

Presidential Advisory Council on HIV/AIDS (PACHA)

39th Meeting

The White House

Eisenhower Executive Office Building

Washington, DC

April 26, 2010

Council Members—Present

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

Dawn Averitt Bridge

A. Cornelius Baker

Praveen Basaviah

Douglas Brooks, M.S.W.

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

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 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 Perez

Rosie Perez

Malika Saada Saar, M.Ed., J.D.

Sandra Torres Rivera

Phill Wilson

Council Members—Absent

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

Ex Officio Government Members

Barbara Edwards, M.P.P.
Director, Disabled and Elderly Health Programs Group
Center for Medicaid and State Operations
Centers for Medicare & Medicaid Services (CMS)
U.S. Department of Health and Human Services (HHS)

Kevin Fenton, M.D., Ph.D., FFPH
Director, National Center for HIV/AIDS, Viral Hepatitis,
Sexually Transmitted Disease (STD), and Tuberculosis Prevention
Centers for Disease Control and Prevention (CDC), HHS

Ann Gavaghan, M.P.H.
Chief of Staff, Office of the U.S. Global AIDS Coordinator (OGAC)
U.S. Department of State

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

David Vos
Director, Office of HIV/AIDS Housing
U.S. Department of Housing and Urban Development (HUD)

Beverly Watts Davis, M.A.
Director, Center for Substance Abuse Prevention
Substance Abuse and Mental Health Services Administration (SAMHSA), HHS

Jack Whitescarver, Ph.D.
NIH Associate Director for AIDS Research and
Director, Office of AIDS Research, National Institutes of Health (NIH), HHS

Staff—Present

Christopher Bates, M.P.A., PACHA Executive Director, Director, Office of
HIV/AIDS Policy (OHAP), HHS

Melvin Joppy, Committee Manager, PACHA, OHAP, HHS

Presenters

James Albino, Senior Program Manager, White House Office of National AIDS
Policy (ONAP), Washington, DC

Michelle Batchelor, Senior Manager, Racial and Ethnic Health Disparities,
National Alliance of State and Territorial AIDS Directors (NASTAD),
Washington, DC

Chris Collins, Vice President and Director of Public Policy, Foundation for
AIDS Research (amfAR), Washington, DC

Jeffrey Crowley, M.P.H., Director, White House ONAP, and Senior Advisor,
Disability Policy, Washington, DC

Ann Gavaghan, Chief of Staff, OGAC, U.S. Department of State,
Washington, DC

Wanda K. Jones, Dr.P.H., Principal Deputy Secretary for Health, HHS,
Washington, DC

Barbara Joseph, Executive Director, Positive Efforts, Houston, TX

Gregorio Millett, M.P.H., Senior Policy Advisor, White House ONAP,
Washington, DC

David Munar, Vice President, AIDS Foundation of Chicago, Chicago, IL

Linda H. Scruggs, Director of Programs, AIDS Alliance for Children, Youth &
Families, Washington, DC

Adelle Simmons, M.P.A., Policy Advisor, White House ONAP, Washington, DC

DAY 1

MORNING SESSION

Welcome

PACHA Chair Helene D. Gayle introduced herself and welcomed all, adding that it was a pleasure to see so many members of PACHA present, as well as guests for the public portion of this 39th meeting of the full Council. Dr. Gayle noted that much had taken place since the full Council's first meeting in February and very preliminary discussions. Now, at this meeting, PACHA will delve into the substance of its charge and, importantly, receive public input as its members engage in discussion and process.

Dr. Gayle introduced PACHA Executive Director Christopher Bates to provide a recap of the February full Council meeting and review of this meeting's agenda prior to the swearing-in of three PACHA members by HHS Principal Deputy Secretary for Health Wanda K. Jones.

Recap of Previous Meeting and Agenda Review

Previous Meeting

Mr. Bates noted that the full Council's first meeting in February was an orientation for members on what they can expect in terms of their roles, beginning with remarks by HHS Assistant Secretary Howard Koh, followed by remarks by HHS Secretary Kathleen Sebelius, and the swearing-in of all but three PACHA members by Secretary Sebelius.

Mr. Bates noted that during that first meeting, Dr. Gayle gave stirring remarks that set the tone for the importance of PACHA's work primarily in terms of the domestic HIV agenda. White House ONAP Director Jeffrey Crowley then provided an understanding of what lies ahead in the development of a National HIV/AIDS Strategy (Strategy) and a glimpse of PACHA's role in that strategy.

In that first meeting, PACHA members learned about what it means to sit on a Federal Advisory Committee Act (FACA) Council, received "dos and don'ts" guidance, and had an opportunity to ask questions about their responsibilities. Two HHS attorneys also briefed members on their ethical responsibilities.

Members also received a general orientation from ex officio Government members to several Federal agencies and offices involved in the domestic HIV arena, with the exception due to lack of time of Ann Gavaghan, OGAC Chief of Staff. The February meeting was then closed jointly by Mr. Bates and Mr. Crowley.

Overview of Today's Meeting

Day 1 of this meeting will feature the swearing-in ceremony, Ms. Gavaghan's presentation, and a panel of black women discussing "a situation brought to our attention in terms of representation on PACHA." Mr. Bates explained that dialogue had recently taken place with groups representing black women, and some of the panel's comments today will reflect that.

Following the panel, Mr. Crowley and Mr. Bates will give brief presentations on reports that reflect community interest in the National HIV/AIDS Strategy and, after lunch, Chris Collins of amfAR and David Munar of the AIDS Foundation of Chicago will talk about a framework document on improving outcomes through a National HIV/AIDS Strategy.

Day 1 will conclude with presentations from the Chairs and/or Co-Chairs of Federal HIV/AIDS Interagency Working Group Subcommittees on incidence and access to care, who are working with ONAP on the National HIV/AIDS Strategy, followed by PACHA discussion and deliberations and public comments.

Day 2

Day 2 will be an administrative day for PACHA members, during which they will break into four Subcommittees for the first time, elect Chairs and/or Co-Chairs, meet with members of the Federal HIV/AIDS Interagency Working Group, and delve into the work they have been assigned on the National HIV/AIDS Strategy. Minutes from Day 2 will not be posted on the PACHA Web site.

Swearing-In of Pending Members

Dr. Jones swore in two pending PACHA members—Mrs. Anita McBride and Rev. Calvin Otis Butts III. Jim Kim was also to have been sworn in but was absent.

Presentation by Ann Gavaghan, Chief of Staff, OGAC

Ms. Gavaghan provided an overview of the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) and OGAC's role in PEPFAR and other global AIDS relief efforts.

Ms. Gavaghan commented that many linkages exist between domestic and international efforts and that she appreciates the opportunity not only to present baseline information but also to talk about ways OGAC and PACHA can work together.

The Global Epidemic

Ms. Gavaghan noted that worldwide, according to the Joint United Nations Programme on HIV/AIDS (UNAIDS), between 31.1 million and 35.8 million adults and children were estimated to be living with HIV in 2008 (Slide 1). Clearly, she said, "AIDS is still a problem." While a great deal of AIDS fatigue exists, the fact remains that AIDS is the leading cause of death of women of reproductive age around the world, and that no matter how many are entering treatment, "more people are getting infected every day." While PEPFAR and other global efforts have made many gains, "we need to continue progress and not backslide." Because the AIDS epidemic is still a problem, "we need to keep reminding ourselves of that fact and use that as a baseline for our discussions."

The U.S. Response to the Global AIDS Crisis

In 2003, the U.S. Government (USG) launched PEPFAR, a 5-year commitment to combat global AIDS. In 2008, Congress reauthorized PEPFAR

for another 5 years (through 2013). To date, the USG has committed about \$25 billion to the bilateral PEPFAR program and to The Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund) (Slide 2).

Ms. Gavaghan noted that the U.S. response to the global AIDS crisis has always been bipartisan and that it continues to be supported by this Administration. She said U.S.-supported global AIDS relief has helped infants and families with AIDS but also has had an impact on health care systems around the world, including better data collection systems. When OGAC talks about achievement of Millennium Development Goal Six, it also talks about the importance of linking this goal to other Millennium Development Goals.

Ms. Gavaghan noted the Federal agencies that work together to implement PEPFAR under the leadership of OGAC and Ambassador Eric Goosby (Slide 3). Recently, OGAC added the U.S. Department of the Treasury (Treasury) to the list to provide technical assistance. This has furthered OGAC's goal to be a model for interagency cooperation through PEPFAR.

PEPFAR Results

In FY 2009, PEPFAR:

- Directly supported antiretroviral therapy (ART) for more than 2.4 million people living with HIV/AIDS (PLWHA)
- Supported HIV counseling and testing for nearly 29 million people, providing a critical entry point to prevention, treatment, and care
- Supported prevention of mother-to-child transmission (PMTCT) programs that allowed nearly 100,000 babies of HIV-positive mothers to be born HIV-free, adding to the nearly 240,000 babies born without HIV due to PEPFAR support from FY 2004 to FY 2008
- Supported care for nearly 11 million people worldwide affected by HIV/AIDS, including more than 3.6 million orphans and vulnerable children.

5-Year Strategy: Vision and Directions

In order to turn the tide of this global pandemic, PEPFAR will work through partner governments to support a sustainable, integrated, and country-led response to HIV/AIDS.

Within this vision, PEPFAR's goals are to:

- Transition from an emergency response to promotion of sustainable country programs
- Strengthen partner government capacity to lead the response to this epidemic and other health demands

- Expand prevention, care, and treatment in both concentrated and generalized epidemics
- Integrate and coordinate HIV/AIDS programs with broader global health and development programs to maximize impact on health systems
- Invest in innovation and operations research to evaluate impact, improve service delivery, and maximize outcomes.

Ms. Gavaghan explained that OGAC envisions partner governments continuing to work with nongovernmental, faith-based, and civil society organizations and in other ways “to make sure they are tapping all the resources available to them so disparities do not exist from area to area.” Partner government accountability will be important.

Ms. Gavaghan emphasized sustainability mechanisms for service delivery. PEPFAR has established health systems where none existed and now wants to make sure those systems are there in the end. Functions include not only training but also “creating demand.” Ms. Gavaghan said, “We want to make sure we are looking at the needs of PLWHA first as people, and then make sure HIV services are integrated with other services, such as malaria prevention for children. We want to make sure more services are available at the clinic level and also that funding streams are coordinated to get care out there in an efficient and quality way.”

Ms. Gavaghan invited members to visit <http://www.pepfar.gov> for more details.

PEPFAR’s 5-Year Strategy: Prevention

Activities:

- Support countries in mapping and documenting current and emerging prevention needs and targeting activities to most-at-risk populations
- Scale up high-impact, evidence-based, mutually reinforcing combination prevention approaches
- Address structural factors, such as existing economic, social, legal, and cultural conditions that contribute to increased risk for HIV infection
- Contribute to the global evidence-base related to prevention.

Targets:

- Support prevention of more than 12 million new infections
- Ensure that every partner country with a generalized epidemic has both 80 percent coverage of testing for pregnant women at the

national level and 85 percent coverage of antiretroviral prophylaxis, as indicated for women found to be HIV-infected

- Double the number of at-risk babies born HIV-free
- In every partner country with a generalized epidemic, provide 100 percent of youth in PEPFAR prevention programs with comprehensive and correct knowledge of the ways HIV/AIDS is transmitted.

Ms. Gavaghan emphasized that an overall goal is to make sure responses match the epidemic and address stigma and discrimination.

PEPFAR's 5-Year Strategy: Care and Support

Activities:

- PEPFAR is working with partner governments to strengthen the capacity of families and communities to provide quality family-based care and support for orphans and vulnerable children.
- PEPFAR is working with countries to expand coverage of a quality basic package of care and support services for PLWHA and their families linked to prevention opportunities.
- Populations that are often marginalized and face discrimination must have equal access to quality care and support services so that all can live healthier lives.

Targets:

- Support care for more than 12 million people, including 5 million orphans and vulnerable children
- Every partner country with a generalized epidemic reaching a threshold of 65 percent coverage for early infant diagnosis at the national level and testing of 80 percent of older children of HIV-positive mothers, with increased referrals and linkages to care and treatment.

PEPFAR's 5-Year Strategy: Treatment

Activities:

- PEPFAR is continuing to support scale-up of treatment.
- Through country- and global-level efforts, PEPFAR is creating increased sustainability and capacity in treatment efforts and supporting countries in mobilizing and coordinating resources from multiple donors.
- PEPFAR is working with countries and international partners to expand identification and implementation of efficiencies in treatment while

ensuring continued expansion of measures to maintain adherence, quality, and retention in care.

- OGAC also is working to raise awareness of unmet needs, which will require the USG through PEPFAR, the countries where we work, the Global Fund, and others to have shared responsibility and response.

Target:

- Direct support for more than 4 million people on treatment, more than doubling the number of people directly supported on treatment during PEPFAR's first 5 years.

Ms. Gavaghan commented that world villages will be a great challenge for PEPFAR over the next 5 years, and that care and support links will often be "the easiest links to get out there."

She also commented that coordination of all efforts to get the most value is a challenge OGAC is working on. Nonetheless, "we are committed to scale up, and we are doing it."

PEPFAR's 5-Year Strategy: Sustainability

Ms. Gavaghan noted that during its first 5 years, PEPFAR demonstrated that it was able to scale up "in a way no one could imagine." Now the emphasis is on how we support this at a governmental and nongovernmental level.

Activities:

- Develop Partnership Frameworks—5-year strategic agreements for cooperation between the USG, the partner government, and other partners—to combat HIV/AIDS in countries through service delivery, policy reform, and coordinated financial commitments
- Expand technical assistance and mentoring activities with partner country governments in order to help create long-term capacity to manage and oversee programs.

Targets:

- Support training and retention of more than 140,000 new health care workers to strengthen health systems
- Ensure that in each country with a major PEPFAR investment (greater than \$5 million), the partner government leads efforts to evaluate and define needs and roles in the national response
- Ensure that every partner country with a Partnership Framework will change policies to address larger structural conditions.

PEPFAR and the Global Health Initiative (GHI/Initiative)

What will help with sustainability goals, Ms. Gavaghan said, is President Obama's GHI, a 6-year, \$63 billion initiative announced in May 2009, that will build on existing programs like PEPFAR to maximize the impact of U.S. global health investments.

PEPFAR is the cornerstone of the umbrella Initiative, which is designed to help with coordination and integration of all U.S. global health programs based on the following principles:

- Implementing a woman- and girl-centered approach
- Increasing impact through strategic coordination and integration
- Strengthening and leveraging key multilateral organizations, global health partnerships, and private sector engagement
- Encouraging country ownership and investment in country-led plans
- Building sustainability through strengthening of health systems
- Improving metrics, monitoring, and evaluation
- Promoting research and innovation.

Ms. Gavaghan noted the existence of a related consultation document, a new version of which will be released shortly.

PEPFAR's 5-Year Strategy—Multilaterals:

- PEPFAR's success is linked to the success of its multilateral partners, particularly the Global Fund. In order to ensure the long-term sustainability of the Global Fund, PEPFAR will support reforms that create conditions for eventual transition of some PEPFAR programs to Global Fund mechanisms.
- PEPFAR will support efforts by UNAIDS to mobilize global action and facilitate adoption of country-level changes that allow for rapid scale-up of key interventions.
- Given the important role of the World Health Organization as the key normative global health institution, PEPFAR is working to expand collaboration and promote best practices with this organization.
- PEPFAR will expand efforts to coordinate with multilateral development banks and support their health systems investments.

Ms. Gavaghan noted that as she speaks Ambassador Goosby is attending the Global Fund Board meeting to discuss issues related to the next funding round.

PEPFAR's 5-Year Strategy—Moving Forward:

- Implementation discussion will be held with the field.
- There will be review and revision of guidance.
- There will be continued participation in the GHI.
- PEPFAR will move forward with Partnership Frameworks.
- PEPFAR also will move forward with new staffing and structures.

Ms. Gavaghan noted that PEPFAR will continue to coordinate with other agencies in the Initiative to ensure support for HIV programs across the board and will be trying to use its own field teams to enforce coordination goals. PEPFAR's annual meeting with partners will take place next month, during which rollout of revised guidance is anticipated.

PEPFAR Issues

PEPFAR has strategies for dealing with multiple issues. To see more, go to <http://www.pepfar.gov>. PEPFAR is also on Facebook and Twitter.

Discussion/Comments/Questions and Answers

Highlights:

- Dr. Gayle noted that while most of PACHA's work will focus on the National HIV epidemic, global issues are also part of PACHA's overall charge. When meeting with Ms. Gavaghan, Dr. Gayle has been impressed by how much we have to learn from each other and the ways in which international efforts can inform domestic efforts.
- Responding to a question about how other multilateral global relief efforts are faring in relieving the pressure on PEPFAR, Ms. Gavaghan said many developing countries have engaged the United States' multilateral partners, including the Global Fund, as well as bilateral partners. At present, U.S. Ambassador Goosby is at the Global Fund Board meeting trying to raise the level of awareness about unmet needs and also "how we work with coordinating mechanisms to strengthen management and coordination between PEPFAR, the Global Fund, and other on-the-ground sources."
- Responding to the comment that there seems to have been a lack of effort to foster interaction, communication, and learning from each other at a national level as pertains to the Caribbean, Ms. Gavaghan said "more could be done," and that OGAC has already been discussing the Caribbean and Central America with OHAP and that the United States recently signed an agreement with Central American nations to increase this interaction.

- Responding to a comment about how domestic epidemics could benefit from integration into the global response, causing domestic and global programs to work more closely in funding, outlook, and outcome, Ms. Gavaghan applauded the speaker, stressing the importance of working on this as well as strengthening communication and information exchange between the domestic and international sides.
- Responding to a query about whether women and girls are a priority in the global epidemic, Ms. Gavaghan noted that the GHI prioritizes implementation of a women- and girl-centered approach and that PEPFAR is working toward that, particularly in Sub-Saharan Africa. PEPFAR has had a gender strategy that addressed gender violence, but now field teams have guidance to implement more strategies on the ground, according to what is happening in their countries, including strengthening PMTCT efforts. Skilled attention at birth and access to prenatal care make a difference, and “we’re working to strengthen that in countries where it has been lacking.”
- Responding to observations about the South African program’s partial focus on women and leadership, Ms. Gavaghan noted that in the context of the GHI, “we often talk about and are addressing women as caregivers and also how women often serve as leaders in services and in their community.”
- It was observed that the Initiative also focuses resources on areas with the highest incidence and new infections and therefore might prove useful to those engaged in or considering changes in domestic policy.
- Responding to a query about biomedical and legal approaches, Ms. Gavaghan said country context and need are being examined, as in, for example, where circumcision might be a possible priority and where general equity could be addressed through new laws. Ms. Gavaghan noted a large study in Kenya that discovered pockets of new infection where both generalized and targeted prevention efforts are needed. She stressed that these efforts need to be mutually reinforcing to help prevent further stigmatization and marginalization of some populations, including injection drug users and men who have sex with men (MSM).
- Responding to a query about PEPFAR support for use of mobile technologies in prevention and access to care efforts, Ms. Gavaghan said OGAC has a “robust” public/private partnership office working with relevant partners, such as Phones for Mobile Health, to pilot innovative projects. Once there is a successful pilot, the question will be how OGAC would work with governments for a national response.
- Responding to a comment about PEPFAR’s budget this year being “only \$6.7 billion” and a query about OGAC’s plan to make sure this funding is spent, Ms. Gavaghan said, “Every person we put on treatment is a

person we have a moral obligation to continue on treatment." When "we hear about potential treatment shortages, we want to know and we will try to troubleshoot them, working with our country teams." When working on the country level, "we are making sure we maintain and expand the number of those on treatment, and we are comfortable that we'll be able to scale up treatment with our budget."

- Responding to observations about PEPFAR and Global Fund cooperation and a query about cases where some nongovernmental organizations continue to be funded by PEPFAR but not the Global Fund, Ms. Gavaghan asked for examples so that she can follow up. She added, "There are always challenges in providing care and cases where supply breaks down," and OGAC is therefore trying to work with the Global Fund to address all these issues."
- Responding to a comment about the Millennium Development Goals and a query as to how PEPFAR is "changing the conversation" for progress on these, Ms. Gavaghan said there has been a review of Millennium Development Goals Four, Five, and Six in terms of where the U.S. global health investments have made progress and "where progress is lacking" in order to facilitate assessment of how better "to align" those investments. In the GHI, the result so far has been a broadened perspective, asking, for example, how the setup of a PMTCT clinic will affect maternal health across the board. Ms. Gavaghan added, "This is a story that needs to be told, that investments in HIV/AIDS are investments that really help across the board."
- Responding to a query about the role of Treasury in technical assistance, Ms. Gavaghan said PEPFAR's reauthorization addresses working with Treasury so that country teams can take advantage of costing analyses and modeling and engage finance ministries as well. OGAC is thinking about whom else it needs to bring in as it works through the GHI to identify other "synergies," such as safe water.
- Responding to how PEPFAR will communicate to communities its analyses of what works and what does not work, Ms. Gavaghan said the question was excellent and that "this poses a major challenge for us, as operations and implementation research is not traditional research." At present, OGAC is exploring how to make sure more best practices get out to the field, in part due to congressional reporting requirements, "which will help OGAC accomplish this."

Discussion Conclusion

Dr. Gayle asked how many in the audience are working on domestic as well as global issues and concluded, after a show of hands, that was most likely a majority. "We've become global in our thinking over the past few years," she observed, adding that funding sources and other programs key to PEPFAR's

success are “all themes PACHA will discuss more in terms of our general roles.”

Positive Black Women Presentations/Panel

Dr. Gayle introduced Michelle Batchelor, Senior Manager, Racial and Ethnic Health Disparities, NASTAD; Barbara Joseph, Executive Director, Positive Efforts; and Linda Scruggs, Director of Programs for the AIDS Alliance for Children, Youth & Families, to give presentations as individuals and as a panel.

Dr. Gayle said it is important for PACHA to have this panel for a variety of reasons, including the impact of HIV on women, particularly African American women and other women of color, and to ensure that the voice of positive African American women “is part of PACHA’s deliberations.”

HIV-Positive Black Women

Presentation by Michelle Batchelor, Senior Manager, Racial and Ethnic Health Disparities, NASTAD

Before beginning her presentation on the epidemiology of African American women living with HIV, Ms. Batchelor explained that in her role at NASTAD, she works with community partners to prioritize black women in their jurisdictions. To date, some 24 State and city teams have taken this model “and done a lot of work.” Most recently, NASTAD has completed an issue brief based on data that highlight the perspective of HIV-positive black women. She also congratulated the Administration on passage of the health care reform act and ONAP for its work on the National HIV/AIDS Strategy. As we move into implementation of both of these, she said, “it will be important to listen to those most impacted by HIV/AIDS.”

A Leading Cause of Death for Black Women

Ms. Batchelor noted that of the estimated number of women living with HIV/AIDS at the end of 2007, 65 percent were black/African American. The disease also is a leading cause of death for black/African American women. The CDC estimates that if the rates of AIDS among the newly diagnosed continue to climb unabated among black women, they will reach rates “that will even rival men’s.” Therefore, “we have our work cut out.”

HIV/AIDS Risk: Contributing Factors

Contributing factors to HIV/AIDS risk include poverty, unequal access to health care, lower educational attainment, employment discrimination, language barriers, incarceration, social networks, stigma, and relationship inequality.

Ms. Batchelor said nearly 25 percent of black people in the United States live in poverty, which influences access to health care and the quality of health

care they receive, including that provided by infectious disease specialists. Lower educational attainment, lower employment levels, and inability to afford insurance are other important factors. “Significant” are language barriers used in messages related to HIV/AIDS; i.e., “are we using language understood” by those most at risk, or “are we too clinical?” Incarceration is a factor due not only to high rates of incarceration in black communities, but because black women tend to date black men, tend to live in segregated situations, and “when our men are jailed, our social network gets even smaller.”

Other contributing factors are stigma, sexuality, disclosure, and, in relationships, dependency on others to house and feed families. Power dynamics in relationships are a factor in the ability to negotiate use of protection, such as condoms, as well as protect oneself from violence and abuse. Ms. Batchelor said that one out of every two HIV-positive women experienced sexual violence before age 18.

Finally, there is a need to consider other perceived risks, such as substance abuse and mental health.

Considerations and Strategies From Positive Black Women

Findings from NASTAD’s recently released issue brief titled “Black Women and HIV/AIDS: Findings From Southeast Regional Consumer and Provider Focus Group Interviews” include the need to prioritize women-specific services, housing, transportation, prevention messages, interventions, advocacy, community collaboration, and inclusion of HIV-positive black women.

During consumer and provider focus group interviews, interviewees stressed the need not only for women-specific but also for culturally competent and sensitive services. Transportation came up as an issue often in the rural South. Interviewers concluded that prevention messages and interventions need to include “home-grown” ones delivered by people “who look like” the affected. “Most importantly,” interviewees stressed they need to be asked to be part of the decisionmaking process.

Introduction of Other Panel Members

Ms. Batchelor introduced Barbara Joseph, Executive Director, Positive Efforts; and Linda Scruggs, Director of Programs, AIDS Alliance for Children, to provide their perspectives as positive black women.

Ms. Joseph spoke first. Ms. Batchelor said Ms. Joseph is a tireless advocate and also has a health clinic named for her in Houston. Ms. Batchelor noted that Ms. Joseph and Ms. Scruggs are both members of the National Black

Women's HIV/AIDS Network. Ms. Scruggs also is a mother of three whose family priorities are "clear in her bio." As the minister of her local church, Ms. Scruggs finds strength and motivation in the HIV community, working tirelessly with women.

Barbara Joseph

When Ms. Joseph was diagnosed with HIV 28 years ago, she was told she had 1 year to live, so she did all the things in that first year she needed to do before dying.

Over the past many years, Ms. Joseph has run into hundreds of thousands of women from all over who have real issues, and, when given an HIV diagnosis on top of all the other challenges, have a deep sense of despair. They have to deal with stigma, although that is "not as bad as it once was," fear of the unknown, and wondering about whether they will die tomorrow.

What others have said is absolutely true, Ms. Joseph said. For example, there is a lack of stable housing for these women. They have to qualify and, in many cases, do not have proper documents. Many have limited education. Many are older women who were once married. Then, suddenly, everyone is gone, and they find themselves having to get back in the workforce and learn new skills. Even with jobs, they make low wages that do not give them accessibility to health care and what they need to survive on.

Ms. Joseph said there are a million barriers to services, and those who do not have to deal with these barriers do not have to think about it. But when everything else is gone, "you really have to think." So, positive black women need to know about their eligibility criteria and ask whether these criteria are too difficult for many in this country. If people are trying to get housing and primary care, and they are asked for a bill showing their home address, some cannot provide that because they live in a shelter or are homeless. "That is a problem." For others, lack of treatment for substance abuse is a problem. If someone says she is ready to go into care, well, there is a 30-day waiting period where Ms. Joseph comes from.

Sometimes Ms. Joseph wonders how she can keep a person in her office and hold her hands because sometimes there are no funds out there to get the person into the care she needs, and "that's a problem, for the community and for that person."

African American women are at the highest risk for HIV/AIDS, and some of the reasons, Ms. Joseph said, are that they thought AIDS "was over." They may have been used to seeing media campaigns, but all of a sudden these messages do not appear anymore. And some people say they hear that

Magic Johnson is well. Therefore, more media campaigns are needed, such as those we see on television about Viagra[®]. We also “need to talk to folks in a way that is understood.” Ms. Joseph said all these acronyms she has heard so far today are not useful in messages. We also need “women and childcare and women and their children, but has anyone thought about those who don’t have children and maybe don’t qualify for some things?”

Ms. Joseph said the Joseph Hines Clinic in Houston was named in part for her because she had done “a lot of raising cane in the community, so to speak,” but there is a problem. “I can’t access care.” Twenty-eight years after being diagnosed, with 25 of those years devoted to working on HIV/AIDS and having a clinic “named after me, I’m not qualified,” Ms. Joseph said.

Ms. Joseph has been told that because she has a nonprofit organization, she must have insurance. And she has fought for some time to get her 10 employees insurance, but if she throws herself into the pool, with her preexisting condition, that is a problem. Ms. Joseph said she has even sought out high-risk pools, at premiums costing \$1,676 per month. “At first, I thought they meant per year.” The upshot is that Ms. Joseph cannot afford insurance, even on her salary. Some have suggested that she go on AIDS Drug Assistance Program (ADAP) drugs, but she does not qualify. Without insurance or assistance, she is looking at having to pay something like \$1,500 for a bottle of ATV [atazanavir], but she cannot afford that, so she does not take HIV drugs. “I probably should, but I don’t. I am healthy still. I have not taken the drugs since 1996. An infectious disease specialist told me that maybe this is a good thing.”

The people Ms. Joseph’s organization advocates for make less than \$30,000 per year, so “how can they afford to take care of themselves?” They cannot do it “if we’re not there to help.”

These are issues that need to be brought to decisionmakers through interaction “so that we’re all on the same ball field,” Ms. Joseph said. A positive trend is that “churches are working with us, much better than they did years ago.” Yet there are waiting lists in many States—waiting lines for treatment, for medication, and for housing. “With all that, how can positive individuals have a quality of life?”

“We in the National Black Women’s HIV/AIDS Network have come to say to you in our voices what is happening out there,” Ms. Joseph said, because the individuals she has been talking about “won’t be able to come talk to you.” And that is why the Network has asked to be part of the PACHA process. “We want to be part of crafting the strategic plan so all have an equal

chance. We're not asking for a handout," Ms. Joseph concluded. "We're asking for a hand up."

Linda Scruggs

Ms. Scruggs said it has been 20 years since she was diagnosed. She called the National HIV/AIDS Strategy a great public health leadership strategy, but she is asking PACHA "to make sure it is not just another document." The United States is part of the global epidemic, and it is important for the Strategy to be implemented, monitored, and evaluated. She advocated that during at least the first 24 months, PACHA receive quarterly reviews of the plan, and that those reviews be available for release. She advocated that PACHA also receive 5-year reports.

Ms. Scruggs urged ONAP to continue community engagement so that "we can act to engage in the rollout of the plan in all phases, particularly rollout among our communities." Other special populations need to be part of the rollout as well, she noted.

Ms. Scruggs said she and the National Black Women's HIV/AIDS Network believe that fulsome participation in the rollout and updates of the Strategy's progress "will gain successes that will help recoup barriers encountered." All along, "ongoing consultation of the process with stakeholders [is necessary] to make sure the Strategy is successful for the most impacted."

Reflecting on contributing factors, Ms. Scruggs asked PACHA members "to sit back and think with me about whether they have ever been someone who could not read or write to their own satisfaction, or ever felt 'less than,' or looked in the mirror and did not like what they saw." She asked, "Were you ever told you were ugly, did anyone ever tell you would not be much or even nothing, or did you ever have to ask for help and did not know where to go? Have you ever stood in a line for a handout or broken a chicken wing in half to feed your two children, been a victim of a violent crime, or even found yourself in a situation where you were committing a crime? Have you ever been stranded with no one to call, ever thought the world would be better without you, or stood on a ledge and wished you had the strength to jump, or sat in a room where someone told you there is no tomorrow?"

These are "big things to have to live," Ms. Scruggs said, and by the time she was 27 years old, she "had lived them all." She thought she was unique, but she found that many other black women she has met have unfortunately felt and experienced these things. So "this is a cry from black women to be in the room with you."

"How did we get there? Was there opportunity there? Sure there was, but opportunity can look like barriers too," Ms. Scruggs said, adding that while she has never lived in poverty and was locked up for 2 days in the Baltimore jail but never incarcerated, in 1988, she made a conscious decision to change her life. "Why that doesn't work for everybody, I don't know, but it worked for me." As a result, she is 22 years drug-free. She pulled up her bootstraps. While it is true she did not live in the projects at that time, "I delivered cocaine to them."

Three raw chicken wings and a bowl of rice to feed four people is "the life of many black women I have talked with," Ms. Scruggs said. But there is another population that she would like to introduce, and that is a population represented by a support group she began long ago. In the support group were 10 black women living in the Washington-Baltimore Metropolitan Area with a median annual income of about \$120,000, some of whom had been diagnosed 10 years and had never revealed it. Ms. Scruggs noted how one of the women simply could not talk about "what was going on with her."

To conclude, Ms. Scruggs said she wants PACHA to be "very conscious" as it makes decisions and serves in its advisory capacity. She asked PACHA to "hold ONAP accountable for the work they need to do to make sure me and my sisters wide and far are represented." Many of these women "still stand in social service lines because many Americans have failed us." Noting that by the time she was 18, she had been raped twice in secrecy and "didn't know where to go," Ms. Scruggs said, "thousands of women we encounter have similar stories." She added that she "hopes some of these women are here next time" PACHA meets because "we need to get to the grassroots level, to the heartbeat of this epidemic. Women like Sheila in Baltimore "don't have to buy chicken wings anymore because she got one of three jobs that my job was turned into." Women like Sheila "don't want you to pay their rent or to get food stamps." Rather, they need the Strategy "to make a difference hitting the ground."

Concluding, Ms. Scruggs said, "We're not asking for a handout. Women need a hand up."

Discussion/Comments/Questions and Answers

Highlights:

- It was commented that at present we lack an operational plan for understanding structural factors, so this is something the domestic response might address, particularly as PEPFAR looks at different models and interventions at the international level.

- It was commented that the stories told this morning are informative, moving, and give a face to the epidemic, “which we don’t hear enough about.” This member of PACHA also expressed the hope that “you will continue to advise us.”
- Responding to a query about the percentage of diagnosed African American transgender women, Ms. Batchelor said she is unaware of data on this offhand but that she is working with NASTAD to look at that with youth populations. At present, NASTAD “separates transgender populations from other communities because the issues are unique.” Ms. Scruggs commented that there is little national data on transgender populations.
- It was commented that a meta-analysis of several transgender studies has shown that as many as “30 percent of transgender individuals are positive” and “few have health care access.” The analyzed studies were conducted in San Francisco, Minneapolis, and New York City.
- Responding to a query as to whether she works with Cecilia Maxwell at Howard University on a voluntary testing program for African American women, Ms. Scruggs said she knows the program but not well enough to say it is a model.

Discussion Conclusion

Concluding the discussion, Dr. Gayle thanked Ms. Batchelor, Ms. Joseph, and Ms. Scruggs for bringing the voice, faces, and the data of the epidemic among African American women to PACHA. “We will continue to talk about these issues,” she added.

National HIV/AIDS Strategy Update: Progress to Date

Dr. Gayle asked Mr. Crowley and Mr. Bates to provide updates on the Strategy.

Update and Community Ideas for Improving the Response to the Domestic HIV Epidemic:

A Report on a National Dialogue on HIV/AIDS, by Mr. Crowley

Mr. Crowley welcomed everyone once again to the White House, adding he was glad to know that representatives from AIDSWatch are present.

Update

Since January, the Federal HIV/AIDS Interagency Working Group has been convening to help ONAP develop the National HIV/AIDS Strategy. The working group has an overarching committee composed of senior leaders and three Subcommittees organized around three goals—incidence, access to care, and disparities. In addition, ONAP has established an implementation group to “help us think about how to roll out the Strategy and ensure that implementation is a success.”

The working group has been meeting every 2 weeks, in person or through conference calls, with the result that a lot of information and ideas are “out there.”

The Subcommittees are looking at comments from the public and have forwarded their top-tier thinking and recommendations to the overarching committee. That process is ongoing. In addition, the overarching committee has heard from PACHA members about better coordination and more accountability, so “that’s another charge—how to do that better.”

At present, ONAP and the working group are on track to have a Strategy ready by late spring or early summer, or so Mr. Crowley hopes. “One of the things we are trying to do very clearly is not produce a laundry list,” he added. Rather, the Strategy will be composed “of a short list of a small number of strategic steps we can take.” A Federal implementation plan also will be developed. It is hoped that “the Strategy will be clear and concise, and then the implementation plan will outline key steps the Strategy needs to take.” Success, Mr. Crowley added, “will be in what everyone does collectively.”

Two Big Steps Coming Up

To ensure broad buy-in to the Strategy, a planning meeting of deputy secretaries from relevant departments will be held in late May before moving forward, Mr. Crowley said.

In addition, “we promised that the community could come to us before we forward our recommendations to the President.” Therefore, prior to the late May meeting, ONAP will sponsor two opportunities on May 14 for the community to provide input, from 11:00 a.m. to 12:30 p.m. face-to-face and possibly onsite at the White House, then from 1:00 p.m. to 2:00 p.m. that day through a conference call. There will be a process for registering to participate in “this opportunity for us to update you on key issues and hear from you.” Mr. Crowley stressed that this is not a rollout but, rather, an opportunity for input prior to forwarding of recommendations to the President. He noted, “We’ve talked to many of you many times in a robust and hopefully fruitful process.”

The ONAP Report

Mr. Crowley then provided highlights from the “Community Ideas for Improving the Response to the Domestic HIV Epidemic: A Report on a National Dialogue on HIV/AIDS,” released by ONAP in April and available at <http://www.whitehouse.gov/onap>.

The report, a summary of community recommendations, is the result of ONAP's conducting 14 community discussions in locations across the United States and its territories, during which more than 4,200 spoke. More than 1,000 written recommendations were received as well.

Key messages received include:

- Reduce incidence
- Increase public awareness
- In terms of scaling up testing, target it and take diverse approaches
- Increase HIV surveillance
- Increase access to condoms
- Lower barriers to needle exchange
- Lower community viral load
- Ensure that all prevention activities are grounded in science.

In terms of data collection and surveillance, "we have more gaps than information, and we heard the need to do better in filling those gaps," Mr. Crowley noted. In the broad issue area of access to health care coverage, "we can all agree that access is important." It is clear that services are needed to get and keep patients in care. In addition, ONAP heard a lot about "comorbidities and structural issues." Also addressed were workforce issues. "We have a fragile workforce, and we will need to focus on it," Mr. Crowley said, as well as on unique challenges in rural areas.

The community also provided a great deal of feedback on specific populations that need to be focused on to reduce the domestic epidemic. "We heard a lot about women of color, and gay and bisexual men, and transgender populations."

ONAP also heard about the need for better coordination across the Federal Government, including coordination of grant application dates, as well as the need to reduce stigma. "In one place, we heard that basic services couldn't be accessed, even in the hospital. We also heard about doctors' being too afraid to get too close. And about women in the Bible Belt being counseled to have abortions. That shows us that we've done some things about stigma, but still have a lot to do."

Mr. Crowley concluded by noting that ONAP is working to get the report translated into Spanish, and he hopes to have that translation available soon.

OHAP's Community Discussions and Report, by Mr. Bates

Community Discussions

Mr. Bates noted that HHS and OHAP staff visited five cities—Memphis, Seattle, Cleveland, Oklahoma City, and New Orleans—to gather community input and had experiences similar to ONAP's.

During the meetings, people shared amazing stories and “told us very intimate things about themselves that gave us a clear picture of the importance of prevention.” Prevention messages “aren't getting through, folks, and until we can talk about sexual behavior and substance abuse...”

Noting that PACHA had just heard women talk about African American women's experiences, during the meetings, “we also heard white, Latina, and Native American women talk about similar challenges—about poverty and class.”

In sum, from OHAP's experience during this outreach with HHS Assistant Secretary Dr. Howard Koh, “we found a lot of similarities from one community to the next, so we have to do a better job on what our best practices are.” People in the communities “asked about that, in terms of how we find out what really works,” leading to the conclusion that “we need a conversation about what is and is not working, who is in and who is out.”

The OHAP Report

OHAP's report on these community meetings is not currently available in print. Rather, members can access it through a link Mr. Bates' office has provided. The report will also be made available to the public at <http://www.AIDS.gov>.

The OHAP report is not an analysis of what was heard. Rather, it reports “what people actually said.” In a way that was painful, although different people spoke, “the messages were pretty much the same,” Mr. Bates said. In short, “we have a lot of work in front of us.”

Morning Wrap-Up

Highlights:

- A PACHA member noted that youth and HIV meetings have generated reports on several different topics, yet it seems that the ONAP report does not delineate youth-specific findings. The member suggested that youth-specific meetings findings would broaden the ONAP report, including addressing the difficulty of transitioning from childhood and adolescence to adulthood and being out on one's own.

- Responding, Mr. Crowley said ONAP can look into doing something “in terms of more details.” While there is a clearance process for posting on ONAP’s Web site, there is no reason youth reports could not be posted elsewhere while ONAP works with interested PACHA members “to post a synopsis on ONAP’s Web site.”
- Responding to a PACHA member’s query about whether ONAP will support HR1964 and its counterpart in the U.S. Senate, which address the need for coordination in terms of resources, tracking, accountability, and other matters of interest to several black clergy across the country, Mr. Crowley said his office does not have authority to take positions on specific legislation, but it can highlight themes that are important.
- Responding, Dr. Gayle said that as the Strategy rolls out, the voices of people in the room today, including PACHA members, “can make sure we are moving forward with such aspects.”
- Mr. Crowley added that ONAP is hoping other stakeholders have their own strategy, as in “here is where we support the Strategy, and here are some other positions.”
- Mr. Bates noted that in the past, PACHA has passed resolutions regarding legislation and, at present, there are continuing opportunities for PACHA “to weigh in on legislation.”
- A PACHA member suggested that the impact and importance of youth and the epidemic need to be indicated in the ONAP report and that the elderly, the “other bookend of the epidemic,” also need to be addressed. It was advocated that PACHA look at how different populations are affected within the structure of disease, so, in addition to youth, “let’s focus on and not lose track of the mature population.”
- A PACHA member and observer at the ONAP meetings said that funding disparities in rural areas are not addressed in the ONAP report. Further, funding distribution is a “sticky subject” in terms of the HUD Housing Opportunities for Persons With AIDS Program and in other HUD offices and departments. Yet “while 41 percent of cases are in the South, the South has a lot less money.” Another PACHA member agreed, advocating that funding “and how it is spread out need to be addressed.”
- Responding, Mr. Crowley said there is no intention to ignore this and that the President has said from the beginning that we need to focus resources on those at greatest risk. In the report, ONAP tried to focus on common themes, and “it’s not that we thought this was too hot to touch.” How funding is allocated “is an important issue.”
- Responding, Dr. Gayle said these are the kinds of issues PACHA can monitor and say are important. Addressing funding allocation and mismatches is “a huge part of that.”

- A PACHA member said that a Joint Center [for Political and Economic Studies] report has been released about funding. The member characterized the report as a “careful discussion” that includes recommended actions. In essence, “it’s really about borrowing from the ways in which PEPFAR looks at funding and incidence and putting funds into areas of most pressing need.”
- Responding to a query as to whether PACHA members have already weighed in on the Strategy or will on May 14, Mr. Crowley said that ONAP “can’t just selectively go to PACHA and selectively say, ‘weigh in.’” ONAP has contacted experts on PACHA about some issues but is hampered by “complex rules regarding interaction with a FACA Council that don’t allow us to meet separately with PACHA.” However, PACHA members can participate in the May 14 meeting.
- A member of the audience expressed concern about criminalization laws across the States regarding having sex with someone who is HIV-positive, even when that status is known to the partner.
- Responding, another member of the audience said that the American Bar Association would be holding a meeting on this subject in the future.

Morning Wrap-Up Conclusion

Concluding the morning wrap-up, Mr. Bates said, “PACHA members will review as wide an array of issues and topics as they choose to undertake and which time permits.” There are no restrictions on what PACHA can deliberate, in short.

In terms of criminalization, Mr. Bates said HHS is currently looking at this question, and the CDC “has taken some leadership on this.” In addition, HHS is waiting for the results of preexposure prophylaxis (PrEP) studies on whether PrEP is effective and, if so, how it could be used.

Lunch

AFTERNOON SESSION

Guest Presentation

Mr. Bates introduced Chris Collins, Vice President and Director of Public Policy, amfAR; and Mr. Munar, Vice President of the AIDS Foundation of Chicago, who gave a joint guest presentation.

Remarks to PACHA Regarding Work Group Recommendations for the National HIV/AIDS Strategy, by Mr. Collins and Mr. Munar

Mr. Collins began by thanking the President for making the National HIV/AIDS Strategy a top priority of his agenda and thanking Mr. Crowley as

well for his leadership and “really impressive efforts” to get community input to this work.

Mr. Collins and Mr. Munar summarized a framework document submitted to ONAP (and provided to PACHA members) by the Coalition for a National AIDS Strategy titled “Moving Beyond the Status Quo: Improving Outcomes Through a National HIV/AIDS Strategy in the United States.” (See also <http://nationalaidsstrategy.org>.)

Mr. Collins said the document was submitted to ONAP because the Strategy “needs to identify what is working well but also bring real reforms where needed.”

Background

More than 2 years ago, a diverse community of advocates for a National Strategy sponsored a series of community-sponsored consultations, which then led to development of the framework document by a small, independent group that included Mr. Collins, Mr. Munar, Randy Allgaier, Dr. Judy Auerbach, Sean Cahill, Rebecca Haag, Dr. Jean McGuire, Pernessa Seele, Dr. Walt Senterfitt, Dr. Dana Van Gorder, Janet Weinberg, and Toni Young. Cornelius Baker, Dr. David Holtgrave, Naina Khanna, and Phill Wilson also were contributors prior to becoming PACHA members.

Mr. Collins said the writers did their best, from their perspectives, to synthesize what they heard from the community and to frame that in the context of responding to the President’s three goals for the Strategy: reduce HIV incidence, increase access to care, and decrease HIV-related health disparities.

Mr. Collins noted there have been many AIDS strategies before, but this one needs to be different. It has to set clear targets and a path for achieving them. The present moment is a unique opportunity to create this kind of Strategy because the President himself has outlined the goals and is putting his name on the process.

Mr. Collins added that a good Strategy would make some tough choices and “step on some toes.” “It will make us work smarter, not just do more of the same.” And, “it needs all of us, even as a few of our toes are stepped on, because we will see that the Federal Government is aiming for improved outcomes.”

Target Recommendations

Mr. Munar said the framework document advances four recommendations.

The first recommendation is that the Strategy set specific benchmarks or targets that will guide all Federal HIV activities and inform State, local, and private sector efforts fighting HIV/AIDS.

Further, “we believe the Strategy should set a limited number of targets, and they should be relevant, inspiring, and easy to communicate, and transparent, and should establish baseline metrics that facilitate tracking over time.”

In order to set relevant targets, the Federal HIV/AIDS Interagency Working Group modeled where the epidemic might be in 5 years, based on current rates of growth and other evidence that might predict the epidemic’s future path. The group compared the status quo scenario against “what we might be able to achieve.” The exercise used simple inputs and assumptions and was not peer-reviewed. Therefore, the Coalition for a National AIDS Strategy urges PACHA to work with members of the working group to develop a scientifically rigorous model that can be held up to public scrutiny, adaptation, and analysis.

The framework document suggests targets in each of the three goals of the strategy informed by a simple concept: achieving a plateau where most people with HIV know their status and are stabilized with needed medical support services, deaths among people with HIV are low, and the rate of annual new infections does not exceed annual deaths.

Reaching such a plateau would be a turning point in the epidemic, sending a bold message that “we have the tools at our disposal to stop the expanding epidemic in its tracks.” Equally important, such a bold target “is inspiring and achievable.”

Achieving this goal in 5 years would allow the next Strategy to manage responsibly a steady decline in HIV/AIDS with measures “that protect the rights and human dignity of those directly affected.”

Coordination Recommendation

Addressing the framework document’s second recommendation, Mr. Collins noted that when talking to people engaged in PEPFAR, PACHA would most likely hear that essential ingredients of PEPFAR’s success included new resources, clear targets, and coordination and leadership from the top. OGAC works across agencies, has budget authority, and reports directly to the Secretary of State.

On the domestic side, “if we want to blast through the fragmented, siloed Federal response on AIDS, we will need an office, new or existing, with clear

authority and mandate to coordinate, cajole, incentivize, and hold Federal agencies accountable for working together." Therefore, "we hope that you will ask 'who is in charge here?' in terms of getting the President's goals accomplished."

While, "many great people are working very hard to address the epidemic," they are "challenged by disincentives to work with other agencies, share resources, or rock the boat in terms of programming and policy."

Mr. Collins said evidence on the ground is pushing us toward a more coordinated effort. For example, "we know too many care providers are not entirely comfortable with HIV testing; that too often, people who get a positive test result don't get linked to care; that too many fall out of care; and that research is revealing how effective HIV treatment is fundamentally linked to good HIV prevention."

Responding to these and other challenges and opportunities requires agencies like CDC, HRSA, SAMHSA, and CMS to work in a streamlined, coordinated fashion, but that requires a place "where the buck stops and that has responsibility to report annually on progress toward the President's goals," Mr. Collins said. This coordinating function could be the responsibility of HHS at a high level or of ONAP. New statutory authority might be needed, but even without legal changes, "what is required most is direction from the President for HHS and other agencies to create a coordinating office with clear authority and a mandate to get the job done on the three Strategy goals."

Initiatives Recommendation

Addressing the framework document's third recommendation, Mr. Collins noted a limited set of suggested activities and initiatives to advance the President's goals, all of which were viewed as "game changers" that have to do not just "with more resources but with more effective and better targeting of resources." For example, the document highlights the concept of linkage into all Federal efforts, from testing, to care, to adherence, which could be called "Test, Link, Care Plus" —TLC Plus—or, simply stated, good public health practice.

Also highlighted is the need for federally funded HIV prevention to follow the epidemiology of the epidemic "much more closely," particularly given findings by the CDC of "serious inconsistencies" between where Federal HIV prevention funds go when allocated by State health departments and "where the epidemic is hitting hardest, including relative underinvestment in prevention for gay men, other MSM, and African Americans."

Also highlighted is the concept of scale in prevention programming. That is, the CDC “needs to be helping local and State jurisdictions implement programming that fits the epidemiological profile and is delivered at a scale that will show population-level impact.”

Targeting, concentrating resources, and coordinating cross-agency “are difficult and politically tough,” Mr. Collins noted. He then quoted a February article in the *New England Journal of Medicine* concluding that the current domestic epidemic is characterized by “low prevalence in the general population, high prevalence among the disenfranchised and socially marginalized, with a concentration in geographic hotspots.” In short, what we do not need is more of the same. Rather, Mr. Collins emphasized, “we need a response that fits our epidemic...that is capable of coordinating multiple health and social services appropriate for communities facing a variety of challenges.”

Furthermore, Mr. Collins said that some of the initiative ideas he just spelled out “are eminently doable.” In fact, “they just represent good public health practices.” By improving outcomes on AIDS in America through reformed, more strategic efforts, “we will in fact be laying a foundation for a more effective public health effort for all Americans.”

Implementation Recommendation

Addressing the framework document’s fourth and last recommendation, Mr. Munar said the Strategy must establish “immediate next steps” for implementation in 2010, 2011, and beyond. Further, everyone involved should play a role in putting the Strategy’s recommendations in motion, including the Congress. In addition, it is recommended that the Administration scaffold implementation activities around important calendar benchmarks, including development of the President’s next proposed budget, World AIDS Day 2010, the President’s State of the Union address, the epidemic’s 30-year anniversary in 2011, and the 2012 International AIDS Conference in Washington, D.C.

PACHA’s Unique Role

Mr. Munar advocated that PACHA “play a unique role shepherding the AIDS community from a focus on development of the plan to focus on implementation, monitoring, and advocacy to ensure that the plan’s forward-looking vision is realized.”

Mr. Munar characterized PACHA’s meeting this week as “critical,” as it coincides with active deliberations by ONAP and the Federal HIV/AIDS Interagency Working Group to develop the Strategy.

In addition, hundreds of people affected by HIV are on Capitol Hill this week for AIDSWatch, and “it is not hyperbole to say that all eyes in the AIDS community are on you to see what leadership you will exercise to help shape a ‘game-changing’ strategy that moves our collective efforts forward.”

Mr. Munar urged PACHA “to take risks, to be bold” in building on the collective wisdom of so many who have made recommendations and offered advice to develop a Strategy that “maps a new course in the fight against HIV/AIDS.”

While there are “many good things” about the domestic response, Mr. Munar said, the outcomes are unacceptable due in large measure to a patchwork system “that remains uncoordinated, is not held accountable enough, and that aspires toward less-than-good outcomes.” This approach must end, and PACHA’s advocacy to change the status quo in the interest of better outcomes “is desperately needed.”

As PACHA begins its work, Mr. Munar urged members to embrace all the qualities “we have asked ONAP to embody in the development of the plan—transparency, accountability, integration, and collaboration.” That means, “we hope your recommendations to the Administration are made part of the public record, as it is certain that they will face public scrutiny.”

Mr. Munar noted that PACHA members are not known for meekness or hesitation to embrace innovation. Moving beyond the status quo “must be our mantra in all we do, and we hope you will take up that mantle.”

Conclusion

In closing, Mr. Munar commented that PACHA’s current meeting may be its last opportunity before the May 14 community briefing of key themes “and possibly the last business meeting before recommendations are made to the President.” Therefore, he urged PACHA to seize the opportunity of this meeting “to make your views known to the Administration.”

Discussion/Comments/Questions and Answers

Highlights:

- Dr. Gayle thanked Mr. Collins and Mr. Munar for “an excellent presentation that cuts across the three areas we’ll be talking about.” In addition, she appreciates the “strong push for PACHA to be bold in pushing for what we think could make a big difference.”

Federal HIV/AIDS Interagency Working Group Presentations Introduction to Federal HIV/AIDS Interagency Working Group of Committees

Incidence Subcommittee Report

Gregorio "Greg" Millett, Senior Policy Advisor, ONAP, gave a slide presentation briefly introducing the Federal HIV/AIDS Interagency Working Group of committees and their respective missions, and then detailing the work to date of the Incidence Subcommittee, for which he serves as Co-Chair.

The working group has four committees, those on incidence, access to care, disparities, and overarching matters:

- The mission of the Incidence Subcommittee is to identify programmatic and policy strategies that will result in reducing incidence of HIV and AIDS.
- The mission of the Access to Care Subcommittee is to identify programmatic and policy strategies that will result in increased access to care and optimal health outcomes among PLWHA.
- The mission of the Disparities Subcommittee is to identify programmatic and policy strategies that will result in reductions in HIV-related disparities.
- The mission of the Overarching Committee is to monitor process across the Subcommittees, identify crosscutting issues, and identify inefficiencies and opportunities for coordinated efforts across agencies.

Mr. Millett noted that the Incidence Subcommittee has been meeting since early this year to get at some of the issues that have already been mentioned, including those mentioned by Mr. Collins and Mr. Munar.

Increase Knowledge of HIV Status Among Positives

According to data published in 2006, 54 percent of persons with new HIV infections in the United States are unaware of their infection (Slide 2). Therefore, the Subcommittee largely focused on the need to increase knowledge of HIV status among positives.

The Subcommittee also focused on (Slide 4):

- Reducing risk of HIV transmissibility among diagnosed positives
- Reducing behavioral risk-taking among HIV negatives
- Addressing structural issues that contribute to HIV incidence.

Mr. Millett stressed that Subcommittee members “felt very strongly” that, in terms of bullet two, “we can’t just look at individual behavioral risk-taking,” but also must take into account structural issues.

Low Risk but Greater Infection Rates Among Heterosexual Black Adults

Slide 5 shows the results of a large study published in 2006 regarding risk differences between whites and African Americans. In sum, Mr. Millett said, Slide 5 shows that “no matter what they do to lower their risk, black heterosexuals have higher incidence levels.”

Comparable Risk but Greater Infection Rates: Black Gay Men

Slide 6 shows rates comparable to those on Slide 5 regarding black MSM. In short, Mr. Millett said, infection is not only about individual risk behaviors but also about a context that “is putting populations at risk.” He added that similar data exist regarding Hispanic populations.

Mr. Millett said the upshot is that one “can’t just look at biological factors and individual behaviors, but must also look at interpersonal relations and some social and structural factors.”

Proxy Measures

In order in part to examine interpersonal relations and social and structural factors and to track what is happening from year to year, the Subcommittee came up with a number of proxy measures associated with HIV incidence “to see which of those may have a leading edge” (Slides 8–11).

Mr. Millett commented that in terms of increasing awareness of HIV status among positives and reducing transmissibility, better measures are needed for unrecognized HIV infection (Slide 8). In addition, measuring aspects such as disease stage at diagnosis and percentage of STD diagnosis within the past 6 months (Slide 9) “are, for example, measures associated with reducing transmissibility, which is why we’re looking at them.”

In terms of reducing risk behaviors among negatives (Slide 10), all the proxy measures listed should be looked at in the context of the past 6 months, such as percentage reporting unprotected sex with HIV-positive or unknown partners, Mr. Millett said. He added that the list on this slide is not exhaustive but, rather, represents “just some of the behaviors we are interested in looking at.”

HIV Incidence Proxy Measures That Address Structural Issues

Turning to Slide 11, Mr. Millett observed that while structural issues that contribute to HIV incidence are discussed often, “that doesn’t mean we have a good definition or operationalization of these factors, so we are interested

in how we can measure them." One such factor is stigma. Even 30 years into the epidemic, "people report high levels of stigma" that result in delayed HIV testing and treatment, so, in order to deal with incidence, "we have to address this."

In addition, current CDC testing guidelines "are not necessarily being followed." If they were enforced, "there would be a greater opportunity to diagnose those who might be positive but unaware."

Other factors in need of measures or possibly better measures are:

- Availability of needle exchange programs
- Housing, poverty, joblessness
- Drug sentencing laws
- Community viral load.

Community Viral Load Predicts HIV Incidence

Slide 12 presents findings from a study published in 2009. In showing the slide, Mr. Millett noted that there has been a great deal of recent interest in community viral load. He explained that "if you look at the number of individual diagnoses and get a mean viral load in any community, then divide that by those who are positive," one can get a measure of community viral load with which one can track incidence, because it "tracks extremely well." For example, as community viral load decreases through diagnoses and linkages to care and other services, so does incidence.

Access to Private Health Insurance and Community Viral Load

Mr. Millett also noted data from San Francisco relative to access versus lack of access to private health insurance. Most striking, he said, is that community viral load "was exceedingly high for those not in therapy, so we could potentially use this measure to track incidence." Unfortunately, "few communities have data" regarding access to private health insurance due to hindrance by "certain laws."

Kaiser Family Foundation Survey: HIV/AIDS Not Perceived as Urgent Health Problem

Mr. Millett noted a 2009 Kaiser Family Foundation survey indicating that the percentage of those who perceive HIV/AIDS as the most urgent health problem facing the Nation has steadily fallen since 1995, from a high of 56 percent of African Americans in 1995, to a low of 22 percent as of March 2009, and from a high of 44 percent of all adults in 1995, to a low of 6 percent among all adults surveyed in March 2009. In sum, Mr. Millett said, "If people don't see this as an urgent health care problem, they won't get tested."

Interagency Conference Call With PACHA Members and Others

Mr. Millett noted that in a recent conference call with PACHA members and others, additional proxy measures were proposed, including the percentage of those who need prevention services and those with acute HIV infection. In addition, there was discussion of what can be achieved in the next 2 years versus a longer timeframe and the role of the private sector in reducing HIV incidence.

Conclusion

Mr. Millett observed that:

- Although he presented a number of targets and variables today, ultimately, “we have to choose three or four.”
- The Subcommittee looked not only at heavily infected areas but also at the need for increased surveillance of those who may very well be underdiagnosed, including Native Americans, Pacific Islanders, and transgender populations, to see if rates reported are true to what is happening on the ground.
- The Incidence Subcommittee will provide PACHA with another update in the next few weeks.

Access to Care Subcommittee Report

Access to Care Subcommittee Co-Chair Adelle Simmons, ONAP Advisor, gave a report on possible strategies to improve access to care and outcomes. She noted that RADM Deborah Parham Hopson, Associate Administrator, HIV/AIDS Bureau, HRSA, also serves as Co-Chair of this Subcommittee.

The Access to Care Subcommittee has reviewed some of the high-level issues concerning access to care. The Subcommittee also has reviewed a range of recommendations and has come up with its own set of ideas. In reviewing recommendations, “we tried to be wide-ranging in delivery and still consider the issues.”

Focus on Availability of Care and Access to Care for PLWHA

Care was discussed “broadly, not just clinical care but related nonmedical and supportive services, such as housing, food and nutrition, and dental care services, particularly important to certain populations, such as women with children.”

The Subcommittee also discussed access for rural communities, especially Native American communities and others living in remote areas. Transportation was recognized as a barrier to care for people in underserved areas, along with the lack of health care providers. The need to increase the number of specialists in HIV care was examined, as was the need for those

providers to have cultural competency and the ability to follow current treatment guidelines.

Health care workforce coordination was discussed in terms of being better able to address prevention and care, and also the intersection between the two. The need for more active engagement in HIV prevention by primary care providers, reproductive care providers, and STD treatment providers was discussed.

Also discussed was the need to engage more private physicians, as the Nation “can’t just rely on publicly funded programs.” In engaging more private physicians and physicians’ offices, Subcommittee members expressed the need to ensure that these health care providers are skilled and trained to address HIV as well as willing to provide care.

Also discussed were the roles of community- and faith-based organizations and peer networks “to promote and support prevention and care services through, for example, outreach and education.”

In addition, the Subcommittee discussed the need to identify mechanisms to ensure access to care until full implementation of health reform and Medicaid expansions.

Focus on Linkage to and Retention in Quality Care for PLWHA

The Subcommittee discussed the importance of assessing individuals’ needs upon diagnosis to connect them to appropriate services, including services that support retention in care. Such services may include mental health care and substance abuse treatment to facilitate HIV treatment adherence. It was noted that person-centered care offers support that people need to help them stay in care.

Also discussed were population-specific issues related to, for example, incarcerated populations and ex-offenders, who often need a range of supportive services to stay in care. It was noted that use of nontraditional sites could help link certain people, such as the homeless, to care.

Further, the Subcommittee discussed promoting high standards of quality care, including preventive services to reduce HIV-related and other comorbidities. Also discussed was access to ART for individuals whose care plans include medication therapy.

Focus on Addressing Data Gaps and Improving Data Systems across All Provider Types

In thinking about measures and targets, the Subcommittee “bumped up against data gaps.” While Federal programs collect a variety of data measures, there are some areas in which no information is available. In order to improve health outcomes, we need “better information about what works and what works most effectively for certain populations.” Therefore, “we will need to disseminate information about effective care delivery models to providers, especially for underserved communities and other target populations.” Also discussed was the role electronic health records can play in monitoring health outcomes.

Conclusion

Ms. Simmons noted that the Subcommittee discussed a number of complicated issues associated with access and structural issues and that what she presented today represents highlights of those discussions.

Disparities Subcommittee

Disparities Subcommittee Co-Chair James Albino, ONAP Senior Program Manager, noted that Beverly Watts Davis, Director, Center for Substance Abuse Prevention, also serves the Subcommittee as Co-Chair.

Mr. Albino stated the Subcommittee’s goal as one of “identifying programs and policy strategies that will decrease HIV-related health disparities.”

Highlights of the Subcommittee’s Work to Date

During a daylong, face-to-face meeting on February 25 at SAMHSA offices, Subcommittee members “took on” a number of issues identified from a broad matrix of input, including some from Mr. Collins and Mr. Munar and from ONAP’s community report.

In discussing issues, the Subcommittee recognized that some of them “congealed” around certain themes, and many tended to overlap with issues being examined by the other two Subcommittees. The Subcommittee did not write off overlapping issues but, rather, included them in its analysis.

The Subcommittee then agreed to the HHS Healthy People 2010 initiative’s definition of health disparities, with the understanding that this definition is currently under review for the 2020 initiative. The definition is as follows: “A health disparity should be viewed as a chain of events signified by a difference in environment; access to, utilization of, and quality of care; health status; or a particular health outcome that deserves scrutiny.”

In examining relevant data, the Subcommittee reached consensus on eight drivers or “buckets,” where HIV-related disparities “are most prevalent,” ranging from social determinants of care to administration issues. The eight drivers are:

- General issues related to testing and access to care, linking to prevention
- Health education and awareness not only in terms of risk behaviors but also in terms of sex education
- Stigma and discrimination
- Delivery systems, which present many challenges, including sustainable funding over the long term and specific, short-term grant funding
- Research, evaluation, and dissemination
- Workforce development
- Housing and supportive services
- Communities in crisis.

Mr. Albino noted that in terms of communities in crisis, the Subcommittee heard from communities where “deep inequalities exist, including [those] administratively at the local level.”

Conclusion

Mr. Albino noted that these eight drivers were grouped into three general but related areas to be addressed, and discussions were held with individual PACHA members and stakeholders. In the end, “we feel the work we did mirrors what we hear from others in the community.”

PACHA Deliberations

Dr. Gayle introduced this portion of the meeting by noting that it is PACHA members’ opportunity to talk about questions that have come up today, including where “some of the gaps” might be.

Mr. Crowley also asked PACHA members to flag gaps or questions. He noted, “We’re also moving into implementation, so even if we get consensus on what we should do, we need discussion about implementation.”

Dr. Gayle responded that while “it is awkward to talk about implementation when we don’t have a Strategy, we have heard general outlines in the three high-priority areas.” Therefore, she suggested that this session take the form of brainstorming “to gain a general sense of where this is going and some of the ways PACHA could be helpful in implementation,” as well as “what we would want to hold people accountable for.”

PACHA Members Speak Large Elephant in the Room

Mr. Wilson said there seems to be “a large elephant in the room, and it is that the AIDS epidemic in black America is unique.” When you look at the AIDS epidemic in the Southeast, “those are black people, and it is not a coincidence that a large percentage of American black people live there.”

Today, Mr. Wilson continued, “we’ve talked about women, gay men, and youth. Yet, no matter how you dice it, the AIDS epidemic in North America is overwhelmingly black.” Therefore, “if the National Strategy has limited targets, it will do a disservice if that fact is not out there. We need to say explicitly what we’re going to do to end the AIDS epidemic in black America.”

Mr. Wilson added that infection rates among black Americans were high, even back in 1986, so “this is not new.” Yet, today, if you ask the CDC about the percentage of infected Americans who are not in care, “it can’t give you a number that tells you what that is in black America. And this is similar for other measures. Mr. Millett showed what happens to the viral burden when people are not in care. We do not know how many positive African American do not know their status. So as we move forward, we need to figure out how to wrap our brains around that because, if we fail in black America, we fail, period.”

Responding, Dr. Gayle said that the notion of being focused and targeted “is a new notion in a lot of ways. Before, we were trying to be everything to everyone, but this is new. This is part of what the strategy is moving forward. A more focused, aligned role is under discussion.”

Broad Benchmark?/Disproportionate Assistance

Mr. Baker said he would like to know what the broad Strategy benchmark is in terms of what is to be achieved within what timeframe. Is the benchmark “trying to get to a certain point by 2016, like 100 percent [reduction] across the board? If so, what kinds of resource allocations will be provided?” This is a “framework question, particularly given dependence in part on the States.”

Continuing, Mr. Baker said that the current reality is “disproportionate assistance,” but it is because of where black people live, “which is where State Governors are not being held accountable.” For example, he noted that Mississippi is suing against health reform.

Responding, Mr. Crowley said that in terms of targets, “one of the things we’re looking at is what we are measuring and what the right number is,” but “we’re not there yet.” The President has always said we need greater

investments, “but we’re in tough times at all levels of Government, so our first position is to ask where we are going as a country.” We “believe we can do significantly better with existing resources and also demonstrate a new direction that will help us get new resources. We are looking at how we can demonstrate real progress over the next 5 years.”

Having Less With Which to Do More/Set Priorities

Responding, Mr. Wilson said, “We are starting with implementation when there are many issues that need to be discussed at a different level. Mr. Baker addressed one. Many of us are dealing with fewer resources, but the issue is that we have less with which to do more, and that is a very big elephant in the room. When talking about resources, we are faced with a difficult situation. The guidelines say we should start treatment at an earlier stage, but there are fewer resources and more people to serve. So how can we do that?”

Mr. Wilson added that he is “cautious,” so he asked the group “not to move immediately into implementation when we haven’t had final discussion of critical issues we need to address.” While he understands there is an agenda to follow and some of these issues are being discussed, “let’s set a priority of issues we want to address in this body.”

Responding, Dr. Gayle said, “What we want to get at is not necessarily implementation programs.” Given that the Strategy will roll out, “what steps do PACHA members think we should think about in terms of rollout? One might be discussion around areas we think are problematic. What are some of the things we need to talk about to make the Strategy successful?”

Put PACHA to Work

Mario Perez responded that a country that invests “\$25 billion across the spectrum but only a small percentage of that toward preventing infection is laughable.” Structurally, a lot of energy in PACHA is in meetings where we only have a day or a day-and-a-half to deliberate. “This is insufficient. Lock us in a room for 3 to 4 days.”

Responding, Dr. Gayle said that tomorrow PACHA “will talk more about how to do our work.”

A comment was made that, given what Mr. Wilson said, we should start to drill down in terms of what we are talking about when lowering disparities. Are we talking about racial and ethnic or geographic disparities? We should define things so that we can set two or three objectives around them.

I Want to Do More

Kathie M. Hiers said that she is “feeling undercut on the PACHA.” She has been on one conference call, with the Disparities Subcommittee, even though she has been on the Council for 3 months. “I don’t feel I’m rolling up my sleeves. I’d like to do more.”

PACHA Needs to Have Time to Advise

Rev. Dr. Calvin Otis Butts III said this is what he was trying to address earlier, and that is the crux of the epidemic as articulated by Mr. Wilson. “If we don’t address where it is, we can be quite sure that it will keep going. At some point, we have to take action.”

Rev. Dr. Butts continued, “We are advisors. That is why I was talking about legislation that targets resources. It seems that, if we’re going to advise something specific, when we are sequestered, we can begin to advise.”

Rev. Dr. Butts concluded that he does not “want to move in a different direction from the Strategy.” Rather, “we will be working hard to make sure the Strategy is understood—in terms of where we need it to go. Or we will reorient the Strategy. Law has to tell Governments what to do. That is why advice is good. But it has to be specific. Yet we do not have time to discuss it. That is one of the reasons I like ACT UP. We need to act as soon as we can, but we don’t have time to be locked up for 5 days in a room.”

Several Needs

Michael Horberg said one area not included in the Strategy that should be addressed is that the U.S. Preventive Services Task Force and the CDC are in conflict as to whom to test, procedures for reimbursement, and CMS guidelines for whom it will cover. “This needs to be explicit and conjoined.”

Dr. Horberg said that Mr. Millett had mentioned good metrics. However, “not all of these are measurable, particularly when one is talking about the undiagnosed.” Therefore, he urged a look at the state of disease at the time of diagnosis and also access to and retention in care. The Association of HIV Medicine and Federal agencies have weighed in on that, but now “pressure needs to be put on the National Council of Quality Assurance to make them part of the Healthcare Effectiveness Data and Information Set,” which is how we measure health plans, “so that private health care settings are held accountable, in line with HRSA and CMS, and you don’t have multiple data systems.”

Dr. Horberg added that one highlight of the Strategy, as it seems to be shaping up, is “TLC Plus, especially the linkage part.” He noted that at Kaiser

Permanente, where he is Director of HIV/AIDS, "although we are very good at TLC Plus, it is a very labor-intensive process. And that means high costs."

Endorsement of Framework Document

David Holtgrave endorsed the document that Mr. Collins and Mr. Munar presented and that he worked on. In terms of materials presented today by the interagency working group Subcommittees, Dr. Holtgrave said he found "not much to disagree with," but "the format of the Coalition's framework document pushes us down the road a bit further, including measures and targeted goals." If one looks at the document appendices, the analysis of the status quo versus change "is roughly right." In short, without change, there could be 180,000 more new infections by 2016. Also, in 4 years, investment in the kinds of programs the document discusses could result in the programs' "actually paying for themselves."

Another Meeting Once Targets Have Been Set?

Dr. Holtgrave commented further that it is difficult to react to targets set by the interagency working group Subcommittees "when targets haven't been set yet." Therefore, he proposed another meeting once these targets have been set.

Take PMTCT Lessons Learned Into Account

Patricia Garcia said PACHA would be "remiss" if it did not take into account lessons learned from the successful reduction in mother-to-child transmission and apply those lessons "a little more broadly, as well as not forget the importance of those gains."

PEPFAR as a Framework?

Mrs. McBride noted that in her previous position at the White House, she was mostly involved in PEPFAR, so the presentations today have been highly educational for her. She commented that PEPFAR has a framework that can be translated domestically, as mentioned earlier. For example, OGAC reports directly to the President, and PEPFAR represents "a huge investment in a single disease that was very targeted and specific." Mrs. McBride advocated looking at where the populations of higher incidence are and where we can have impact as well as measurable outcomes in a short period of time that "will help us go to the problem we all face, which is a limited amount of dollars."

Need Short-Term Projected Success Rates

Mrs. McBride added that we "want to be serious about providing the President with a measure of success. So let's take a step back and have some short-term projected success rates." We "all want the country to be healthy again, financially, but let's focus on trying to help the President have some success."

Local Issues Need to Be Part of the Solution Set

Douglas A. Michels echoed others' comments about the framework document, adding that he "throws his support" to what other PACHA members have mentioned as well, which is that out in the field, "the challenge isn't necessarily around Federal funding on treatment, but [on] State and local funding. Without making sure local issues are part of the solution set, we'll fail miserably." Cities and States are slashing resources and capacity across the board, despite having Federal funding, he said, so "we have to look at this holistically, or we won't succeed."

Feeling "Undertapped"

Rosie Perez said she too "feels undertapped." Like everyone, she "has a lot to say and many ideas," so if it is not possible for PACHA to meet for an extended period, it should hold a conference in some other way and possibly produce a report, as Mr. Collins and Mr. Munar have. PACHA just needs an opportunity to do so. Therefore, Ms. Perez asked if it is possible for PACHA Subcommittees to meet outside this room, brainstorm together, and come up with specific suggestions for the President.

Address Youth

Ms. Perez also supported Praveen Basaviah's statement that one population "no one is really addressing is youth." She noted that if a teenager is infected, even as young as 13 years of age, that person will be living with AIDS for a long time, and "their behavior could be very scary." Therefore, "I want to know if it is possible to have a national media awareness campaign." In addition, "we need to revitalize AIDS education by telling children in our schools about it because kids think that AIDS is over and that everyone has herpes. These are A+ students."

In sum, "we need to help the younger generations rethink the severity of this epidemic."

Two Gaps

Ernest Darkoh-Ampem noted two gaps for PACHA's consideration, the first being delivery system issues. Ms. Simmons touched on this, but those on the ground "need to be emphasized." Dr. Darkoh-Ampem noted that most of his work is global, and one of the biggest challenges there is delivery systems. "The model of health care we currently have is largely broken. It is not based or embedded in communities." Therefore, when we discuss community models, "we need to define them so that they become leading actors." Dr. Darkoh-Ampem said he is not sure quite yet how PACHA can do this, but he feels that PACHA has not heard enough about delivery systems and models.

The second gap, Dr. Darkoh-Ampem said, is schools, as Ms. Perez mentioned. While he is not sure where they come in, in terms of prevention and trajectory, everyone aged 15–17 is going to have sex, become exposed, and enter into a high-risk age group. “So where are the programs that address them?” he asked, adding, “Schools need to be an important component of this Strategy.”

Learn From What Is Going on Right Now, Like Waiting Lists

Ejay Jack noted that he has to tell his clients in Omaha that there is a waiting list, and that is an issue. He advocated the need to learn from “what’s going on right now, and we need new strategies.”

Unique Relationship

Jack C. Jackson, Jr., noted that, as a member of the Navajo Nation, he is still considered a ward of the Federal Government. Historically, the resources the Federal Government has dedicated to Tribal lands “have not met our needs.” We “are at the lower rung of everything in terms of Tribal lands; many of the contributing factors discussed today are double and triple for us, and we’re only 1 percent of the population.” Mr. Jackson asked that the unique relationship Native Americans have with the Federal Government be taken into account in future discussion about the relationships of local governments to the Federal Government regarding the epidemic.

Strategy Will Not Address Everything

Ms. Khanna echoed Mr. Jackson’s comments in that she thinks PACHA should focus on the Strategy but also think about its other commitments “because the Strategy won’t address everything.”

Minimum Standards

Addressing the Strategy, Ms. Khanna advocated not looking at a scale-up of “what’s already happening, because more resources won’t solve systems already broken.” Rather, “we can think about minimum standards that aren’t even in place right now,” including linkage to care. Ms. Khanna advocated starting to build definitions around such standards and also targeting initiatives involving multiple stakeholders. Last, while upholding the rights and dignity of individuals who are HIV-positive, “we can’t talk about testing and services if we’re not addressing the real reasons they wouldn’t want to get tested.” Therefore, “we have to incentivize the test and lifetime access to care and support.”

The South/Transparency

Ms. Hiers commented that she comes from a State where the Governor does not want to put millions of dollars into health care while failing to mention that doing so would bring the State billions in Federal Government funds. Ms. Hiers added, “The Southern States are a mixed bag.” In terms of Federal

funding, she does not expect Federal funds to fix Alabama's Medicaid program, for example, but she is interested in the number of Federal dollars that actually make it to people in need in the State. Overall, at present, most on the waiting lists across the country are Southern and are black people.

Take Chances

Mr. Basaviah commented that it seems that "we like to be safe, middle-of-the-road. But why not take some chances? It should be a criminal offense to practice abstinence before marriage in this country. Why does it take decades?"

Mr. Basaviah added that he is "confused about my role as a PACHA member." Since "we met, I haven't heard anything." Once the Strategy comes out, the Government will have some things it promises to do, but "you will rely on the country to take some initiatives, too." During community discussions last year, he felt that he was witnessing representative democracy in action, "like people were being listened to. I felt like we were contributing to action steps." So, now "what are we as PACHA going to do to take some radical steps and galvanize the populations?" As mentioned in youth reports resulting from youth discussions, amazing models exist in St. Louis, for example. But "why it is so hard to do what they do really well? I don't want my kids to inherit a country where things move so slowly."

Best Practices/Galvanize the Country

Mr. Basaviah concluded by proposing that PACHA look at best practices internationally and domestically and also "get teens in this room." Heartbreaking, real things "should be listed in the Strategy," he said, adding that perhaps PACHA could set up satellite councils to galvanize the country, not just PACHA and the interagency working group.

Summary

Dr. Gayle noted that a few things have come out so far about the role of PACHA and how we are going to work:

- Many have said they want to do and give more. This will be discussed more tomorrow.
- There is a sense of urgency and the need for speed in action.
- Many have expressed that "we're too middle-of-the-road."

Invitation

In light of discussion so far, Dr. Gayle invited PACHA members and members of the public to address what they would like PACHA to do.

Responses

Dawn Averitt Bridge said she was struck by what Mr. Basaviah said because one of the things PACHA has been charged to do is come together and “engage in some really expansive thinking.” So, “we don’t start by honing in on tiny details.” Rather, “we start by talking about how to change things in the broadest ways and then talk resources.” If we do not have the opportunity to engage in those discussions, “we won’t be able to do our job well.”

Addressing Mr. Crowley, Ms. Perez proposed that before the end of today and tomorrow, “let’s expand the schedule so we can work and be effective,” adding that she would “be hurt if PACHA ends and nothing was done and my name was on it, and I think every member in the room feels the same way.”

Mr. Baker said that tomorrow will be much better, and then he asked not to meet in the South Court Auditorium again because “it was unfortunate last time, and this time, even worse.”

Public Comments

Mary Elizabeth Marr, Executive Director, AIDS Action Coalition, AIDS Alabama, and operator of a Ryan White CARE Act (RWCA) clinic, said she has told clients to leave the State “not because we don’t provide quality care but because we don’t have the level of funding that other areas of the country do.” In 2002, the AIDS Action Coalition funded 198 clients in Alabama. Recently, “we received only 1 of 15 expansion grants.” Now, “we are serving more than 600 clients with the same funding as in 2002.”

Every RWCA clinic “should receive the same level of care, and the same is true for having the same formulary for ADAP,” Ms. Marr continued, maintaining that New York State has 440 drugs on its formulary, and “we have less than 200.” It “is not fair to tell a client in Alabama that he or she doesn’t need as much as someone in New York City.” In addition, comprehensive prevention is needed for at-risk individuals. “Someone needs to say this,” Ms. Marr concluded.

Debra Fraser-Howze, Vice President, Government and External Affairs, OraSure Technologies, Inc., advocated “bringing the President into this.” That is, the epidemic is in African American communities. At some point, “that needs to be acknowledged,” and, at some point, the President has to say that as an African American President, “because it’s the truth.” Ms. Fraser-Howze added that “this is a public health epidemic, and you have to tell the truth, because if you don’t, you’re not doing public health.”

Ms. Fraser-Howze suggested that the best way for the President to address the truth about the domestic epidemic is somewhere in the Strategy, in his State of the Union address, in meeting with the Council, privately, and/or in some press event. "However it is done," there does need to be a meeting between PACHA and the President for some discussion of the priorities he is working on and a statement by the President that "he wants the country to get ready to support your effort as a priority for the Nation." That is how to get the Nation back, she concluded, because this President is "the biggest salesperson ever."

Michele Lopez, of New York, said she would like to see PACHA engage in ensuring that, as a black Latina, she will have direct access to care and treatment "eventually," despite "the 5-year exclusion of illegal immigrants from Medicaid." Ms. Lopez said New York has a model for care and treatment of those who are documented and undocumented, so best practices do exist to ensure that everyone who tests positive has access to care and treatment.

The importance of routine testing is clear, Ms. Lopez added, but "I've asked how we can do this if we don't have access to care." Therefore, she is asking PACHA "to look into TLC Plus so that every positive individual has a mechanism for getting into care."

Last, Ms. Lopez noted that resources have been discussed "but not necessarily human capital and infrastructure," particularly "when we talk about black America." If "we're going to discuss resources and strategy in the United States, we have to talk about who is going to be doing the work on the ground." In addition, it is important to learn about differences between the various generations. One of the biggest differences in young people in their 20s today is that they are "distracted and also hate authority. Young adults between the ages of 13 and 29 need a seat at the table because we can't allow ourselves to be advocated for by anybody else." In addition, "we have to remember in everything we do that those who live with HIV/AIDS are not looking to harm anybody. We're looking to save lives."

An unidentified member of the public from Baton Rouge, Louisiana, said he/she had been living with HIV/AIDS for the past 20 years and is in agreement about black Americans. In addition, Mr. Crowley mentioned that ONAP's community document would be translated into Spanish, which points to the "big need for Latino community involvement." The member of the public continued, "I think we are the forgotten population." Therefore, "I would like PACHA to support or give some input into the immigration bill.

Many are undocumented. If what happened in Arizona happens in every State, we're going to be in very big trouble."

BJ Cavnor, Public Policy Coordinator, Cascades AIDS Project, Portland, Oregon, recalled that the last time he was at the White House, it was as a member of ACT UP. Now he is here for this meeting and AIDSWatch. Mr. Cavnor noted that a good friend was recently diagnosed but only after having pneumonia, from which he almost died. In Oregon, "44 percent learn about their status from hospitalization for opportunistic infection a year after being infected. This is a public health and social justice issue. And we can't forget the impact this epidemic has on gay men."

An unidentified member of the public who has been on ART since 1996 said he wanted to discuss "the elephant that has a personal impact, and that is the alarming rise in cost of lifesaving medications." As we try to "get more tested and into care sooner, this will be a major strain on ADAP programs as well as various programs that will come about as a result of health care reform."

The speaker went on to note the effects of rising drug costs on his private health insurance premiums and coverages. For example, his heart therapy medications now cost \$800–\$1,100 per month. In addition, in recently switching his ART due to concern about his liver health, his medication cost skyrocketed from \$220 to \$1,136 per month.

In sum, as "we attempt to collaborate, particularly with the private sector, I hope that pharmaceutical companies are held more accountable for draining our resources."

A member of the public who identified herself as Barbara said she hears frustration and feels it, as an individual and as a member of the HIV-positive African American women's community. Therefore, she wants to ask PACHA to advocate for expansion of the Council to include more openly infected African American women, or at least to agree to have an HIV-positive African American woman on the Council as a full participant. This needs to be done and, "we'll continue to fight for it" because there are many issues across the country for many people, and "all of us need to be on the Council."

An unidentified member of the public said, "Black infected women are not visible at the decision table. When you look at the Strategy, you look for a bullet point that says this, when enacted, will have a role for involvement for those with HIV/AIDS." It is important to note, "often, other positive women are most helpful, in my experience, in linking others to care."

Regan Hofmann, Editor of *POZ* magazine, said she speaks at high schools across the country, and that students are having anal and oral sex in order to maintain their virginity.

Ms. Hofmann noted that many newly diagnosed individuals call her magazine, and “it would be a great strategy for PACHA to work with providers to get routine screening.”

Ms. Hofmann said we need the media to be engaged, commenting that PACHA “has the power to talk to media leadership and make clear this is a public health emergency” because right now, treatment and criminalization seem to be the focus of journalists, and “this focus needs to be broadened.”

Last, Ms. Hofmann said, “we need the ultimate celebrity, Mr. Obama, to help everyone understand.”

A member of the public not clearly identified said she is HIV-positive and a high school teacher, and that teachers like her do not have “responsibility to mandate condom education in public schools across the country.” Sometimes, a teacher will tell her students at the end of school on a Friday to “use your condoms,” to which her students sometimes respond, “don’t say that, you’ll get fired.”

The speaker added that she has been living without insurance for 10 years because “I can’t get it. This should be appalling to someone somewhere.”

The speaker said PACHA needs “to push the President to get involved in a few ways, and more than just in teen pregnancy” because, although through the No Child Left Behind legislation there is a program that talks about sex education, it talks about that “in every way but for infectious disease.” PACHA needs to ask, “What we are doing to push for the sexual health of young people and for HIV/AIDS to be addressed?” In conclusion, “the Department of Education needs to be in this conversation. It needs to be here.”

Andrea Johnson said she is a newly affected African American infected “by my husband, not any other risk factor.” The messages about HIV/AIDS in her community “were not for women like me. They were for prostitutes and others.”

Ms. Johnson said she is a youth advocate. While teaching about the disease, she acquired it. Now she thinks, “What a better example I am now.” Through her teaching and other experiences, she has found that many youth and

adults still think you can acquire HIV from a toilet seat. This, she feels, "is a race thing" and she is "so angry" because no one came into her community or others like it to talk about the severity of a disease "that can actually eliminate us if it is not checked." And "it is not fair that it hasn't been checked." Therefore, she is "asking for help. We don't need one more person infected with a disease they can't get rid of."

Instead of fighting, Ms. Johnson said, "Let's start to solve this issue. It is not a power issue. It is an issue to save lives. The more fighting, the more lives are being lost. And do it quickly. Please do something, and do it quickly."

An unidentified attendee from Las Vegas said he was born in 1981 and therefore has never lived in a world without AIDS. When he was in high school, and even to this day, he has been told, "you can live with it." But "they don't tell you what it is really like, including mental effects." In talking to Las Vegas' AIDS Director, the attendee recently learned that 10 percent [of PLWHA] commit suicide within a year of diagnosis, although he has not seen documentation of this. And that's one of his points. "We still don't have research on this, even though in the past 3 years, I have witnessed eight suicides."

This attendee said he is HIV-positive, and his attitude about that is, "if you don't like me because of that, you're ignorant." To date, he has helped in 70 diagnoses. In short, "we have to start being out there." At one time, cancer had a huge stigma attached to it, but today, people can stand up and say, "I have it." HIV-positive people need to get to that point. "Get us involved in addressing the stigma of who wants to stand in line to get help. Get us involved in addressing mental illness. We are dying off at higher rates than anyone realizes, in part because we think we are invincible."

Ronald Johnson, from the AIDS Action Council, stated that he is gay, positive, and over 60 years of age, and wants to address PACHA about an aspect of Mr. Collins' and Mr. Munar's presentation—accountability, which "we lacked for this epidemic"—and how it can be achieved through the Strategy.

Mr. Johnson suggested that PACHA recognize the first week of June 2010 as "the beginning of 30 years of this epidemic, and therefore it would be good for the President to start off a year of accountability at that point, moving forward with the game-changing that we need."

Gregory Pappas asked PACHA to support repeal of the Helms amendment, because "it is illegal in the United States to talk about sexuality in communities." While AIDSWatch is on Capitol Hill today asking for more

money in the fight against the epidemic, “we support Jeff in our need to use our resources more effectively.” Dr. Pappas noted that the Helms amendment had bipartisan support in 1987, and called for a bipartisan effort to repeal it.

An unidentified representative of the Sexuality Information and Education Council of the United States (SIECUS) said, “We need everything that comes out of this Administration to address a wide range of sexuality issues and a wide range of skills.” She said SIECUS “has been trying to get STD and HIV/AIDS prevention to be part of the Administration’s efforts to prevent teen pregnancy” for a year now, yet the organization has yet to hear back from the White House.

In terms of the Secondary and Elementary Education Act, SIECUS hopes sexuality “will be part of that strategy, but it is not clear how involved the Department of Education is, and that’s problematic, because we not only need them to be involved, but we need funding.” Everyone has heard about how States and localities lack funding, “but we can’t say we want comprehensive sex education in the schools without funding it, including sex education teacher training.”

The SIECUS representative concluded, “As the Administration moves forward on these matters, it needs coordination from inside.”

Marsha A. Martin, from Get Screened Oakland, brought greetings from Oakland Mayor Ron Dellums, a former PACHA member, and an invitation to PACHA to visit Oakland for a meeting.

Dr. Martin said she was asked to present to Dr. Gayle a report titled “Toward Global Routinization of HIV Testing,” which is the result in part of efforts by Oakland and its Sister City, Cape Town, South Africa. The report, which was made available to members, is offered “as a way for PACHA to rethink the way we go about testing, and engage all sectors of the community.” Specifically, the report advocates moving away from the assumption that “we can scale up without engaging 90 percent of the rest of the community in addition to community-based organizations and clinics.” It “takes a lot to do this, but once you do, you can increase testing and access, and it ends up being an intervention in the community and in our domestic response to HIV.” In short, “it’s time to ask the whole community to get involved.”

Dr. Martin also asked PACHA “to keep these meetings as open as you can.” She added, “There aren’t enough younger people involved in these dialogues or engaged and committed.” This is important in part because “some of us are going to retire and not be part of the conversation.”

Juanita Chavez Hill, community organizer for Community HIV/AIDS Mobilization, said that the epidemic is “fueled by our lack of addressing inequities in our society.” We are “good at saying there is AIDS in the prisons, but we’re not good at prison reform,” for example. It is at these points of intersection where “we need to see action.” In addition, “the agencies need to be accountable.” Also, “it’s not so much what you do within your Council, but the influence you have outside the Council.” Last, “think outside the box, because these intersections that we point out need recommendations that lay out what needs to be done.”

Carl Schmid, Deputy Executive Director, The AIDS Institute, read from a prepared statement that stated appreciation for the work the President and PACHA are doing to develop a National HIV/AIDS Strategy, but stressed that the critical issue of emergency funding for ADAP must be addressed “right now.”

Highlights from Mr. Schmid’s statement included the following:

- In February [2010], the ADAP waiting list totaled 362 people; now the waiting list has grown to 938, an increase of almost 300 percent. Yet no action has been taken by the Administration or the Congress.
- Without immediate additional funding, the situation is going to get “much worse.”
- At PACHA’s last meeting, The AIDS Institute asked PACHA to address this issue and join in support of an additional \$126 million in FY 2010 emergency funds for the ADAP Supplemental.
- Today, The AIDS Institute repeats this request. Specifically, it urges PACHA to ask the President to request from Congress emergency support for the ADAP Supplemental this year and to work with HRSA to ensure that the funds flow to the States that need the funding most.
- A letter has been sent to the President by nearly 250 HIV/AIDS organizations from around the country urging him to support this emergency funding request.
- The AIDS Institute hopes PACHA will not leave Washington again without acting on this issue.

Helen Burke, who stated that she is HIV-positive and from New Jersey, said she works in social services in rural, suburban, and urban areas, and what she is seeing is that if we do not address minority issues across the United States, the epidemic will spread.

Ms. Burke noted the emergence of the social media network, which has enabled youth to expand their horizons beyond their own communities and

neighborhoods. She urged PACHA to get the message out that “all are at risk, so that I’m not having a conversation with someone in my church about how their kids aren’t at risk.”

Ms. Burke urged PACHA to work with the media and with members and celebrities such as Ms. Perez to “use your access to get your message out to black, Hispanic, and white communities.”

A member of the public who identified herself as Louise advocated “fast thinking outside the box” about people like her. She has suffered from sickle cell anemia, cancer, and HIV infection, which occurred during a period in her life when she was homeless in Los Angeles.

Louise said she does not need the President to speak for her; rather, she needs the organizations already in place “to do what they’re supposed to be doing already.” She noted her frustration in applying for or qualifying for assistance when she goes to live with a friend, for example, because that would be viewed “as my needs already being met.” She added that her options should not have to be to decide between chemotherapy and standing in line for housing,” or having to “bang on my doctor’s door for 9 months before I could get an appointment.”

In sum, “you have to talk directly to those on the bottom and think about what you would do if you were homeless with HIV. It doesn’t matter that you have HIV and are homeless. What if you were homeless? People are dying for no other reason than ‘it’s a process,’”

Shaquan Clark, who is part of the Ryan White HIV CARE Network, said she has AIDS and two beautiful boys. She is 34 years old and lives in Albany. AIDS “has been around,” she noted, and now we have uneducated youth and also uneducated older adults “who just don’t know that.” While she provides services to about 300 clients, she is happy but also sad, because if she had been educated years ago that HIV “is more common than you think, I wouldn’t have it.”

Ms. Clark said that, fortunately, she has a lot of support and that as much as she would love to see the President, “he can’t speak for me.” “I speak for myself and other positive individuals. If you aren’t positive, you don’t understand what we go through, whether you are sensitive or not.”

Ms. Clark concluded by saying she does not have 5 years to wait for a National Strategy to work, because “if I can’t work, I’ll need to apply for Social Security all over again.” She added that it was a pleasure to see Ms. Perez and that “PACHA should be ashamed she is here and things aren’t

getting done. We need linkage to care and also need to talk to the youth and the children out there.”

Responding, Ms. Perez said, “We haven’t had a chance to do what we need to do. This is a golden opportunity. We are representing everyone. I know how to make things move fast. I am here because I have been in the trenches. But we haven’t done anything yet.”

A written statement from the AIDS Healthcare Foundation was given to the meeting reporter during the period of public comment, but its content was not discussed.

Public Comments Conclusion

Dr. Gayle thanked everyone for “very rich comments.” She concluded that there was no way she could summarize the discussion at present, but she noted that Mr. Crowley and Mr. Bates had been writing down major points.

Many spoke eloquently today representing the different faces of AIDS, Dr. Gayle observed, adding that PACHA really appreciates that and also the voice of AIDSWatch.

Tomorrow, PACHA will go into its deliberations, “talking about how we organize ourselves and thinking about what this means for us, and how we are going to do our work in responding to the urgency you’ve been talking about.”

Dr. Gayle advised members that the schedule for tomorrow may be altered, and the congressional briefing that was scheduled at noon may be rescheduled so that PACHA will have more time to deliberate.

Closing Remarks/Next Steps/Logistics

Closing Remarks, by Mr. Crowley

Observing that he had heard the comments made about what PACHA has done so far, Mr. Crowley noted that the main purpose of Day 2 of the meeting is “to get organized for you to do your work.”

Mr. Crowley added, “It’s not all about me controlling you.” Rather, PACHA is “an independent advisory body to the President.” Tomorrow, “we’ll get more clarity by getting Subcommittees set up.” ADAP waiting lists and resolutions will be discussed in Subcommittee tomorrow. Meanwhile FACA process rules will be looked at to see whether a vote on such matters is possible. Going forward, PACHA will operate in “a more formalized way.”

Mr. Crowley noted some ongoing "tension" between PACHA's representative role and development of the Strategy. He observed that some of this has to do with FACA. He said, "We've tried to push the limits to listen to the public and how to work with PACHA, yet we are constrained by FACA rules." In the end, "some of the tension will naturally go away because we'll have a Strategy, hopefully, and you'll give us some slack."

"If the Strategy is a road map going forward, then PACHA and many others will have an opportunity to respond and, hopefully, as a country, help sharpen our response." Said Mr. Crowley.

ONAP is open and "wants more from PACHA," but found out from legal counsel that "we couldn't do what we wanted to do." Hopefully, "we've compensated by demonstrating dedication in listening to you and taking your advice to heart," added Mr. Crowley.

Next Steps/Logistics

Mr. Bates said that tomorrow, PACHA members will meet at the White House Conference Center. Members will need identification to get in. He asked members to take everything with them tonight, given the change in meeting locations.

Mr. Bates noted that tomorrow is a nonpublic administrative day when members will be breaking into Subcommittee meetings for the first round of deliberations relative to the Strategy.

Mr. Bates noted that he hopes to have future PACHA meeting data posted on the Web site soon.

Adjournment

Day 1 of PACHA's 39th meeting was adjourned at 4:15 p.m.