. Brooks concluded by mentioning that Richard Wolinsky and Greg Millett would be useful sources of information and guidance in this matter.

### **The Housing Agenda**

Subcommittee Co-Chair Kathie Hiers noted that since the last time the full Council met, the Disparities Subcommittee has "adopted the housing agenda," including modernization of HOPWA, which the NHAS implementation plan mentions as a deliverable by the end of 2011. Ms. Hiers recently met with the Secretary of HUD and top-line HUD and HOPWA staff, and now HUD, with the assistance of the Subcommittee, is looking for input on principles for reforming "the formula."

Several advocacy groups are already at work on this, including the National AIDS Housing Coalition, and there will be talking sessions around the country on the topic, the first one of which “may be AIDS Watch.”

Ms. Hiers said she may have more to report on at the next full Council meeting.

### **Establishing a Baseline**

Mr. Wilson said the last issue the Subcommittee is working on is establishment of a baseline. “If the goal is to reduce disparities, we need to know where our jumping off place is, so we are working with the department to have a baseline so that we can measure and determine whether or not we are making progress.” Safe disclosure is part of this, and housing is another, as are the VA’s use of GIS technology and the use of HIV testing as a performance indicator.

Concluding, Mr. Wilson said that what the Subcommittee would like now is discussion with PACHA as a whole on these various issues.

### **Discussion/Comments/Questions and Answers**

- Responding to queries about the possibility of gathering people’s thoughts about disclosure by holding meetings across the country and whether the Disparities Subcommittee is specifically charged with stigma issues, Mr. Wilson said that he does not know if the Subcommittee is explicitly charged, “but we have taken that on in the context of disparities.”
- Responding to the same queries, Subcommittee member Mr. Brooks said the NHAS implementation plan gives a deadline of the end of this calendar year and that he and Mr. Bates have talked about the need for feedback from around the country. At present, nothing has been decided on how to accomplish that, although videoconferencing could be an option.
- Mr. Brooks said that although the Subcommittee may not specifically be charged with helping to determine how to reduce stigma, that action does fall under the NHAS’s disparities goal, “so perhaps we are.” Nonetheless, “we didn’t want to charge down the path without consultation on whether you want us to lead.”
- Ms. Perez commented that the issue of stigma affects all the Subcommittees, so all should comment on it, in addition to following up on the idea of going to the 12 ECHPP cities.
- Ms. Khanna agreed that the issue affects all the Subcommittees and that the Incidence Subcommittee has held many discussions about how to reduce stigma and about liaison with the Disparities Subcommittee. What she would like to do is join an ongoing effort, not start a new one. Second, she agrees it is critical that people with HIV become very involved in the process of creating safe disclosure guidelines, adding that the effort to gather that input should not be limited to town hall meetings. Concluding, Ms. Khanna asked for consideration of creative ways to use community capacity to gather “safe place input” that would not require “tons of resources from us, although we also could take public comments.”

- Ms. Perez advocating covering all bases but also targeting two groups in particular, the MSM community and the youth community. In her work, she has seen that these communities are the most greatly affected by stigma and need help in obtaining testing and housing.
- Dr. Gayle concluded from discussion so far that the Disparities Subcommittee will take the lead on stigma and that the other Subcommittees should arrange to coordinate with it.
- Responding, Mr. Brooks asked to receive today, if possible, a list of individuals from other Subcommittees with whom to coordinate.
- A brief discussion between Dr. Gayle, Dr. Valdiserri, and Mr. Cruz indicated some interest in gaining access to VA data “in a meaningful way” and demonstrated Dr. Valdiserri’s great familiarity with VA’s case registry, which enables the agency to know, once a veteran is diagnosed, how quickly he/she gets into care. Dr. Valdiserri emphasized that in terms of access, it is extremely difficult for the VA to share patient information due to Health Insurance Portability and Accountability Act regulations. On occasion, HRSA will request information related to veterans, but it is shared only as long as that sharing avoids issues of confidentiality.
- Mr. Jack commented that HRSA’s CAREWare is “an analogy to using the case registry.”
- Mr. Wilson said the Disparities Subcommittee wanted to share what it is working on and “get guidance on input mechanisms in working with other Subcommittees.” So far, there are several subjects to tackle. Two are “the VA question” and performance indicators for Medicare as relates to testing. Of interest in these two areas is the concept of connecting resources that already exist “to help us move forward to accomplish the goals of the Strategy, with the assumption that there are resources out there not yet identified that can capitalize on existing resources.” Mr. Wilson said he anticipates recommendations in this area later and invited other members of PACHA to work with the Subcommittee on this as well as on safe disclosure.
- Concluding that PACHA is tasked with making a recommendation on safe disclosure, Ms. Khanna suggesting determining how to work on that with the CDC’s advisory committee. She added that PACHA has other deliverables as well, so she suggested that when gathering community input, PACHA should do it in a comprehensive way that gathers input in a number of issue areas.
- Responding, Dr. Gayle noted that so many issues are integrated that PACHA should have a list of them for review by each Subcommittee and then review “by folks who are integrators.”
- Dr. Gayle asked Mr. Bates what resources PACHA has to tackle these tasks.
- Mr. Bates and Mr. Joppy will provide information to Dr. Gayle on what resources are available to PACHA.

**Presentations on HIV Criminalization by Catherine Hanssens, Executive Director, Center for HIV Law and Policy, and Allison Nichol, Deputy Chief, Disability Rights Section, Civil Rights Division, DOJ**

Ms. Hiers introduced Ms. Hanssens to discuss the work her Center has done related to HIV criminality.

**When Sex Is a Crime and Spit a Deadly Weapon: The Need for a Federal Response to Criminal Prosecutions of People Who Test HIV-Positive, by Ms. Hanssens**

Ms. Hanssens said it would be impossible to deal seriously with safe disclosure and disparities without considering that people have been imprisoned for long periods of time for being infected with HIV, not just in the past but now.

Even though the treatment evolution began 15 years ago and, today, effective ART reduces the already very low risk of HIV transmission to nearly zero, the effect of this on punitive laws passed mostly before 1990 has been undetectable.

**Elements of HIV-Specific Criminal Laws**

- Thirty-six States and territories have some version of an HIV-specific criminal law.
- The RWCA addresses intentional transmission, but intentional transmission is not the focus of most State laws.
- Some State laws penalize the person being charged if that person knows that she or he is HIV-positive.
- Typically, actual transmission is unnecessary to be charged; rather, exposure without disclosure is enough.
- In some laws, proof of consent is a defense.
- Some laws punish nonrisk contact, such as spitting, biting, and scratching, and HIV-positive BOP inmates “get serious time for” doing these kinds of things even though no transmission occurs.

**Facts of HIV-Specific Criminal Laws**

- These kinds of statutes impose penalties from an era when HIV infection was regarded as invariably fatal, which is a problem related to stigma.
- Arrests are often coordinated with wildly sensationalized news stories.
- These kinds of statutes do not take into account the changing nature of the epidemic, and spitting and biting have produced criminal convictions and severe sentences despite the absence of HIV transmission.
- Disclosure is often the only defense to prosecution, but it is typically difficult to prove.
- Condom use is rarely a successful defense.
- Low viral load is not factored into statutes or prosecutions.
- A common factor is that the criminal defendant knew his or her status; another is severe prosecutorial ignorance of the routes by which HIV is actually transmitted; and a third is

### **Prosecutions: More Facts**

- State laws that make it a misdemeanor for those with STIs to have sexual contact with others are virtually never enforced.
- Laws treat health risk as one-directional, so the risk to the person with HIV via exposure from the partner's STIs is never a factor in prosecutions.
- HIV-specific prosecutions discriminate against people with HIV because
  - No other similar harm or disease has been the subject of specific criminal laws and prosecutions
  - HIV infection is typically treated as evidence of wrongdoing
  - The threshold for convictions is low, and the severity of punishments, high.
- The result of prosecution is exposure of status due to an “amazing lack” of a wall between public health entities, law enforcement entities, and the press on this issue.
- Severe sentences perpetuate the misconception that HIV-positive people are highly infectious, toxic, and dangerous, which is an extra burden to bear even when you are not the target of prosecution.
- Laws are selectively applied, targeting those already socially and economically marginalized (overwhelmingly, those who are prosecuted are people of color, poor, and men who meet other men on line).

Ms. Hanssens provided several examples of recent criminal prosecutions, extreme sentencing disparities, and Federal and/or Federal military prosecutions (Slides 9, 10, and 11).

### **Impact on Doctor–Patient and Public Health–Patient Relationships**

HIV-criminalization laws put pressure on doctors to disclose HIV-related medical records (they get subpoenas, not court orders, but they do not know the difference) and to share documentation of private conversations with patients.

In some States, Government health officials participate in creation of evidence that can be used against PLWHA and require forms to be signed in which HIV-positive persons acknowledge “potential liability.” Until late last year, Mississippi used post-test forms requiring acknowledgment of the “necessity to avoid causing pregnancy or becoming pregnant.”

### **Studies on HIV Criminalization Impact**

Ms. Hanssens said many studies exist on the impact of these statutes, some of which she summarized in Slides 14 and 15, including that such statutes weaken the message that sexual health is the responsibility of both partners during sex.

### **Challenges to Decriminalization**

Challenges (already in motion or to contemplate) include:



- Challenging mischaracterizations of HIV transmission risk (we really need to rethink how to talk about transmission)
- Challenging mischaracterizations of the law, such as the fact that criminal transmission laws are really failure to prove disclosure laws (there is not an epidemic of intentional transmission in this country)
- Challenging broad misunderstanding of the nature and transmissibility of HIV
- Challenging the silence of the public health community/encouraging the public health community to:
  - Publicly affirm evidence that would support advocacy for repeal or an end to HIV-based prosecutions
  - Make clear statements on real transmission risks, the inability of criminal law to protect against HIV transmission, and how laws and policies that criminalize consensual and low-risk behavior undermine HIV testing and prevention goals.

### **Inconsistency of Public Health Community**

Ms. Hanssens emphasized the public health community’s inconsistent positions in advocating for changes in HIV testing laws while remaining silent on criminal laws that act as barriers to testing, and in characterizing HIV as serious/deadly versus chronic/manageable in public policy debates.

### **The NHAS on Criminalization**

The NHAS states that “working to end the stigma and discrimination experienced by people living with HIV is a critical component of curtailing the epidemic.” Ms. Hanssens said she thinks this is a correct statement, and she hopes PACHA will take this message and make it concrete, as well as work with the CDC/HRSA HIV/AIDS Committee to develop recommendations for ways to improve the safety of voluntary HIV status disclosure by those who are HIV-positive because “if you can be prosecuted for disclosing, that impedes safe disclosure.”

Ms. Hanssens further noted that under the NHAS, by 2011, the DOJ is to examine and report on HIV-specific sentencing laws and the implications for PLWHA, and, in addition, working with HHS, is to identify a departmental point of contact and provide TA resources to States considering changes to HIV criminal statutes to align laws and policies with public health principles.

### **The Role and Responsibility of the Public Health Community**

The public health community should

- Ensure evidence-based approaches to disease control across all areas of law and public policy
- Provide sound public education and ensure understanding of all public health threats
- Treat like risks alike
- Take vigorous public stands against laws and policies that negatively target and stigmatize PLWHA.

## **Actions Needed**

Ms. Hanssens' last nine slides (Slides 24-33) outlined a long list of actions needed, beginning with recognition by the Federal Government that HIV criminalization

- Is both a symptom of and a driver of HIV disparities
- Signals a lack of commitment to real HIV prevention
- Directly undermines Federal commitments and goals for the diagnosis and prevention of HIV.

Other actions needed include the DOJ providing funding for "essential" training of criminal bench and bar related to prosecution, defense, and judgments in HIV criminalization cases; HHS/HRSA taking action to interpret the legal barrier removal language in the RWCA; and CDC/HIV/AIDS Prevention (DHAP) issuing a clear statement summarizing the problem of HIV criminalization and punishments.

Much of the work that needs to be done by CDC/DHAP, sometimes in cooperation with the DOJ, to show, overall, how HIV criminalization laws are "inconsistent not only with CDC recommendations but are in contravention of prevailing legal, public health, and human rights positions (such as those taken by UNAIDS)."

Action is needed, also, by all branches of the military (Slide 31) and the BOP (Slide 32), including regular training of all BOP staff on routes and risk of transmission, lack of transmission through contact with saliva, urine, feces, and so on.

## **Action Needed by PACHA**

Last, Ms. Hanssens provided a "very draft" resolution to be considered by PACHA, as follows:

"BE IT RESOLVED that the President's [sic] Advisory Council on HIV/AIDS recommends that the DOJ and HHS/CDC immediately launch a review regarding opportunities for creation of specific guidance and incentives to State attorneys general and State departments of health for the elimination of HIV-specific criminal laws and to develop recommendations for treatment of HIV within the civil and criminal justice systems that parallels the treatment of similar health and safety risks."

## **Untitled Presentation by Ms. Nichol**

Ms. Hiers introduced Ms. Nichol, noting that she oversees litigation and was the lead counsel in some of the Nation's first ADA cases.

Ms. Nichol complimented Ms. Hanssens, saying it was "invaluable" to have her research.

HIV criminalization is a subject Ms. Nichol has "great passion for and strong opinions about." However, she is here as much to listen as to brief.

### **First Question**

Ms. Nichol said the first question is, is there any behavior that people engage in related to HIV and transmission that should be criminalized? One has to answer that question first, for everything else proceeds from that.

Continuing, Ms. Nichol said “no” is a different answer from “yes.” And that makes arguments about whether transmission occurred more difficult to make. If one says “yes,” and that includes transmission of the virus, then it is more difficult to argue or convince a prosecutor that you ought to wait for that. It is difficult to make fine-line distinctions. So, in many ways, that is the beginning of trying to answer the first question.

This problem can be broken into three or four categories. There is “the low-hanging fruit” or the obvious cases category, where there was biting or spitting and zero transmission risk. At this level, one could ask the National Association of State Attorneys General to partner to address this situation. Because there really is no risk of transmission, education efforts could “make immediate progress.”

### **Second Question**

After the first question is answered, there is the second question. If you have a person who is a sexual predator who is engaging in activity that can transmit, but that activity in the absence of this law would otherwise be legal, what are you going to do about that guy, regardless of whether transmission occurs or not?

To make progress on this issue, Ms. Nichol said, “you need to be able to answer that second question in a way that is satisfactory to prosecutors and others in the communities where this has occurred, however rare the occurrence.”

Continuing, Ms. Nichol said that the answers to the first two questions inform everything else.

In terms of reform, Ms. Nichol said another piece of low-hanging fruit is completely adult, consensual contact, “where everyone has equal responsibility to protect themselves from the virus.” And “some education around that issue could make that understood.”

One of the problems we have, Ms. Nichol said, is that she is in the anti-discrimination business, which is very different from being in the anti-stigma business. She is in the business of changing people’s behavior, not in the business of whether they are redeemed. She is not about “changing their view.” That “is not my job.”

The point is that stigma and discrimination are very different, yet we need a common language and common approach for these kinds of things. The reason she wants to say this, Ms. Nichol continued, is that “one way to reduce stigma and make inroads is essentially by rebranding HIV/AIDS.”

## **Normalize HIV/AIDS**

HIV/AIDS “comes laden with a fierce history,” so one way to reduce the stigma of it is “to normalize it.” One way to do this is to refer to it “as a medical condition, a manageable medical condition.” If that were the common feeling in the country, “you wouldn’t have some of these laws because some of them are based on fear and the old history of the pandemic.”

## **The Problem**

The problem with normalizing HIV/AIDS is that it contrasts with messages about how this is “a major pandemic, which is the major drumbeat of public health.” Ms. Nichol acknowledged that, in some ways, “this is a conundrum.” We have been telling people “forever that you need to view this differently.”

## **Progress Predicted**

Yet, “we are going to have to come to consensus on some of the problems identified, and at this time next year, we will see some progress.” We “have lots of ways to educate and open dialogue at the State and local levels.” At the same time, “it is very hard for me to say to a State government, you stop doing what we are doing, such as in the Federal Bureau of Prisons.”

Ms. Nichol closed by saying she wants to hear members’ ideas and questions, for HIV criminalization is an issue “under very close study by the DOJ which, alone, is a form of progress about which PACHA will see and hear more.”

## **Discussion/Comments/Questions and Answers**

### **Highlights:**

- Dr. Darkoh-Ampem asked whether, if there is something wrong with the law, there is some way to address that in a centralized way and then to educate. He added that in terms of the “predator,” for him, the law would be the law. If it is legal for him to do that, his having HIV “shouldn’t make a difference, in my opinion.”
- Addressing the second question, Ms. Khanna said her organization has found much evidence that criminalization laws are a burden in terms of accessing testing and care. In human rights training, she has learned of cases where doctors disclosed to partners, adding that “we need to not allow laws to justify someone else’s stigma.” In addition, “we need to focus on other elements, such as homophobia, that have an impact on the community.” Also, she works with the most marginalized populations, and a big reason they are not in care in the first place is fear and a lack of trust, including fear about talking about “what their lives really are like.”
- Mr. Baker noted that most of advocates are repulsed by the injustices recounted by Ms. Hanssens, but Ms. Nichol’s presentation brought to the fore the messiness of the real world. Relating how he was involved in a case that involved a predator of young people, Mr. Baker said, “We have to say when there are things that are wrong, yet at the same time make strong cases against discrimination in ways that don’t reinforce stigma or injustice.”

- Mr. Baker asked how the DOJ thinks the law can be better framed and what its obligation is concerning informing the public about HIV/AIDS, particularly when, in terms of personal health, being HIV-positive is a serious matter but, at the same time, it should not be framed in a way that rouses fear that results in stigma and injustice.
- Mr. Baker also asked what kind of social marketing one engages in to tell people about the law and help prevent discrimination.
- Mr. Baker then observed that having a fulfilling sexual life as an HIV-positive person is possible and also involves responsibilities. “We’d like to get to where there is a better, more balanced approach to the law; better engagement with the public; and an understanding about everyone’s rights and responsibilities.”
- Ms. Perez said she was a little worried that she would be the only one with Mr. Baker’s point of view as relates to elimination of all HIV criminalization laws because she is very concerned about a case she knows of where a girl was infected by a boy who was angry about being positive and other cases as well, where someone was infected but lied about it. The laws need to be updated and revised. When it comes to normalization of the disease, “it hasn’t worked. A lot of people then thought it was no big deal if you take pills because then it will be fine.” So what is needed is sexual health education.
- Mr. Wilson said there is a relationship between stigma and discrimination, for if we look outside to the real world of HIV law on a host of issues, one can see factoring in individual circumstances to determine the actual nature of the crime, which allows one to be clear about the law and how to apply it. When Ms. Perez talks about the young boy, we can be clear about our position in terms of intent to infect while working on stigma so that PLWHA aren’t automatically considered to be demons and monsters.
- Mr. Wilson added that while he is not certain how to put those thoughts into operation, for PACHA’s work, there is a relationship between stigma and discrimination, and it is “important for us to understand it.”
- Mr. Perez said that while he has an appetite for normalization, a number of signals suggest that HIV/AIDS is exceptional. His department talks with SSA and seniors with disabilities, including HIV, and from a purely public health point of view, “we’re talking years of potential life loss.” Also, diabetes as a chronic condition is different from a communicable disease as a chronic condition. Yet it is true that “we are sending a lot of mixed messages in this country about how to address HIV.
- Dr. Holtgrave asked the presenters to address “like risks.”
- Responding, Ms. Hanssens recalled a case involved a young black man whose contacts were mostly white women who tested positive before he tested positive. She has talked with him and thinks he has mental challenges but is not a “monster.” When this young man first tested positive, he cooperated but then stopped because photos of him were being shown in the schools. Ms. Hansen said all the fury around him did not affect the conduct of some of the women he slept with, as several of them had had other partners. So far, this young man has served 11 years and has been turned down for probation every time. “This is what I’m talking about in terms of like treatment.”
- Ms. Hanssens said that a majority of HIV criminalization cases are bad breakups where the partner, as Dr. Darkoh-Ampem pointed out, has a way to retaliate. “We don’t need

- Equivalent harms, Ms. Hanssens added, might be, for example, herpes, which is a life-long communicable infection with many implications. Another example might be people who subject their children to secondhand smoke and the risk of associated diseases. But today, the additional factor of being HIV-positive “is resulting in decades of time spent in prison.”
- Ms. Hanssens added that she is on the same page as Ms. Nichols in terms of the need to rebrand HIV/AIDS.
- Ms. Nichols asked how one can accomplish nondiscrimination with rigorous enforcement and public outreach, then answered that “this is a place the DOJ excels.” In terms of treating like things alike, “there have to be several approaches” to HIV criminalization reform. Treating “like risks alike and reducing time for people who are in prison are areas where one could probably make some headway.”
- Responding to a query about whether someone convicted under an HIV criminalization statute that had spent considerable time in prison would have an ADA claim, Ms. Nichol said “no.”
- Concluding, Ms. Nichol said that if a community feels its young girls, for example, are being targeted by a predator and “there is no law against it, there will be.” That’s “how laws get made.” In terms of sexual gender and sexual orientation, “the way you reduce stigma is you come out, like Harvey Milk.” Also, if we stopped talking about this as a pandemic, HIV positivity would “become normalized” over time. However, if someone asked me whether they should come out at their job, “I’d say are you out of your mind? There is this tension.” In the end, “I say we must work to reduce stigma, but the risk of disclosure is real, and the harm can be profound.”
- Dr. Gayle asked members to digest all this and also review Ms. Hanssens draft resolution.

### **Public Comments**

**Carole Treston**, Executive Director, AIDS Alliance for Children, Youth & Families, said the Alliance represents many youth and young adult HIV service providers who are part of the Ryan White Part D networks of comprehensive HIV services. In addition, the Alliance serves youth and young people living with HIV, including LGBT youth and heterosexual youth, particularly young women of childbearing age from communities of color across the United States. On their behalf, the Alliance asks that PACHA reserve time during its next meeting to examine the special issues facing youth living with or at risk for HIV. Since 25 percent of new infections are among youth and young people, to effectively meet the goal of reducing incidence, effective prevention programs for young people are critical in any implementation plan. In addition, the unique challenges in access to care should be addressed, including the vulnerabilities of LGBT youth and poor young women, and the stigma and marginalization factors that then contribute to health disparities must be understood by all Agencies involved.

The Alliance supports the 12-cities concept as a centerpiece (but not the sole focus) of implementing the NHAS. Demonstrating success in these model cities in meaningful ways that can then be repeated makes strategic sense as a first step that will require funding, coordination at the local and national levels, and effective oversight and authority from HHS leadership and the Administration.

Further, as relates to funding, while the Alliance applauds the requirement of an assessment of the portfolio of resources and plans for appropriate allocation of resources in the 12 cities and appreciates that this is not an easy task, there must be ongoing funding for coordination and monitoring. Therefore, the Alliance encourages PACHA to advocate for adequate funding for the continuation and expansion of the 12-cities plan.

Further, as relates to coordination, cross-HHS coordination is critical. The Alliance applauds Dr. Valdiserri's description of this yesterday. However, coordination at the local level will be an operational challenge that requires both carrots and sticks. Title X, Population Research and Voluntary Family Planning Programs, must be included in this coordination at the local level as the entry point into health care systems and one of the most likely spots for HIV prevention, testing, and linkage to care for poor young women of color in many communities. PACHA must ensure that entities not currently viewed by all as part of the HIV portfolio (such as Title X) are included in this coordination.

Further, as relates to oversight and authority, implementing the full, coordinated, comprehensive evidence- and outcomes-based approach that is the vision of the 12-cities model will be challenging. Although it is hearsay until plans are reviewed, the Alliance has heard that some jurisdictions are viewing the ECHPP planning process as primarily a CDC prevention initiative. The concept of ECHPP as step 1 in a larger initiative needs to be better articulated, and the appropriate mechanism for oversight and authority must be determined. In addition, the Alliance is concerned that no system is in place that monitors and corrects directive and guidance from various HHS Agencies that may inadvertently contradict the intent of the NHAS and the Affordable Care Act.

The Alliance applauds the efforts described yesterday by Dr. Valdiserri regarding coordination and formation of the Steering Committee for the 12-cities initiative. The Alliance asks PACHA to examine and make recommendations to the Administration regarding the oversight and authority needed to ensure optimal implementation of the NHAS.

Last, speaking as a nurse and clinician, Ms. Treston asked the Disparities Subcommittee to consider recommendations for improving the unintentional ways that clinicians promote stigma. "We need a paradigm shift in which all clinics have accurate information and are given permission to give accurate information to their patients, because there is a big difference between CDC guidelines and what risk counselors actually tell patients."

**Ian Royer**, who indicated he has some association with UNAIDS, asked PACHA to consider creating a Youth Subcommittee "because there is no outlet or forum for youth to be involved in

decisionmaking at this level.” In addition, youth could provide considerable assistance to PACHA in terms of the use of technology and social media. Mr. Royer suggested that PACHA could reach youth and gather information about youth this way, as well. Mr. Royer made a comment about how many “other non-abstinence programs” would have a “wider impact” in terms of sex education, then concluded by reiterating his request that this PACHA “pioneer a Youth Subcommittee.”

Responding, Dr. Gayle asked Mr. Royer to leave his name so that PACHA could call on him.

**Victor Barnes** of AIDS United indicated that public/private partnerships are important and urged PACHA to use its authority to re-engage the Office of HIV/AIDS Policy in particular in moving forward with AIDS United.

**Sabrina Heard** of The Women’s Collective asked PACHA to look at innovative prevention strategies as part of its investigation “into what it is you do.” Ms. Heard said she has been involved in dramatizations of the lives of women who are HIV-positive to help decrease stigma.

**Vincent Sather** from Gulfport High School in Gulfport, Mississippi, said he is a member of an organization called “SAINTS” that is against infection and advocates for young people to receive the information they need about STIs and AIDS. Every day in Mississippi and across the world, people are dying of infection, and the main cause is lack of education. Mississippi as a State dictates “that only abstinence can be taught, and many teens are not taught even how to properly use a condom.” AIDS cases are climbing “at an alarming rate” in Mississippi, as is teen pregnancy. It has been shown that STIs and teen pregnancy “are drastically lower where better education is available ”

Concluding his remarks, Mr. Sather said he agrees with “Ms. Rosie” that PACHA needs an advisory group of youth to know what is really going on. He then personally volunteered to be a member of such a group.

**Daria Boccher-Lattimore**, with the New York/New Jersey Alliance for HIV Education and Workforce Development said the Alliance endorses the NHAS. The Alliance realizes that the vision of the NHAS will require health care workers to have access to education on how to work with the neediest populations.

Ms. Boccher-Lattimore explained that AIDS Education and Training Centers (AETCs) are components of the Ryan White program. Building capacity through education is what they do. Regional AETCs are based in leading academic centers across the country and in the territories. In a recent 8-month period, more than 40,000 health care workers were trained on testing initiatives in a collaboration that involved AETCs. In addition, AETCs are helping reduce disparities with support from the Minority AIDS Initiative in a “partnership model.”



## **Administrative Note**

Mr. Bates asked all those providing public comments today to make their statements available to him or to Mr. Joppy for the record.

**Tina Salazar** from Mississippi spoke on behalf of the SAINTS organization, of which she is a member. Ms. Salazar said teens “are in desperate need of real life knowledge.” She would like to work with PACHA as a colleague. SAINTS is taking the “extra step” of being willing to provide one of the first young people to sit on PACHA. “We have to start with youth. We need to address AIDS, teen pregnancy, and STIs.”

Responding, Dr. Gayle applauded the Mississippi youth contingent for being “pretty strong.”

**Angela Green**, from a women’s’ recovery and counseling center, said that as supportive as she is of the testing initiative, “testing alone will not end this disease.” Other services and deliverables “need to be kept in place.” Stigma against African Americans, youth, and the homeless “is on the rise.”

Ms. Green said she was “greatly disturbed” by the BOP statement on the first day of the meeting “about condom distribution” and sex in prison primarily being a matter of “manipulation.” Even “if it is rape, it is unacceptable to say there is no consensual sex going on in prison,” she added. Therefore, services available on the outside must be made available on the “inside.”

Ms. Green said young people transitioning out of foster care system are at risk for HIV/AIDS, STIs, and homelessness.

Ms. Green urged PACHA not to allow Congress to provide \$50 million for abstinence-only education because “we need comprehensive sex education in our schools.” If such education were provided, “we would not have to worry about young girls being manipulated.” Boys also need tools with which to make informed decisions about their sex lives.

**Suzanne Miller**, Health Policy Manager, National Coalition of STD Directors, said her organization represents STD program directors in health departments across the Nation. At the last PACHA meeting, she made comments regarding the CDC’s Division of Adolescent and School Health (DASH).

For more than 20 years, DASH has worked with schools across the Nation to build the necessary infrastructure to provide a coordinated approach to school health education. Two-thirds of DASH’s annual appropriation of \$40 million goes toward funding State and local education Agencies to closely collaborate with health departments to deliver effective STD and HIV prevention programs for youth.

When the Senate Appropriations Committee passed its FY 2011 Labor HHS appropriations bill this past July, DASH’s funding was effectively eliminated. Ms. Miller’s organization worked with

many advocates to preserve DASH's current funding structure. This hard work paid off, and "we were successful in maintaining DASH's funding in the Omnibus Appropriations package."

Although the Omnibus appropriations package was ultimately not enacted, and DASH remains unchanged under the current Continuing Resolution, this issue "must remain on our radar." As "we enter a new Congress with inevitable spending freezes and cuts on the horizon, we must be prepared for increased scrutiny of all HIV prevention programs, including DASH."

To this end, the Coalition urges PACHA to pass a resolution affirming DASH as a fundamental part of our Nation's efforts to combat HIV/AIDS, particularly among youth.

### **End of Public Comments**

Dr. Gayle thanked speakers for their comments and closed the Public Comments session.

## **LUNCH**

## **AFTERNOON SESSION**

### **General Discussion**

#### **Public Comments Reflection**

Dr. Gayle said that clearly the issue of youth stood out in Public Comments as well as in the earlier discussion, and there seem to be three or four young people eager to become part of PACHA's investigations of comprehensive sex education, the importance of innovative prevention strategies, and making sure "we have new ways of reaching new opportunities and strong partners, like the AETCs."

### **Resolutions**

Dr. Gayle asked to return to the two resolutions still before the Council.

#### **Incidence Subcommittee Draft Resolution on Prevention**

Dr. Holtgrave provided copies of a re-draft of the Incidence Subcommittee's original draft resolution on prevention. He noted that the title has been changed to "U.S. HIV Prevention Impact Resolution." A fourth "whereas" was added, and parts of the "be it resolved" sections altered. The re-draft in its entirety reads as follows:

**Presidential Advisory Council on HIV/AIDS  
Incidence Subcommittee  
Draft Motion**

WHEREAS, the HIV prevention funding investment is far too small in the U.S. to truly change the course of the epidemic according to the 2008 sworn testimony of the Director of the Centers for Disease Control and Prevention and other witnesses, as well as according to peer-reviewed published articles;

WHEREAS, the current level of investment continues to shrink when adjusted for inflation (dropping over 20 percent since FY 2002), and the purchasing power of the HIV prevention investment in the U.S. is now approximately only what it was in 1993;

WHEREAS, the HIV prevention funding in the U.S. only accounts for about 3 percent of the total U.S. investment in HIV/AIDS;

WHEREAS, investment in HIV prevention can actually save public-sector funds in HIV medical costs averted;

WHEREAS, all HIV prevention funding (be it current or future) must be subjected to the highest standards of transparency, effectiveness, and efficiency so as to be fully accountable, maximally impact the epidemic in the U.S., and assure attainment of the goals of the President's National HIV/AIDS Strategy;

BE IT RESOLVED that PACHA urges the Administration and Congress to achieve the following:

- (a) As rapidly as possible, fully fund the HIV prevention efforts in the U.S. at levels previously described as necessary in Congressional testimony and peer-reviewed publications so as to assure attainment of the goals of the National HIV/AIDS Strategy;
- (b) By June 2011, develop a system of annual reporting whereby all HIV prevention funding in the Federal Government is described in a publicly available document containing all funding amounts, uses, and measured or estimated outcomes; and
- (c) Work closely with PACHA by July 2011 to develop and implement a set of recommendations for any necessary redirection of current Federal HIV prevention funding and other HIV funding from its existing use to more impactful utilization.

#### **Vote**

All members in favor in the room raised their hands to so signify. All members on the phone were asked to state "aye" or "nay." Mr. Wilson, who was on the phone, asked for the redrafted resolution to be read.

After counting the votes, Dr. Gayle and Mr. Bates stated that the "ayes" have it.

#### **Global Subcommittee Draft Resolution on Continued Scale-Up of AIDS Programming Internationally**

Dr. Gayle asked for discussion of the Global Subcommittee's draft resolution presented earlier today.

#### **Discussion/Comments/Questions and Answers**

- Dr. Gayle asked how often PACHA should put forward funding resolutions. She asked if there is a way to cluster such resolutions.

- Mr. Frost said the Global Subcommittee felt a certain amount of urgency in putting forward this resolution given the current budget cycle. He added that this is the second full Council meeting where the Subcommittee has proposed a resolution to PACHA and been sent back to the drawing board. Mr. Frost expressed his own disappointment at an inability to arrive at a conclusion on this resolution, this time, as it feels “we’re going around and around.”
- Mr. Frost said the Subcommittee worked diligently to come up with something, only to be told it has to be done another way. He said he is feeling frustration “around something that shouldn’t be this complicated.”
- Dr. Gayle said that this time a slightly different issue is involved in sending this resolution back to the Subcommittee. She added that “we can do what we did before, which is express a strong sense from PACHA around the need to hold to the commitment of our bilateral programs.” That carried weight before, she added. As for the resolution, “it seems that people are just not prepared to sign off on everything in it...”
- Dr. Gayle then asked the Global Subcommittee to take the resolution and find a way to come back to this issue, adding that “it is a matter of waiting and of doing a bit more work.”
- Dr. Gayle asked the full Council to move into Executive Session. Members of the public exited the room.

## **PACHA Executive Session**

Dr. Gayle requested a focused discussion. Some subjects for discussion include youth and public/private partnerships.

### **What Is Our Legacy?**

Dr. Gayle noted that a topic in need of discussion is “what is our legacy?” She asked how PACHA can have the greatest impact if it is nothing more than a body that authors resolutions and passes them. She concluded that this “is not the only impact we want to have.” If that is the case, “how can we constructively help our Administration and the Congress do the right thing while maintaining our passion and activism? What are the processes we should use?”

Dr. Gayle said Mr. Frost made a good point about how PACHA is not working as seamlessly and on as timely a basis as it could. So she suggested that PACHA review its mission and have it “be part of our materials on a regular basis.”

### **PACHA Mission Statement**

The Presidential Advisory Council on HIV/AIDS (PACHA) provides advice, information, and recommendations to the Secretary regarding programs and policies intended to promote effective prevention of HIV disease and to advance research on HIV disease and AIDS. The role of the Council is solely advisory. The Secretary provides the President with copies of all written reports provided to the Secretary by the Advisory Council.

ONAP Director Jeffrey Crowley and ONAP Senior Program Manager James Albino joined PACHA members at the table.

### **Survey of Members**

Mr. Crowley noted that he and Mr. Albino began a survey of PACHA members in September 2010, but that they have received responses from only about one-third of the members so far. He urged members to send in their responses and let him know if the questions asked “aren’t the right ones.”

What Mr. Crowley, Mr. Bates, and Dr. Valdiserri are primarily interested in is how members of the Council feel the Council is working. Mr. Crowley said it feels to him as if things are beginning to gel and that PACHA is forming a group. But he wonders what members’ expectations are.

### **Helpful Work**

Mr. Crowley said that ways in which the work PACHA is doing is helpful includes serving as an external monitor of NHAS implementation. Here, Mr. Crowley explained that the Administration is planning to do its own monitoring, so “you have a different role, such as

identifying specific things that we don't neglect completely but that need more attention." Mr. Crowley said that he is sure there are many ways PACHA can add value here, especially since "we're all trying go to the same place."

Also, Mr. Crowley said he read some of the resolutions and had some feedback or thoughts about that mechanism. He asked others for their thoughts about the value of resolutions. One of his thoughts is that "you need to think how you are trying to influence people" In his job, he has to think about "how I might be marginalized, so I have to position myself to be taken seriously, and I urge you to do the same." Mr. Crowley noted that, sometimes, PACHA "may want to pressure us, but for me, personally, it would be more effective for me to hear from you personally, before a resolution." However, the ADAP resolution "was helpful" because when he or Dr. Koh are not particularly focused on something, "people need to challenge us." But "if we're moving in a way that is consistent with your thinking, I feel you have to give us some space."

Responding, Dr. Gayle said it would be useful to know "if there's a good way to signal that." Some "of our job," she added, "is to make you a little nervous, too. It's not always that we should be in agreement. There are things in which you have a sense of how you are going to do battle, and we should keep that bridge open. Chris and I can be the conduits. Your willingness to give us feedback would be useful. "

Mr. Crowley reiterated that the ADAP resolution was useful.

### **Further Discussion**

Mr. Bates said he agrees with Mr. Crowley about the energy in PACHA. He has felt it sitting in on Subcommittee meetings. However, there are two challenges. One involves what vehicles are available to PACHA "to move the conversation." Resolutions are one of those vehicles, but they are not intended just to go to the Secretary and then to Mr. Crowley. Rather, resolutions should inspire PACHA members as individuals "to write editorials, Op Eds, and so on." When writing like this, "you don't have to refer to yourself as being on PACHA because you have credentials of your own."

The other challenge, Mr. Bates continued, is that no PACHA has been a rubber stamp of the Administration, "but it is not supposed to be a battle, either." Sometimes a tug of war "provokes fresh thinking." We "won't be able to get away from the public expectation that when you talk budget, you are expected to raise the flag and say there is not enough money. I heard Dr. Gayle say be careful not to look foolish, but some of the public wants you to push the envelope." Again, here, "you yourselves can push the envelope." Your "importance lies not just in what you do here but in your own individual roles."

Dr. Valdiserri said he sees PACHA's basic job as "one of influence, and it's a challenge to try to determine how you can influence different sectors and segments of society, not just the Federal Government, so that we can achieve the goals of the Strategy."

## **Liaison with CDC Advisory Committee?**

Dr. Valdiserri suggested that PACHA consider having a member of the CDC advisory committee liaison with/attend PACHA meetings because “developing a line of communication with a group that gives advice directly to CDC’s leadership might be useful.”

In addition, earlier in Public Comments, Mr. Barnes from AIDS United raised the possibility of public and private partnerships and “how you can help foster relationships between the Government and the private sector.” Further on this topic, Dr. Valdiserri noted that since the latest news about the PrEP trials, HHS has been discussing how to move those good results forward, including through demonstration projects. A question has been raised about whether the private sector can be brought in to support that.

## **Discussion/Comments/Questions and Answers**

### **Highlights:**

- Mr. Baker said he has questions. He briefly outlined the evolution of the ways advice has been given over time by PACHA or its equivalent. Against this backdrop, including the time when there was a National Commission on AIDS that had responsibility for speaking to the American people, he is wondering who PACHA’s primary audience is, how PACHA should seek staffing, what funds are at PACHA’s disposal for communicating to its audience, how PACHA is staffed in terms of communications, and who does the White House see that communication going out to. What is the current vision and expectation? How “should we see ourselves by comparison to past issues?”
- Responding, Dr. Gayle thanked Mr. Baker for the history, which strikes her in part as having been reactive, then she suggested that PACHA think about what it has to offer in today’s world and today’s epidemic. For example, the discussion about HIV criminalization clearly contains issues to be tackled, so “how can we develop a consensus around these tough issues that no one else wants to tackle?” Or how about abstinence education? “We should be figuring out how to get ahead of things and help with the more nuanced issues that need to be put on the table.”
- Dr. Gayle then asked Mr. Bates to address PACHA resources.
- Mr. Crowley noted that as pertains to criminalization laws, for example, “you can do some things I can’t.” He added that having a communications role is a good idea, “but I doubt you will get more staff, so that will add to the challenge.”
- Ms. Perez asked about gathering information from focus groups, especially with youth, to which Mr. Crowley responded that from where he sits, there are no constraints, “but there are budgetary constraints.”
- Asked about their aspirations concerning where PACHA can make an impact, members responded.
  - Ms. Hiers said PACHA’s most important role is to serve as a monitor for the NHAS. To that end, she has questions, including the following: Will the implementation plans be made public? Will Agencies that did not present their plans at this meeting come up with plans? Does PACHA have clarity on how it will monitor?

- Mr. Perez said that if PACHA is to influence and advise, it needs a concrete mechanism, yet members are “getting a mixed message on that.” We “need to know what tools are in the box and when we use which.”
- Dr. Holtgrave said PACHA should aim to ensure that the Strategy becomes a reality. “We can cook up metrics, resources, and redirections that may be needed over time.” The “collective failure will be failure. If we see something isn’t on track, that will be worse failure.”
- Mr. Basaviah asked what actions PACHA is actually going to take and with what tools, as he is still unclear on when to use what. He added that he agrees there are other councils “we should learn from.”
- Mr. Basaviah added that PACHA has missed opportunities over the past year. Some people now “look for PACHA’s presence in the coming year.” So, “if someone is asking for a PACHA member to attend this or that, let’s see if we can do that.” By the time the terms are up, he does not want to think “PACHA hasn’t lived up to its potential.”
- Mr. Michels said that the usual intent behind formation of an advisory council is to get specific advice on specific issues. In the case of this PACHA, “we were formed into Subcommittees to provide information around the Strategy’s specific topics.” If what PACHA is supposed to be doing is different from that, “what are we getting together for every 2 weeks?”
- Mr. Michels added that he has little interest in monitoring the success of the Strategy or its implementation because he sees that as the role of Government Agencies. In fact, Mr. Crowley says he is measuring all those things, “so I don’t see that as our primary role at all ”
- Ms. Perez said she was about to say the same thing. “We need to be very specific about our advice and requests and how we provide those.”
- Mr. Baker agreed. “We need to ensure that the sense of the Strategy is not lost in the planning and policy process. It should reflect the concerns we have heard. Part of our mission is to keep that voice at this table.”
- Ms. Khanna said she sees PACHA’s role as one of “looking at open doors.” We are “in a key moment of possibility, and I want to see us use that in a few issues we can move the needle on—funding, accountability, metrics. I’m not interested in duplicating work that is already being done. Many of the issues mentioned today, such as sexual health and abstinence education, are key policy issues I hope we have an impact on.”
- Continuing, Ms. Khanna advocated that PACHA “reframe and talk about how we see the epidemic today, take a few things on, and use whatever leverage we have to bring unusual and new stakeholders into the process.” The Strategy is trying to build multisectoral involvement, so “how are we engaging with other national advisory bodies on different issues pertaining to community health and different civil rights issues? How are we engaging with obvious stakeholders, like the faith community?”
- Responding, Mr. Brooks agreed with Ms. Khanna. He added there is a role for PACHA in leading and advising on “some really different conversations.” While there may be expectations for PACHA to communicate on budget and funding, “our role may be



- Dr. Darkoh-Ampem said that while he thinks PACHA’s mission is well spelled out, “it doesn’t say monitoring.” He agrees with Mr. Michels’ comments. Giving advice, providing information, and making recommendations is the heart of the mission. So how does PACHA make those most effective? So far, PACHA has discussed a few mechanisms, including white papers. He would like to suggest meetings with key decisionmakers, such as members of the congressional Foreign Relations and Foreign Affairs committees.
- Dr. Darkoh-Ampem added that he still does not know what the impact of each of the mechanisms is, such as where resolutions go and whether they are actually read. Therefore, “we need to figure out what the impactful mechanisms are. I also think we need to mix up our repertoire beyond the resolution process and be allowed to do that. If not, we need to push for it.” In a recent discussion with Administration officials, he was advised that PACHA has to “not be too tentative.”
- Dr. Horberg said that giving advice is a key role for PACHA, and monitoring can have a positive connotation, but today, “we’ve been giving it a negative connotation.” PACHA can point out the successes of the NHAS and where it is moving the needle. PACHA can highlight and advise on where its expertise lies. Some of this is in metrics, some in stigmatized populations, and some in criminalization. “We can have multiple roles. We just need to figure out the mechanism.”
- Dr. Horberg added that he now wants to challenge Dr. Gayle and Mr. Bates about structuring the Subcommittees along the lines of the NHAS, for he thinks this may not be a good idea. He added that more work is needed on formatting the meetings.
- Mr. Greenwald said that in terms of access, he feels the Affordable Care Act piece is not yet on PACHA’s table, even though it is one of the most important things PACHA can deal with in terms of the bridge between now and then and pushing the message out to the community.
- Mr. Cruz said PACHA has a role to influence current events. Therefore, it has multiple roles, and it needs to prioritize those in order to address them effectively. There are things that are whispered in the community but not often discussed, so PACHA can bring those things to the fore, too.
- PACHA members have, Mr. Cruz continued, an opportunity to bring the expertise of many colleagues to the table and have done a great job of that so far. PACHA “could be facilitator of the voice of the community, coming all the way to Washington. We have opportunities to give better structure to the Strategy.”
- Mr. Frost said he does not have much to add. Advice does seem central to why PACHA is an organization and why it was organized into these particular Subcommittees. But his expectations have largely not been met. He has been disappointed so far.
- Dr. Garcia said she hopes PACHA will not shy away from shining the light on missed opportunities.

- Mr. Wilson said that this PACHA has to define its role based “on the time.” PACHA is an advisory body, and whether that advice is sought or even wanted, “now we’re in this role and have an obligation to advise and particularly on the issue of the Strategy.”
- Mr. Wilson added he is unsure about the terms of monitoring, but, nonetheless, PACHA needs to advise the Administration and the Agencies for the NHAS to be as effective as possible.
- Mr. Basaviah asked if PACHA can invite the public to draft resolutions that PACHA would then edit.
- Responding, Mr. Bates said he could see no reason why not.
- Dr. Gayle suggested “that we don’t go that route, as that is others defining us and raises whether we are put in the awkward position of responding to things that we may not think are the highest priorities.” She added that “a key part of organizing is to always stay on message, figure out what that is, and stay on message.”

## **Some Conclusions**

### **Liaison with CDC Advisory Committee**

Dr. Gayle said that arranging for a CDC advisory committee liaison to PACHA is a good idea. She suggested that PACHA arrange for the same. “Let’s work on that and get back to people with suggestions on that.”

### **The NHAS**

Dr. Gayle noted many comments on whether PACHA’s role is to monitor and/or oversee implementation of the NHAS. “Many have said we can micromanage the Agencies. What we have done thus far is to have input into the process, and it has been useful. However, this may be a chance for PACHA to step back and get updates as part of our regular meeting through Dr. Valdiserri and others, as the Agencies need time to do some work.”

### **New Work?**

Dr. Gayle suggested that PACHA add a new role or new work, and look at key policy areas. She asked for an e-mail that reflects “your top three or five issues, and two or three that we really want to hammer on, whether it is youth or health care reform or...” Members will receive an invitation for their input. Members could add the 10 worst practices or policy that made sense 20 years ago, but not today—“those kinds of things.”

### **New Ways to Work?**

Dr. Gayle added that perhaps meetings should be arranged around working groups and that not so much time be spent on Subcommittees. Good topics include youth, public/private partnerships, health reform, and where we are on the 2012 AIDS Conference, in which PACHA should be involved.

## **PACHA Budget and Appointment Terms**

Responding to Dr. Gayle's inquiry about PACHA's budget, Mr. Bates said that, in the past, PACHA has had "a very austere budget" and only a few times "more than two staff." There have only been a few times that activities occurred outside the full Council.

So far, staff has not finalized PACHA's budget for this year. PACHA's budget does not come from one place. For several years, the NIH supported the budget to the tune of roughly \$500,000 each year, but the kinds of things that have been discussed at this meeting suggest the need for additional resources.

This will need to be thought through with the Chair, Co-Chairs, and the Agencies who will be contributing to the budget. Mr. Bates will call on Mr. Crowley to help. "We are not going to have 1 million dollars," Mr. Bates said, but if PACHA can add a few hundred thousand dollars to its budget to have a meeting out of town and/or solid input through a conference call, that would be good.

Mr. Bates said that by PACHA's next full meeting, the budget will be resolved, and "we can talk about what's next then." He added that some members are given 2-year appointments and others, 3-year appointments. Some members have expressed concern about that, so that too will be discussed.

## **Member Replacement Needed**

Dr. Gayle noted that PACHA member Jim Kim has stepped off the Council, so there is need of a replacement.

Ms. Hiers advocated for a black HIV-positive woman to replace Dr. Kim. She also advocated for "another Southerner."

## **Attending Other Meetings**

Mr. Bates noted there are opportunities for PACHA members to attend other meetings.

Outstanding questions are who will be the liaison with the CDC advisory committee and also who will be the liaison with the NIH OAR advisory body, in terms of research.

## **Winding Down**

Noting that some members must leave soon to catch flights, Dr. Gayle began to wind down the meeting, saying that work would get done through e-mail. She added that it would be well to get information from members on their availability to attend meetings and on their particular interests. "Then we can make some decisions."

Ms. Hiers advocated for more time for the Executive Session and a more focused agenda. Dr. Gayle agreed, adding that "we also have to have discipline ourselves."

## **Survey of Members**

Mr. Brooks said it is important for Mr. Crowley and Mr. Albino to resend the survey of members and ask people to say whether or not they have received it “because a one-third response is unacceptable.”

Further:

- It was noted there are indications that some members never received the survey.
- Responding, Mr. Bates said staff will be aggressive about this and follow up an e-mail with a phone call, for the survey helps staff do it work.

## **PACHA Mechanisms**

Dr. Darkoh-Ampem asked that four or five mechanisms through which PACHA communicates be defined, particularly in terms of their relative impact.

Further:

- Responding, Mr. Bates asked if staff could propose and members react.
- Responding, Dr. Gayle suggested examples from the past.
- Mr. Perez said PACHA needs a follow-up loop about what happens, such as what happened with regard to PACHA’s recommendation on the Global Fund.
- Dr. Gayle said she informed PACHA members on the outcome of their appeal regarding the Global Fund. Mr. Perez said the communiqué was specific as regards the “wellness fund and preserving it.” Dr. Gayle said she is not sure the communiqué was clear.
- Mr. Crowley said that resolutions seem to say that “something is wrong.” The “mechanisms might not mean as much as what is positive,” he added.

## **Responding to Breaking News/Resolutions**

Mr. Baker noted that an issue on the general discussion agenda from Day 1 was “responding to breaking news.” He asked whether some thought has been given to whether PACHA members will get a real-time briefing on what will be asked of them in responding to breaking news.

Responding, Dr. Gayle said she was sorry that time does not permit exploring this fully today. She encouraged members to think about what breaking news they might want to tackle.

## **Future Full Council Agendas/Executive Sessions**

Ms. Khanna asked if members could get a draft of full Council agendas in the future so that they could weigh in. Dr. Gayle responded in the affirmative, adding that even a month beforehand would be good. Responding, Mr. Bates noted that sometimes the agenda changes just a day before a meeting.

Ms. Khanna then asked if PACHA could have an Executive Session on both meeting days. Dr. Gayle responded that was supposed to happen.

## **Adjournment**

After noting that PACHA has accomplished a great deal so far, that the group has started to coalesce more, and that although the group is grappling with exactly what its place in the world is, “we are narrowing it down and looking at some of the mechanisms,” Dr. Gayle adjourned the meeting at 3:23 p.m. with a last appeal for further input from members as “welcomed and helpful.”