

**Presidential Advisory Council on HIV/AIDS (PACHA)  
45th Meeting  
The White House  
1600 Pennsylvania Avenue, N.W.  
South Court Auditorium/Room 430  
Washington, DC 20001  
February 28 and 29, 2012**

**Council Members Present**

Nancy Mahon, PACHA Chair  
Douglas Brooks, M.S.W., PACHA Co-Chair  
A.Cornelius Baker  
Praveen Basaviah, B.A.  
Dawn Averitt Bridge, Co-Chair, Global Subcommittee  
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, Co-Chair, Global Subcommittee  
Patricia Garcia, M.D., M.P.H.  
Robert Greenwald, J.D., Co-Chair, Access to Care Subcommittee  
Kathie M. Hiers, Co-Chair, Health Disparities Subcommittee  
David Holtgrave, Ph.D., Co-Chair, Incidence Subcommittee  
Michael Horberg, M.D., M.A.S., Co-Chair, Access to Care Subcommittee  
Ejay Jack, M.S.W.  
Naina Khanna  
Douglas Michels, M.B.A.  
Mario Perez, Co-Chair, Incidence Subcommittee  
Rev. Vanessa D. Sharp, M.Div.  
Sandra Torres-Rivera  
Phill Wilson, B.F.A.

**Council Members Absent**

Jack Jackson, J.D.  
Anita McBride  
Rosie Perez  
Malika Saada Saar, M.A., J.D.

**Staff Present**

Christopher Bates, M.P.A., Executive Director, PACHA, U.S. Department of Health and Human Services (HHS)  
Melvin Joppy, Committee Manager

## Presenters

Douglas Brooks, PACHA Co-Chair and Senior Vice President, Justice Resource Institute

Gina M. Brown, M.D., Microbicides Research Coordinator, Office of AIDS Research (OAR),  
National Institutes of Health (NIH), HHS

Mardge Cohen, M.D., Senior Physician, John H. Stroger, Jr., Hospital , and PI, Women's  
Interagency HIV Study (WIHS), Departments of Medicine, Cook County Health and Hospitals  
System and Rush University, Chicago, Illinois, and Boston Health Center for Homeless  
Program

Laurie Dill, M.D., Medical Director, Medical AIDS Outreach of Alabama

Dazon Dixon Diallo, M.P.H., Founder and President, SisterLove

C. Virginia Fields, President, National Black Leadership Commission on AIDS, and Chairperson,  
30 for 30 Campaign

Andrew Forsyth, Ph.D., Senior Science Advisor, Office of HIV/AIDS Policy (OHAP), Office of the  
Assistant Secretary for Health (OASH), HHS

Sharon Hillier, Ph.D., University of Pittsburgh School of Medicine and Microbicide Trials  
Network

Antigone Hodgins Dempsey, Liaison to PACHA from the CDC/HRSA Advisory Committee on HIV  
and STD Prevention and Treatment (CHACHSPT [informally known as CHAC])

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

Aaron Lopata, Program Examiner, White House Office of Management and Budget (OMB)

Kevin Malone, Office of Policy, Planning, and Innovation, Substance Abuse and Mental Health  
Services Administration (SAMHSA), HHS

Cecelia Munoz, Director, White House Domestic Policy Council

John O'Brien, M.A., Senior Advisor, Health Care Financing, Office of Policy, Planning, and  
Innovation, SAMHSA, HHS

Kathleen Sebelius, M.P.A., Secretary, HHS

Linda Scruggs, Director of Programs, AIDS Alliance for Children, Youth, and Families

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

Phill Wilson, PACHA Member and President and Chief Executive Officer, Black AIDS Institute

Gail Wyatt, Ph.D., Professor, University of California, Los Angeles, Department of Psychiatry and  
Biobehavioral Sciences; Director, UCLA Sexual Health Program; Director, UCLA Center for  
Culture, Trauma, and Mental Health Disparities; Associate Director, UCLA AIDS Institute;  
Clinical Psychologist and Sex Therapist

Carmen D. Zorrilla, M.D., Professor of OB-GYN, University of Puerto Rico School of Medicine,  
and Principal Investigator, CMI, MI-HMHR, UPR-CTU, PR HVTU, PR-CCHD, Maternal-Infant  
Studies Center (CEMI)

## **Day 1**

### **MORNING SESSION**

#### **Welcome**

White House Office of National AIDS Policy (ONAP) Senior Advisor James Albino welcomed everyone to the South Court Auditorium of the Executive Office Building of The White House and introduced PACHA Executive Director Christopher Bates. Mr. Albino explained White House security procedures and encouraged all PACHA members and members of the public to be aware of them in order to regain entrance to the building.

#### **Logistics**

Mr. Bates noted that the first two rows in the auditorium are for PACHA members. He asked members and guests to try not to wander in the building, for security reasons. A box lunch is available for \$11 from the White House caterer. Order through Melvin Joppy.

#### **Agenda Preview**

Mr. Bates noted this is the 45th PACHA meeting and the second to be held at The White House. Today's line-up of speakers is distinguished, beginning with Howard Koh, Assistant Secretary for Health, HHS, followed by the HHS Secretary herself. Then the Day One agenda will focus on women and the impact of HIV on women and girls through presentations and discussion with a dynamic group of presenters.

Mr. Bates invited any questions about activities or the agenda to be directed to him, Mr. Joppy, or Mr. Albino.

#### **New PACHA Chair**

Mr. Bates introduced PACHA's new Chair, Nancy Mahon, who is Senior Vice President of MAC Cosmetics and the MAC AIDS Fund.

#### **Remarks by Ms. Mahon**

Ms. Mahon said she is very happy and pleased to be here today. She has been getting to know the PACHA members through phone calls and meetings. This is a "very gifted, passionate, and focused group."

We are at a critical moment in the epidemic. The Secretary will speak on that, as well as Dr. Koh, who is a gifted physician and advocate. Ms. Mahon acknowledged the contributions of the Secretary's right-hand person, Dora Hughes, and Mr. Albino. She noted that the newly appointed Director of The White House Domestic Policy Council, Cecelia Munoz, would speak later this afternoon. So, "we have the A team here."

Even bettors would not have chosen treatment as prevention as our first bet, "but it has changed the picture of what we do. " At MAC, the MAC AIDS Fund portfolio has changed as a result. And to the Nation, on World AIDS Day, the President showed that he is set on getting to zero new infections.

How about resources to do the job? Early in her career, Ms. Mahon worked with George Soros. A month into her job, Mr. Soros asked Ms. Mahon if she had enough money, and she was able to say no. It was a privilege to be asked that because it helped Ms. Mahon realize that there is never enough time and money. “We’re at this moment in the United States and abroad where we have to take what we have, the resources and the knowledge, and ask how we most effectively pick our targets and focus on the issues that will make the biggest difference.”

With “all my heart,” Ms. Mahon said, she is “honored to take on that task with you.” Ms. Mahon added that the relationship between the Chair and members “should always be dialogue.” Then she gave a shout out to the PACHA members who put together the session on women and HIV that will be featured today.

“HIV is still the leading killer of young black women in our country,” Ms. Mahon noted. So “let’s roll up our sleeves.”

### **Remarks by Dr. Koh**

Dr. Koh welcomed PACHA members and guests to The White House. He is delighted to see everyone and to have an opportunity to thank the leaders of PACHA. He is thrilled to have a new dynamic leader in Ms. Mahon. Some people you never forget after you first meet them, and for him, Ms. Mahon is such a person. He remembers meeting her at the International AIDS Conference in Vienna, where he was immediately struck by her energy, passion, commitment, and creativity. He is very happy she was chosen to be PACHA’s new Chair, as she has many new ideas and is committed to public health in the most profound way.

Dr. Koh acknowledged Ron Valdiserri, the Deputy Assistant Secretary for Health and Infectious Disease; Mr. Albino, who has stepped up at the Office of National AIDS Policy (ONAP) with the departure of its director, Jeff Crowley; and Mr. Bates, but “most important, all of you, as you are the jewels in public health.”

This is “a critical time for us,” Dr. Koh said. “We have advanced with treatment, realigned HHS dollars to best meet the epidemic, launched the 12 Cities Program, and are raising awareness and attention to health disparities in our populations.” HHS is also “close to finalizing a distinct set of metrics for harmonization of data, and the Centers for Medicare & Medicaid Services are working closely on HIV/AIDS treatment and care coverage and support with others, including the Department of Housing and Urban Development and the Federal Bureau of Prisons.” And today, at this meeting, we will address some key issues involving HIV/AIDS and women.

Dr. Koh thanked PACHA for its energy, ideas, and creativity around the meeting of strategic goals.

Dr. Koh also noted that he had heard of the logistical challenges some members faced in getting to the meeting today. He apologized for any problems and asked that they be reported to Ms. Mahon and he and Ms. Mahon would fix the problem. Members spend much of their valuable time in traveling to PACHA meetings, so Dr. Koh wants to make sure they can give their full attention to ending this epidemic in the future.

Dr. Koh then introduced HHS Secretary Kathleen Sebelius. Secretary Sebelius has been a tremendous champion of public health and of treatment and care and prevention, particularly around HIV/AIDS. She addressed PACHA's inaugural meeting at The White House and has spoken with passion on the issues PACHA addresses. She will be a highly visible leader when the United States hosts the International AIDS Conference here in July.

This Secretary "always wants to learn more and do more to advance the cause—to reach even higher, longer records of public service."

### **Remarks by Secretary Sebelius**

Secretary Sebelius thanked Dr. Koh and the audience for the warm greeting. She is delighted to spend time with everyone but will have to leave shortly to speak to the House Ways and Means Committee. "I'd much rather be with you," she said.

Secretary Sebelius thanked Ms. Mahon for her years of advocacy across this Nation and for her willingness to step into this critical lead role.

PACHA's work "could not be more important," for the Council informs HHS and the Secretary's Office on a regular basis. Now the Secretary is happy for the Council that Ms. Mahon has stepped up, for "the one thing needed to make any committee work is an energetic, focused leader."

Secretary Sebelius said she has been fortunate to have great teachers in the efforts to fight HIV, Drs. Koh and Valdiserri in particular. "Howard and Ron both have worked in this space for a long time and are at the right place at the right time, because we have an historic opportunity in front of us."

For the President, ending the HIV/AIDS epidemic is one of no more than ten issues he personally checks on a regular basis. "He wants to know we are making a difference and making progress." Another of many people around her holding the Secretary's feet to the fire is her public health counselor, Dr. Hughes, who is passionate about HIV/AIDS "even when I may turn my attention elsewhere."

There "are many around me who bring me back to the fact that we are at a pivotal moment, with gains in research and prevention that reduce infections and advances in treatment that provide a whole new portfolio. That treatment can be one of the most important means of prevention is important and presents a whole new set of questions on how fast we can get to an AIDS-free generation."

Two years ago, this Administration adopted the National HIV/AIDS Strategy (NHAS or Strategy). It had been a missing piece. "Now we are looking at our Strategy and the resources and problems in this country. We have taken the global strategy and translated it into an action plan." The people in this room have an important role to play in helping expand testing, getting people into care, and working on supporting those in care. "But we have some real gaps, such as staying in treatment and reaching into some of the most targeted, affected communities." There "are some places where we are falling real short."

It is heartening, Secretary Sebelius said, to see partners in the fight in high gear as groups across the country begin to embrace the Strategy. One thing she is tackling now, “and it is not easy,” is to begin to move resources. Year in and year out, this President “has enhanced our budget, and in the proposed 2013 budget, he continues to invest,” such as by authorizing \$60 million of program funding to be spent in support of collaborations across HHS. Yet even as progress is being made, according to the Centers for Disease Control and Prevention (CDC), “three out of four living with HIV do not have their infection under control, in part because 20 percent don’t know they are infected and of those who do know, only 50 percent receive treatment.”

Today, 30 years after the epidemic began, “we are at a real crossroads, so we welcome the International AIDS Conference in July, for as we prepare, this is a critical opportunity for our Nation.” We can “showcase our Nation’s response, domestically, and what we have done around the world.” Over the past 3 years, the number of people the United States Government (USG) supports directly on antiretrovirals is just under 4 million, and the President has set a goal to increase that to 6 million by the end of 2013. World leaders “are eager” for us to fulfill our promise, and “we need to push our friends and allies to help as well. “ There is continued discussion with China, for example. Discussion includes that China needs “to stop being a recipient country and step up with significant resources as a donor country.”

At a time when fewer people than before think HIV/AIDS is a pressing issue, it is important to continue to highlight the epidemic and young black men and Latinos and young black women and Latinas. The dialogue has been launched, “but we need to turn the volume way up.”

This year, we can make more concerted effort to combat stigma and discrimination, but “we need to start that work today with your expertise.” PACHA’s “insight and analysis continues to inform our decisionmaking process. We really do use your advice on how to deploy assets and resources across the Department. We need feedback from experts on the ground. We want to take your recommendations and apply them to the agencies,” including in terms of the CDC’s new approach to funding, modernizing housing opportunities for people living with HIV/AIDS, and overhauling performance metrics, which is underway now. Core metrics that are in the process of being finalized will reduce grantee reporting burdens by 35 percent, the Secretary said.

Ending the epidemic is an Administration-wide priority, but Government cannot do the job alone. “We have to make the most of our partnerships, including with State and local governments and national foundation leaders.” In fact, the Secretary and Ms. Mahon have been collaborating around a meeting of private partners because “we think those public/private efforts need to be refocused.” Leaders in this have been invited to the table to play a part.

Secretary Sebelius also asked how HHS can build on last year’s momentum. “What do you want to see come out of HHS? How about other Departments? This is what I want to hear from you.”

In 2014, the Affordable Care Act (ACA) will begin to be implemented “to fill a horrendous gap in health coverage in our country. “ There is a whole new world ahead, “but we know that means redeploying Ryan White CARE Act (RWCA) assets and using the infrastructure on the ground to

ensure those efforts aren't lost." Secretary Sebelius said she knows "many of you are concerned about how the Act fits with RCWA. Dr. Mary Wakefield is very informed on this. It is one of our top priorities to get ahead of what will happen in 2014."

Concluding, the Secretary said she would like to hear more about what PACHA learns today about the impact of HIV on women and girls. PACHA's presence, expertise, and feedback about critical issues inform both national and international strategy. Together, "we can build on great momentum and on the vision of an AIDS-free generation."

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

Ms. Mahon noted that PACHA's Subcommittee Co-Chairs have been working hard on brief, specific outcomes recommendations and issues. She then noted that PACHA members have 5 minutes to ask questions of the Secretary.

Robert Greenwald thanked the Secretary for taking on the Herculean tasks of the Strategy and the ACA. As Co-Chair of the Access to Care Subcommittee, he is most concerned about the essential health benefits package. The six protected classes guarantee protection, but now he is hearing about flexibilities for some States that "would undermine our ability to meet strategic goals." So, how can we meet the prevention and care goals of the ACA and of the Strategy?

Secretary Sebelius said she could not agree more with the need to address this issue. She said one must look at the entire law. Ten mandatory categories are in the law itself, and they must be treated equally. That framework helps, "so if a State has a benchmark plan with less than that, the plan doesn't meet the benchmark." There are also anti-discrimination provisions, and "these will be vigorously enforced."

In addition, there is language about how, in the 10 categories, you can choose to emphasize some and not others. "We do know that States regulate insurance, and they will have oversight over these plans. The employer plans are very similar across the country, but what really changes is cost-sharing, for example. Plans have to be affordable, available, and must already have been priced in the marketplace."

The Secretary then asked the assembly to take a moment of silence given the recent shootings at a high school in Ohio. "This reminds us of how challenging our world really is. We have to be very sensitive and reach out."

Ms. Mahon thanked Mr. Greenwald for his question and acknowledged Phill Wilson.

Mr. Wilson, who has served in the past as Co-Chair of the Health Disparities Subcommittee, said that we cannot get to zero infections if 20 percent of those infected do not know their status, so one piece of low-hanging fruit that could be addressed is Medicare performance indicators for HIV testing. He hopes we can do something on this right away.

Secretary Sebelius said Mr. Wilson has a great idea with tremendous potential, so she will be thinking with Dr. Koh on how to follow up. She noted that there is always "a welcome to Medicare screening." HHS is also trying to drive measures through electronic health records adoption, "so that could be a very important measure to add to each of those puzzle pieces." Somehow, she added, "we have to get to folks before Medicare does."

Secretary Sebelius noted that she has two children now 27 and 30 years old, and when they were growing up, “testing was more of a focus.” Now, however, that focus “has disappeared.” Concluding, she said she “loves that Medicare idea.”

## **Women and HIV Presentations**

### **Introduction**

Mr. Bates noted that the HIV and Women and Girls special session was about to begin. He noted that such sessions help PACHA decide what advice and recommendations to provide to the Administration. He acknowledged PACHA members Naina Khanna, Dawn Averitt Bridge, Patricia Garcia, Kathie Hiers, and the Reverend Vanessa Sharp for leading this effort.

Ms. Khanna and Ms. Averitt Bridge noted that the full planning committee for this session included PACHA members Jack Jackson, Ejay Jack, and Sandra Torres-Rivera, with the support of Mr. Bates and Mr. Joppy. Advocates who do not sit on PACHA, such as C. Virginia Fields, also helped.

Ms. Khanna said women living with HIV today are living at a time of incredible opportunity and in an environment where there is much work to be done to stress prevention and care for women and all communities. The Strategy’s vision is that “the United States will become a place where new HIV infections are rare and when they do occur, every person regardless of age, gender, race/ethnicity, sexual orientation, gender identify, or socioeconomic circumstance, will have unfettered access to high-quality, life-extending care, free from stigma and discrimination.”

In this context, Ms. Khanna continued, as embraced by Ms. Mahon, Secretary Sebelius, and Dr. Koh, “we know that treatment works and is effective as part of prevention.” Now to achieve the Strategy, “we have to figure out how to make these systems work for everyone.”

### **Domestic Epidemic Focus**

Because there is not enough time to focus on all the issues, today’s session will primarily be focused on the domestic epidemic. The unique issues of transgender women also will not be discussed per se today for lack of time. Therefore, the planning committee will be recommending that PACHA consider holding another session on the needs of that community.

Now, Ms. Khanna continued, is a time of new science, new politics, the Strategy, and the ACA but also a time when we face extraordinary attacks on women’s rights. “We have to talk about human rights and women’s rights as part of achieving testing and care goals. There will be some discussion on that and on HIV criminalization laws, which the Strategy identifies as a problem to be revisited. In addition, there are major barriers to achieving testing and care goals and obstacles also in the form of discrimination in employment and health care settings as well as discrimination against people who are LGBT, sex workers, and drug users.”

The agenda that follows was constructed by looking at prevention, disparities, access to care, and research. “We will also be driving through metrics on how to measure in a way that is more gender-centric.”



**“Disparities for Women Living with Trauma and HIV: A National Priority,” by Gail Wyatt, Ph.D., Professor, University of California, Los Angeles, Department of Psychiatry and Biobehavioral Sciences; Director, UCLA Sexual Health Program; Director, UCLA Center for Culture, Trauma, and Mental Health Disparities; Associate Director, UCLA AIDS Institute; Clinical Psychologist and Sex Therapist**

Who is disproportionately burdened by this epidemic?

Slides 3 and 4 show the estimated rate of new HIV infections in 2009 by gender and race/ethnicity and estimates of new HIV infections in 2009 among the most affected U.S. subpopulations.

Dr. Wyatt said it is clear from these data that, first, among women, African American women are the most affected, and second, of the subpopulations, African American heterosexual women are the fourth most affected, just behind Latino men who have sex with men (MSM).

### **Sexual Violence and Its Impact**

Sexual violence is also a huge problem for American women. U.S. Department of Justice data indicate that one in six American women will be sexually assaulted over the course of their lives, and this is only the reported cases.

Research looks at both nonconsensual and consensual sexual behavior (Slide 6). In her 30 years of research, Dr. Wyatt has seen that HIV-positive women, regardless of ethnicity, are 2.5 times more likely to report sexual and physical abuse than HIV-negative women with comparable demographics; one in three HIV-negative women report consensual sexual abuse (CSA), which is “extreme and often overlooked”; and one in four HIV-positive African American and Latino men report the same.

Such trauma has long-term effects (Slide 7), but “we don’t currently incorporate that into our work.” Some “of our assumptions that people have regular sex lives is a fantasy, and it is hard for providers to get the information they need.”

The assumptions upon which HIV interventions have traditionally been based “must be changed” (Slide 8). These assumptions are being challenged by many investigators (Slide 9). In short, “we need a context for sex.”

### **African American Women More at Risk: Why?**

Why are African American women more at risk with regard to HIV? Slide 10 shows seven distinguishing factors, beginning with the structure of relationships, whereby the fact that there are fewer African American men to women than for any other ethnic/cultural group is unique in the world. Other factors include that African American bodies age quickly through cumulative trauma and stress over time, generational poverty, undereducation and poorer quality schools, historical health disparities, and perceived worth. “There are targeted people not getting the message that they are worthy.”

In addition, the African American community is not just one community (Slide 11).

Other facilitators of disparities include the lack of availability of mental health services for HIV-positive women in the community. This despite a California study that showed that 70 percent of agency staff often encountered positive women with histories of child sexual abuse; four out of five often encountered positive women with trauma symptoms; 100 percent of agency staff reported that they often encountered positive women with depression; 95 percent said they often encountered positive women with substance abuse issues; and one out of two reported that positive women attending their agency were faced with domestic violence and assault in their lives and that they often encountered positive women working as prostitutes (Slide 12).

One hundred percent of agency staff reported they frequently encountered HIV-positive women who had too much to cope with (Slide 13).

Facilitators of disparities on a societal level include a history of oppression that externalizes self-control, normalizes violence, contributes to family breakdown, and increases healthy paranoia about just who is available to help you and whether they can be trusted (Slide 14). In addition, there are environmental and social influences, such as degrading music in which women are depicted as sex objects, men are sexually insatiable, and sex is inconsequential. According to a Rand Corporation study, girls who listen to such degrading music were twice as likely to engage in early sex (Slide 15).

### **The Media's Role**

The media's role (Slides 16-19) includes such toxic messages as the one sponsored by MissouriLife.org about how "the most dangerous place for an African American is in the womb." This is a signal and code to those who believe old stereotypes, Dr. Wyatt said, and they constitute targeted victimization messages.

### **Findings from the Center for Culture, Trauma, and Mental Health Disparities (NIMH, Wyatt, PI)**

After examining predictors of depression and post-traumatic stress syndrome(PTSD) in more than 550 low-income African American and Latino men and women, this study found the most consistent predictors were racial/ethnic discrimination; chronic stress burden (such as losing one's home, community violence, and unemployment); and sexual and physical trauma experiences not addressed in most HIV/AIDS interventions. These are variables "that we can't get funded to study" (Slides 20-23).

In addition, there are disparities in the diversity of investigators of major studies. For example, African Americans are 13 percentage points less likely to receive NIH investigator-initiated research funding (Slide 24).

### **Are Issues of Violence and Trauma Being Addressed in Current HIV/AIDS Research?**

Dr. Wyatt noted that in the recent 052 study, there was a broadly drawn exclusion criterion (Slide 27), but, most likely, it did not take into account experiences of the couples involved that might have included rape, coerced pregnancy, interpersonal domestic violence, and/or forced prostitution, and so on (Slide 28). "We need to be aware of these and concerned about the

messages we are imparting across the board,” Dr. Wyatt said. She then showed Slides 29-31, which constitute an action plan for health providers and health care facilities, including retraining to help providers identify and screen for histories of sexual and physical violence and trauma.

Regarding evidence-based prevention and intervention programs (EBIs and DEBIs), Dr. Wyatt’s proposed action plans (Slides 33 and 34) include screening adolescents and adults for histories of violence and trauma before enrolling them in interventions; prioritizing dissemination of evidence-based interventions that address the link between violence, other factors, and HIV risks within a gender and sociocultural context; and NIH revision of its requirements for investigators receiving Federal funding.

Dr. Wyatt then noted her latest NIMH-funded program with an intervention for HIV-positive women with histories of sexual and physical violence, which addresses symptoms of PTSD and depression and teaches skills to minimize these symptoms. It has been implemented in Los Angeles and New York and is under consideration by SAMHSA’s National Registry of Evidence-Based Programs and Practices (NREPP) (Slides 35 and 36).

Beginning her conclusion, Dr. Wyatt called for implementation studies of evidence-based interventions for women who experience violence in rural and urban community centers, the funding of more minority investigators to conduct HIV/AIDS research, and affordable health care that includes services for survivors of violence and trauma (Slides 37-39).

### **Change Is Real, and Girls Need To Be Part of It**

Last, Dr. Wyatt asked what role women played in the developing of the National Strategy and showed a photograph of a young boy rubbing President Obama’s head to see if our first black President’s hair felt like his. Change is real now, Dr. Wyatt said, and it is important that little girls be part of it, too.

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

Ms. Mahon asked that questions be held until the end of this session.

#### **“Research on Women Living with HIV,” by Gina M. Brown, M.D., Microbicides Research Coordinator, Office of AIDS Research (OAR), NIH, HHS**

Unless we address all the issues involving women and girls and HIV/AIDS, Dr. Brown began, we run the risk of looking up later and finding ourselves still in the middle of an ever-growing epidemic.

Context is important. The first substantive slide (Slide 2) shows what we know: women are more than 50 percent of the worldwide epidemic, with the highest percentage—about 60 percent—in sub-Saharan Africa. However, the Caribbean is rapidly climbing toward the 50 percent mark. When you work in certain parts of the country, you see the air bridge that links the Caribbean and the United States at work. Therefore, it is important to focus on this group when talking about the U.S.-based epidemic.

Slide 3 shows a map of rates of HIV infection diagnoses among adult and adolescent females in 40 States and 5 U.S. dependent areas. There is a far greater rate in Louisiana, for example, than even in next-door Mississippi. However, what stood out for Dr. Brown was the rate in the U.S. Virgin Islands (24.6), which far outstrips anything reported in the United States and Puerto Rico as well (15.4).

Slide 4 shows a map of rates of adult and adolescent females living with a diagnosis of HIV infection in 40 States and 5 U.S. dependent areas. Dr. Brown asked viewers to look at the red States, which are mostly in the South but also include New York, Connecticut, and New Jersey. Then there are the rates for the U.S. Virgin Islands (519.3) and Puerto Rico (349.7). She noted that the District of Columbia is not on this map. “There are pockets of infection we must pay attention to. Understanding where the epidemic is is part of the research that needs to be done.”

Slide 5 shows diagnoses of HIV infection among adult and adolescent females by race/ethnicity for 37 States and 5 U.S. dependent areas. This number has approached 7,000 for black and African American women. This is about 5,000 individual diagnoses higher than the next lines down, which represent the diagnoses of approximately 2,000 Hispanic/Latina women and, also, of some 2,000 white women.

That more black/African American women have been diagnosed than other groups “doesn’t mean you don’t pay attention to the other groups,” Dr. Brown said. It is important to look at the numbers. Women are 24 percent of the epidemic in the United States, but African American women are 66 percent of that at a rate wildly out of proportion with their proportion of the general population. There are groups that stand out, Dr. Brown observed, “And we have to pay attention.”

### **When We Understand the Women’s Epidemic ...**

Slide 6 makes points about the importance of conducting research on women living with HIV. There “really are differences in research in women and in men,” Dr. Brown noted. There is, for example, a difference in HIV risk. “When we understand the women’s epidemic, that will give us a better understanding of the epidemic overall.”

Women’s HIV risk is biological/anatomical, behavioral, sociocultural, situational, and educational; has to do with race; and involves socioeconomic status. We need to understand these factors, Dr. Brown said, such as what situational is and that it can include survival sex (Slide 7).

Showing slides of women’s anatomy, Dr. Brown noted that the normal vaginal environment is designed to be protective, but there are things that disrupt it, such as infection, micro-abrasions, and possibly semen (Slide 10). Semen pools in the vagina, prolonging exposure to the virus. Anal sex is a factor, too. It is not that it is anal sex but that “there is less use of condoms.”

Dr. Brown noted factors that modulate mucosal HIV infection (Slide 12), mucosal immunity and HIV risk (Slide 13), how hormones matter in terms of protection (Slide 14), and how hormones may matter in aging and HIV risk in women (Slide 15). Here, declining estrogen levels lead to

thinning vaginal mucosa and decreased vascularity, as well as possibly a suppressed vaginal immune response and altered vaginal permeability.

## **Women Tend To Get Sicker**

Moving on to Slide 20, Dr. Brown noted how pathogenesis and treatment differ for women. Women tend to get sicker, with AIDS at higher CD4 counts and lower viral load, for example. There also are dose requirements for pregnancy and Kaletra and medication contraindications for pregnancy.

Women's research has contributed to general HIV science over the years. Prevention of mother-to-child transmission was the conceptual basis of treatment as prevention through pre-exposure prophylaxis (PrEP). Also the discovery of mitochondrial toxicity during pregnancy has informed treatment and monitoring changes. And understanding mucosal immunology has informed etiology, pathogenesis, vaccine research, microbicides research, PrEP research, and a growing conceptual understanding of how men get infected anally, for example (Slide 21).

## **Research Has Informed Practice, So What Research Is Needed Now?**

Also, as is well known, research has informed practice in prenatal care, treatment and management, monitoring HIV disease, and primary and secondary infection (Slide 22).

What research is needed now? "We need to better understand women's issues, including the basic sciences of how infection occurs. And how to do that without causing greater harm" (see Slide 23).

## **"HIV Prevention in Women: Challenges and Priorities," by Sharon Hillier, University of Pittsburgh School of Medicine and Microbicide Trials Network**

Dr. Hillier began by noting that when she was growing up 40 years ago, she discovered she could have sex and not get pregnant because her physician prescribed oral contraception for her. This sowed the seed in her that all of us need to have the opportunity to control our own health by using tools to prevent infection, and that is now her sacred mission—to have tools to protect us from HIV.

## **Overview**

Today, Dr. Hillier will discuss what is known about female barriers, will provide an update on PrEP and microbicide studies to date, examine what is next for sustained delivery and combination products, as in new tools, note special populations and their needs, discuss harnessing treatment for prevention, and issue a call to action.

In terms of male condoms, even though using them may seem simple, "we just have to accept that people don't like to use them." While male condoms are a good tool, "we need better because many people can't work using them into their lives in a regular or comfortable way" (see Slide 3).

## **Female Condoms**

Diaphragms do not work to prevent HIV, and while female condoms are effective, they are more expensive than male condoms, they are not discreet, and there is no evidence of how they work (Slide 4).

Dr. Hillier noted that what changed treatment into prevention, a profound discovery, is research. “We don’t have research on female condoms. There are questions that could be answered through research. There are other questions, too, such as ‘could’ clinical trials be conducted to assess female condom effectiveness for HIV prevention, and how should provision of barriers be prioritized relative to biomedical prevention methods such as PrEP and microbicides?” (See Slide 5.)

## **Why PrEP or Microbicides?**

Why consider PrEP or microbicides? First, they allow discretion and control, they are not disruptive, and they allow for conception for women who desire that (Slide 6).

Why pursue tenofovir and emtricitabine-tenofovir for PrEP? These are potent, safe, and easy to take, but there is concern about resistance and NRTI cross-resistance (Slide 7). Dr. Hillier also noted that Truvada has been used for these trials because Gilead was willing to make it available, which is also true of the tenofovir gel that has been evaluated in the CAPRISA 002 study and VOICE trial (Slide 8).

## **The PrEP Puzzle**

Dr. Hillier showed a puzzle and how PrEP trials of tenofovir were designed to fill in different parts of it for different populations. So what has been the result? “Interesting.” In July 2010, tenofovir gel was reported to reduce HIV infection by 39 percent in high-risk women, and in December 2010, oral Truvada was reported to decrease HIV infection in MSM by 42 percent. Yet early the next year, oral Truvada was found to be ineffective as prevention in young women yet highly effective in HIV-serodiscordant couples in Kenya and Uganda and heterosexuals in Botswana (Slides 9-11).

Dr. Hillier noted the design and some of the findings from the VOICE (MTN 003) trial (Slides 12 and 13), noting that VOICE continues to test the safety and efficacy of oral Truvada tablets despite some set-backs. “What happened is emblematic of the entire field,” she said, and then moved to Slide 14, which depicts all the PrEP efficacy trial results to date. The slide clearly shows that some of the same interventions have yielded very different results in very different populations.

So, Dr. Hillier said, turning to summary Slide 15, “that old puzzle has been quite puzzling.”

Why the discordant results? The short answer is “we don’t yet know.” Is it adherence, biological differences, behavioral differences, and/or differences in types of hormonal contraceptives used? In the future, we will “probably have tools that lessen our reliance on daily use adherence” (Slide 16).

## **FDA Approval of Truvada for Prevention Possible Soon**

The next generation of products for HIV prevention, Dr. Hillier predicts, will use sustained delivery methods. She noted that Phase III effectiveness studies results should be available in 2015, and it is possible that vaginal rings could be combined with hormonal contraceptives to provide both family planning and HIV prevention in a single product (Slide 17). Another option would be injectables (Slide 18). Even though the antiretroviral-based HIV prevention timeline (Slide 19) is a moving train, “we could have FDA approval of Truvada for prevention, for example, by July of this year” (Slide 20).

So, new tools are coming, but what will be the barriers to use by women who need oral PrEP or microbicides? Who will provide services? Who will pay? How will we avoid tension between finding funds for treatment versus providing these drugs for prevention? (Slide 21)

Dr. Hillier noted that pregnant and breastfeeding women are excluded from all effectiveness studies at present, and yet these women are the least likely to be able to negotiate condom use. So how can they be protected? The Microbicide Trials Network (MTN) is evaluating the safety of tenofovir gel in such women. This could be complicated and difficult, but “not impossible.” There are also questions about adolescents and mature women, the latter of whom have not been included in PrEP studies to date (Slide 22).

Treatment will prevent a lot of infection, Dr. Hillier said. There are five new infections for every two who go on treatment, she added (Slide 23).

Concluding, Dr. Hillier ran quickly through the seminal HPTN-052 findings (Slide 24), noted that many research gaps remain (Slides 25 and 26), listed her top research priorities (Slide 26), and ended by emphasizing that her passion is to have tools women can use to take control of their own health, tools that are just right for the individual and for which there exists good evidence of safety and efficacy.

### **“Where We Enter: Women, the Community, and HIV Prevention Research,” by Dazon Dixon Diallo, M.P.H., Founder and President, SisterLove**

Ms. Dixon Diallo said she would provide the community voice and perspective on what has just been shared by others.

In 1892, Anna Julia Cooper wrote, “Only the black woman can say ‘when and where I enter,’ in the quiet, undisputed dignity of my womanhood, without violence and without suing or special patronage, then and there the whole...race enters with me.”

### **The American South**

Ms. Dixon Diallo said she also represents a voice of the South, which Slide 3 shows as having some of the highest rates of women living with HIV in the country. “Unique challenges exist in our section of the country that are highly parallel with and comparable to other southern regions of the globe.” Ms. Dixon Diallo also showed the graph of new HIV infections among U.S. subpopulations, where the highest rate of new infections (approximately 5,400) is among black heterosexual women (Slide 4).

## **SisterLove**

SisterLove, which was founded in July 1989 and is based in metropolitan Atlanta, serves more than 5,000 women, men, and youth each year with an annual budget just over \$1 million. Its mission is “to eradicate the impact of HIV/AIDS and other reproductive health challenges upon women and their families through education, prevention, support, research, and human rights advocacy in the United States and around the world.” Most important, Ms. Dixon Diallo said, are SisterLove’s principles of practice (Slide 7), which the organization hopes to advocate across the board through policies and programs.

Ms. Dixon Diallo’s Slide 8 shows how behavior is a 360-degree construct that involves not only the individual but community, society, and government and industry. It is with this knowledge that SisterLove uses the research available to advocate change. The next slide depicts a program entitled ISIS at Emory University and teams learning healthy love through, in part, the use of condoms.

## **Adding More Tools to the Normally Depicted Tool Box**

Turning to combination HIV prevention for women (Slide 10), Ms. Dixon Diallo noted she had added a few more tools to the typically depicted toolbox, such as family planning, violence prevention, and reproductive justice, especially for women living with HIV. “We also want to decriminalize sex work and reduce the fastest growing incarcerated population in the South—women.”

Today’s challenges as noted on Slide 11 are really important for all women, including transgender women, Ms. Dixon Diallo said. Beyond antiretrovirals, “we need improvement of female condoms.” In addition, Ms. Dixon Diallo is interested in any and all policy and its impact on health outcomes. And she feels the impacts of community engagement and participation are often unspoken and left unacknowledged.

## **Can Research Change the Picture?**

Slide 13 asks if studies change things, then answers, “no.” They do not, Ms. Dixon Diallo explained, because first, we need more evidence-based behavioral prevention interventions and community-level education and interventions to address gender inequities and provide parity and equity in resource distribution for services, among other things (Slide 13).

But, yes, studies can change things because they “will help us reach our goals faster.” Research studies help increase women’s level of health and research literacy; require greater integration and incorporation of HIV, sexually transmitted disease (STD), and sexual and reproductive health and rights; help strengthen the bridge between the women of the deep South and the global South; may help the Nation reach the goals of the Strategy faster; and will help advance advocacy on the intersection of prevention and treatment (Slide 15).

## **Recommendations**

Ms. Dixon Diallo’s recommendations are (Slide 17):



- To increase investment in a specific pipeline for women’s HIV and sexual/reproductive health researchers and service providers
- To invest in promoting community-based participatory research (CBPR) among HIV and sexual reproductive health organizations and institutions
- To fund more integrated research that bridges behavior, social, biomedical, observational, and community practice
- To fund more high-quality “non-random-controlled trial (RCT)” research or invest in more RCT plus
- To pay attention to women or pay more money out later.

Ms. Dixon Diallo also noted that SisterLove is currently hosting meetings on what women are saying about PrEP now.

Concluding, Ms. Dixon Diallo noted discussions about whether to prioritize gay and bisexual men or women, but she thinks priority should be placed on both. It was the movement of the gay community “that kicked down the doors to change our response.” Now “it is time to close the door on this epidemic by including women.”

Ms. Dixon Diallo ended with a quote from Martin Luther King, Jr.: “We are caught in an inescapable network of mutuality; tied in a single garment of destiny. Whatever affects one directly, affects all indirectly...I can never be what I ought to be until you are what you ought to be. You can never be what you ought to be until I am what I ought to be....”

**Presentation by Carmen D. Zorrilla, M.D., Professor of OB-GYN, University of Puerto Rico School of Medicine, and Principal Investigator, CMI, MI-HMHR, UPR-CTU, PR HVTU, PR-CCHD, Maternal-Infant Studies Center (CEMI)**

### **Five Take-Home Messages**

Dr. Zorrilla’s five take-home messages include the following (Slide 3):

- We need to fill gaps in prenatal HIV testing in the United States.
- Women who begin highly active antiretroviral therapy (HAART) before pregnancy do better.
- Facilitating HIV screening during family planning services will enhance early identification of women living with HIV, will facilitate preconception care, and will probably have an impact on the epidemic if combined with early care/treatment.
- We need to determine the real impact of hormonal contraception on HIV transmission/susceptibility in the United States.
- We need to determine if the PK interactions of OCs also affect ovulation and fertility.

Slide 4 emphasizes the 2006 revised recommendations for HIV testing of adults, adolescents, and pregnant women in health care settings, and subsequent slides note the rates of prenatal testing for HIV, hepatitis B, rubella, and syphilis at that time. Slide 7 graphically depicts the beginning in 2007 of a downhill slide in rates of diagnosed perinatally acquired HIV infections among blacks/African Americans from a slightly earlier high of 15 per 100,000 live births. Slide 8 depicts information about the timing of antiretroviral treatment in HIV-infected pregnant

women or exposed infants for the birth years 2006-2009, showing a steady decline for the most part in the number of births for which there was no known treatment.

Slides 9-12 show diagnostic outcomes among infants by timing of antiretroviral treatment in the birth years 2006-2009; timing of maternal HIV testing among infants with perinatally acquired HIV infection in the same birth years; and the number of perinatally acquired HIV infections in children born during 2009, including in five U.S. dependent areas. In that year, in Puerto Rico, there were 0 acquired infections in children by contrast with New York (10); Florida (9); Texas and Illinois (7 in each); and Mississippi (5).

Key issues when treating pregnant women (Slide 13):

- Drugs that cross the placenta and reach fetal circulation
- Drugs that do not (or in a very limited way) cross the placenta
- Knowing the plasma prekallikrein (PK) profile of the drugs
- Avoiding drug interruptions in pregnancy
- Labor and delivery treatment (if labor is prolonged)
- Neonatal antiretroviral treatment (ART) and infant formula.

Slide 14 indicates several mechanisms of action, beginning with reducing viral load in pregnant women and extending to post-exposure prophylaxis after delivery. Slide 15 notes management during pregnancy, labor, and postpartum. Slide 16 goes into risk factors of preterm delivery and low birth weight in HIV-positive pregnant women based on a study published in 2011. Slide 17 reports on extremely low risk of mother-to-child transmission (MTCT) in women starting HAART before pregnancy. Slide 18 notes pregnancy considerations for HIV-positive women.

Slide 20 notes methods of contraception for women with HIV, based on an American College of Obstetrics and Gynecology (ACOG) Practice Bulletin from 2010. Slide 21 goes on to note a piece from the same practice bulletin issue about HAART and oral contraceptives that identifies ART agents that decrease hormone levels and those that increase hormone levels. Slide 22 depicts 2011 abstracts regarding combined oral contraceptives and the effect of hormonal contraceptive use on time to AIDS or death in female HIV seroconverters.

### **Summarizing the Data**

Summarizing all that guidance and data, Dr. Zorrilla emphasized that the literature is conflicting on the safety of hormonal contraception and progression of the disease. Specifically, as Slide 23 notes, there have been findings of no association between hormonal contraception and HIV disease progression; findings that associate the use of Depo-Provera or oral contraceptives with accelerated HIV disease progression and death; and findings that associate drugs such as Depo-Provera with an elevated HIV-1 RNA setpoint when used at the time of HIV acquisition, which could result in more rapid disease progression. Some of these differences could have to do with different prevalence levels and populations, Dr. Zorrilla commented.

One bottom line is the need for comprehensive strategies for women, as noted on Slide 24, and to pay attention to Dr. Zorrilla's initial five take-home messages as recommendations.

Dr. Zorrilla ended with a quote from Paulo Coelho's *The Alchemist*: "When someone evolves, everything that surrounds him or her also evolves. When we try to become a better person, everything around us also improves."

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

Ernest Darkoh-Ampem noted that in South Africa, where he lives, "we don't talk about sex." He understands risk mechanisms, systemically, and when he looks at how we are geared to address them, he finds fixed structures. So what he thinks Ms. Dixon Diallo is talking about is knowledge and control, and he does not think we can get at these through fixed institutions. If we want to scale up and focus on wellness, how do we think about this?

Dr. Wyatt said Dr. Darkoh-Ampem's concerns are warranted. It is frustrating to her to have been at this so long yet never to be asked to meetings where decisions are made. Small groups of people have to talk to each other. They must be asked to voice what they know, but they are not being asked. We have to engage people the way they are, but they are not being integrated in the way all this is being addressed now.

We need institutional communication and tailored intervention approaches, Dr. Wyatt said, adding that we have been through 5 years of undoing 30 years of individual intervention. We need to talk to couples and communities. For example, she hears that, in Africa, men like unlubricated sex, so how will we get women to use something that makes their vaginas not dry?

Dr. Wyatt thanked Dr. Darkoh-Ampem for his comments and question. "Your voice is important on PACHA."

### **Keeping One's Diagnosis to Oneself and Undoing the Silence**

A representative of Housing Works in New York noted that his sister died of AIDS complications at age 56. She was silent from the time she was diagnosed about her diagnosis. She never even confided in him.

Ms. Dixon Diallo responded that this is a big issue. She knows that on average, 5 years can pass from the time a woman knows her status and the time she tells a single soul. We also know that in that time period, the virus is doing the damage it will do. Lack of disclosure means many things. Many issues come into play, particularly for women who are mothers. Stigma itself is huge. That is why SisterLove developed a video entitled "Everyone Has a Story," which is about living positively out loud. It is being used as a basis for undoing the silence.

### **Enabling Safe Conception**

Dr. Garcia said she did not hear discussion per se about reproductive justice and enabling safe conception. She asked specifically if the speakers had any thoughts on "the absence of our ability to help people know about safe conception for discordant couples."

Responding, Dr. Hillier said there have not been good studies on this in the past. However, next week at CROI, the results of some new studies will be released showing that fertility-drug-assisted reproductive technology could be efficacious and safe.

The Rev. Sharp said she has been HIV-positive for more than 22 years. She is also working here and in Kenya and Ghana. She noted that Dr. Brown had mentioned survival sex and how semen stays inside women. Yet African American women do not talk openly about sex and “that is why we haven’t been able to move forward as much as we need to.”

The Rev. Sharp said things that have been said here today, including about survival sex, constitute the kind of language that needs to be more prevalently heard in our churches. So what can we do to move this in the needed direction?

## **Puerto Rico**

One of Dr. Zorrilla’s patients for the past 24 years began to speak in Spanish. Dr. Zorrilla translated. “There are areas in Puerto Rico that lack quality of care and that have only one general practitioner who has no idea about women’s care and particularly women with children.” This is why Dr. Zorrilla’s clinic is applying for an RWCA grant to extend services to these kinds of areas.

A representative of the Women’s Collective asked for thoughts about new recommendations for taking counseling out of testing and how women can be reassured that the way sex happens for women is acknowledged and “we are not lost.”

## **Testing Counseling Needed**

Responding, Dr. Wyatt said counseling needs to be put back into practice. She is not sure how it got lost. She noted that some women have never experienced being taken to a medical specialist. They need to know they are important and valued. Yet, many people still expect not to be treated well.

## **IOM Recommendations**

Ms. Dixon Diallo said this is an important time for us. She noted the Institute of Medicine (IOM) report and recommendations on ACA. She said, “it is up to us to educate providers and women about the recommendations made for women’s general preventive care and that need to be provided by providers.” This “is absolutely necessary.” It is necessary that this becomes part of linkage to routine care.

Also, The Rev. Sharp’s revelation on how to converse with faith leaders is a new revelation for some. Ms. Dixon Diallo has this to say about that: “The gift of life is the greatest gift for those of us who believe. If it wasn’t, why would God choose that as a way for us to procreate? If they look hard enough at the Bible they will find the blessing.”

## **LUNCH**

## **AFTERNOON SESSION**

**“Caring for Women with HIV Through the Life Course,” by Mardge Cohen, M.D., Senior Physician, John H. Stroger, Jr., Hospital, and PI, Women’s Interagency HIV Study (WIHS),**

**Departments of Medicine, Cook County Health and Hospitals System and Rush University, Chicago, Illinois, and Boston Health Center for Homeless Program**

Dr. Cohen noted she has been a physician in the Cook County system for 35 years, 25 of those years doing research on women and HIV. She has learned a great deal about people and social justice.

**Public Health Imperative**

Our challenge is that because early ART initiation reduces rates of HIV sexual transmission and clinical events, and women are 50 percent of persons living with HIV globally, we face a public health imperative to:

- Understand how women start, stay on, and respond to ART
- Assess how this therapy impacts HIV/AIDS and HIV-associated non-AIDS (HANA) conditions
- Support women with HIV to enable longer and healthier lives throughout the life cycle.

**Presentation Focus**

Dr. Cohen noted what she will focus on in this presentation, including management changes and a proposal for a prognostic score card to empower patients and enhance provider focus.

Of the HIV-infected persons living in the United States, only a fraction gets adequate treatment (Slide 4). As previously noted, women and African Americans do the worst in terms of viral suppression (Slide 5), and, most disturbingly, HAART has not reduced racial disparities in death rates for females diagnosed with HIV (Slide 6).

When one looks at the findings in a study of the generalized HIV epidemic in Washington, D.C. (Slide 7), and the excess vulnerability to HIV acquisition among African American women experiencing socioeconomic inequality, lower health literacy, inadequate access to high-quality health care, and high-risk environments, one is seeing the social determinants of health at work (Slide 8).

One day back in 1987, the woman depicted in the photograph on Slide 10 knocked on Dr. Cohen's door and asked why she was not taking care of women with HIV. Dr. Cohen could not say no to this woman, and so the women and children with HIV program began at a time when women made up 8 percent of the U.S. epidemic. The program tried to address multiple vulnerabilities to create an ambience of caring, so as to engage people to stay in care. This was before therapy.

**Young Women and Adolescents**

What Dr. Cohen has learned since then about young women and HIV: Slide 11 shows how young women and adolescents have increased susceptibility to transmission, poor ART adherence, and psychological, gynecologic, and medical problems, all of which require receipt of full medical and psychosocial care, including sexual and reproductive counseling, contraception, and obstetric services.

Dr. Cohen noted a study of post-exposure prophylaxis use among female adolescent sexual assault victims (Slide 12), adding that an important issue was the need for the patients to feel that the health care provider was on board completely, “plus they needed their own motivation.”

Dr. Cohen noted poor ART adherence in adolescents with HIV and its correlates, adding that to improve this adherence “requires a lot of labor-intensive work” (Slide 13).

Dr. Cohen then documented poor care for women with HIV based on a study of a linkup of data from the South Carolina Medicaid and the HIV/AIDS reporting system. The study involved 1,543 women, 18-64 years of age, 563 of whom were found not to have had a Pap smear test for 4 years running (Slide 14).

Dr. Cohen noted changes in contraception use with age among HIV-positive women at risk for pregnancy (Slide 15), adding that these results were well discussed this morning “as a place we have failed.”

Slide 16 discusses the sexual health of women with HIV. Dr. Cohen noted that Dr. Hillier had done a good job earlier talking about this and how providers do not talk about sex.

## **As Women Age**

The impact of menopause: as women age, many issues arise. Those that specifically affect HIV include osteopenia and osteoporosis, dyslipidemia, metabolic and weight changes, enhanced cardiac risk, and inflammation/immune response changes (Slide 17).

Dr. Cohen then noted chronic diseases associated with the aging of women with HIV. In addition, even women whose HIV infection has been well treated stand a chance to experience premature aging (Slide 18).

In the WIHS study, participants receiving therapy and continuing on therapy “are doing pretty well right now,” Dr. Cohen said, but, as the graph on Slide 19 indicates, “it took a long time to get them into therapy in a good way.” Now, however, adherence is up and new diagnosis and death rates are down (Slides 20 and 21).

Dr. Cohen said that now, non-HIV-related mortality “needs to be a focus,” ranging from non-AIDS liver and heart disease to various non-AIDS cancers and pneumonia or infection (Slide 22).

Dr. Cohen then showed a series of slides addressing, in turn, cardiovascular disease (Slide 23); liver disease (Slide 24); cancer, particularly lung cancer (Slide 25); and bone mineral density (BMD) (Slide 26).

Turning to psychosocial comorbidities and high-risk behaviors, Dr. Cohen emphasized chronic depression (Slide 28), cigarette smoking (Slide 29), and the association of abuse with mortality (Slide 30). Dr. Cohen also emphasized alcohol abuse (Slide 31) and traditional gender roles, as in related to inequity (Slide 32).

Dr. Cohen cycled back to smoking, depression, abuse, and alcohol and the big impact all of these have on inflammation (Slide 34), which is important because HIV inflammation persists

even when HIV is controlled (Slide 35). Dr. Cohen stressed that inflammation could be a cause of comorbidities and the consequence of a fatigued immune system, so having fixed the virus, “we need to heal the immune system.”

### **Risk Index/Prognostic Index**

Slide 36 is a model that summarizes what Dr. Cohen has just been focusing on in terms of immunopathogenesis. Slide 37 depicts a model for how non-AIDS disease is influenced by HIV, treatment, and behaviors and conditions. This VACS model is important, Dr. Cohen said, because the VACS risk index derived from it (Slide 38) and/or the proposed women’s prognostic index (Slide 39) could help people living with AIDS( PLWA) in many ways, including figuring out and understanding their prognoses.

Such an index, if validated in different geographic settings, could be a tangible tool directed toward better outcomes. Women could have their own scorecard and work with providers to improve their prognoses (such as stop smoking and so on). Such a scorecard could potentially be generalized to men with HIV as well (Slides 40 and 41).

Beginning her conclusion, Dr. Cohen stressed the need to increase the empowerment and self-efficacy of PLWA, perhaps by developing a peer-led model of scorecard implementation and a way to assess efficacy, including patient satisfaction, behavior changes, and outcomes (Slide 42). The scorecard could also be a tool to engage providers as well as encourage community-level changes, such as smoking cessation programs (Slide 43).

### **Policy Implications**

Dr. Cohen summarized the policy implications of her presentation (Slide 44):

- The need to think and plan beyond pills,
- The need for the highest quality comprehensive integrated care to address the complex needs throughout the life course of women with HIV,
- The utility of a scorecard as a tool to increase patient ownership and provider engagement, and
- The need to address organizational requirements, such as reimbursement for comprehensive care service and venues (including community groups) and creation of distributed specialized networks, such as Telemed.

What is the context for all this? Dr. Cohen noted in Slide 45 that:

- Women with HIV are living longer but not living as well as they should.
- Socioeconomic inequality, lower health literacy, inadequate access to high-quality health care, and high-risk environments that result from racial and sex biases are responsible.
- Logistic support (clinic access, transportation, childcare, and housing) is basic and necessary.

Last, “we have the potential for a positive agenda whereby (Slide 46), we”:

- Care about women throughout the life course “to better prevention and treatment,”

- Include women with HIV in addressing care issues, and
- Provide drug treatment, smoking cessation, mental health, and trauma care.

Ms. Mahon said it is very helpful that Dr. Cohen made so many concrete recommendations.

**“Access to Care for Women and Girls with HIV/AIDS: Voice from the South,” by Laurie Dill, M.D., Medical Director, Medical AIDS Outreach of Alabama**

Dr. Dill undertook to lead “a tour of what the AIDS epidemic looks like in the South.”

The South knows a lot about barriers to care, as the Southeastern United States carries a disproportionate burden of those infected with HIV in the United States. Taking a closer look at a map of the region (Slides 5 and 6), one can easily see the disproportionate burden carried by African Americans and by women and girls.

CDC data from 2009 provide evidence of the disproportionate burden and of new AIDS diagnoses in the South (Slide 7):

- The rate of new HIV infections per 100,000 population was the highest in the Southern United States, indicating this region had the greatest proportion of residents testing positive for HIV.
- Half of newly reported HIV infections were in the South, although the South accounted for only 37 percent of the U.S. population at that time.
- The South accounted for nearly half (46 percent) of new AIDS diagnoses, and the AIDS diagnosis rate in the Southern region was second only to the AIDS diagnosis rate in the Northeast region.

Dr. Dill noted that the disease burden is not evenly spread, not even inside the State of Alabama (Slide 8). Incidence is highest roughly through the middle part of the State. This band is called the black belt of Alabama, originally for its rich black soil. These counties are at the heart of the cotton plantation South, which was once the richest part of the South, when cotton was king. Now this band experiences high rates of poverty. It is very rural. There is no public transportation and very poor access to health care. There are also “extremely inadequate public education systems.”

Slide 9 shows the prevalence and incidence levels for the United States, for Alabama, and then for four counties in Alabama—Dallas, Lowndes, Macon, and Montgomery. Dr. Dill noted the infamous Tuskegee syphilis study, which took place in Alabama and did not end until 1972. “This is not ancient history. Black men were studied and denied treatment. And one wonders at the distrust in the community around HIV/AIDS.”

Medical AIDS Outreach of Alabama (Slide 10):

- Serves 26 counties of South Central Alabama
- Is currently serving some 1,200 patients who would otherwise be without treatment for HIV, and has reached 22,000 people through community education and outreach in the past year
- Provides free HIV testing



- Provides compassionate, comprehensive, and confidential care to those infected and/or affected by HIV
- Has a 99 percent success rate with newborn initiatives, treating more than 100 HIV-positive women, ensuring their babies are born free of HIV
- Accesses medications for 100 percent of uninsured and underinsured patients.

Slide 11 notes that in the United States in 2009, CDC data indicated that nearly one-fourth of all new HIV infections were among women, and that regions with the highest proportion of new infections among women were the South (25 percent) and Northeast (27 percent) regions. Medical AIDS Outreach of Alabama's patient population is now 37 percent women.

Slide 12 notes that African American women are particularly affected by HIV in the South, as the majority of new HIV diagnoses (71 percent) among women in the South between 2005 and 2008 were among African American women, and half of the new HIV diagnoses among Hispanics/Latinos occurred in the South. Seventy-nine percent of Medical AIDS Outreach of Alabama's female patients are African American.

The HIV/AIDS epidemic takes place in an environment of structural violence that requires us to look at systems of poverty, stigma, domestic violence, rural challenges, health funding and infrastructure challenges, and inequality. Slide 13 notes one definition of structural violence as "the physical and psychological harm that results from exploitive and unjust social, political, and economic systems [and the dynamic] in which the AIDS virus lurks."

Barriers to care for women in the South, ranging from poverty to health care funding challenges (Slide 14), constitute a "synergy of plagues," in that each of these barriers makes the others worse. "Poverty constricts choices. Race, the highest correlate with infection, is much stronger than education or poverty. Poor education should be on the list as a legacy of slavery and racial discrimination. Stigma, as we are in the Bible belt, runs deep and strong, so deep and strong that we don't advertise our clinics. Domestic violence, I think, is the greatest barrier to women protecting themselves in this country. I know of purposeful infections as a means of control. Rural challenges were already mentioned. And health funding and infrastructure challenges entail the fact that the entire treatment infrastructure in the South is very fragile: we have the greatest shortage of providers and HIV providers and of HRSA and CDC money, yet delivery to care costs more, and a large percentage of our ADAP and Medicaid programs are restricted. Southern States," Dr. Dill concluded, "cover fewer individuals and pay less."

One "really wonderful solution we're working on is AIDS United, an access-to-care initiative to set up telemedicine sites "as a "tool for rural access and continued communication" following mobile unit visits (Slides 15 and 16).

Dr. Dill concluded by reporting on the project's first year of progress, adding that the project hopes to move to mental health visits.

Ms. Khanna commented that integrating reproductive health care into HIV care seems to be a striking need, "given what we've heard today."

## **“Understanding the Landscape of Women’s HIV: An Issue of Rights, Health, and Dignity in the United States,” by Linda Scruggs, Director of Programs, AIDS Alliance for Children, Youth, and Families**

Ms. Scruggs brought slides for PACHA’s consideration. By and large, she spoke extemporaneously.

Ms. Scruggs noted that she is a founding member of the Positive Women’s Network. (Slide 16 describes the network as a project of Women Organized to Respond to Life-Threatening Disease [WORLD] that is driven by and led by HIV-positive women who work with allies to improve the quality of women’s lives by supporting HIV-positive women as leaders and encouraging Federal policy change. The network also applies a gender equality and human rights lens to the HIV epidemic to achieve Federal policies grounded in the reality of women’s lived experiences.)

Ms. Scruggs asked the audience to focus for a moment on key players of women support and voices used to support her talk today (Slide 3), adding that the 30 for 30 Campaign should also be on that slide.

When she was asked to speak, Ms. Scruggs called on her sister girls to help so that she would not feel so alone speaking as a positive woman. “I love the power that women bring,” she said. In her generation, she was taught “very early that I am woman and I have power.” Now she chooses “to teach it and pass it on.”

### **The Strategy: Left Out in Many Ways**

Ms. Scruggs invited the audience to speak the names of women who have had an impact on us inside or outside this disease. “It is important for us to reflect, as the Strategy is being implemented, that in many ways, we are left out. As wonderful as the Strategy is, there is much work still to be done. As we improve health care in this country, there is a lot of work to be done.”

### **Defining Moment**

“We are at a defining moment. We have the tools to end the epidemic in America. We can make it happen,” Ms. Scruggs said. She “honestly believes we are at a defining moment to end inequality toward women in America.”

HIV/AIDS is the leading cause of death among women of reproductive age around the world. These sisters “have yet to find themselves.” Now “they and we have to be at the table and no longer sit on the side.” We are at a pivotal moment where “we are ready to address all this.”

Ms. Scruggs told a quick story about a young woman she knows named Maria. Ms. Scruggs added that, unfortunately, she has met thousands of women with HIV. Maria is from New Orleans. She was molested by a brother, and the community boys found out. She experienced gang rape at the age of 13. She learned that “boys were taking things from her.” At age 14, Maria was actively sharing her body with everyone who thought her attractive, and at age 22, she was pregnant with her second child. She dropped out of school. She also tested positive for HIV.

At this time, Maria was in a violent relationship, and she was afraid to tell her status to her partner. She and the baby went through treatment and still, 2 years into this, she had not told him. Only when she found herself in a clinic with others like her did Maria find beauty and support.

### **A Changed Life Is Possible**

One day, a peer said to Maria that if she did not want to go home, she could come to a shelter. It was a three-room shelter in Los Angeles. It was not licensed, but it served well as a safe haven. Then, just 2 weekends ago, Ms. Scruggs found herself at an important meeting at The White House, and Maria was there, with a changed life.

Concluding, Ms. Scruggs said to PACHA members in the audience that we do not have another 30 years to wait. “We need you to go to the tables and bargain and negotiate. We are counting on you to be our advocates, not only on paper but in funding. And to ensure that women are meaningfully involved. Reinstate counseling into prevention and testing. Sex is also OK to teach. That needs to be put back into counseling. We also ask that you ensure that prevention is a research priority.”

### **“Making HIV Prevention, Care, and Treatment Work for Women,” by C. Virginia Fields, President, National Black Leadership Commission on AIDS, and Chairperson, 30 for 30 Campaign**

Ms. Fields said that all of us collectively need to recommit ourselves to elimination of HIV/AIDS among women and all populations.

Ms. Fields characterized the 30 for 30 Campaign. Campaign literature and a briefing paper were given to PACHA members today. The campaign is a “far-reaching group of women—400 individuals and organizations deeply committed to ensuring that the unique needs of women are not forgotten. “

Today, Ms. Fields said, “We find ourselves in a fast-paced change of times for all people,” and “there are great opportunity and many challenges.” In order effectively to meet the challenges based on what we know, Ms. Fields and the Campaign have three priorities and recommendations for PACHA. If we take specific actions, “we believe we can see an impact.”

### **Three Recommendations**

First, get women into care. In order to do that, “expand and expedite women-centered services, including housing services, for women living with HIV.” To be effective, prevention and treatment services for women “must be family-centered and integrated to include transportation, housing, child care, and peer support services, among others, to support them and ensure that they remain in care.” In the end, this will be cost-effective, Ms. Fields said, because in the end, one is providing care for more than one individual. Policy implications here include the need to ensure continuation of the Ryan White CARE Act (RWCA), to reject any budget cuts, and to support increased funding for housing opportunities for women living with HIV/AIDS (WLWHA).

Second, retain women in care. Make women-centered integrated care more widely available. Integrated service delivery should be made available to WLWHA and women affected by HIV/AIDS. Women need HIV/AIDS prevention, care, and treatment as well as sexual and reproductive health services and help with domestic violence. Women should be able to receive all those services in a supportive environment where they trust the providers and the providers are culturally competent. Many more women will be reached if they are offered HIV-related care in an environment in which they are already comfortable and have already developed trust. One such environment is the Memphis Center for Reproductive Health, a founding member of the Campaign.

“We know what works, but the question is whether we have the political will,” Ms. Fields said, adding that what she is asking for “will require greater collaboration and coordination among Federal agencies.”

Third, better data and more targeted research are needed to meet women’s needs. The framework is nothing less than Government accountability, Ms. Fields said, and “that case has been clearly made today.” Data “must be more targeted and disaggregated by sex and gender,” for example, and women also urgently need more investment in and research into current and future HIV prevention tools, including female condoms.

Ms. Fields indicated that additional briefing documents on these recommendations would be made available to PACHA after today’s meeting.

### **Resolution Request**

Ms. Fields called on PACHA to pass a resolution calling on ONAP to require agencies to prioritize these three actions and to include in the resolution a section calling on ONAP to add to the Strategy the goal of reducing incidence in women as part of ONAP’s 2-year implementation review.

Ms. Fields also asked PACHA to ensure that ONAP adds specific goals and objectives to the Strategy for integrating prevention and care, sexual and reproductive health, and intimate partner violence prevention and counseling services.

Ms. Fields also asked PACHA to ensure that relevant Federal agencies assess the impact that Strategy implementation and Medicare expansion will have on supportive and integrative services and to ensure that implementation and expansion will help with these services.

Ending, Ms. Fields said she believes if PACHA gives these matters serious consideration, it will support “everything we’ve heard today.”

### **Recommendations to PACHA**

Ms. Khanna and Ms. Averitt Bridge made the following recommendations to PACHA. They said that the women’s session planning group would come back to the Council with a refinement of these recommendations in the form of a proposed resolution:

- NHAS metrics must incorporate social and structural factors that disproportionately place women at risk for acquiring HIV and at risk of poor outcomes once diagnosed.

- Prevention research needs to invest in research on women-controlled prevention options and acceptability/accessibility issues in the U.S. context, e.g., the intersection between sexual and reproductive health and HIV. Special attention should be given to interactions between hormonal contraception and HIV acquisition/disease progression and to PrEP for women in the U.S. context. There should be additional focus on novel delivery mechanisms and on microbicides and vaccine research.
- Securing women- and family-centered care entails
  - Ensuring that critical RWCA services that facilitate women’s access to care (including peer support, transportation, psychosocial support, and child care) are retained through ACA implementation,
  - Calling for a women’s prognostic index with sex- and gender-specific measures as part of metrics for the NHAS, and
  - Prioritizing HIV specialty care inclusive of mental health, sexual and reproductive health, and intimate partner violence services.
- In integrating sexual and reproductive health (SRH), violence against women (VAW), mental health, and HIV, full integration of HIV care and prevention with SRH and VAW services is needed for HIV-positive and at-risk women. Needed is
  - Investment in researchers and research projects that intersect these three areas,
  - Integration through ACA implementation, and
  - Ensuring that IOM recommendations for counseling, screening for violence, HIV testing reimbursement, cervical cancer screening, and so on are fully implemented for women living with and vulnerable to HIV.
- In terms of stigma and discrimination, call for a Presidential statement condemning HIV-specific criminalization laws and statutes.

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

Responding to a query about where HIV-positive heterosexual men fit in this conversation, Ms. Khanna said we have to stop singling out special groups and not play them off of one another in prevention or management or the associated money. “We have to look at programs and approaches that address HIV. We have to make the pie big enough that we can care for everyone.”

A question came up around women’s experiences with public health departments as related to surveillance issues, particularly in the South, but Ms. Fields continued to speak to the question on the table about positive heterosexual men.

Where heterosexual men fit at the table, she said, is that we are talking about what we must do in our community, because the same support we focus on for women, we must make sure it is available for men and that they do go to those centers.

An unidentified member of the public said, “Men listen to men. Men standing up and saying this is not helpful is very powerful.”

Ms. Dixon Diallo said, “Our straight men have to get with treating women equally. There is a room where straight men have to get straight with each other first. There are gender norms for men that do not service us anymore. You can do it. We can help. But you can do it.”

Dr. Zorrilla said we have the same issues in our community, and we have to deal with it. In Puerto Rico, there is no clinic for men’s health that men can attend. To the extent we generalize and open our doors, we will have men as part of our clinics.

Dr. Wyatt said that in her biobehavioral studies, among serodiscordant couples, she found a lot of sexual dysfunction regardless of sexual orientation, including inability to get erections. “We don’t talk to men enough about their satisfaction. I told you I am a sexologist. So here you go. We’ve got to give men more voice in saying what is going on when we are trying to practice safer sex. We need to hear how this is working for them. It is a circular issue. We are not asking the kinds of questions we need to ask to help men.”

Before introducing Cecelia Munoz, Ms. Mahon thanked those involved in the women’s session and said she would take the recommendations back to PACHA’s Executive Session this afternoon.

Ms. Munoz, Ms. Mahon said, is a great advocate around minority issues. That ONAP is located under the Domestic Policy Council “speaks volumes for this President.” Ms. Mahon noted that she was present for the President’s World AIDS Day presentation. She said, “This should be the President and the PACHA to end AIDS.”

#### **Remarks by Cecelia Munoz, Director, White House Domestic Policy Council**

Ms. Munoz said she has been in this job for 6 weeks and that she is honored to be part of the PACHA to end AIDS. She is here to introduce herself and thank PACHA members for their leadership. Ambitious goals are on the table, and she is thrilled about engaging them together.

The fact that ONAP is part of the Council is a real asset. She has already observed the importance of the work going on around HIV/AIDS and the Strategy, including its importance to other Domestic Policy work. There is a team, for example, on disability and civil rights. All of these things are deeply interconnected.

Ms. Munoz’s first job with this President was as Director of Intergovernmental Relations. She learned that it is important for our work to be integrated and not to leave any resource on the table. She worked very closely with Mr. Albino on Puerto Rico issues. She was the head of the President’s Task Force on Puerto Rico.

Ms. Munoz is thrilled PACHA is spending the day on girls and women. She is the mother of daughters, and on March 14, “we will be shining the spotlight on issues facing women and girls, particularly on violence and gender inequality across the globe.”

Ms. Munoz said that she is new to the Council, but she is not new to these issues, for she served as the manager of La Raza’s public policy portfolio. She worked there with Miguel Gomez. She realized early on in the epidemic that “this was important and important to focus on, particularly as it affects people of color.” She has witnessed the “immigration exclusion and the harm it caused.”

While we have a lot of work to do, “it is important to reflect on and celebrate how far we have come. We invested in ART, and people are living full and vibrant lives. Because of new tools, mothers and babies are thriving, and the global rate of infection and death is declining. We are winning this fight, and we intend to win it. But it is not over, not for those living with it and those infected every day. It is not over for their families, their communities, or anyone here or this President.”

Ms. Munoz noted that “We’ve been holding steady for more than a decade on our rate of infection. Young black gay men’s infection rate has increased by 50 percent over 3 years, Latinos are dying sooner, and black women have been forgotten, despite their high rate of infection.”

The President is seriously committed to ending this for once and for all. Secretary of State Clinton is as well. But “we can’t do it alone. We need every pair of hands if we are going to get to an AIDS-free generation.”

The blueprint is that the Strategy is guiding work overall. The short-term plan is the Federal budget and “important investments in this next budget.” The proposed budget “fully funds the balance of the President’s 4-year pledge to The Global Fund.” The proposal is “also very focused on fighting the epidemic in the United States. HHS is to transfer \$60 million to support cross-cutting linkages, and RWCA is expanded by \$75 million for care and treatment. Resources are prioritized for high-risk groups and new investments in preventive care and research. We are also looking at the RWCA and ACA implementation intersection. We understand these intersections better, for both are instrumental for those in care to stay in care. We know it saves lives and prevents new infections.”

Ms. Munoz concluded that “we are in the position to make this happen.” We “need to be guided by your work. It is no small matter to look people in the eye and say we’re in striking distance of ending this epidemic.” Thank you “to the many of you who are making this your life work.”

## **Public Comments**

Ms. Mahon and Mr. Bates announced it was time for Public Comments. Mr. Bates read a list of names he had received and noted everyone has 2 minutes. Ms. Mahon invited those providing public comments to contact her directly, if needed, and she also invited submission of written statements.

**Marsha Martin**, who is from UCHAPS (Urban Coalition for HIV/AIDS Prevention Services)—“the urban areas most heavily impacted by HIV,” thanked Ms. Averitt Bridge and Ms. Khanna for a wonderful day. Her question to PACHA is how this can be more than just a 1-day event, so that “the information is included in the algorithm being developed that helps us see the end.” We “need numbers to help us understand that if we don’t do this, the goal of an AIDS-free generation will be farther away.”

**Nancy Bernstein**, National AIDS Housing Council Coalition, said homelessness magnifies risk, as does housing instability. Housing instability can be addressed by investing in proven and cost-effective housing programs. Despite this, HUD reports that more than 145,000 U.S. households

living with HIV have a current unmet housing need. One barrier is the disconnection between those who pay for health care services and those who implement structural interventions that reduce illness.

Ms. Bernstein asked PACHA to take the lead to make housing the central component of the U.S. response.

**Carl Schmid**, Deputy Executive Director, The AIDS Institute, said he would focus today on the resources necessary to carry out the goals of the NHAS. While “funding is far from necessary to achieve the goals on time, the budget the President proposed earlier this month will help achieve continued progress in meeting the goals.” Given the fiscal state of the country, the Institute is pleased that many domestic HIV/AIDS programs would receive increases under the proposal and that the President rejected continuation of some policies instituted by Congress that would impede prevention.

Under the President’s budget, funding for ADAP would increase by \$102 million over FY 2012 appropriated levels. According to NASTAD, there are 4,251 people on ADAP waiting lists in 11 States, and more than 445 people in 6 States who have been disenrolled from the program due to budget constraints and growing enrollment. Every month, on average, 2,710 new people or more than 32,500 annually enroll in ADAP. Recognizing the need to keep up with this unprecedented growth, President Obama announced an additional \$35 million for ADAP on World AIDS Day. The President’s budget continues that funding and increases it by \$67 million for a total of \$102 million.

The President also proposed an increase of \$20 million for Part C to fund primary care and announced \$15 million for Part C on World AIDS Day.

Despite these proposed increases, we are concerned about flat funding of other parts of the RWCA program and the proposed decrease of \$8 million to Part D, which funds programs for children, youth, women, and families. The Institute intends to work with Congress to reverse this.

In terms of prevention, the President has proposed an increase at CDC of \$40 million, including restoration of \$10 million to HIV Adolescent and School Health (DASH). That cut, initiated by Congress in FY 2012, amounted to loss of 25 percent of that program budget.

Medical research at the NIH would remain flat-funded, and funding for the HOPWA program would be cut by \$2 million. “We are concerned with the reduced funding level, but we are highly supportive of the Administration’s proposal to distribute HOPWA funding based on HIV cases adjusted for fair market rent and poverty rates rather than the outdated formula that distributes funding based on cumulative AIDS cases.”

In keeping with the policy of following the science of HIV prevention, the President’s budget rejects the imposition of the Federal funding ban of syringe exchange programs and rejects discretionary funding of failed abstinence-only-until-marriage programs.

The budget again proposes an up to 1 percent tap of domestic discretionary HHS HIV programs to be made available to Dr. Koh’s Office to support the Strategy. We look forward to learning



more about how the Administration proposes this funding would be spent if Congress approves the language.

While not perfect, the budget the President has proposed again demonstrates his strong commitment to ending HIV. Now it is up to Congress, which may have different views on how to address spending and the deficit. Whatever path is taken, it is critical that programs of public health significance, including HIV/AIDS, are adequately funded. This summer, when the International AIDS Conference will be held here, the eyes of the world will be on the United States to see if we are adequately addressing the epidemic. President Obama has shown leadership by developing the Strategy and bolstering it with the dollars to implement it. We hope the Congress will follow his lead.

**Christopher Watson**, whose affiliation was undefined, said in the past year the NIH has funded research but now it needs to increase minority researchers for minority protocols.

A representative of the HIV Justice Alliance, who is also a steering committee member of the Positive Women's Network, said meetings like this are an important step moving forward, particularly the interplay between younger and older women. This spokesperson is younger. He encourages PACHA to address the issues of the transgender community. He observed that so many transgender issues overlap with women's issues.

**Nelson Olson** is HIV-positive and here to help Housing Works, which is an independent living "agency" in New York City. More of these are needed to educate those with and those without the virus.

**Ken Hargrove**, who is a case manager with Housing Works, said there is a need for culturally based outreach programs, particularly in rural communities. He was first diagnosed via a rural mobile unit. Mr. Hargrove is thankful to the service organization that reached deep into his community to help him and provided resources. Housing Works encourages PACHA and President Obama to help reduce infection in rural communities.

**Someone** from the public thanked Nancy Bernstein. He said he is a 60-year-old African American man from Housing Works, which is a healing community of people affected by HIV/AIDS. He was infected in 1991, but he has never been sick. He smoked crack for more than 20 years and was homeless. Today, however, he lives in a small studio, and he has the keys to his landlord's entire building.

"Housing was always important for me. Today I'm living in a place that I love." It is important that we have affordable housing, for "if I was not housed, I would be on the street and would most likely not care if I was using a condom or not."

But now he has priorities, is psychologically and physically healthy, and enjoys a social life. "I'm productive. This comes from having a house. And I'm not the only one who was out there looking for a place to stay. "

**Felicia Carol**, also from Housing Works, said she is an African American woman who has been infected for 21 years. Over the past 29 years, she has watched the rates of infection for girls and women go up. Women of color, girls and women, are dying. When she saw the Strategy, at

first she scanned it, and then someone asked her “if I’d really seen it.” So she read it this time and, “I was appalled because it could’ve been a more comprehensive plan for women like me and for young women like my daughters. I asked myself what the hell is going on here. We started discussing it. But it never hit on issues of women and girls.”

Continuing, Ms. Carol said, “Sometimes HRSA is slow with the money. Those who receive it should be able to access girls and women. If there are barriers to that, they should be addressed in a timely manner.” Also, an issue is “the young girls who get tested but never come back.”

**Carole Treston**, representing the AIDS Alliance for Children, Youth, and Families, provided a written statement, the highlights of which were:

- Women living with HIV are disproportionately low-income: 64 percent of women in care have annual incomes below \$10,000, compared to 41 percent of men.
- Women living with HIV are more likely to have caretaking responsibilities: 76 percent of women in care have children under 18 in their homes, and women most at risk or living with HIV are more likely to have experienced sexual or intimate partner violence at some point in their lives (nearly one in four women report “severe physical violence” by an intimate partner).
- Transgender women and girls face pervasive violence from their families, partners, strangers, and peers.
- The combination of all this, in addition to mental health needs and resultant self-medication through substance abuse, heightens the need for case management and coordinated and accessible wraparound services to get and retain women in effective HIV care. How do we ensure that the hope of the National Strategy is as obtainable for them as for men?
- In Ms. Treston’s opinion, building on effective models and sustaining success while working toward the three primary goals of the NHAS in a gender-sensitive and youth-friendly way is key.
- The current unprecedented recompetition of the entire Part D portfolio has been defined in the funding opportunity announcement (FOA) as a response to the NHAS. “You can’t argue with that as a motivator, but it is also a microcosm of this challenge: sustaining current successes and maintaining patients in effective care while likely reconfiguring the distribution of resources to contribute toward achieving the NHAS goals.”
- Currently, 91 grantees are funded by \$78 million. In August, up to 200 grantees will be funded by \$70 million. “How will all of us, HRSA, ONAP, PACHA, and the community, ensure that redirecting resources to areas where there is the greatest unmet need does not create that same unmet need in currently funded areas in a few years?” Who will be monitoring not only the impact of where the funding is going but where it has been taken from?
- Getting more people (women and youth in terms of the Alliance) into medical care and reducing disparities (i.e., increasing “UDVL”) is a laudable goal. But how do we get there? Strategic shifts, such as a deemphasis on case management and supportive services in the current Part D FOA compared to medical care, “doesn’t account for the

- Last, the new FOA may lessen capacity and services for young men who have sex with men (YMSM), the exact population fueling the epidemic in many areas. The intention is that all applicants will service the target populations of youth and women, but this “one size fits all” undermines existing youth capacity and expertise.
- Until now, 17 Part D youth grants totaling nearly \$7 million targeted primarily YMSM in high- incidence areas, such as Chicago, San Francisco, and Baltimore.
- Some were stand-alone sites, such as Larkin Street Youth Services, a runaway and housing program for street youth in San Francisco, and some represented an additional youth grant to a larger Part D Comprehensive Women Infant Children Youth (WICY) network, such as the STAR Adolescent program serving YMSM up to age 24 in Baltimore.
- Under the new FOA, “stand alone” must provide services to women and youth and can only apply for their current award amount, so for Larkin Street to partner with a women-serving organization would mean a net reduction in YMSM programming. And combined grantees can now only put in one application and only apply for the amount of their WICY grant, so resources for YMSM programming at these sites are projected by applicants to be 30-40 percent of what they were until now
- Coincidentally, the Part D FOA as well as the President’s proposed budget for FY 2013 is for \$70 million, \$7.8 million less than 2011, close to the nearly \$7 million amount of 2011 resources specifically targeted to youth. Ms. Treston would argue in 2012 and 2013 that “we need more resources, not less, specifically targeting youth.”
- Closing, Ms. Treston asked PACHA to be as concerned as her organization about unintended consequences of the shifts and changes that will undoubtedly come over the next year and beyond “as we attempt with limited or shrinking resources to meet the NHAS goals, not only through the Part D recompetes, but with other strategies and actions as well. Who will be monitoring not only the impact of where the funding is going, but where it has been diminished or taken from?”

**Ellen Collier**, from Housing Works, has been living with HIV/AIDS since 1985. She said hepatitis C has also become a threat. In some places, it is diagnosed at almost the same rate as HIV/AIDS. African Americans and our Latino and Latina brothers and sisters are not getting the information they need to protect themselves from both.

**Vic Quezada**, also a member of Housing Works, is from Brooklyn, a very large community. Before moving to New York City, his knowledge of HIV/AIDS was limited. Now he wants to talk about Rosa, who works with Housing Works, and her three children. Rosa’s life is not easy. She is infected. It is important to equally distribute resources that people like Rosa need.

**A patient of Dr. Zorrilla’s** spoke, with Dr. Zorrilla translating. Dr. Zorrilla said this patient is 19 years free from injection drug use (IDU). She is involved in needle exchange activism in her area. She has been at many meetings where people say a lot of things, but not much is done. The best example of disparities is that there are only six vouchers for people in Puerto Rico. Now she is asking for parity in HIV care for those living in Puerto Rico. Care should include

vitamins and nutrition help. She also said this same thing 3 years ago. Last, the needle exchange program needs continued funding. She works on such programs and sees the impact.

**Sarah Audelo**, Advocates for Youth, made a statement about not championing places for immigrants to go for care when these are places “where immigrants cannot be.”

### **Update on HIV Disclosure Recommendations**

PACHA Co-Chair Douglas Brooks reported that he and Antigone Hodgins Dempsey had been working on recommendations that would emphasize safe and voluntary disclosure of HIV status, as noted in the Strategy.

Ms. Hodgins Dempsey is Co-Chair of CHAC. CHAC and PACHA were both charged with working on this. Mr. Brooks is PACHA’s liaison to CHAC, and Ms. Hodgins Dempsey is CHAC’s liaison to PACHA.

Mr. Brooks said that a meeting was held with the White House to get a better understanding of what the White House has been thinking about in terms of disclosure. Much of what has been said about stigma and discrimination ties into what PACHA and the Disparities Subcommittee have been thinking about, such as the need to fight criminalization of HIV. Secretary Sebelius mentioned stigma and discrimination and using the International AIDS Conference to highlight ways to eliminate them.

Now an HIV disclosure work group has been formed, with representatives from PACHA, CHAC, HHS, and the U.S. Justice Department. This work group will work on the recommendations. This group met with Mr. Bates and Dr. Valdiserri last week. At that time, Dr. Valdiserri suggested thinking about a set of principles and then following up with a set of recommendations.

Mr. Brooks said he and Ms. Hodgins Dempsey think that if they “could get the right people in the same space over the course of 3 days, we could knock this out. For some of us there is a sense of urgency around this because we would like to have something ready for the International Aids Conference.” Mr. Brooks briefly outlined what those 3 working days would accomplish each day.

Mr. Brooks said he has given some thought to the fact that “sometimes the safest thing may be not to disclose.” Therefore, one of the recommendations could be “to advance disclosure.” Ms. Hodgins Dempsey said she and Mr. Brooks have a more complete idea, too, of writing a concept paper and having a summit around creating safe environments in which people could disclose when they chose to do so. Ms. Hodgins Dempsey added that she is HIV-positive, and there are times when she has chosen to disclose and there are other times when she has chosen not to disclose.

Mr. Brooks ended the update by noting that he too lives with HIV. Disclosure recommendations are professionally and personally “important to both of us.” He was thrilled during the meeting at the White House to speak with the President and to thank him for his commitment. “The President looked at me and said ‘We really need to get this done.’ ” Therefore, Mr. Brooks encourages those involved to stick with this work and get it done.

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

None.

### **Adjournment**

Mr. Bates noted that the second day of the meeting will begin at 10 a.m. and will be held in Room 430, which is not large. First come will be first served. It will be necessary for attendees to find a seat, as they will not be allowed to stand.

Ms. Mahon then adjourned the meeting at 4:12 p.m.

## **Day 2**

### **MORNING SESSION**

#### **Welcome**

Ms. Mahon welcomed everyone and thanked them for coming to the second day of PACHA's 45th full Council meeting. She noted that she is PACHA's new Chair and that PACHA has some key policy issues to consider today.

As members take up these and other issues today, Ms. Mahon asked that they consider "what now?" and not only "what we can do but also what we would encourage others, such as HHS and possibly State legislatures, to do."

Access to Care Subcommittee Co-Chair Robert Greenwald noted his Subcommittee's support for ACA implementation that will meet the needs of PLWHA. John O'Brien and Kevin Malone from SAMHSA will speak next on ensuring that necessary details are addressed in the areas of mental health and substance abuse treatment and prevention.

#### **Presentation to PACHA, by John O'Brien, M.A., Senior Advisor, Health Care Financing, Office of Policy, Planning, and Innovation, and Kevin Malone, Office of Policy, Planning, and Innovation, SAMHSA**

Mr. O'Brien said, given the direction of much of the guidance around ACA, "we're seeing the States being key players and, frankly, we are seeing local providers playing a very important role too."

In the first few weeks after passage of the ACA, many key stakeholders asked what they should pay attention to. There was a need to focus the agency's energy, so SAMHSA decided to focus on three or four things. The first is eligibility enrollment. This is because "it does not make sense to talk about better services if we can't get people enrolled." SAMHSA therefore said it would initially devote a year and a half to enrollment and outreach. Second, SAMHSA decided to focus on services covered by the essential health benefit. On the list, mental health and substance abuse is fifth, but "we must think broadly" about how mental health and substance abuse is covered elsewhere as well. Third, SAMHSA decided to look at providers, as "we have a workforce shortage issue." The sheer number of providers is a challenge, but "even those

providing may not have the business or political acumen to deliver services under ACA, so we are working to see where we can enhance their capacity.”

Mr. O’ Brien then introduced Mr. Malone, who is his “left and right hand on eligibility enrollment.” Mr. O’Brien said Mr. Malone has done a great job of analyzing ACA impact and the work of the Centers for Medicare & Medicaid Services (CMS), “for there is a part of CMS that is working hard on eligibility, which is another reason we need to pay attention to education and outreach for vulnerable populations.”

Ms. Mahon noted to Mr. Malone that one of the “great heartbreaks is that one out of every two who begin treatment drops off.” So, she asked, “How can that number be affected and those people retained in care?” Mr. Malone thanked the Chair for that great question and pledged to address it.

Mr. Malone said he is the agency’s lead on outreach. Redetermination of eligibility is a key component of that. He will talk mostly about expansion of eligibility groups and prevalence data and the demographics of those who will become eligible.

What Ms. Mahon was just addressing is another significant component, which is the way in which eligibility is determined and, as he just mentioned, redetermined. Components of Medicaid eligibility and rules are coming out this week. Also, components of exchange eligibility rules will move the ball toward sustained coverage. If all goes to plan, there should be improvements in the way eligibility is determined and the process individuals have to go through to stay in a program.

Mr. Malone said that today, he and Mr. O’Brien shared with other divisions of HHS the prevalence of the uninsured (Slide 3). There are 37.9 million people uninsured across the Nation, 19.9 million of whom will be ACA exchange eligible and 18 million ACA Medicaid eligible. Twenty-nine percent currently uninsured have behavioral health conditions. The challenge of getting these people in care “is significant.” The challenge will be faced by Federal and State agencies, and “it keeps me up at night how the promise of expanded coverage can become a reality.”

#### **The Behavioral Health Enrollment Challenge (Slide 4):**

- Uninsured populations have disproportionate rates of behavior health conditions.
- Symptoms and income/housing volatility cause challenges for accessing and maintaining coverage.
- Behavioral health providers have limited enrollment experience.
- Traditional outreach workers have limited training in working with individuals with behavioral health conditions.

Mr. Malone showed slides of prevalence data (Slides 5 and 6). “You can see prevalence of mental health issues and substance abuse disorders is very high,” he said. Responding to Dr. Horberg, Mr. Malone confirmed that prevalence is even higher among PLWHA.

Demographic data are available for Medicaid expansion and exchange populations, Mr. Malone noted (Slides 7-10). These data were pulled together to help States and the USG do a better job

of planning by helping them recognize distinct differences between the populations. The uninsured 18- to 64-year-olds with substance use disorder (SUD) slide (Slide 10) depicts a population that will present significant enrollment challenges. These men are “very unlikely to be using health services.” Mr. Malone added that in many cases, such as in Massachusetts, “we saw this group more likely to pay a penalty than get enrolled, and when they do present, it is likely for emergency help for substance abuse.”

Mr. Greenwald said that for some, “the penalty isn’t crippling.” Responding, Mr. Malone said “it is incumbent on us to come up with unique messages and mechanisms that show the utility of enrolling.”

### **Key Takeaways from the Data (Slide 11):**

- There is high prevalence of behavioral health conditions among the uninsured.
- 2014 will potentially bring coverage to 11 million individuals with behavioral health conditions.
- Behavioral health organizations must play an active role in outreach and enrollment.
- Traditional outreach workers must be prepared for high behavior health condition prevalence among the uninsured.

### **Working with the States**

Mr. O’Brien said a “full court press” with the States took place this spring, “with Navigator programs to get them to pay attention to the populations we care about.” We “have also done work on what the right messages are, particularly to those who will need to reply.”

The essential health benefits package rule came out, also, so SAMHSA needs to work on that once it gets past work on enrollment. Under the rule, States “would have options on what they could choose as their benchmark plan.” States with an exchange “will have about 10 options.” If a State is not going forward with an exchange, there is one option called “default.” We knew when the rule came out that “we had to be somewhat careful during public comment period.” Because “we knew we couldn’t reach all the States at the same time, we turned to State mental health and substance abuse directors’ associations and said, ‘it is time for you to help with the analysis in your State’.”

Subsequently, Mr. O’Brien has been working with these associations on their analyses. Mr. O’Brien has found that “they didn’t know a lot about private insurance and the essential health benefit. Our message is that the two things we want to ensure are that there is good mental health and substance abuse coverage and whether that coverage meets some test.”

Mr. Greenwald said a good job is being done of “trying to integrate concerns into State plans.” He added that “the question around the churning issue of retention in the context of HIV/AIDS is not just about enrollment, it is about retention.” When one is talking about outreach and enrollment, “this is not a one-time occurrence.”

Ms. Mahon said “the penalty structure will make that more foreboding,” to which Mr. Greenwald responded that the penalty structure is “not highly relevant for our population.” He added there is “a huge issue around why people fall out of care.”

Responding to Mr. Cruz, Mr. O'Brien said one thing "we're working on with the States and our partners in CMS and HRSA is mental health and substance abuse integration. And we can't just pay attention to mental health and substance abuse but also HIV/AIDS. Even if you have insurance in any form, you don't necessarily have a primary care provider."

Some clinics say they would "prefer not to have our clients in their clinics. Some of the clients we have see a mental health and substance abuse provider as their health home, so we're bringing more primary care into our mental health systems because that is where people go." In other areas, we "are trying to facilitate mental health agencies for better capacity. We are working with the States and HRSA to build that capacity. ACA really helps that."

Returning to service issues (Slides 12 and 13), Mr. O'Brien said he is very concerned about the lack of good retention rates for substance abuse treatment. If people drop out of treatment, "we've not done much, so we want to make sure they get the services they need, but we looked at what those services should look like, and it is like a bathroom sink." Therefore, SAMHSA is helping the States and CCIIO review coverage options for the essential health benefit.

Also critically important is the evidence behind those services, and "this may be an accessibility issue, as in what do we know about the providers?" Also "what are the critical activities, and who were the recipients of those services?" In addition, everyone gets training in cognitive and behavioral therapy, but sometimes, that is not the best therapy. "Now that we have that kind of information, we can message it to Federal and State partners."

Quickly moving through the balance of the presentation slides (14-17), Mr. O'Brien said that about one-third of mental health and substance abuse providers have not participated in insurance and do not have experience in submitting or tracking bills. "It is tricky communicating with providers," he added, "as we don't want them to be marginalized."

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

Dr. Horberg noted that the workforce issue is part of the Strategy. He also noted that mental health capacity "has been decimated in recent years." Responding, Mr. O'Brien said that in terms of coverage, what is in the network will be critical for States to understand. On the mental health side, "we do have parity, so some of the issues around length of stay and aggressive substance use management will be addressed because of that." What SAMHSA has seen are "some good and some squirrely things are happening with how plans are integrating this. Part of this is the benefits issue, and part of it is management. "

Mr. O'Brien added that SAMHSA's efforts with HRSA are very important because the behavioral health field, mental health especially, has about one-third of the loan repayment program participants in 2011. The HRSA program for this has grown "tremendously." Related trade associations are getting the word out, and also, there is more demand.

## **Model Program Components?**

The Rev. Sharp said that retention requires trust, time, and housing stability. Also, some patients are very impatient, so they need someone to help them walk through the process. The



Rev. Sharp added that when considering low-income population, accessibility is important. This includes cutting down the time to appointment. Also, it is important to take down signs in the waiting room that make people feel belittled.

Ms. Mahon commented that this sounds like model programs, adding “we can look at this.”

## **Los Angeles County**

Mr. Perez said that in Los Angeles County, “we’re migrating about one-third of RWCA into the County program.” Jurisdictions will need to take the existing infrastructure participating “in all of this” and leverage and cross-train them. The amount of eligibility screening that will be needed “is huge, and capacity is sorely lacking.” In terms of workforces, “we can migrate mental health to health homes, but many jurisdictions are struggling with capacity.”

In addition, Mr. Perez said, there is a great deal of concern in the substance abuse world about lack of capacity this year to address the substance abuse needs of LGBT brothers and sisters. “We need more addiction medicine models, like the St. John’s model you are funding, because the cognitive behavioral therapy is not sustainable for us.”

Ms. Hiers said, “We don’t have a clinic, but we do have substance abuse and mental health programs.” In the South in general, “we have a dearth of providers, and many without facilities.” At present, “we are in a certain level of panic about retention.” If “we are no longer part of the larger picture, how do we align ourselves in this new world?”

Mr. O’Brien said this is a good question, as “many of our buyers are struggling with what you are.” Some of the answer is “partnerships you can develop with organizations that are getting grants so that you can get some attention paid to your issues.” Responding, Ms. Hiers said that in many States in the South, “we’re being shut out of the conversations.”

Wrapping up, Mr. Greenwald said the Access to Care Subcommittee could not find presenters to present on the implementation of ACA as it relates to HIV/AIDS, so now “we need HRSA and HHS to step up and focus on how all this is going to work, including work being done with the community and advocates as well as the CDC.”

Mr. Greenwald said, “We don’t have an equal effort at CDC,” adding that “HIV/AIDS is not on the list of six prime health conditions, but now it is number seven, after a lot of work.”

Mr. Greenwald suggested that at a future meeting, PACHA could talk about New York, where 64,000 PLWHA in the City are eligible for home health, and “how that can happen across the States.”

## **Possible Action Item**

Ms. Mahon said she will work with Mr. Greenwald, Dr. Valdiserri, and Mr. Bates to obtain such an analysis, joining hands with SAMHSA and “potentially other chronic disease groups.”

## **Presentation on the HIV/AIDS Budget, by Aaron Lopata, Program Examiner, White House Office of Management and Budget (OMB)**

Mr. Lopata said that when a proposed budget is released is a good time to discuss it and to answer questions. He apologized for not having slides or printouts of his presentation. It will be posted on the PACHA Web site. What follows will be a brief summary overview of HIV/AIDS funding in the President's proposed budget for FY 2013. Mostly, Mr. Lopata would like to leave time for questions and answers. He noted that the information he will be presenting is already publicly available. He does understand the desire for discussion as pertains to RWCA, ADAP, and Part C.

### **Highlights:**

- \$28.4 billion has been proposed for domestic and global HIV/AIDS programs. Of that, about \$22 billion is for domestic programs. Most of this grand total is mandatory spending, such as Medicare, Medicaid, and Social Security Disability supplemental income. The remaining is discretionary. Most of the domestic discretionary spending is taken up by the RWCA programs and CDC prevention activities.
- The proposed amount for RWCA is \$2.4 billion, an increase from FY 2012. Within that, \$1 billion is proposed for ADAP, and that is an increase. "The idea there is with that investment and the \$35 million the President has transferred, we can reduce and maybe even eliminate waiting lists, but this would require States to keep up their contribution as well."
- The other big chunk of domestic discretionary spending is for CDC prevention activities, and the proposed amount there is \$826 million, which is an increase. Also, \$ 40 million has been proposed for the DASH program. In the proposed budget there is a testing initiative aimed at groups at highest risk, including IDU, in 36 jurisdictions.

Ending his presentation, Mr. Lopata noted that "it is important to identify those who aren't aware of their status. Once they know, the risk of transmission decreases dramatically."

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

Mr. Brooks noted that the Disparities Subcommittee asked for Mr. Lopata's presentation. He noted that yesterday, PACHA had a fulsome session on disparities faced by women, notably black women, in terms of HIV and the lack of culturally and clinically competent providers. Mr. Brooks said millions of dollars go to organizations that provide capacity building and technical assistance (TA). So now his question to Mr. Lopata is, "How do we know we're spending those dollars well? How much actually goes out for capacity building and TA?"

Mr. Lopata said that "we don't always track at that level of granularity. With Ryan White, at least currently, we have less flexibility since the statute is so prescriptive. Perhaps we can visit that when the Act comes up for reauthorization." He added that "once ACA kicks in in 2014 and expanded coverage goes into effect, the role of the Ryan White program will probably change. It probably has to. Once we get to 2014, we'll be looking at this type of thing."

The focus now, Mr. Lopata continued, "is to get an idea of what Ryan White's role is if a good portion of the clients have insurance. There is thinking that a lot of it will be wraparound

coverage. I hope with health homes and increased funding for that that Ryan White will have a big role to play in rounding that. But a lot of it will be making sure TA and capacity dollars are being used most effectively.”

### **Possible Action Item**

Mr. Lopata said he “needs to work with HRSA and quantify it.” Ms. Mahon said Mr. Brooks’ question was a great question, and “we’ll follow on.”

Dr. Valdiserri said that in its operational plan, HHS asked the agencies to provide a breakdown in terms of domestic spending. According to the reporting entities, about 6 percent of the “not entitlement budget” was primarily devoted to TA. CDC reported about 11 percent of its domestic budget was focused on TA.

Dr. Valdiserri added that “we can talk more about that at PACHA’s next meeting.” He explained that OHAP has been working across HHS and other Departments to take inventory of current prevention programs for African Americans as requested in the Strategy, and “part of that will describe how those dollars are used.”

### **HOPWA**

Ms. Hiers thanked the Administration for protecting and increasing the HIV/AIDS-related portfolio. Meanwhile, HOPWA is a small program, but it is a high scorer in HUD, and it is critical. It will always rise to the top, but it was cut by \$2 million. “We’re looking at modernizing it, but it still needs more money.”

Ms. Mahon then asked Mr. Lopata how PACHA can constructively push him on HOPWA.

Mr. Lopata said he is not the HOPWA examiner, but “I do think this is something where we can make much greater gains, not only with crucial modernization but a lot can be achieved by HOPWA working more closely with HRSA and Ryan White and the resources on the ground.” There is, he added, a degree of waste when on the ground offices are not communicating as well as they could be, so “we’re working on that across the Departments in terms of the budget.”

In this budget, Mr. Lopata added, Ryan White got an increase. The HUD proposal “could have been even worse,” he added. “This is not to say HOPWA doesn’t require more resources. HOPWA has talked about wanting to work more closely with HRSA,” but “we’re under some restriction under the RWCA. Perhaps in the future, more flexibility could make those collaborations more fruitful.”

### **The 1 Percent**

In terms of the CDC, Dr. Holtgrave asked, what if PACHA wanted to make recommendations beyond the 1 percent.

Mr. Lopata said, “it is in the base.” He added that “we don’t know what Congress will do. CDC is always a struggle with Congress.” As pertains to the 1 percent “tap,” we “included that language again this year.” Previously, “Congress came back and said you don’t need that

because you have the Secretary’s transfer authority,” but “it doesn’t get us there in terms of funding.”

## **Part C**

As pertains to Part C, Mr. Lopata continued, “because of the accounting structure in the appropriations language, we could not transfer \$15 million into Part C directly.” There “were people who broadened the Secretary’s transfer authority to allow transfer between appropriations. But the broken down structure still makes it difficult. “

Mr. Lopata said “there are also challenges to doing the transfer.” We “did transfer \$10 million in Part C, but when you do that, you are always taking money from somewhere to do it. This is not only difficult on the Hill, but some agencies aren’t happy either.” He added that “having this 1 percent—if Ron and his team had more resources, it would allow us to implement the other 99 percent of resources more powerfully. I think this is a powerful argument.”

## **New Demonstration Project**

Dr. Valdiserri noted Minority AIDS Initiative (MAI) funding, adding he is very happy to report that OMB gave HHS language “in the passback” needed to do a better job in how we use those resources. It was “suggested we put together a demonstration project to concentrate those resources in a locale to see if we can get better impact.” So Dr. Koh signed off recently on the matter of funds coming from the Secretary’s fund (\$14.5 million every year for 3 years) “to focus on health disparities among racial and minority men and women in the South. “

Dr. Valdiserri said that after about 3 months of discussion and negotiation, those dollars have been directed to the CDC to write a funding announcement. The team developing the announcement will include Dr. Valdiserri’s Office, HRSA, SAMHSA, and the Offices of Women’s Health and Minority Health.

Dr. Valdiserri is not sure what the exact language of the announcement will be, as yet, but at present, “we envision that these resources will be limited to the use of appropriate epidemiological parameters in the Southern States to look in part at mortality rates.” These dollars “will go to State Health Departments, and at least 25 percent will go from the Health Departments to minority community organizations. Dr. Valdiserri’s Office is now in the process of moving funds to the CDC to develop this program.

## **Internal Competition**

The remainder of the MAI—about \$36 million—will be the subject of an internal funding competition limited to HHS agencies and staff offices. The announcement has been released internally. It specifically asks for activities in preventing infection in racial and ethnic minorities and improving outcomes.

Dr. Valdiserri’s Office is now in the process of notifying those who competed for the award, and he will “make public who got what.” He added that “we have taken a fair amount of input from PACHA on this as well as from the 30 for 30 Campaign and other groups.”

## **Cuts to Medicare and Medicaid Impact**

Mr. Greenwald asked about cuts to Medicare and Medicaid and the impact of that, given ACA and its impact on already-eligible beneficiaries. Mr. Lopata responded that “we are working on an assessment on that.” We “are attacking it from the perspective of how Ryan White will be supportive, as I am the examiner of HRSA and Ryan White. Some in Congress will say, ‘we can just cut Ryan White.’” But “our argument, going in, is this is where Ryan White will have a role not in making up for cuts but at least in providing some support.”

## **OMB Analysis on Impacts Underway: Lopata Will Report on Progress**

Mr. Lopata said he “knows that is not an answer,” so he added that OMB is “now working with health economists in our shop to determine the impacts.” In addition, “you provided helpful documents. We will let you know when we make progress.”

## **Global Funding Hit**

Mr. Frost said the domestic side did well in the proposed budget, “but global didn’t as in PEPFAR and The Global Fund.” Responding, Mr. Lopata said he does not know that much more than Mr. Frost. He did talk with the international affairs division of OMB, and “their priority was to meet The Global Fund commitment. PEPFAR took the decrease. I know they are trying to spread the money out to other global health diseases. They feel they can meet their commitment with the levels requested.”

Mr. Frost said PEPFAR is the one program on the Hill with bipartisan support, so the decrease “was a shock.” It is “not clear why this is happening, but this will now move to the Hill because the President’s budget didn’t do it.”

## **Expand WIHS Study**

Ms. Averitt Bridge made a plea to engage the NIH on expanding the WIHS study into the South. “This is an opportunity for synergy.”

## **Part D Cuts**

Ms. Khanna asked about funding for Part D. It is striking, she said, that it is “the only piece of Ryan White cut, so what is the rationale for that?” Responding, Mr. Lopata said “it is a matter of trying to show where our priorities are. In trying to maximize the funding, we can put it in Part C. Also, Part C is going through a recompeting of grants. Also, some of the Part C and ADAP increase came from Part D.”

## **Presentation on HOPWA Modernization, by David Vos, Director, Office of HIV/AIDS Housing (HOPWA), Office of Community Planning and Development, HUD**

Speaking extemporaneously, Mr. Vos discussed statutory changes being requested under HOPWA modernization. Other aspects of changes coming to HOPWA involve flexibility, capacity building, and TA. “We are looking to improve TA and are thinking about competitive approaches to comparatively assess, first. Then we will build on that.”

Mr. Vos said that HOPWA “alone works pretty well, but other housing resources need to be at the table as well.”

HOPWA was cut in the proposed budget, but there are increases to homeless assistance and there will be implementation of new authority in the area of homeless prevention. “We know from that field that there are 21,000 PLWHA who present as homeless.”

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

Mr. Wilson said mainstreaming HIV homeless “begs the question around capacity and training of people to be able to manage the unique needs of PLWHA.” To the point, “what are you doing in capacity building?”

Mr. Vos said that when you look at the larger Federal plan for all this, “capacity building is integrated.” The “real issue is to have programs aligned and moving together, and that begins with assessment. We have tremendous models across the country for that.” Mr. Vos added that “the more troubled African American PLWHA” are a priority, and “special client needs are being taken into consideration.”

Mr. Perez said when HOPWA modernizes, it needs to “fully integrate HIV services along an entire continuum, truly integrating medicine and housing.” In Los Angeles County, “we are penetrating ZIP codes that need help the most, but the HOPWA world is 15 years behind that.” So “you would build on the Ryan White system rather than create a parallel system.”

Responding, Mr. Vos said, “HUD will not be well positioned to address other health issues.”

Mr. Cruz asked if HOPWA is using HIV cases or HIV/AIDS cases because both should be used. Also, HOPWA seems to be moving to “short-term intervention for housing when what is needed is longer term intervention.”

Mr. Vos said he would be happy to learn more about Mr. Cruz’s concern and work with New York. He added that “modernization is about the formula, using CDC data on both HIV and AIDS.” Also, “the short-term program is just one option. We want people to have a housing plan that addresses long-term stability and that doesn’t disconnect them from care.” That plan “can come from us or elsewhere.”

Ms. Torres-Rivera asked how HOPWA will coordinate with transportation, for example, which “HRSA is not planning to cover.” Responding, Mr. Vos said “our special needs section is aware of these needs.” As Ryan White changes, “we will support good outcomes.” He added that “government programs should link together better and get communities to think more comprehensively.”

Ms. Torres-Rivera said “our concerns are how new changes will affect what we have in place,” to which Mr. Vos replied that “we’re not changing “and “HOPWA has the ability to be flexible.”

## **LUNCH**

### **AFTERNOON SESSION**

#### **PACHA Subcommittee Updates**

Ms. Mahon said her query about “what now” applies during these updates.

## **Access to Care Subcommittee**

Subcommittee Co-Chair Mr. Greenwald said there is nothing particularly new but for the fact that the Subcommittee continues to be fully engaged in trying to ensure that ACA is implemented to meet the treatment needs of PLWHA.

Discussed today was the essential health benefits package, “but there are many other issues before us.” Printed out and made available to members today are PowerPoint slides that lay out all the issues “we are focused on.” In addition to ACA, another ongoing priority is integration of RCWA into ACA. As noted in PACHA’s Letter to the Secretary, “it is premature to discuss either health care reform-related cost-offsets or destabilization of Ryan White Program-supported HIV care, treatment, and disease management services...” We “want to see ACA up and running and then talk ways to retool.”

Another ongoing access-to-care and quality-outcomes challenge is to maximize accountability and effectiveness by overhauling HIV-related performance metrics. Later today, Andrew Forsyth will provide a presentation on that.

Subcommittee Co-Chair Dr. Horberg said the Subcommittee is also concerned about subpopulations and mental health, substance abuse, and women and the epidemic.

## **Incidence Subcommittee**

Incidence Subcommittee Co-Chair Dr. Holtgrave said that, like the Access to Care Subcommittee, his Subcommittee is very interested in metrics issues. There is much interest around HIV testing as a quality-of-care metric. There is also much interest in talking about how to refine what we mean by prevention-based programs, which is one place prevention and treatment come together. Updating the Gardner Cascade is a good idea, as well as a conference on the state of the evidence from program and research around treatment as prevention and realizing the promise of O52.

The Subcommittee is also interested in budget issues and prevention as a cost-effective public health strategy, whether budgets are sufficient to make the Strategy a reality, and backsliding on key policy victories in the last few years as in the fact that needle exchange restrictions are back in place, that there is still a need to fund comprehensive sex education, and that, despite the travel ban having been lifted, there are still reports of HIV-positive individuals having trouble getting visas to visit the United States. It is particularly important to fix this in advance of the IAC this July.

Last, FDA is considering a few items of interest, including Truvada as prevention and a home kit for rapid testing.

Discussed briefly was whether PACHA wants to make a statement around these items. Dr. Holtgrave suggested getting presentations on the matter.

## **Action Items**

Ms. Mahon asked the Subcommittee Co-Chairs to get back to members regarding FDA-related presentations.

Ms. Mahon asked to see the Cascade. She also asked for a meeting with Mr. Bates, Dr. Valdiserri, and the Incidence Subcommittee.

Ms. Mahon asked for key points PACHA could make around backsliding.

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

### **A New Cascade?**

Mr. Wilson said PACHA has the Gardner Cascade. It talks about the overall epidemic. However, given disproportional impact, is there not a need to create a black cascade? What is being done to create such a cascade?

Dr. Holtgrave said that perhaps Mr. Bates or Dr. Valdiserri could answer that in a meeting. Mr. Wilson said he agrees, adding that “it is important to know all we can know in terms of the cascade, even insurance status. An important part of a meeting like this would be bringing all the evidence together.”

### **Possible Action Item**

Ms. Mahon said Mr. Wilson has raised an important question, and we should have a cascade meeting discussion. She asked whether this is primarily a CDC question. “Or where can this be pulled together?”

### **HRSA/FDA**

Mr. Baker said to follow on what Mr. Wilson said, in terms of the black community, “it is important not to bifurcate youth, men, and women.” Our experiences are so common that to make splits creates a false dynamic. Along with the cascade and the data, “it would be helpful to have access to care and HRSA more engaged in general.” It would be helpful to know what data HRSA is collecting and who the people are in the cascade.

When one thinks about capacity building and then looks at the HRSA-driven services and providers infrastructure, one sees “very few black organizations,” Mr. Baker said. We need to get a sense of the workforce because “we direct funds that may not be building capacity to address the epidemic.” In addition, even if another PACHA meeting does not take place before FDA takes up PrEP, we might look at the implications of approval rather than deal with the approval process itself.

Dr. Holtgrave agreed. “In terms of financing, delivery, and support, we have more to say than on the narrow question of approval.”

### **Impact Study on CDC FOA?**

#### **Incidence to Make the Request to CDC?**

Mr. Cruz said it is important to assess the impact and anticipated consequences of the CDC prevention FOA and another issue involving surveillance raised on the first day of this meeting. He asked that PACHA consider an impact study on the FOA, as it seems no one is doing that kind of assessment. “We want to make sure change is happening in this redirection. Otherwise



the gains we've made may be in jeopardy or rolled back." Responding, Ms. Mahon said, "Incidence would make that request to CDC."

### **Suggestion in Re: The Cascade**

Following up on Mr. Wilson's and Mr. Baker's comments, Ms. Khanna said, "As a Council, we should understand the data at every point in the cascade, so let us include this topic on the agenda for the next Council meeting and have those data presented to us. It is a timely topic and has been on many minds."

### **Update on Youth and HIV Discussion**

Mr. Basaviah said he is, with permission, using the Global Subcommittee's time to give this report.

PACHA's Youth and HIV session at its last meeting provided much food for thought, so he has asked "Jen" to review key information from that session and provide updates on what has happened since.

### **DASH Resolution**

Mr. Basaviah also provided members with a draft resolution to support funding for the Division of Adolescent and School Health (DASH). Mr. Basaviah said he would take edits and/or comments from members here or online. He said PACHA could have a public call to vote on the resolution.

Ms. Mahon noted that she needed a copy of the resolution, so the best we can do now is to ask Mr. Basaviah to highlight key points and key drivers, take comments after that, and then pass the resolution or not at the next meeting of the full Council, such as a public call.

Jen noted that there has been discussion in PACHA recently to ensure adequate followup after amazing presentations. Now, she wants to remind members of some of the key recommendations that came up during and/or after the Youth and HIV session and provide some positive and negative updates on things that have happened since then.

### **Education Is Key**

As we heard during the Women and HIV session yesterday, sexuality is a lifespan issue. If we are going to reach the President's goal of zero new infections, "we have to prioritize young people." At the Youth and HIV session, we heard what various agencies are doing for youth and what some of them are not doing. The Department of Education "was noticeably absent, for example." During the Women and HIV session, we heard that "education is key and we have to talk issues of sex with young people."

Jen noted a recommendation from the last PACHA meeting for the Letters to the President and to the Secretary specifically to address youth issues.

### **DASH Budget Hit**

Jen said she also wants to talk about DASH and Part D. DASH took a budget hit of 25 percent in the FY 2012 budget. Now "we're seeing the impact of that." DASH provides the only Federal

funding dedicated to school health for HIV, sexually transmitted infection (STI), and unintended pregnancy prevention. It is key to the sex education infrastructure in the States and large urban districts.

## **DASH Resolution**

The DASH resolution Mr. Basaviah has provided addresses about three requests, Jen said. Key background is that when the FY 2012 budget was finalized in late December, it included a devastating \$10 million cut to DASH. As a result of that and flat-lining over the past 10 years, DASH HIV coordinators in the States are already doing more with less. Therefore, the roughly three requests are for the Administration to restore the FY 2012 funding for DASH; for a DASH funding level of \$50 million for FY 2013 or for Congress to at least fund the Division at the President's budget request level of \$40 million; that PACHA support continuation of DASH as a stand-alone division in the CDC's National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention; that PACHA support that DASH funding remain dedicated to State, local, and Territorial education agencies as well as the nongovernmental organizations (NGOs) that support their efforts; and that PACHA ask that DASH funding be increased to at least \$50 million in the President's FY 2014 budget request.

## **Other Recommendations**

Jen continued with recommendations outside the DASH resolution recommendations, including appointment of a young person to the Council. She noted that Lawrence Stallworth, who addressed PACHA members during the Youth and HIV session, recently spoke at the United Nations about "Getting to Zero: Youth and HIV/AIDS" and also, working with Mr. Wilson, addressed the Black Gay Men's Town hall at the U.S. Conference on AIDS.

## **Resolution Process**

Mr. Basaviah said there is 1 minute for questions. Alternatively, members can provide edits to him online.

Dr. Holtgrave asked to map out the process on this. For example, he and Mr. Perez are interested in "what we are buying with an increase of \$10 million." He suggested that Mr. Basaviah "give us a couple of weeks to e-mail in comments and then have a public call."

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

Mr. Perez noted that PACHA heard from DASH last year, but "there are still questions around the effectiveness of this effort." Are "we really using these resources as wisely as we can?" Also, we have high risk in young black gay men above age 18. DASH does not address the needs of those above age 18. Also, "what set of interventions do we need for ages 13–29?" Last, "some districts do a better job than others with DASH assistance."

Mr. Cruz said Mr. Perez said much of what he wanted to say. This resolution asks for money for a specific area, but "there are many other areas where we would like to request funding." Mr. Cruz is asking for PACHA to think broadly.

Mr. Jack said he wanted to make sure members understand that the proposed resolution asks for restoration. In addition, “the increase for 2013 is already in place.” In terms of 2014, Jen did point to lack of staff and TA for teachers to administer these programs. As far as which populations are touched by DASH, DASH assistance also goes to community-based organizations that target the population above age 18. Mr. Jack added that “this is one piece of education, but there are other monies for wraparound for this age group. “ Last, K-12 education in the United States is a longstanding institution, so “these conversations need to at least be started there.”

## **Resolution Process**

Mr. Baker voiced frustration with the PACHA resolution process. He asked how PACHA wants to have an impact going forward. It is hard to vote against resolutions. Like this one, they are Mom and Apple Pie, but not big thinking, necessarily. We had a meeting that dealt with a lot of these issues. Afterwards, “we didn’t have a full discussion of the Office of Adolescent Health, where millions are being deployed.” The questions that exist about that Office, about the NIH agenda, and those that Ms. Treston and Jen have raised about Part D are critical. We also need followup on the CDC SPINS project. They “learned a lot from that project, and now they are cutting it.” In addition, we have global issues around youth, so now we have “this very small resolution about DASH as opposed to a broader, all-hands-on-deck.” How do we respond to it? How do we address it? Can we think more about it in Executive Session?

Dr. Darkoh-Ampem said he appreciates the resolution, but what is missing is an addressing of the magnitude of what we need to do.

Ms. Mahon observed that part of this is about the work of the Council and the scope of that work. “So how many issues do we choose to take on? We keep coming back to this. We don’t have as much staff as we could use. We need conversation on what is realistic.” Ms. Mahon asked that this not be heard “as criticism.”

## **PACHA Will Discuss and Get Back**

### **Possible Action Item**

Ms. Mahon asked if other Council members had comments. Hearing none for the moment, she said “we will discuss this and get back to you (Mr. Basaviah) about whether the Council wants a more broad-armed approach. We will let you know what we need from you.”

Mr. Brooks agreed with Ms. Mahon, adding that “when we had the youth presentations, we said it was important to think this way.”

Ms. Hiers said she does not disagree with Mr. Perez and Mr. Baker, but “given the environment on backsliding, I don’t think anyone disagrees with key points here and the importance of the advocacy groups represented here.” Ms. Hiers expressed her thanks for Mr. Basaviah’s and the advocacy groups’ work, adding “This is not about ya’ll.”

Ms. Khanna agreed that we “need to be more strategic,” and resolutions “are not necessarily high impact.” So now the Council needs a robust dialogue about all the mechanisms. “Let’s

move on this quickly,” she added. “I don’t want us to be immobilized. If this is a time-sensitive issue, maybe we should take that into consideration in terms of this resolution or a statement of some kind?”

### **Resolution: Time-Sensitive**

Jen responded that this is time-sensitive, given that the appropriations process is underway, during which “we will be fighting once again for DASH funding.” Having PACHA on record supporting that and weighing in with the Administration and Congress will have impact. “This is crisis management \$40 million for the entire country. For some States, that is 14-16 cents per student. The goal is to reach kids before they are sexually active, ideally before they are out of school, but looking at all the sex ed programs, roughly about 2 percent of students are being reached, and it is not enough.” Jen added that much of what IS happening is a result of DASH.” It is a “both not an either/or situation,” she concluded.

Ms. Mahon asked Dr. Holtgrave and Mr. Perez for their advice on how to handle this.

Dr. Horberg said that he agrees with the resolution. Sex ed has to happen earlier rather than later. But “you need to be broader here to have the impact.”

### **Help with Rewrite**

Ms. Mahon said, “We have to help them rewrite it.” She asked who is going to do it. She suggested doing it by topic, not by population. “I hear tension between subject matter and the populations, so how do we move forward on this and do a gut-check on the larger question of how work gets done and in what form?”

### **Process and Remedy?**

Dr. Holtgrave asked if Mr. Basaviah and Jen want to take all this into consideration and come back to the Council. Should consideration be given, also, to a broader resolution that we commit to work on?

Mr. Wilson said that what Dr. Holtgrave just said might be a process and a remedy to this thing. “We have a structure, as imperfect as it might be,” so he proposes that because this is a population that might be included in the Disparities section of the Strategy, the resolution be referred to that Subcommittee. He would then work with everyone concerned “to move this process forward.” All the issues would be worked out at the Subcommittee level first.

### **An Informal Vote**

A show of hands in favor of this approach won, but not unanimously, for there was at least one abstention. Ms. Mahon said this proposal seems to have passed.

### **Continued Discussion**

Mr. Greenwald noted that PACHA has had Subcommittees working together as a coalition, so he would like to know if there are others who want to participate. Mr. Wilson agreed with this. The Rev. Sharp noted this is the way it worked with the women’s group.

Mr. Bates said that his Office would set up a meeting call and invite all PACHA members to it. They can then self-select whether they want to be part of the process and move it from there. Also, “if we need additional expertise, we will find that and bring them into the process.”

Mr. Wilson said this has to be housed in a Subcommittee, however, and that Subcommittee then has responsibility.

Mr. Bates said OK. So now it is the Disparities Subcommittee with an invitation to everyone.

Ms. Mahon said what she is hearing is the desire for a broader approach and that “we have process.”

Mr. Basaviah then asked if members can think about how to propose National Awareness for Youth.

Mr. Bates said CDC already has two campaigns. He then proposed that concept be folded into the work we are doing around the resolution.

### **Disparities Subcommittee Report**

Disparities Subcommittee Co-Chair Ms. Hiers noted that all the Subcommittees worked together on the Letters to the President and the Secretary and that HOPWA modernization was high on the list of priority recommendations.

Meanwhile, the Disparities Subcommittee met this past Monday night. It has been suggested that “we’ll be looking at the Subcommittee and whether we want to keep them as they are.” Also, there will be an inventory of all the resolutions and different topics that have been themes in this PACHA. She is thinking that HIV criminalization is one of them, but “what have we done about it?” Youth and stigma come to mind, too. “There are a lot of issues out there.”

At present, the Subcommittee has only about four active members, which is challenging, although Ms. Hiers wants members to know “we are heading in the right direction.”

Meanwhile, “we have great new leadership for the PACHA.”

In conclusion, Mr. Jack will be looking at transgender individuals. This “needs to be a concern because unlike other populations, we have no data collection on transgender individuals.”

### **Priority Items Document Needs Vote**

Mr. Bates said “the document all received outlines priority areas going into 2012.” Two versions exist, “one longer and one shorter.” The Council needs to vote on the document so that it can be posted on the Web site and sent to the Secretary. “The two-page document was included in her briefing material before she attended the meeting yesterday. We need a vote today.”

### **Document Adopted**

There was a motion to adopt. There was a second. There was a vote by a show of hands. The result was unanimous adoption of the subject document.

## **Notation**

Mr. Greenwald said there was a call for changes to this a month ago. Someone said, “We have to pay attention to deadlines.”

### **“Implementing Common Core Indicators, Streamlining Data Collection, and Reducing Reporting Burden for HHS-Funded HIV Programs,” by Andrew D. Forsyth, Ph.D., OHAP, OASH, HHS**

Pressed for time, Dr. Forsyth said he is entering his slides into the record.

Douglas Michels asked what PACHA wants from this presentation? Is this for information? Do we want a vote on this?

Dr. Holtgrave noted that the Metrics Working Group cuts across all the Subcommittees. The reporting burden for grantees is high, so we need a more strategic look at this. It will also help chart a course for implementing the Strategy. Dr. Forsyth’s group has come a long way and is close to the finish line. This presentation is for our information prior to its being given to the Secretary.

Dr. Forsyth noted that “many have provided feedback, including but not limited to Dr. Valdiserri, Dr. Horberg, and Dr. Holtgrave.”

Dr. Forsyth reviewed the key principles for implementing common core HIV/AIDS indicators (Slide 6) and moved rapidly through the three types of indicators of interest (Slide 7) and measuring progress toward Strategy goals (Slide 8). He then noted Slide 12, which contains the OASH-proposed recommendations for reducing reporting burden. These are:

- To limit progress reporting to 1–2 times per year
- To reduce data elements by 20–25 percent
- To eliminate duplicative data elements
- To consolidate FOAs within Operational Divisions (OpDivs) or Staff Offices, when possible.

Dr. Forsyth moved to the timeline for proposed HHS recommendations to its OpDivs and Staff Offices (Slide 14). The timeline is:

- Within 90 days, work with OASH to finalize a set of common core HIV/AIDS indicators
- In the subsequent 90 days, finalize plans with OASH to implement core indicators, streamline data collection, and reduce reporting burden for HHS HIV/AIDS grantees
- Fully deploy this operational plan by the start of FY 2014.

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

Mr. Greenwald expressed deep appreciation for Dr. Forsyth’s report, for it shows that “they have heard us and acted on our recommendation.” This was “an incredible effort and shows what PACHA should be exploring.”

Mr. Cruz said this is one of the most important, critical areas, for “we are overburdened by funding reductions and increasing demands.” How to collect a core set of data to reduce

burden “is of great use.” Now Mr. Cruz recommends an inventory of what has already been done and use it “to facilitate the process.” New York would be useful, he added.

Mr. Michels said as regards the objective of reducing reporting requirements, in his experience “one size fits all can be quite dangerous.” Some programs “can benefit from more reporting so one can intervene sooner, as necessary.” Mr. Michels told Dr. Forsyth that he should reevaluate one size fits all, to which Dr. Forsyth responded, “You are correct. We are talking about a common set. Additional indicators may be needed.”

### **Cost Savings/Public Reports**

Mr. Baker said the purpose of this effort is to monitor and correct, if necessary. He then asked about discussion of public reports to measure quality. Dr. Forsyth said there is much conversation around return on investment but no precedent for assessing what the savings could be. It “does cost a lot to maintain different reporting systems.” Some consideration is being given to assess costs in some way. He asked for PACHA to let him know of any strategies that would be useful. As pertains to public reports, thought is being given to it. Again, Dr. Forsyth asked for comments and ideas.

Mr. Cruz said that, essentially, New York has been engaged in a similar effort for some time. A problem, however, is lack of standardization in Federal definitions and in the systems available. “These issues need to be addressed.”

Ms. Khanna asked if consideration has been given to integration of programs and assessing that, to which Dr. Forsyth responded that this concept “is well ahead of the curve for us.” We “have thought about it.” As a side project, “we are working with private partners to make more available information about various services being funded across the country. Your suggestion is a great one.”

Addressing Mr. Cruz, Dr. Forsyth added that “we will take into account the lessons learned before us.”

### **International AIDS Conference Update and Discussion**

Gregorio “Greg” Millet introduced this topic, and Mr. Wilson gave a slide presentation on it entitled “AIDS 2012 PACHA Update.”

There are two U.S. members on the International AIDS Conference Coordinating Committee (CCC): Jesse Milan from The Black AIDS Institute and Ms. Khanna, PACHA member and representative of the Positive Women’s Network.

Key deadlines have already passed, including for early registration, which is now \$940 (it was \$785).

If PACHA wants to do a satellite, the deadline for applications is March 31, 2012. Another date of possible interest to PACHA is April 20, the deadline for affiliated independent events applications.

All 15 plenary speakers have been announced. On the first Monday of the conference, Anthony Fauci, NIH, will present on ending the HIV epidemic. Mr. Wilson will present on the U.S.

epidemic. Bart Haynes will address vaccines in mid-week. And Judith Currier will address noncommunicable diseases and aging after that.

Decisions in process include review of all abstracts and program applications, including for a youth program. Mr. Wilson also noted upcoming March meetings relative to program planning, abstracts, international civil society partners, and the CCC. The outcome of March meetings will include fully decided program for the Global Village and youth program. Mr. Wilson said all this is information and background for PACHA members.

Mr. Wilson provided information relevant to hubs webinars in connection with the conference. On March 7, 2012, there will be an informational session on how to host an AIDS 2012 conference hub. Mr. Wilson then listed a number of U.S. outreach webinars already planned, emphasizing that the next one will be held March 16, from 12:30 to 2 p.m. Topics include making a plan for AIDS 2012. Registration information is available from [AIDS2012@blackaids.org](mailto:AIDS2012@blackaids.org).

## **The USG Leads**

Mr. Millet noted that the two USG leads for this conference are himself and Jack Whitescarver, NIH Associate Director for AIDS Research, and Director, NIH Office of AIDS Research (OAR). Two committees have been set up across the USG to help with planning. For each plenary, there is a specific message. The first message is ending the epidemic; the second, challenges and solutions; the third, turning the tide on transmission; the fourth, “dynamics”; and the fifth, HIV in the larger global health context.

Mr. Millet said the USG is preparing messages for each of these plenaries so that the American people and Congress “understand the major selling points for this conference.” We “need to make a case to both audiences that investment in AIDS here and abroad is critically important and that we need to continue it.”

Challenges include much communication about visas and making sure that HIV-positive individuals are allowed entry into the United States. There are other visa issues as well, involving IDUs and commercial sex workers, as to shoot drugs and sell sex are criminal offenses by law in our country, and these individuals “could be prosecuted.” The USG is helping make sure there will be a plenary for those groups in India where those visa issues do not exist. At the conference here, “there will be surrogate voices to represent these groups.”

## **PACHA’s Role?**

Ms. Mahon asked how PACHA might play a role. She asked for some thinking out loud about ways PACHA could help with the goals regarding the American public and Congress. “Can we further the goals?”

Responding, Mr. Millet said “there are satellite events and affiliated events.” A satellite event would be at the conference itself, and an affiliated event would be outside the conference. An affiliated conference could be set up for free. We “have many Federal buildings. We’ve set space aside. PACHA could invite many guests, including Members of Congress.”



Mr. Wilson said PACHA could formally reach out, for example, to Representative Barbara Lee (D-Calif.) and, perhaps more broadly, the HIV Caucus.

Mr. Millet suggested that the event be kept as bipartisan as possible.

### **National HIV Awareness Participation?**

Ms. Averitt Bridge noted that “many of us have been involved in staking a claim for National HIV Awareness activities throughout July to bring attention to domestic HIV.” Civil society at large and the private sector would be engaged. It would be “important for PACHA to demonstrate that we are not just looking to Federal agencies to make this happen but also the private sector, and it costs nothing.”

Ms. Averitt Bridge said she hopes PACHA will choose to be a part of this. There is much synergy behind it and involved in it. “An awareness month might be a way to get the attention of Congress and others not quite as interested in the international conference.”

Ms. Averitt Bridge added that it is up to the agencies to decide to participate in this.

### **Subcommittees Meeting Needed**

Ms. Mahon suggested a Subcommittees meeting, pulling Ms. Averitt Bridge into it, and thinking very quickly about what PACHA might do. “Let us/me know what you think PACHA could do to make a difference.”

### **Resolution**

Ms. Khanna noted that she and others involved in the women’s session yesterday have a resolution for PACHA’s consideration.

Ms. Mahon said her advice would be that “there may be many folks interested in being involved.”

Ms. Khanna summarized the resolution as a request to the Council to call on ONAP to prioritize action in three areas to ensure greater gender responsiveness in the Strategy. It also calls on ONAP to include a specific goal for reducing HIV incidence among women in the implementation plan for its 2-year review, as no such goal currently exists. All told, the resolution contains five “be it resolved” sections with recommendations to ONAP.

Ms. Khanna asked if the women’s session planning committee agrees with referring the resolution to a Subcommittee.

Ms. Averitt Bridge suggested thinking about a cross-cutting white paper on cross-cutting issues. “We could review cross-cutting issues that speak to all the Subcommittees, then work a way to elevate it and uniquely call out critical areas for resolution so that we are not so reliant on series of resolutions.” Ms. Khanna responded that there are time-sensitive issues here that we want to be worked into the 2-year report, such as looking at the metrics.

Ms. Khanna said, “Let’s make a decision on referral to a Subcommittee and introduce a resolution within a month. And then vote over the phone.”

### **Resolution Referred to Access to Care Subcommittee**

Mr. Greenwald said “Post it, wait, and then we can vote. I would be happy to have it sit in the Access to Care Subcommittee.”

PACHA members agreed to Mr. Greenwald’s request.

### **Executive Session**

Ms. Mahon announced the beginning of a closed session for members only and asked the public to leave the room.