

**Presidential Advisory Council on HIV/AIDS (PACHA)**  
**50th Meeting**  
**Hubert H. Humphrey Building**  
**U.S. Department of Health and Human Services (HHS)**  
**Washington, DC**  
**February 7–8, 2013**

**Council Members—Present**

Nancy Mahon, J.D., PACHA Chair  
A. Cornelius Baker  
Praveen Basaviah (by telephone)  
Dawn Averitt Bridge  
Douglas Brooks, M.S.W. (by telephone on day 2)  
Humberto Cruz, M.S. (by telephone on day 2)  
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. (by telephone on day 2)  
David Holtgrave, Ph.D.  
Michael Horberg, M.D., M.A.S.  
Ejay L. Jack, M.S.W., M.P.A.  
Jack C. Jackson, Jr., J.D.  
Naina Khanna  
Douglas A. Michels, M.B.A. (absent on day 1; by telephone on day 2)  
Sandra Torres Rivera  
Rev. Vanessa D. Sharp, M.Div., M.A.C.M., M.A.T.M.

**Council Members—Absent**

Rev. Dr. Calvin Otis Butts III, D.Min., M.Div.  
Kathie M. Hiers  
Anita McBride  
Mario Perez, M.P.H.  
Rosie Perez  
Phill Wilson

**Staff**

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

## **Federal Liaisons**

Antigone Dempsey, Centers for Disease Control and Prevention (CDC)/Health Resources and Services Administration (HRSA) Advisory Committee for HIV and STD Prevention and Treatment (CHAC) Co-Chair, CHAC Liaison to PACHA

Adelle Simmons, Office of the Assistant Secretary for Planning and Evaluation, HHS

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

## **Presenters**

Keisha Allen, Consumer, Chicago House and Social Service Agency

Kellan Baker, M.P.H., M.P.A., Policy Analyst, Center for American Progress

Walter Bockting, Ph.D., Research Scientist, Co-Director, Initiative for LGBT Health, Division of Gender, Sexuality, and Health, New York State Psychiatric Institute/Columbia Psychiatry with the Columbia School of Nursing

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

Anthony S. Fauci, M.D., Director, National Institute of Allergy and Infectious Diseases (NIAID), National Institutes of Health (NIH)

RADM Deborah Parham Hopson, Ph.D., R.N., FAAN, Assistant Surgeon General, Associate Administrator, HIV/AIDS Bureau (HAB), HRSA

JoAnne Keatley, M.S.W., Director, Center of Excellence for Transgender Health, University of California, San Francisco

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

Eva Margolies, M.P.A., Associate Director for Planning and Policy Coordination, National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP), CDC

Harlan Pruden, First Nations Cree

David W. Purcell, J.D., Ph.D., Deputy Director of Behavioral and Social Science, NCHHSTP, CDC

Eric Sawyer, Joint United Nations Programme on HIV/AIDS (UNAIDS)

Rev. Stan J. Sloan, Chief Executive Officer, Chicago House and Social Service Agency

Laurel Sprague, Global Network of People Living with HIV, North America (GNP+NA)

Karina Walters, Ph.D., University of Washington, Choctaw Nation of Oklahoma

## DAY 1

### Welcome

PACHA Chair Nancy Mahon called the meeting to order at 9:35 a.m. and welcomed the participants.

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

Dr. Koh welcomed PACHA members and thanked them for their hard work. He praised the tremendous leadership team of PACHA, specifically Ms. Mahon, PACHA Executive Director Kaye Hayes, and Deputy Assistant Secretary for Health, Infectious Diseases Ronald O. Valdiserri.

Dr. Koh reviewed accomplishments under President Obama's first term, including developing the first National HIV/AIDS Strategy (NHAS), hosting the first International AIDS Conference in the United States in 20 years, approving new HIV drugs, making scientific advancements related to treatment as prevention (TasP), streamlining HIV indicators for grantee reporting, addressing minority health disparities, and improving the AIDS Drug Assistance Program (ADAP). Many of these achievements came to fruition thanks to the work and commitment of PACHA members, said Dr. Koh.

Dr. Koh went on to say that the second term promises to be exciting and dynamic. Implementation of the Affordable Care Act (ACA), the Ryan White program, and NHAS are all in flux, he noted, and PACHA can help shape the broad goals and direction of those programs as related to HIV in the United States.

In light of National Black HIV/AIDS Awareness Day, Dr. Koh noted that the CDC has two new campaigns promoting HIV testing that target African American audiences. In another effort to address target populations, the White House hosts a Working Group on the Intersection of HIV/AIDS, Violence Against Women and Girls, and Gender-Related Health Disparities, Dr. Koh stated.

Dr. Koh said 2013 will be a big year for health care, with open enrollment in October and new coverage under ACA beginning in January 2014. He invited participants to visit the rebuilt Web site [HealthCare.gov](http://HealthCare.gov) and sign up for text-message updates about ACA implementation. Dr. Koh said many participants weighed in on the guidance related to essential health benefits (EHBs), which has significant consequences for people living with HIV/AIDS (PLWHA). He said he hoped participants would share lessons learned from their States about Medicaid expansion, the Ryan White program, and other programs to inform progress. Dr. Koh concluded by thanking each PACHA member individually.

## **Roll Call and Agenda**

Ms. Hayes called the roll. Ms. Mahon noted that the agenda was being revised so that participants could avoid travel delays associated with the pending snowstorm on Friday afternoon. She urged PACHA members who could not attend on Friday to participate by phone.

## **PACHA Resolution on HIV Criminalization**

### **Douglas Brooks, M.S.W., Co-Chair, PACHA Disparities Subcommittee**

Mr. Brooks thanked Kathie Hiers, Co-Chair of the PACHA Disparities Subcommittee, for integrating PACHA members' comments and editing the resolution.

#### **Motion**

Mr. Brooks moved to approve the resolution Ending Federal and State HIV-Specific Criminal Laws, Prosecutions, and Civil Commitments, and David Holtgrave seconded the motion. Members voted unanimously in favor, and the motion passed.

## **Subcommittee and Working Group Updates**

### **Disparities Subcommittee: Douglas Brooks, M.S.W., Co-Chair**

In addition to the HIV criminalization resolution, the Subcommittee is proposing two other resolutions at this meeting. Ejay L. Jack will present a resolution addressing the transgender community, and Jack C. Jackson, Jr., will present one on the needs of male-bodied, two-spirit individuals. The Subcommittee continues to work on recommendations about disclosure and is working with Federal leaders to determine how to advance PACHA's concerns in a meaningful way. Mr. Brooks praised the support from Subcommittee members and Allison Nichol of the Department of Justice (DOJ), who want to help PLWHA safely and voluntarily disclose their HIV status while ensuring that protections and barriers are addressed. He noted that there are partners at the Federal level who support the Subcommittee's efforts on disclosure.

### **Access to Care Subcommittee: Robert Greenwald, J.D., Co-Chair**

Mr. Greenwald said resolutions passed at the October 2012 PACHA meeting on the implementation of ACA and ongoing support for the Ryan White program originated with the Access to Care Subcommittee, as did the recommendation that HHS appoint a senior-level staff person to coordinate the transition to ACA for PLWHA. Since the November 2012 election, several ACA regulations have been published, and some progress has been made on areas of interest to PACHA. For example, the EHBs now provide much better access to HIV drugs for PLWHA in most States than originally proposed. However, the new EHBs fall short of the Medicare Part D model, which guarantees access to needed drugs.

Mr. Greenwald said there must be increased focus on the details of ACA implementation. Approximately 70 percent of PLWHA receive care through the Ryan White program or Medicaid, so they will be strongly affected by upcoming changes. PLWHA will not see a smooth transition without a lot of oversight and work, he noted. The Subcommittee is very concerned about the lack of communication from HRSA and HHS to providers about the imminent transition. The tremendous opportunity offered by ACA will not be realized unless efforts are made to ensure

that PLWHA and their providers are aware of the changes to come, said Mr. Greenwald. The critical role of the Ryan White program now and after full implementation of ACA is the main focus of the Subcommittee's work.

Ms. Mahon proposed that the next PACHA meeting focus entirely on ACA and the Ryan White program. Mr. Greenwald said this meeting should be promoted to the public and held in a large, open space to encourage public involvement. Ms. Mahon said such a meeting would offer an opportunity to gather richer public comment.

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

The Access to Care Subcommittee will assist with organizing a full PACHA meeting focused on ACA implementation and the Ryan White Program. PACHA staff will work with members to determine a date (possibly in April). Representatives of Medicaid (e.g., Cindy Mann, director of the Center for Medicaid and State Operations), the HHS Office of Health Reform, and the White House should be asked to present about their efforts related to ACA implementation. PACHA members and Federal liaisons should send Mr. Greenwald their suggestions for additional presenters.

Michael Horberg added that the Access to Care Subcommittee also is working on the issues of workforce development and the impact of coinfection with HIV and hepatitis C.

#### **Global Subcommittee: Kevin Robert Frost, Co-Chair**

Mr. Frost said the Subcommittee has been "out of commission" because both Co-Chairs have been on extended sabbaticals. The Subcommittee met by phone last week and will meet again today to reestablish its goals. Ms. Mahon suggested that PACHA reconsider the need for the Global Subcommittee. If it seems appropriate for the Subcommittee to continue, its focus should be clearly defined, she added.

#### **Incidence Subcommittee: David Holtgrave, Ph.D., Co-Chair**

Dr. Holtgrave said the Subcommittee has been addressing the science of TasP and keeping up with biomedical prevention efforts. The Subcommittee also is concerned with the costs of unmet prevention needs and mechanisms in public health to fund prevention services.

The Subcommittee met with NIH representatives to discuss new incidence assays and may bring the issue to the full PACHA in the future. Dr. Holtgrave cited progress in HIV metrics, thanks to the implementation of the seven core HIV measures to gather uniform information from grantees across HHS programs. Finally, Dr. Holtgrave said, the Subcommittee is seeking new members to replace outgoing members.

Ms. Mahon pointed out that breaking out the so-called cascade by ethnicity has changed how the field understands incidence. Dr. Holtgrave added that there has been discussion about breaking the cascade down in other ways. The CDC has presented the cascade by age, gender, and race/ethnicity. It would be interesting to see the cascade in terms of insurance status and geography, among other characteristics. Understanding and refining the cascade is an important ongoing conversation.

### **Follow-Up Item**

At the PACHA meeting on ACA and Ryan White, there should be a presentation discussing the implications of the cascade and what information it provides about moving forward.

Dr. Valdiserri noted that data presented by HRSA at its Ryan White grantee meeting suggest that Ryan White programs have client retention rates higher than the national average. These data have implications for the transition to ACA.

### **Discussion of Subcommittee Efforts**

Ms. Mahon proposed discussing the interaction of Subcommittees at a future meeting. Mr. Brooks said he hoped Subcommittee Co-Chairs would talk with PACHA members about stepping up to take on Subcommittee leadership opportunities.

### **Follow-Up Item**

At the next meeting of the Subcommittee Co-Chairs, Co-Chairs should identify the top three issues on which they are focused, and discussion should address how the Subcommittees work together to avoid creating silos.

## **A Hidden Crisis: HIV/AIDS in the Two-Spirit Community**

**Harlan Pruden, First Nations Cree, and Karina Walters, Ph.D., University of Washington, Choctaw Nation of Oklahoma**

Mr. Pruden pointed out that Native Americans often are not included in the conversation about HIV/AIDS. The demographic picture of American Indians/Alaska Natives (AIs/ANs) is skewed by the fact that many fall into the category “multiracial” or identify themselves in surveys as Hispanic/Latino, and a significant number live in urban areas. Furthermore, definitions of “Native American” and “Indian” vary; not all tribes and affiliations are recognized by the Federal government or all State governments. The Indian Health Service (IHS) primarily serves the 22 percent who live on a reservation; less than 1 percent of IHS funding goes to urban areas.

Native men, as described by the presenter, have higher rates of chronic disease compared with other racial/ethnic minorities; half die by age 54. Suicide is the fifth leading cause of death. A high percentage of Native women and men experience violence. Dr. Walters emphasized that victimization, structural inequities, high poverty rates, and discrimination all intersect to affect health for AIs/ANs.

Mr. Pruden explained that the concept of the two-spirit individual refers not to sexual orientation but to gender analysis. Traditionally, a two-spirit individual was held in high esteem and played a unique role within his or her community as a gender distinct from the others.

Different tribes and nations have different definitions and interpretations related to gender and spirit. In the past, two-spirit individuals traditionally took on roles as mediators of interpersonal relations and sometimes as a bridge to communication with the unseen world. Modern two-spirit individuals often fulfill roles as therapists and mediators in social work, psychology, law, and education. Mr. Pruden emphasized that contemporary AIs/ANs must reclaim the language, traditions, and history of the two-spirit concept and revitalize the roles they play. Dr. Walters added that the translations of language often do not capture the true meaning.

Dr. Walters applauded NHAS but said its focus on addressing communities where HIV is most heavily concentrated is problematic for AIs/ANs. “This is where we get erased,” said Dr. Walters, because the numbers do not reflect the reality that AIs/ANs are disproportionately affected by HIV. In proportion to the population, AIs/ANs rank third in the impact of HIV/AIDS. Those who do not identify solely as AI/AN are categorized as multiracial, and many indigenous people identify as Latino, so the effect of HIV on AIs/ANs gets lost in the categorization. Mr. Pruden pointed out that in 2009, the Onondaga Nation reported three cases of HIV—but the tribe includes only 2,000 people. He called for more and better data on the effects of HIV in small communities struggling to survive.

Mr. Pruden continued that AIs/ANs have a 60 percent higher rate of AIDS than whites, and AI/AN men have a 60 percent higher rate of AIDS than white men. Between 2006 and 2009, diagnoses of HIV decreased overall in the United States but increased among AIs/ANs. Furthermore, AIs/ANs have a shorter span between HIV diagnosis and AIDS diagnosis and a much shorter AIDS survival span than any other racial/ethnic group. Approximately 73 percent of HIV infections among AIs/ANs occur among men who have sex with men (MSM). Dr. Walters described more surveillance data, noting that cumulative AIDS cases reported through 2009 indicate that AI/AN men ranked first in contracting HIV through sex with other men and injection drug use (IDU) compared with any other ethnic group. Among women, cumulative AIDS cases through 2005 indicate that AIs/ANs ranked first in contracting HIV through IDU when compared with any other ethnic group.

Dr. Walters said these shockingly high numbers probably underestimate the real figures, as AIs/ANs are often misclassified or lost in categorization. Worse, until 2002, some national reporting did not identify AIs/ANs in any way, because it was thought that the population was so small that it would be too unstable for data analysis. Only in the past decade have areas with high populations of AIs/ANs implemented tracking measures. Dr. Walters emphasized that current surveillance mechanisms are failing AIs/ANs.

A federally funded study of HIV among two-spirit individuals underscores the crisis of HIV among this population. The number of people who have or are at risk for HIV is comparable to rates found in sub-Saharan Africa, said Dr. Walters. In this study, very high percentages of two-spirit MSM reported recent experience with post-traumatic stress disorder (PTSD), unprotected sex, sex work, and a history of sexually transmitted infections, among other risk factors for HIV infection and transmission. A substantial number also reported marginal housing status, symptoms of depression, indicators of alcohol dependence, and a history of sexual abuse. A

high reliance on sexual risk “cognitions,” which can be described as rationales for not taking steps to prevent HIV infection, also contributes to the spread of HIV, as does concurrency—having sex with multiple, overlapping partners, Dr. Walters explained. A number of AIs/ANs limit their partners to other AIs/ANs, which increases risk within the community. In addition, rapid spread of HIV among those who have both male and female concurrent partners underscores the need to reach out to bisexuals.

Mr. Pruden described the high rates of mental health disorders among two-spirit and transgender AIs/ANs and framed them in the context of historical trauma. He emphasized the importance of recognizing and grappling with the consequences of widespread policies and actions against a culture that strips people of their land, language, family, and heritage. The resulting trauma is cumulative, collective, and persistent across generations. Mr. Pruden offered many examples of historical trauma that have been ignored or glossed over.

Dr. Walters added that microaggression—the everyday experience of discrimination and marginalization—further contributes to chronic stress. She believes that historical trauma and contemporary, individual trauma work together. Dr. Walters presented preliminary data from a study about individual and family history of trauma; these data demonstrate that chronicity of events matters, the amount of trauma experienced affects mental health, and stress caused by discrimination matters. These factors increase risk behaviors, such as smoking. However, connecting with one’s cultural identity has a protective effect. “Culture is the cure,” said Mr. Pruden.

## **PACHA Resolution**

### **Jack C. Jackson, Jr., J.D., PACHA Member, Disparities Subcommittee**

Mr. Jackson presented a resolution developed by the Disparities Subcommittee that addresses the needs of male-bodied, two-spirit individuals living with or at risk from HIV. The goal of the resolution is to provide an overview of the issues unique to this population and outline some initial steps. The logical next step would be to review existing Federal funding that affects this population. PACHA members agreed that the current resolution should include a recommendation for analysis of Federal funding, as well as analysis of epidemiologic and program data, for AIs/ANs with or at risk from HIV. To the extent possible, State-level data also should be analyzed. Members offered other editorial changes to make the resolution more directive and more accurate. Some offered suggestions to help the speakers advance their own advocacy efforts, such as focusing on the disproportionate effects of HIV on AIs/ANs.

### **Motion**

Mr. Jackson moved to approve the resolution, with suggested edits, on the Needs of AI/AN Male-Bodied, Two-Spirit Individuals Living With or at Risk From HIV.

Mr. Brooks seconded the motion. Members voted unanimously in favor.

## **CDC Update**

**Eva Margolies, M.P.A., Associate Director for Planning and Policy Coordination, NCHHSTP, CDC**

Speaking on behalf of Rima Khabazz, M.D., deputy director for Infectious Diseases, director of the Office of Infectious Diseases, and acting director of NCHHSTP, Ms. Margolies said the NCHHSTP is recruiting a new director. She encouraged interested parties to contact her. More information is available online at [USAJobs.gov](https://USAJobs.gov). Ms. Margolies noted that adolescent and school health was recently added to the Center's portfolio.

## **Ending the HIV/AIDS Pandemic: From Basic Science to Public Health Implementation**

**Anthony S. Fauci, M.D., Director, NIAID, NIH**

Dr. Fauci said we have the tools to dramatically decrease the HIV/AIDS pandemic globally, but the challenge is to implement those tools properly. Effective implementation requires countries to take ownership of the effort, build capacity, strengthen health systems, and foster committed partnerships, among other things. It also requires removing legal and political barriers and eliminating stigma. While we have seen some progress globally in decreasing infection rates, the United States remains stuck at about 50,000 new infections per year for the past 10 years. There is no excuse for that figure, said Dr. Fauci, because we have the means to do something about it.

Minority populations in the United States are disproportionately affected by HIV. Adolescents and young adults of color, particularly young black MSM, are facing the highest rates of infection. About 60 percent of people ages 13–24 years who have HIV are unaware of their infection. About half of new infections are transmitted by someone who does not know he or she is infected. On that basis, Dr. Fauci posited that if all people knew their HIV status, the infection rate would decrease by 50 percent.

Dr. Fauci depicted HIV intervention and prevention strategies as building blocks, with a base of behavioral approaches—such as testing, counseling, education, and condom use—that worked even before biologically based interventions were available. In light of the NHAS goal to reduce HIV incidence, testing and counseling could have a significant impact. About 20 percent of the 1.4 million people with HIV in the United States do not know they are infected, and they account for about half of all new transmissions. Implementing the proposed recommendation that all individuals ages 15–64 years old get at least one HIV test could have a significant impact on new infections, said Dr. Fauci.

Other behavioral interventions are effective but lack widespread funding or support. Methadone treatment, for example, reduces the risk of HIV infection by 54 percent. Syringe exchange programs successfully decrease HIV infection rates and do not promote drug use, and it is shameful that we do not have Federal support for such programs. Treatment of HIV is “the

showstopper,” said Dr. Fauci, as demonstrated by a recent study that found a 96 percent reduction in transmission with early treatment among serodiscordant couples.

Effective implementation means understanding the relationship between a biomedical intervention and real-world behavior and adherence. Dr. Fauci noted that preexposure prophylaxis met with mixed results, probably because the clinical subjects were not adhering to the drug regimen.

The early, basic science of HIV identified drug targets, and more than 30 drugs are now available. When used in combination, these drugs extend the anticipated lifespan of PLWHA; a recent study found that people treated early add as many as 50 years of life—the most dramatic medical advancement in the past 30 years, said Dr. Fauci.

The cascade shows the weak links along the continuum from testing to viral suppression, and efforts should be concentrated on repairing those links, Dr. Fauci said. Recent studies show that enhanced testing approaches that include links to care and treatment and that target African Americans in urban areas are effective. San Francisco’s test-and-treat policy for all dramatically decreased HIV incidence.

Some efforts are already underway to reduce HIV-related health disparities. For example, ACA will increase access to testing and treatment, eliminate the ability of insurers to deny PLWHA coverage on the basis of preexisting conditions, and enhance coordination of care. Developing a vaccine and a cure for HIV/AIDS remains an important goal, said Dr. Fauci, but much can be done with the tools we have right now. The goal is to foster an AIDS-free generation globally, and we in the United States can and should be the first to reach that goal, Dr. Fauci concluded.

### **Discussion**

Dr. Fauci pointed out that behavioral interventions worked before there were any biological interventions. Both are needed, and it is a false dichotomy to force a choice between the two, he said. The NIH, for example, is fostering partnerships among NIAID, the National Institute for Mental Health, and the National Institute on Drug Abuse to integrate biological and behavioral research and programs. Moreover, researchers can design studies that integrate behavior and social issues specific to those at high risk (e.g., gay men), including stigma. We already know which populations are most vulnerable, said Dr. Fauci.

Questions were raised about Federal funding for research by minority investigators and for public health infrastructure that serves minorities. Dr. Fauci said the NIH is trying to address minority funding disparities and also focusing on bolstering the pipeline of future minority researchers.

A member noted, and Dr. Fauci agreed, that public programs that succeed in reducing HIV infections are seeing cuts in funding that reverse the gains. Dr. Fauci also agreed with the comment that the infrastructure created to address HIV/AIDS should be maintained and expanded for the future.

Reiterating the point that half of transmissions are caused by people who do not know they are infected, Dr. Fauci said the reasons for not testing are fallacious. There are now effective treatments for those who test positive. While stigma lingers, even in the United States, we must fight it, he said. Asked what PACHA can do, Dr. Fauci said it is clear that we need to work aggressively, particularly in target populations, to increase testing, linkage to care, and retention in care. PACHA can facilitate discussion from those knowledgeable in the field to identify all the obstacles to testing, including financial, legal, and local issues.

Should sequestration (i.e., a dramatic, across-the-board budget cut) come to pass, the NIH is unlikely to lay off staff, said Dr. Fauci, because experience has shown that reduction in force costs the agency more than it saves. Funding for investigator-initiated grants and proposals would likely diminish, as would investments in programmatic initiatives (such as HIV research). Fewer qualified grant applications would be funded. Dr. Fauci believes that Federal funding for science and health should not be discretionary but rather obligatory.

Several questions revolved around how to overcome barriers to available prevention and treatment options. Dr. Fauci said targeting the most vulnerable populations is effective, but research is underway to better understand how to reach the most recalcitrant, particularly those for whom the stigma is as frightening as the disease.

## **Program Implications of the New HIV Science**

**David W. Purcell, J.D., Ph.D., Deputy Director of Behavioral and Social Science, NCHHSTP, CDC**

Dr. Purcell explained that combining HIV prevention approaches changed the thinking about HIV prevention. It was recognized that not all interventions are effective, and not all effective interventions work equally well across populations. Selecting and combining interventions to achieve maximum impact is known as high-impact prevention.

For each potential intervention, efficacy in clinical studies must be balanced by effectiveness in the real world. Economic aspects should be considered, given that resources are limited, and the feasibility of scaling up interventions must be addressed. NCHHSTP is working with grantees and on a larger scale to develop epidemiologic models to project the impact of interventions, prioritize them, and implement and evaluate programs.

The CDC's Enhanced Comprehensive HIV Prevention Planning (ECHPP) project spurred health departments in 12 cities to look closely at all of their funding sources and reprioritize them to focus on required and recommended interventions. The project particularly succeeded in spurring more awareness and collaboration within communities. Changing funding allocations is slow, however, and using resource allocation tools requires highly trained people. Moreover, the science of combination prevention efforts is new, so programs had limited data or experience on which to base decisions.

To help with decisionmaking, the CDC worked with the Philadelphia Department of Health to develop a resource allocation model. A complex algorithm was developed to incorporate actual city-specific data on the number and characteristics of PLWHA, the department's annual budget, the reach of the department, and other factors. The factors were combined to calculate the cost of an intervention per infection averted. The model determined that testing MSM in nonclinical sites, for example, is the least expensive intervention in terms of cost per infection averted at \$18,000, while behavioral interventions for people who are not HIV-positive cost more than \$15 million per infection averted.

Dr. Purcell stressed that the model drives health departments to consider how they allocate funds. Behavioral interventions, for example, remain important and merit funding, particularly when the higher-impact strategies are not likely to reach more people. He acknowledged the limitations of the model but said it is effective for understanding programs and supporting decisionmaking. The CDC is now funding similar models in three other health departments and will compare them. Other Federal efforts include increased funding of local health departments to implement the most effective strategies (HIV testing, treatment, policy changes, and condom distribution) and the Care and Prevention in the United States (CAPUS) demonstration project, which targets the social determinants of health among racial/ethnic minorities.

Dr. Purcell summarized the evolution of behavioral interventions, from initial prevention efforts to targeted prevention and treatment to evidence-based approaches. While the CDC encourages dissemination and use of evidence-based interventions (EBIs), limitations persist—for example, lack of evidence relevant to target populations, lack of relevant outcome data, and lack of tools to facilitate the intervention. The CDC is expanding its compendium of EBIs and making it available online. Questions remain about the impact of behavioral interventions relative to biomedical treatment, and Dr. Purcell said he agreed with Dr. Fauci that both are needed.

### **Discussion**

Dr. Purcell said research focusing on transgender people is fairly new. The CDC compendium of EBIs does not include any interventions specifically tested among transgender populations, but some interventions are adapted for that population, and two such interventions are being tested. In response to a question about the perceived difficulty of scaling up behavioral interventions, Dr. Purcell said issues of scale apply to both behavioral and biomedical interventions.

Regarding the limitations of modeling, Dr. Purcell pointed out that it is important to evaluate findings in a real-world context. In Philadelphia's case, the Department of Health had already invested heavily in reaching certain at-risk populations and did not think that increasing that particular investment would expand reach and yield better results. If the program's reach were better, the Department might choose to spend more on certain high-impact prevention interventions.

To better assess the role of policy or structural barriers to care, Dr. Purcell said the CDC focuses heavily on three areas: State laws consistent with routine testing, Medicaid payment for testing, and routine reporting of CD4 counts and viral load. There is some interest among States for using more surveillance data to inform public health decisionmaking. Ms. Margolies added that the CDC also is looking at State laws on criminalization and on surveillance, such as those that prevent information exchange. Ideally, she said, the CDC will offer an online, interactive map that provides data.

Referencing the earlier discussion, Dr. Purcell noted that the CDC recognizes the importance of continued funding, particularly for successful programs, and the continued need for behavioral interventions as well as biomedical treatment.

## **Ryan White Reauthorization Update**

**RADM Deborah Parham Hopson, Ph.D., R.N., FAAN, Assistant Surgeon General, Associate Administrator, HAB, HRSA**

Introducing Dr. Parham Hopson, Ms. Mahon said that PLWHA who get Ryan White services do better than those who do not, and she called for continued advocacy by Dr. Parham Hopson and her colleagues in support of the Ryan White program. Dr. Parham Hopson said preliminary, client-level data from calendar year (CY) 2010 demonstrate that the Ryan White program provides high-quality care, and CY 2011 data will be available soon. Under the program in CY 2010, about 546,000 people received at least one Ryan-White-funded service. Dr. Parham Hopson described the demographics of the population served, noting that 76 percent were retained in care. Among Ryan White clients, 70 percent of those who had at least one medical visit achieved viral suppression, compared with 25 percent nationwide.

Of 14 new performance measures for infectious disease endorsed by the National Quality Forum and taking effect in 2013, four were developed by HAB: HIV medical visit frequency, gap in HIV medical visits, HIV viral load suppression, and prescription of HIV antiretroviral therapy (ART). Additional measures are needed to assess retention, especially with the transition to new insurance plans under ACA, said Dr. Parham Hopson.

Internal discussion continues about Ryan White program reauthorization, and last week HRSA was among those invited to discuss the matter with the White House ONAP. Stakeholders are very aware that authorization for the Ryan White program ends in September 2013, said Dr. Parham Hopson. HRSA is excited about new insurance options for PLWHA as ACA is implemented and recognizes the need to prepare providers and clients for the transition. HRSA is learning from those States that have already expanded their Medicaid programs.

Questions about the transition can be sent via e-mail to [RWP-ACAquestions@hrsa.gov](mailto:RWP-ACAquestions@hrsa.gov). The agency addresses such questions on its Web site in a frequently-asked-questions format. Grantees primarily use HAB'S Web site, so it provides links to additional ACA information and resources.

From a budget perspective, the Ryan White program is operating on a continuing resolution through March 27, 2013. Partial awards will be granted for certain programs, with the balance issued when the 2013 budget is finalized. Programs that start in mid-2013 will be issued full awards when the 2013 budget is finalized. In January, HRSA issued three new funding opportunity announcements for AIDS Education and Training Center education for nurse practitioners and physician assistants, and both demonstration and evaluation efforts related to culturally appropriate interventions of outreach, access, and retention among Latino/a populations

### **Discussion**

Dr. Parham Hopson said PACHA could advocate for the continuation of the Ryan White program by raising awareness about the benefits of the program for PLWHA and by translating the lessons learned from the program into the new systems under ACA. She emphasized the importance of retaining expertise and knowledge. Dr. Parham Hopson agreed to assist PACHA with planning a meeting devoted to ACA and Ryan White program issues.

Dr. Parham Hopson noted that the Ryan White program cascade begins with a significantly different denominator (i.e., only those people receiving Ryan White services) from the CDC cascade (all PLWHA in the United States). In addition, the data only reflect those receiving medical care or medical case management under the Ryan White program, not other services. HRSA and the CDC are discussing how to reconcile their respective data. Some PACHA members felt that the Ryan White program cascade sets up a false comparison and may misrepresent the reality. Dr. Valdiserri emphasized that the data appear to indicate that Ryan White clients have better rates of retention and viral suppression than the overall population, which is consistent with a program focused on retention. It was noted that accurate data are needed to provide an accurate picture. Also needed is a better understanding of the factors of the Ryan White program or other comprehensive, specialty care programs that contribute to better outcomes.

### **Follow-Up Items**

For the PACHA meeting on ACA and the Ryan White program, discussion should include identifying effective interventions for various populations at each stage of the cascade. Factors related to stigma, providers, payers, and geographic location should be addressed. The role of specialty providers sensitive to the needs of PLWHA (and the related issue of workforce development) also should be covered.

For the PACHA meeting on ACA and the Ryan White program, consider a presentation by the Federal Working Group on the Intersection of HIV/AIDS, Violence Against Women and Girls, and Gender-Related Health Disparities on best practices for trauma-informed care, because the key elements of comprehensive programs for PLWHA should be consistent with those of trauma-informed care.

## Transgender Panel

### **Review of Relevant Research and Research Gaps: Walter Bockting, Ph.D., Research Scientist, Co-Director, Initiative for LGBT Health, Division of Gender, Sexuality, and Health, New York State Psychiatric Institute/Columbia Psychiatry with the Columbia School of Nursing**

Dr. Bockting offered a broad definition of “transgender” and estimated that transgender people make up about 0.5 percent of the population. In *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*, the Institute of Medicine (IOM) pointed out that while transgender people share an “otherness” with lesbian, gay, and bisexual people, each group has unique needs, and within each group, subgroups face different stigmas and inequities. The IOM found substantial gaps in research and called for a comprehensive research agenda that looks beyond HIV and addresses transgender health within the context of lesbian, gay, bisexual, and transgender (LGBT) health issues. The IOM specifically recommended that NIH-funded research address explicitly the inclusion or exclusion of sexual and gender minorities in their samples.

Dr. Bockting summarized findings on HIV prevalence from the few studies that include transgender people. He noted that African American transgender women have a much higher rate of HIV infection than their white or Latino counterparts and that transgender MSM report high rates of HIV risk behaviors. Transgender people also report high rates of co-risk factors, including mental health issues, violence, social isolation, economic marginalization, incarceration, and unmet health care needs. At the same time, HIV testing rates among transgender people are low, and Dr. Bockting stressed the need to promote HIV testing for this population. Transgender people are less likely to get treatment for HIV, and the significant barriers to care (including lack of sensitivity among health care providers) must be addressed.

From his own Internet-based research, Dr. Bockting concluded that stigma affects all transgender people and has serious consequences, including employment and housing discrimination and incarceration. Rates of mental health disorders are high among transgender people and also are associated with HIV infection. Dr. Bockting found that family and social support buffered the effects of mental health disorders and stigma, and he called for more research on resilience.

Research to date has been limited to small convenience samples. Interventions should be developed “on the ground,” with input from transgender individuals, to address the health care needs of transgender people, said Dr. Bockting. Large, multisite cohort studies are needed to build the evidence base. Access to care in particular must be improved.

### **Factors Affecting Transgender People and HIV: JoAnne Keatley, M.S.W., Director, Center of Excellence for Transgender Health, University of California, San Francisco**

Ms. Keatley described some of the barriers to collection of data about transgender people, noting that her organization is working with the CDC and others on recommendations to improve data collection. There are no population-based studies of transgender people. Health

surveys often lack gender identity variables. Transgender people often are not included in research because of stigma on the researchers' (or funders') part. Transgender people may prefer to be anonymous or to leave behind the transgender community once they have made a successful transition. Pathology-based research leads to a disproportionate focus on transgender women (e.g., for HIV, sexual violence, incarceration, and trauma), and few transgender men have health insurance, are employed, or use the public health system. Data on transgender people are often conflated with data on MSM.

A recent meta-analysis estimated that transgender women are 48 times more likely than other populations to be infected with HIV. The factors that increase HIV risk in general hit transgender people particularly hard, and Ms. Keatley gave examples of several risk factors, including the following:

- Social stigma
- Unemployment (and lack of workplace protections to prevent discrimination)
- Survival sex work (and gender identity validation through sex)
- Substance abuse, particularly IDU
- Unsafe sex practices (lack of negotiation skills for safer sex)

Ms. Keatley also pointed to the lack of cultural competence and EBIs for transgender people. Even the San Francisco Department of Public Health, which does better than most in developing programs for transgender people, has not succeeded in bending the curve for new AIDS diagnoses or survival rates among transgender people.

Transgender people face many barriers to adequate health care, such as insensitive or even openly hostile care providers, inadequate screening and treatment, and insufficient coverage for care. Ms. Keatley noted that the issues affecting transgender people are distinct from those affecting MSM. Transgender people have higher per capita rates of unemployment and housing and education discrimination, greater avoidance of medical providers, unique health care priorities (access to transgender-specific care), higher numbers of transgender women in sex work, and self-identification by gender identity, not birth sex status.

While the CDC is developing EBIs for transgender people, none have been published. It is challenging to adapt EBIs created for MSM to address transgender people. Like Dr. Bockting, Ms. Keatley called for more homegrown interventions developed with direct input from transgender people. Ms. Keatley reiterated her frustration with the lack of inclusion of transgender people in State and Federal data collection and federally funded interventions.

**Chicago House: Serving the Transgender Community: Rev. Stan J. Sloan, Chief Executive Officer, Chicago House and Social Service Agency, and Keisha Allen, Consumer, Chicago House and Social Service Agency**

Rev. Sloan explained that despite his work with Chicago House, which provides wraparound services for homeless gay men, he had little experience with or knowledge about the needs of

transgender people. Recently, Chicago House received a HRSA grant to provide comprehensive services to transgender women of color to help them get and stay in care.

Ms. Allen described her experience as one of eight children of a single parent on public assistance. She was always teased for being feminine; at age 15, she realized that she was not gay but rather transgender. At 16, Ms. Allen was kicked out of her home by her mother and turned to sex work to survive. At 45, she said, her life is not much different. She remains homeless. She was incarcerated for 7 years on trumped-up charges. At 27, Ms. Allen was diagnosed with HIV, had no health care, and bought hormones on the black market. When Rev. Sloan asked her how she would like to see her life at age 50 or 60, Ms. Allen said she wants a home and a job in which she does not worry that every day will be her last. She recognized that her lifestyle is not healthy, and she told Rev. Sloan that she needed a chance to break into the system and wanted to help others who feel trapped.

The public health emergency system does not work for people who are homeless and transgender, said Ms. Allen. In classic homeless shelters, identity is always a problem. Ms. Allen said she is routinely sent to the male housing quarters, where she risks being sexually abused and assaulted. Shelters also subject clients to showers and body searches that are embarrassing and difficult for transgender women, she said. With traditional public assistance, employment, and even food assistance, abuse exists at every turn. Ms. Allen said that even traveling to Washington from Chicago, she and Rev. Sloan were prepared for trouble—for example, would the Transportation Safety Administration agent question the difference between her documented identification and who she is?

To change her life, Ms. Allen said, she need the same opportunities provided by the emergency and social service systems available to other homeless, low-income people. The new TransLife Center opened by Chicago House offers transgender-friendly housing, employment opportunities, and onsite health care, with safe access to hormone therapy and providers who are educated about and welcoming of transgender people. It also offers legal services to help transgender people get appropriate identification documents and address criminal records.

Ms. Allen asked that PACHA support the resolution proposed by the Disparities Subcommittee to address the needs of transgender people. “I am just one voice, but my story is not unique,” she said. The resolution can help her and others get support and a break from the cycle of poverty and pain, she concluded.

Rev. Sloan explained that in addition to shelter, health care, and other services, Chicago House operates a bakery. Although he had worked with homeless people for decades, Rev. Sloan said, it was only when transgender women began working at the bakery that he understood the unique barriers they face, particularly because homeless shelters are so dangerous for them. The service gaps he sees in Chicago translate to the whole country. The TransLife Center is providing even more services than Chicago House does for its other homeless clients. Because of persistent discrimination against transgender people, Rev. Sloan called the decision to provide comprehensive services for transgender homeless people “not smart, but right,” and it

has transformed the whole agency. As a result, the agency has found new respect among the community.

**Policy Approaches for Addressing Transgender Health Disparities: Kellan Baker, M.P.H., M.P.A., Policy Analyst, Center for American Progress**

Mr. Baker reiterated many of the factors that affect transgender health, noting that the combination of discrimination, racism, sexism, and poverty results in the public health disaster that characterizes the HIV epidemic among transgender people. Key concerns are lack of insurance coverage and the fact that even transgender people who do have insurance have plans with specific language that you are not covered if you are transgender. However, ACA, NHAS, Healthy People 2020, the HHS LGBT Data Progression Plan, and the Top Health Issues for LGBT Populations toolkit from the Substance Abuse and Mental Health Services Administration are among the resources that offer opportunities to change the way transgender people are treated.

ACA, for example, focuses considerable resources on HIV/AIDS, some particularly for transgender people; improves data collection; and offers protections against discrimination on the basis of gender identity. Insurance companies will no longer be able to deny coverage based on preexisting conditions, which will open up access to many PLWHA and people living with other conditions. Efforts are underway to ensure that EHBs cover essential services, regardless of gender identity. Transgender people face barriers getting preventive care, and more coverage of preventive care will help.

To improve access and care for transgender people, said Mr. Baker, HHS should develop measures to better identify gender status and use them to identify and address HIV risk and prevention efforts among transgender people. Agencies such as the CDC, the NIH, and the Patient-Centered Outcomes Research Institute should develop research portfolios to address transgender people and include transgender people in their study samples.

Mr. Baker called for dedicated funding to evaluate issues particularly important to transgender health, such as the use of black market hormones and cultural competence. The Center for Consumer Information and Insurance Oversight should develop guidance that specifies that transgender-specific exclusions violate Federal nondiscrimination regulations. PLWHA should retain the services they receive under the Ryan White program after the transition to ACA. Cultural competence should be required of all those who receive Federal funds, and not just HHS grantees but also those funded by the departments of Labor, Housing, and Justice, for example.

Mr. Baker said he hoped the convergence of policy opportunities would spur a renewed commitment to prioritizing HIV prevention and treatment for transgender people. "When we are not thought of, we are actively pushed down through the cracks," he concluded.

## **PACHA Resolution**

### **Ejay L. Jack, M.S.W., M.P.A., PACHA Member, Disparities Subcommittee Member**

Mr. Jack presented a resolution from the Disparities Subcommittee addressing the HIV/AIDS epidemic among transgender people. He explained that it reflected input from the presenters and their organizations, which represent the top experts in the field. Several members commented that the resolution was very long, but none offered specific suggestions on how to shorten it. Rather, several suggested including additional topics, such as the following:

- Insurance coverage for transgender-related procedures
- Access to appropriate identification documents
- Research on community-driven prevention programs (by various Federal agencies, not just the CDC)
- Protection for sex workers (decriminalization and increased access to condoms)

There was some concern about creating divisiveness by drawing distinctions between transgender people and MSM. It was questioned whether the resolution that Federal grantees and contractors provide culturally competent service would require an Executive Order. Mr. Baker said HHS has discretion to include cultural competence and nondiscrimination requirements for transgender people in its funding requirements.

It was suggested that resolution number 1 specifically request increased funding for a CDC program that supports transgender people. Ms. Margolies said the CDC has the capacity to specify a funding preference as part of its grant process that would give priority to applicants who serve transgender people (for a given funding announcement). She added that the CDC does not fund EBIs but rather synthesizes information from all available research, regardless of funding source.

In response to concerns about the feasibility of the proposed resolutions, Mr. Baker explained that many were adapted from existing Federal recommendations. For example, resolution number 9 to establish a cross-NIH coordinating mechanism to integrate research comes from the NIH's response to the IOM report.

### **Motion**

Mr. Jack moved to approve the resolution on Effectively Addressing the HIV/AIDS Epidemic in Transgender Populations, and the motion was seconded. Twelve members voted in favor, and two abstained. The motion passed.

Throughout the discussion, members offered comments and suggestions related to PACHA's process for drafting, disseminating, reviewing, and approving resolutions. The following suggestions were made:

- Consider developing a template for resolutions.

- Consider whether a white paper may be an appropriate alternative.
- Send draft resolutions to PACHA members well in advance of meetings.
- Present draft resolutions on meeting day 1 and plan for a vote on meeting day 2.
- Consider which is more effective: broad or targeted/specific resolutions.
- Track the progress of resolutions after PACHA approves them.

**Follow-Up Item**

The next meeting of Co-Chairs will evaluate the process for developing and approving resolutions.

**Conclusion**

Ms. Mahon concluded the meeting for the day at 5:34 p.m.

## DAY 2

### Welcome and Roll Call

Ms. Mahon welcomed the participants and called the meeting to order at approximately 9:30 a.m. Ms. Hayes called the roll.

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

Dr. Colfax expressed his appreciation to PACHA members for their work and provided an overview of the implementation of NHAS. Its guiding principles are alignment of resources with the epidemic, shared responsibility, accountability, and an evidence-based approach. He added that effective interventions should be implemented in a manner that recognizes the needs of individual communities and that allows flexibility at the local level.

Dr. Colfax reiterated some data on the incidence of HIV, noting that the epidemic is concentrated among gay men and people of color. Although the rate of new infections is stable, disparities continue.

In conjunction with the July 2012 International AIDS Conference (AIDS 2012), ONAP issued an update on Federal implementation of NHAS. Dr. Colfax reiterated that the ECHHP project was successful in improving coordination and collaboration at the local level and that the Philadelphia model to assess intervention costs per infection averted using local surveillance data. He also noted that the CAPUS project reflects NHAS's aims of focusing on integrating care, reaching populations most affected, and targeting areas with the highest disparities in care.

The U.S. Department of Veterans Affairs (VA) demonstrated that by engaging its clinicians in screening for HIV, it doubled the number of veterans tested in just 2 years. Recognizing the role that housing plays in HIV prevention, the Department of Housing and Urban Development proposes to better target Housing Opportunities for Persons With AIDS funding to address current data on PLWHA and allow more local-level flexibility.

Dr. Colfax said that understanding why PLWHA drop out of care at different points along the cascade is critical to the future of the Ryan White program, the use of EBIs to improve care, and the realization of ACA's promise to increase coverage for PLWHA. He pointed specifically to the cascade for black MSM with HIV, who are more likely than others to have low income and fewer health care visits and who have poorer outcomes at every point in the cascade. To better understand why, Dr. Colfax said, we need more research that explains the reluctance to seek or remain in care, such as the study that looked at the prevalence by race of the belief of MSM in HIV-related conspiracy theories. That study revealed high rates of mistrust, especially among MSM of color, that should be addressed by cultural competency training, education, and messaging. The VA's success, for example, may offer some lessons about effective interventions.

Dr. Colfax summarized some key benefits of ACA that contribute to meaningful change now, many of which were discussed earlier in the meeting. Some ACA regulations specifically benefit women, such as guaranteed access to preventive services without cost-sharing, including HIV screening and counseling.

The Federal Working Group on the Intersection of HIV/AIDS, Violence Against Women and Girls, and Gender-Related Health Disparities has been meeting regularly since March 2012. It has compiled an inventory of programs to identify areas of potential synergy and has conducted three workshops to identify research gaps and catalogue existing research. The working group has received stakeholder input through webinars and online comments. It is developing specific target areas for focus and action. Dr. Colfax said more details will be available soon.

Among the issues the working group is considering is the association of trauma with the risk of treatment failure and mortality. Women with HIV have very high rates of PTSD and intimate partner violence. These women are more likely to see ART fail and to die from AIDS. Violence and trauma are critical components that must be addressed to improve outcomes of HIV care, said Dr. Colfax.

Dr. Colfax portrayed the components of comprehensive HIV care that make up the Ryan White program but also translate to other chronic conditions. The medical home model was developed and sustained in treating PLWHA, and that expertise should be sustained in the transition to ACA. Dr. Colfax said PACHA should consider how to bring the Ryan White model into the new world of ACA. He described one successful model of HIV care in Baltimore that he hoped could be amplified under ACA with expanded health care coverage.

Regarding the future of the Ryan White program, Dr. Colfax said a current assessment of insurance coverage among clients receiving Ryan White services supports the need to maintain these services to ensure that the concept of the patient-centered medical home is fully integrated and to address the problems identified by the cascade. People who receive Ryan White services do better than those without such services, and that will not change. More people will have access to insurance, but the patient-centered medical home is key. The Obama Administration recognizes the continued need for the Ryan White program and understands that the program must evolve. Echoing Dr. Fauci, Dr. Colfax said we know how to do the right things, but we need to focus on getting it right “on the ground” and on the outcomes across the continuum of care.

Dr. Colfax noted that DOJ is making progress toward NHAS goals by fighting discrimination against PLWHA and working with HHS to address criminalization statutes. The Department of Labor is enforcing workplace rights and raising awareness about labor issues in light of the increasing longevity of PLWHA. In the broader policy context, said Dr. Colfax, research shows that marriage equality increases social capital for marginalized populations, which translates directly to improving the health of gay men.

The creation of seven core HIV indicators is a step toward harmonizing data across HHS agencies and streamlining data collection. These indicators will enable measurement of HIV-related outcomes and contribute to the goal of accountability. These data also will contribute to assessing progress toward the NHAS goals for 2015. Dr. Colfax reviewed the key ingredients of successful implementation, through which we will achieve the goals of NHAS.

### **Discussion**

Dr. Colfax said the Federal working group is not ready to speculate on pilot projects to address trauma and violence, but it would like to encourage implementation and measurement of sustainable interventions within the current system. He noted that the U.S. Preventive Services Task Force (USPSTF) recommendation to screen for violence is an A-level recommendation. Dr. Colfax added that the Federal working group would like to have deliverables in place in time for the upcoming National Women and Girls HIV/AIDS Awareness Day.

Ernest Darkoh-Ampem pointed out that a program in South Africa to increase access to care found that follow-up (i.e., retention in care) and suppression rates were much higher among those PLWHA who had access to a private care provider near their home than those who sought public health care at a clinic far from home. The dropout rate is expensive given the effort invested to engage people in care, he added. Dr. Colfax said one challenge of research is that most data address people who are engaged in the system. He agreed that more research is needed to understand why people drop out of treatment. He also said a survey of members of the National Medical Association (primarily black providers) found that many providers are uncomfortable offering routine HIV screening despite the USPSTF recommendation. In addition to patient issues, there are provider issues to address.

Dr. Colfax said getting an accurate picture of the costs of implementing NHAS is complicated by the many players involved, and it is not clear whether a cost model could provide information that is both meaningful and precise enough to be useful. Even if costs were identified, it would be difficult to correlate them directly with benefits. Tracking intermittent markers of progress of NHAS is a big step, he said.

In response to a question, Dr. Valdiserri said care models for other chronic conditions, such as diabetes, may serve as models for supporting retention in care. The CDC is considering support for a model that would engage pharmacists in rural areas to support people on ART between visits to health care providers who are not nearby (e.g., by managing medication side effects and encouraging adherence).

### **Follow-Up Item**

PACHA will invite representatives from the CDC to give more in-depth information about the Philadelphia model for assessing HIV intervention cost per infection averted.

PACHA will discuss the components of care models for other chronic conditions that may transfer to retaining PLWHA in care.

## **Stigma Index**

### **Eric Sawyer, UNAIDS, and Laurel Sprague, GNP+NA**

Ms. Sprague noted that NHAS identifies stigma and discrimination as key issues to address in combating HIV in the United States. She explained that GNP+NA has implemented the Stigma Index around the world, and this year marks the first time it has been allowed to initiate its program in the United States. Mr. Sawyer said UNAIDS has been supporting the U.S. implementation of the Stigma Index with technical advice.

Stigma and discrimination are an affront to human dignity, said Ms. Sprague. Remarkably, more PLWHA in North America report that stigma is a barrier to prevention and treatment services than PLWHA elsewhere in the world. The Stigma Index could play a role in research to understand the reasons that PLWHA drop out of care. To this end, UNAIDS has proposed a collaborative research agenda across Federal entities, academia, and nonprofit organizations in the United States, said Mr. Sawyer.

Ms. Sprague said the process of developing the Stigma Index is as important as the results. PLWHA are trained to interview other PLWHA about stigma and discrimination. The experience of individuals is translated into information that decisionmakers can use. The resulting information lays the foundation for advocacy efforts. The process builds capacity for networks of PLWHA, contributes to skills-building for individual PLWHA, and fosters solidarity across networks. The process also promotes public leadership of PLWHA.

Academic partners analyze and interpret the data gathered from the private interviews and use them to inform interventions at both local and national levels. Los Angeles County is funding the first pilot in the United States. Numerous HIV/AIDS advocacy organizations have expressed interest. Ms. Sprague emphasized that projects will not go forward without support of top-level representatives of the affected communities.

The interview covers a broad range of areas in which stigma and discrimination occur. It can be a long process, but many PLWHA are willing to talk at length about their experiences, especially with other PLWHA. Ms. Sprague noted that the questionnaire can be expanded to include additional topics identified by U.S. partners. Mr. Sawyer expressed the hope that the Stigma Index findings would be used to develop recommendations, for example, to address criminalization.

Ms. Sprague noted that PLWHA have reported that conducting the interview and being interviewed both have strong positive effects. Therefore, GNP+NA will measure the effect of the Stigma Index process as an intervention in itself.

The sources and manifestations of stigma and discrimination vary by country, and Ms. Sprague summarized some interesting findings from the United Kingdom, China, the Philippines, and Kenya. Countries use the data to identify priorities and devise strategies and interventions. The draft Stigma Index process for the United States is being finalized now, and Ms. Sprague said

she hoped that five sites would begin implementing the program this year, contingent on funding. Mr. Sawyer said he hoped that PACHA would express support for the Stigma Index, which would assist in securing funding.

### **Discussion**

Ms. Sprague explained that the interview process can take an hour or more and usually takes place at an AIDS service organization. In addition to the national Stigma Index steering committee, communities implementing the program have their own steering committees to address, for example, the ideal setting for such interviews. It was suggested that consideration be given to interview sites outside of public health settings.

Naina Khanna said the U.S. Positive Women's Network fully supports the Stigma Index; she emphasized the need for building an evidence base for low-cost interventions that contribute to both community health and workforce development. She also noted that peer support networks for PLWHA are disappearing. Peer support has been very helpful in other countries.

Ms. Sprague clarified that the Stigma Index also involves other methods, including surveys, but human interaction provides the best data. GNP+NA is determining how to centralize some functions of the program to reduce the costs. It was suggested that the 1990 report *AIDS in America* be considered as a potential source of baseline data.

### **Follow-Up Item**

At their next meeting, PACHA Co-Chairs will discuss mechanisms for responding to the request for a resolution or letter of support for the Stigma Index.

### **Public Comments**

**Lindsey Dawson** of The AIDS Institute stressed the urgent need for greater preparedness for the interaction of ACA and the Ryan White program, which will be critical to ensuring that PLWHA make a smooth transition to the new system while ensuring that the excellence and expertise of the Ryan White program are preserved. She reiterated the request made by PACHA in a recent resolution that HRSA and the Centers for Medicare and Medicaid Services work collaboratively to help Ryan White clients transition to health care coverage under ACA. She also reiterated a request that The AIDS Institute has been making for 2 years that HRSA form a work group with outside partners to address smooth implementation of ACA.

The need for guidance is urgent and includes topics such as the Ryan White program payer of last resort issues, the use of case managers to determine eligibility and assist with enrollment, the use of ADAP funds for insurance premiums and copayments, the inclusion of Ryan White providers in provider networks, and the establishment of billing systems. Toolkits and guidance should be developed and disseminated to Ryan White grantees and clients. The current lack of preparation is a real concern and could have a devastating impact on PLWHA, their care networks, and their communities. If we expect to improve the treatment cascade, meet the

goals of NHAS, or see an end to AIDS, we must leverage both the Ryan White program and ACA and ensure they function cohesively together, Ms. Lawson concluded.

While it is not customary for PACHA to respond to public comment, Ms. Mahon noted that PACHA formed a working group to address the Ryan White Program and ACA, at the request of HHS Secretary Kathleen Sebelius. She acknowledged that the situation is challenging, because only partial information is available to answer many questions. Ms. Mahon encouraged The AIDS Institute and others to keep advocating for more information.

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

PACHA staff will contact The AIDS Institute during the planning process for the PACHA meeting on ACA and the Ryan White program.

**Sarah Audelo** of Advocates for Youth asked that PACHA support the first national Youth HIV/AIDS Awareness Day on April 10 and recommend that the Secretary recognize it alongside other HIV awareness days. Young people do not know a time without AIDS. Every month, 1,000 people between 13 and 24 years old are infected with HIV, and young men of color are disproportionately represented among them. Youth HIV/AIDS Awareness Day will offer an opportunity to increase awareness and encourage policymakers to address the issue. More than 130 organizations and 15,000 individuals have already endorsed the creation of Youth HIV/AIDS Awareness Day.

Ms. Audelo noted that for 20 years, the CDC Division of Adolescent and School Health has funded HIV education and prevention efforts in public schools, but the most recent funding announcement includes a 25 percent cut to the program. Without full funding, whole swaths of the country will have no HIV education and prevention programs for young people, and the communities hardest hit by HIV will lose the only education and prevention infrastructure they have.

Ms. Audelo asked that the next PACHA meeting include a discussion about the content of curricula included on the HHS list of Evidence-Based Teen Pregnancy Prevention Programs, as time is running out before the next funding announcement related to teen pregnancy prevention. Finally, Ms. Audelo requested that young people be represented in future PACHA membership. They could bring important knowledge, perspective, and insight to the table.

In response to the Advocates for Youth request, PACHA members discussed various mechanisms for expressing support for a dedicated annual Youth HIV/AIDS Awareness Day.

#### **Motion**

Mr. Frost moved that PACHA declare its support for a dedicated Youth HIV/AIDS Awareness Day, as suggested by Advocates for Youth, and Dawn Averitt Bridge seconded the motion. Members voted unanimously in favor of the motion.

**Sarah Henke** of the National AIDS Housing Coalition said her organization is alarmed by the rates of LGBT homelessness and asked that more be done to ensure that all members of our society have access to safe, affordable, and appropriate housing. Of the U.S. homeless youth population (1.6–2.8 million), 20–40 percent are LGBT (disproportionately higher than the general population). These individuals often run away from home and become victims of blatant housing discrimination, abuse, victimization, and sexual assault. They are more likely to abuse alcohol, use illegal drugs, and have unprotected sex than their heterosexual counterparts. Housing status is linked closely to individual HIV risk behavior, and increasing access to stable, supportive housing can dramatically decrease the risk of HIV. When housing improves, PLWHA reduce drug-related and sexual risk behaviors by as much as half.

The current housing system fails to protect gay and transgender youth. Federal funding geared toward homeless youth is minimal, and in the austere fiscal climate, the number of youths served by Federal programs has decreased by more than 80 percent. The National AIDS Housing Coalition believes that more should be done to protect LGBT youth from becoming homeless and contracting HIV. Ms. Henke asked PACHA to call on leaders to demand that housing be considered as an essential component in the fight to improve the lives of LGBT youth and to reduce the spread of HIV/AIDS.

**Arthur Jackson** of North Carolina sent written comments. Representing rural and small communities, he said that barriers to access to care can have a devastating effect on how care counselors and coordinators serve clients. Numerous barriers disproportionately affect small and rural communities and hamper client retention, treatment adherence, disease awareness, and morale. Limited and inconsistent transportation options force programs to spend dollars on transportation instead of care or to seek alternatives, such as mobile care clinics. Mr. Jackson also pointed to the lack of recognition and funding for successful community-based programs, as well as the funding imbalance between urban and small/rural communities; he called for greater accountability for funded programs and mechanisms to support effective, cost-effective, community-based programs.

To counter religious bias, Mr. Jackson suggested that programs reach out to faith-based organizations and build relationships not based on religious doctrine but on the need for access to good health care. HIV criminalization laws impede care. They perpetuate a “separate and unequal” status and should not be allowed to stand. To improve care and care models, Mr. Jackson requested that PACHA hold regional meetings to learn about community programs that work. Because advisory boards like PACHA lack members who live, work, and receive care in the rural South, the issues of small/rural communities are not being addressed. What has been done in the past is not working, because rates of HIV infection among young black MSM are rising. Organizations receiving the most funding are not showing the outcomes needed. Community programs involving peer outreach need more support. Better partnerships across governments and more accountability are needed, Mr. Jackson concluded.

**Carol Treston, R.N.**, of the Association of Nurses in AIDS Care (ANAC), said her organization advocates for compassionate, science-informed public policy on issues concerning PLWHA.

ANAC supports the development and implementation of public policy that advocates for changing laws and policies that criminalize HIV and homosexuality. Criminal law is an ineffective and inappropriate tool to prevent HIV exposure and transmission. There is growing evidence that HIV criminalization and punishments are counterproductive and undermine current HIV testing and prevention priorities. They dissuade people from accessing needed diagnostic and treatment services and compromise the ability of PLWHA to openly and honestly communicate with their nurses and other health care providers. Furthermore, they place the responsibility of HIV prevention solely on PLWHA and undermine the public health message that HIV prevention is a shared responsibility, regardless of HIV status. ANAC supports the PACHA resolution on HIV criminalization and applauds PACHA for bringing it forward and approving it. ANAC hopes it will bring better attention to these issues and stimulate actions by Federal agencies to lead the effort to modernize ineffective and harmful HIV criminalization laws and policies, Ms. Treston concluded.

## **Conclusion**

Ms. Mahon thanked all the commenters and participants, especially those who came to the meeting in person, and said meeting attendance is very important to PACHA. She noted that some PACHA members are reaching the ends of their terms, and some have already received a 6-month extension. Those nearing the end of their terms who wish to continue serving on PACHA should contact Ms. Mahon or Ms. Hayes. The formal process for nominating new members has not been finalized, but nominations can be informally communicated to Ms. Mahon or to ONAP staff.

### **Follow-Up Item**

When PACHA staff is notified about the formal process for nominating new PACHA members, it will forward that information to PACHA members.

PACHA staff is already seeking a large, public space for the meeting focusing on ACA and the Ryan White program, possibly in April.

Ms. Hayes said resolutions approved at this meeting would be sent to the Secretary, along with a transmittal letter from Ms. Mahon. The Secretary considers the resolution, then determines the next steps and refers the issue to other agencies within HHS as she sees fit. Ms. Mahon said that PACHA resolutions are an important tool for advocacy organizations in holding the government accountable for its actions.

## **Adjournment**

Ms. Mahon thanked the participants and PACHA staff and adjourned the meeting at approximately 11:48 a.m.