

**Presidential Advisory Council on HIV/AIDS (PACHA)
52nd Meeting
Hubert H. Humphrey Building
U.S. Department of Health and Human Services (HHS)
Washington, DC
September 18–19, 2013**

Council Members—Present

Adaora A. Adimora, M.D., M.P.H.
Dawn Averitt
A. Cornelius Baker
Douglas Brooks, M.S.W.
Cecilia C. Chung
Humberto Cruz, M.S.
Ernest Darkoh, M.D., M.P.H., M.B.A.
Kevin Robert Frost
Patricia Garcia, M.D., M.P.H.
Robert Greenwald, J.D.
Kathie M. Hiers
David Holtgrave, Ph.D. (by telephone)
Michael Horberg, M.D., M.A.S. (by telephone on day 1; in person on day 2)
Ejay L. Jack, M.S.W., M.P.A.
Naina Khanna (by telephone)
Douglas A. Michels, M.B.A.
Mario Perez, M.P.H.
Alton B. Pollard III, Ph.D.
Rev. Vanessa D. Sharp, M.Div., M.A.C.M., M.A.T.M.
Elizabeth Styffe
Phill Wilson

Council Members—Absent

Nancy Mahon, J.D., PACHA Chair
Praveen Basaviah
Sandra Torres-Rivera

Federal Liaisons

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

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

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

Staff

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

Panelists

Barbara Broman, Associate Deputy Assistant Secretary for Human Services Policy, Office of the
Assistant Secretary for Planning and Evaluation (ASPE), HHS
Victoria Cargill, M.D., M.S.C.E., Director, Minority Research and Clinical Studies, Office of AIDS
Research, National Institutes of Health (NIH)
Laura W. Cheever, M.D., Sc.M., Associate Administrator and Chief Medical Officer, HIV/AIDS
Bureau (HAB), HRSA
Grant Colfax, M.D., Director, White House Office of National AIDS Policy (ONAP)
Timothy Harrison, Ph.D., Senior Policy Advisor, Office of HIV/AIDS and Infectious Disease Policy
(OHAIDP), Office of the Assistant Secretary for Health (ASH), HHS
Ernest Hopkins, Director of Legislative Affairs, San Francisco AIDS Foundation
Evelyn Kappeler, Director, Office of Adolescent Health (OAH), HHS
Jennifer Kates, Ph.D., Vice President, Director, Global Health and HIV Policy, Kaiser Family
Foundation
Jeanne Keruly, M.S., C.R.N.P., Assistant Professor of Medicine, Johns Hopkins University School
of Medicine, Division of Infectious Diseases
Kali Lindsey, Director of Legislative and Public Affairs, National Minority AIDS Council (NMAC)
Carolyn McAllaster, J.D., Director, AIDS Legal Project, Duke University School of Law, Southern
HIV/AIDS Strategy Initiative (SASI)
William McColl, Esq., Political Director, AIDS United
Greg Millett, M.P.H., Senior Behavioral Scientist, Division of HIV/AIDS Prevention, CDC
Richard Moore, M.D., M.H.S., Professor of Medicine, Director, Johns Hopkins HIV Clinic, Johns
Hopkins University School of Medicine
Dan O'Connell, Director, AIDS Institute, New York State Department of Health
Karen Pearl, President, God's Love We Deliver (GLWD)
Debbie A. Powell, Deputy Associate Commissioner, Administration for Children, Youth and
Families (ACYF), Family and Youth Services Bureau (FYSB), HHS
Miriam Vega, Ph.D., Vice President, Latino Commission on AIDS
Tim Westmoreland, J.D., Visiting Professor of Law, Senior Scholar in Health Law, Georgetown
University Law Center
Mildred Williamson, Ph.D., M.S.W., HIV/AIDS Section Chief, Illinois Department of Health

SUMMARY

Day 1—September 18, 2013

Roll Call and Welcome

In the absence of the chair, designated Federal official and PACHA Executive Director Kaye Hayes, M.P.A., called the meeting to order at 9:06 a.m. and called the roll. She welcomed four new members of PACHA:

- Adaora A. Adimora, M.D., M.P.H.
- Cecilia C. Chung
- Alton B. Pollard III, Ph.D.
- Elizabeth Styffe

Ms. Hayes explained that day 1 of the meeting was organized to facilitate discussion about the Affordable Care Act (ACA) and the Ryan White Care Act (RWCA) through multiple panel discussions representing a range of perspectives. Day 2 of the meeting will feature an update on HIV/AIDS among black men who have sex with men (MSM) and a discussion of the curricula approved for HHS Teen Pregnancy Prevention programs.

Remarks

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

Dr. Koh praised PACHA and its staff for their leadership and contributions. He noted that open enrollment for insurance through State-wide marketplaces begins soon, thanks to the ACA; Massachusetts has already demonstrated what health care reform can do. Recently, through an Executive Order, President Obama asked HHS to focus more explicitly on the HIV care continuum (also known as the cascade). Dr. Koh and Grant Colfax, M.D., director, ONAP, are co-chairing the effort. Dr. Koh said he was eager to hear PACHA's thoughts about the ACA and RWCA reauthorization, among other topics. He commented on the timeliness of the discussion about black MSM, noting that the Congressional Black Caucus is holding its Annual Legislative Conference at the end of September. Dr. Koh swore in the new PACHA members.

PACHA Report: *Achieving an AIDS-Free Generation*

Ms. Hayes announced the release of PACHA's report, *Achieving an AIDS-Free Generation*, which summarizes PACHA's work over the past several years. The report is organized around the topics of its four Subcommittees. Co-Chairs of each Subcommittee summarized key points of the document.

Mario Perez, M.P.H., Co-Chair of the Incidence Subcommittee, said that to reach the national goal of reducing HIV/AIDS incidence by 25 percent by 2015, we must be able to capture HIV infection data better. The development of common metrics contributes to more accountable, more effective HIV programs. Investing more in preventive health care will result in saving billions of dollars, said Mr. Perez. To meet the goals of the National HIV/AIDS Strategy (NHAS), we need a funding package that gives us a fighting chance, he noted. PACHA sent a strong message to the Administration not to backslide on key HIV prevention victories, such as needle exchange programs. PACHA recommendations also contributed to the reallocation of HIV prevention resources based on HIV case data.

Michael Horberg, M.D., M.A.S., Co-Chair of the Access to Care Subcommittee, said PACHA also called for better, more standardized data as a mechanism for improving access to care. PACHA supports full enactment of the ACA and preservation of Ryan White programs to address unmet needs after ACA implementation. Other recommendations in support of access to care include improving continuity of care by standardizing the quality of care across publicly funded programs and improving coordination of program oversight. The report describes the lessons learned from the success of Massachusetts and the challenges faced by California in their early efforts to reform health care. Dr. Horberg said PACHA resolutions led to the inclusion of HIV testing as routine screening that will be covered under the ACA and facilitated emergency funding for Ryan White programs, and called for Federal cooperation across departments to address in the NHAS the needs of women living with HIV.

Douglas Brooks, M.S.W., Co-Chair of the Disparities Subcommittee, highlighted PACHA resolutions addressing equity in housing and for women and transgender people living with HIV/AIDS (PLWHA). As a result of PACHA efforts, several public health awareness campaigns addressed HIV testing and treatment, Federal funding was redirected from AIDS prevention to HIV prevention, and HHS improved data collection related to HIV measures. Mr. Brooks noted that PACHA and CHAC together crafted recommendations on safe, voluntary disclosure of HIV status; they included efforts currently underway to establish a permanent position in the U.S. Attorney General's office to address laws that discriminate against PLWHA.

Kevin Robert Frost, Co-Chair of the Global Subcommittee, said the report recognizes the inextricable link between domestic and international health. Despite advances in technology and treatment approaches, efforts to address HIV/AIDS around the world have been undermined by reduced donations. The U.S. Government remains the largest donor, and PACHA has called for increased resources, scaling up of proven interventions, and better program alignment to address global needs. Mr. Frost urged PACHA to resist efforts to diminish resources or accountability for international funding programs and to support operations research for global HIV/AIDS treatment and prevention.

HIV Care Continuum Initiative

Grant Colfax, M.D., Director, ONAP

Dr. Colfax explained the President's Executive Order establishing the HIV Continuum of Care Initiative (CCI) to:

- Prioritize focus on the HIV care continuum
- Promote expansion of successful HIV testing and service delivery models
- Encourage innovative approaches to addressing barriers to accessing testing and treatment
- Ensure that Federal resources are appropriately focused on interventions that improve outcomes along the care continuum.

The CCI will be overseen by a Federal working group, co-chaired by Drs. Koh and Colfax, charged with presenting next steps to the President in 6 months.

Dr. Colfax summarized recent data describing the drop-off of people in care at every stage from diagnosis to viral suppression (known as the continuum or cascade). Racial and ethnic disparities persist, but we need to improve outcomes for all, he said. Dr. Colfax pointed out that black MSM do worse than other populations; compounding the issue, they are less likely than whites to have insurance or see a health care provider.

Some key advances in treatment and prevention have influenced policy—findings on treatment as prevention and early treatment, more accurate testing, and broader testing guidelines. The HIV CCI Working Group is charged with making recommendations that will translate these advances into better care across the continuum. The working group is planning webinars and other efforts to gather input from stakeholders.

Dr. Colfax added that the President's Working Group on the Intersection of HIV/AIDS, Violence Against Women and Girls, and Gender-Related Health Disparities published a report and recommendations in early September. He said the White House is committed to ensuring that HHS and other departments act on the recommendations in that report.

Ryan White Two Decades On: Taking Stock and Looking Ahead

Introduction: Robert Greenwald, J.D., PACHA Member

Mr. Greenwald highlighted some of the major provisions of the ACA that will benefit PLWHA, such as access to insurance regardless of preexisting conditions. He pointed out that in States that are not expanding their Medicaid programs in conjunction with the ACA, some PLWHA with income above the poverty level will be eligible for subsidies to buy insurance, but many will continue to rely on Ryan White programs. Ryan White programs provide some services for PLWHA that are not covered under the ACA, such as medical nutrition counseling, home meal delivery, home-based care, visual and dental care, and housing support. Coverage completion,

as the complement of services is known, is the hallmark of Ryan White programs, and it demonstrably improves the number of PLWHA retained throughout the continuum of care.

Continued support for Ryan White programs can help address gaps in insurance affordability. While the Federal subsidies for insurance are significant, the premiums and copays for care may present barriers. Many southern States are not expanding their Medicaid programs, and those individuals with low incomes who are not eligible for subsidies will suffer. Undocumented immigrants will not benefit from the ACA, Mr. Greenwald pointed out. The ACA is an incredible opportunity to reduce the number of uninsured people, but many challenges remain for PLWHA.

Mr. Greenwald cited data from Massachusetts as an example of how Ryan White programs could complement the ACA. In Massachusetts, 95 percent of the population has health insurance, and Ryan White funds are used to provide coverage completion and to offset some of the costs of purchasing insurance. Since reforms began (with expansion of Medicaid coverage for people living with HIV/AIDS [PLWHA] beginning in 2001), the State has seen a 45 percent decrease in new HIV diagnoses and a 20 percent decrease in AIDS-related deaths. Universal access to care has led to success across diverse populations, Mr. Greenwald noted. Two studies show that more than 70 percent of PLWHA in Massachusetts have achieved viral suppression, surpassing NHAS goals, he concluded.

Federal Perspectives on Ryan White

Moderator: Douglas Brooks, M.S.W., PACHA Member

Mr. Brooks said panelists were invited to consider the implications of not reauthorizing the RWCA, how to reach PLWHA in areas with limited services, how to manage comorbidities, and how to achieve the goals of successful prevention and treatment.

Grant Colfax, M.D., Director, ONAP

Dr. Colfax stressed that the Administration recognizes the need to continue Ryan White programs to improve outcomes for PLWHA, as reflected in the President's 2014 budget, which provides a \$20 million increase in discretionary dollars. At present, 70 percent of Ryan White beneficiaries have some insurance coverage, and while that figure is likely to change, some will still need Ryan White services. As Ryan White programs evolve under the ACA, we must determine what interventions should be prioritized, how to ensure that resources are used efficiently, how to better meet the needs of marginalized populations, and how to maximize workforce capacity to care for PLWHA. The bigger question to answer, said Dr. Colfax, is what legislation should be enacted or rules adjusted to effectively and equitably allocate resources.

Laura W. Cheever, M.D., Sc.M., Associate Administrator and Chief Medical Officer, HAB, HRSA

Dr. Cheever described some of the activities funded by the RWCA that contribute to better outcomes for those who receive Ryan White services than for others, such as extra efforts to retain patients in care. The RWCA funds staff at the Federal and State levels to evaluate policies

to better serve PLWHA, such as how to address workforce and capacity development to meet growing needs and how to ensure high-quality care.

Ryan White programs serve more than 500,000 PLWHA, or more than 60 percent of all those infected, so the capacity to improve is large, said Dr. Cheever. While it is the payer of last resort, the RWCA will still be needed even after ACA implementation to engage and retain the insured and meet the needs of the uninsured, as well as to provide nonmedical services such as intensive case management and housing assistance. For the portion of the RWCA that does not include the AIDS Drug Assistance Program (ADAP), neither the customers nor the services that the RWCA provides will change much, Dr. Cheever noted. However, ADAP will change significantly; Dr. Cheever anticipated that ADAP funds will be used to help low-income people cover their insurance premiums and copays.

Grantees are expected to vigilantly pursue other forms of payment before turning to Ryan White funds, and HRSA is providing guidance to help grantees. HRSA and the Centers for Medicare and Medicaid Service (CMS) sent a joint letter to States encouraging State-level AIDS program and Medicaid program directors to work together. HRSA issues waivers to some grantees regarding the amount of Ryan White funds that must be spent on core services. The agency also is encouraging grantees to align their screening and eligibility determinations with the health insurance marketplace so they can take advantage of the open enrollment period.

Open enrollment continues through March 2014, and grantees are expected to make plans to encourage beneficiaries who are eligible for private insurance to enroll, including explaining the penalties for not enrolling. HRSA has crafted policies concerning using Ryan White funds to cover premiums, deductibles, and copays. Dr. Cheever concluded that grantees must make sure that using Ryan White funds is more cost-effective than going through private insurance.

Ernest Hopkins, Director of Legislative Affairs, San Francisco AIDS Foundation

Mr. Hopkins called the RWCA a hallmark of public-private partnership and the legislation authorizing the program “brilliant” because it addressed issues of interest to all members of Congress. The effort created a parallel system of care that was needed to ensure treatment in the face of stigma and ignorance. The current structure of Ryan White, however, has not kept pace with the epidemic or biomedical innovations, said Mr. Hopkins, and reauthorization will have to address that shortcoming. According to Rep. Fred Upton of Michigan, the Republican-controlled Congress will not support any disease-specific program in this term and would prefer to see PLWHA integrated into the broader health care system.

The delay in reauthorization is an opportunity to think through what we need from Ryan White programs in the future and what kind of system we can create, said Mr. Hopkins. Although Ryan White programs are effective and there is much excitement about the promise of the ACA, he noted, much work remains ahead, as the current system is not ideal for PLWHA. Too many black and Latino men, for example, are not getting tested or lack sufficient care. And although Ryan White programs have better results, the ACA will push more people into other systems. As

we encourage more people to seek care, we should better understand what is happening in health care systems and what prevents PLWHA from using them to the fullest.

Finally, Mr. Hopkins hoped the community would cooperate to realize a vision of the RWCA as a source of services for those ineligible for insurance under the ACA and as a bridge to other systems for those who are. However, history suggests that when resources are limited, we devolve into factions. He expressed concern about barriers to open, honest dialogue.

Discussion

To engage community health centers (CHCs) that are not already receiving Ryan White funds in treating PLWHA, said Dr. Cheever, HRSA is focusing on integrating routine HIV testing and linking people to care as a first step. She emphasized that CHCs are required by law to care for the people in their service areas; discussion is underway about how to ensure that CHCs do not discriminate against PLWHA. She asked for input on how to improve. Mr. Brooks said some CHCs are reluctant to treat PLWHA because they lack the expertise; he wondered whether enhanced payment would be an incentive to care for more Ryan White beneficiaries. Dr. Cheever said some publicly funded centers offer providers enhanced rates for HIV care because such care is more expensive.

Dr. Cheever explained that most Ryan White dollars are allotted according to the number of current cases of HIV. Areas with generous Medicaid programs will have more Ryan White dollars to use for other services. To address disparities, HRSA has supplemental funding for areas of severe need. Thus, HRSA has some flexibility to target resources where they are needed most, but not a lot, said Dr. Cheever.

In terms of the future of Ryan White programs, Mr. Hopkins said one approach under discussion is the expansion of Ryan White into a coverage completion program for people with a range of chronic diseases. Ronald O. Valdiserri, M.D., M.P.H., underscored the importance of thinking about HIV as a chronic disease. Dr. Cheever noted that stigma distinguishes HIV from other chronic diseases. Furthermore, since it is a transmissible disease, preventing the spread of HIV is a public health imperative, she added.

Dr. Cheever said some providers may be holding off on treating coinfection with hepatitis C because they anticipate that a new treatment regimen is coming. HRSA is developing an approach to treatment once a new regimen becomes more widely available. Dr. Cheever said that in many cases, hepatologists do not see Ryan White beneficiaries as good candidates for hepatitis treatment, even though data demonstrate otherwise.

Dr. Cheever agreed that a program that silos HIV does not work for providers or patients because it overlooks other needs, such as the multiple chronic conditions that accompany aging. Early in the ACA implementation, HRSA encouraged grantees to partner with CHCs around a multidisciplinary, medical home model. Success was limited, and further efforts are needed.

Dr. Cheever asked for suggestions on improving integration and other models of care for PLWHA.

Mr. Hopkins said advocacy groups are pushing for ACA implementation in States that have been reluctant. Many believe the situation will improve once the fall elections are over, leaving time for people to enroll in insurance plans through the exchanges. Mr. Hopkins said the issue of companies aiming to avoid providing insurance for their employees is a deeply problematic development. Advocates may try appealing to those companies' stockholders and chief executive officers.

Dr. Colfax said the HIV CCI has some flexibility to address NHAS goals and improve the continuum of care even if RWCA reauthorization is delayed. It seeks to provide guidance on using the best evidence-based interventions and using data to inform local community efforts. Dr. Colfax called for more contemporary data demonstrating the benefits to both individual and public health to continue Ryan White programs and support efficient use of resources. The HIV CCI will evaluate the allocation of resources in light of the latest evidence, Dr. Colfax said.

Dr. Cheever said HRSA is encouraging programs to implement interventions that have worked for others and to collect more data on the impact. Dr. Colfax said it also is important to focus on getting data to planning councils, providers, and community members about improving care.

Mr. Perez called for modernizing the Ryan White structure, taking bold steps either to better support services along the continuum of care or align the program more consistently with the NHAS goals. Dr. Colfax said the timelines and goals of NHAS are clear, and HHS is committed to them. Stakeholders agree that delaying reauthorization is the best course for now, he noted, and there is a robust safety net to support the RWCA as is during the transition to the ACA.

Dr. Cheever acknowledged that Massachusetts has been working to reduce HIV infection for a long time; its results were not instantaneous. She believes that in the near future, 70 percent of the people served by Ryan White will need the same services they have now.

Regarding the apparent contradiction in Congress of representatives who oppose health care reform yet would support expanding Ryan White to cover other chronic diseases, Mr. Hopkins explained that there is widespread acknowledgement that the RWCA is a lifeline and should not be disrupted until it can be replaced. However, Rep. Upton believes the current structure of the RWCA should not be perpetuated, and he would not reauthorize it as is. Others have proposed expanding Ryan White to other diseases, Mr. Hopkins clarified.

Dr. Cheever said HRSA hopes that with better access and more options, PLWHA will seek out more convenient care providers in the broader community, but also fears that they could receive lower-quality care from those providers who are not trained in HIV care. It will be important to monitor quality-of-care indicators, such as the number of HIV patients with an undetectable viral load, in settings outside of Ryan White-funded centers, she noted. Ideally, PLWHA will have access to care wherever they are, and providers will refer them to better care

when needed. The AIDS Education Training Centers (AETCs) have been helpful in that respect and will take on a larger role as the ACA is implemented, said Dr. Cheever. Providers also can refer to national guidelines for HIV, which are more robust than they are for other chronic diseases, she added.

Dr. Cheever said that unlike many health services, oral health care for adults will not improve greatly with the ACA implementation, but as more people are able to buy insurance, Ryan White grantees can consider investing some of their savings in more dental care. Also, dental care is significantly different from other HIV care; it is usually the first or second unmet need, but it rarely requires an HIV specialist. The RWCA aims to use the AETCs to train dentists, among whom stigma against PLWHA is prevalent. HRSA also is considering other needs related to aging among PLWHA. Mr. Brooks concluded the session by noting that we must think now, not later, about how to pay for care under the ACA and Ryan White.

Ryan White History and Perspective—Where We Started, Where We Are Now, and Where We Are Going

Moderator: Kevin Robert Frost, PACHA Member

Providing a historical perspective on the Ryan White legislation, Mr. Frost shared excerpts from an interview with Sen. Ted Kennedy in which Sen. Kennedy described the debate, calling the ultimate passage of the legislation “an extraordinary triumph of common sense, decency, and justice over prejudice, bigotry, and hatred.”

Tim Westmoreland, J.D., Visiting Professor of Law, Senior Scholar in Health Law, Georgetown University Law Center

Mr. Westmoreland explained that the House and Senate had different motivations for passing the RWCA. House members were mostly motivated by the urgent need to remove barriers to counseling, testing, and early treatment for PLWHA, although some wanted more testing as a way to isolate and punish PLWHA. The Senate was motivated by emergency department (ED) overcrowding in urban settings, because PLWHA were crowding out those with other conditions. Mr. Westmoreland believes that the structure of the RWCA—grants for services as opposed to a medical program for PLWHA—was a function of the procedures available to those in Congress who supported the legislation.

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

Dr. Kates emphasized that the RWCA has withstood many changes, but the mission has remained the same. The need for the RWCA will remain as long as there are uninsured and underinsured PLWHA, she said. The Kaiser Family Foundation published a report on the RWCA in the context of the ACA, the NHAS, and recent advances in treatment that proposes changes in four broad areas:

- Retooling the RWCA to better support PLWHA at each stage along the continuum (e.g., by collecting better data)

- Using Ryan White to build HIV care networks in underserved and poor communities and targeting resources
- Integrating HIV care expertise into mainstream health care
- Allocating Ryan White resources fairly (e.g., evaluating whether the program targets funding in the most effective way).

Dr. Kates anticipates that Ryan White programs will continue to change, because the health care environment is changing in every State. At the same time, the programs must consider how to incorporate new research and understanding about HIV.

William McColl, Esq., Political Director, AIDS United

Mr. McColl emphasized that the ACA still has bipartisan support. However, since the RWCA was last reauthorized in 2009, 150 new Congressional representatives have taken office, and they are not aware of the scope of the HIV epidemic in their own communities. HIV/AIDS is no longer a top health issue. Advocates must educate Congress about the disease. Even those who propose cutting funds are open to messages when it is explained that costs for HIV care could be better controlled with a stronger system that identifies infections early and supports viral suppression. With opposition to the ACA and conservative efforts to shrink the role of government, we should expect cuts to Ryan White programs, which force communities to look more closely at everything they do.

Mr. McColl said a major fight over appropriations is coming. He believes that the RWCA could be reauthorized if other fiscal issues were addressed. With a unified voice, advocates could succeed in negotiating reauthorization of the RWCA despite opposition to a disease-specific program. With Ann Lefert of the National Alliance of State and Territorial AIDS Directors (NASTAD), Mr. McColl co-chairs the Ryan White Work Group, which aims to galvanize the HIV/AIDS community around a common approach to reauthorization. Such an approach succeeded in 2009. The Ryan White Work Group is revising the community agreement from 2009. Everyone is waiting to see how the ACA plays out before moving forward with any changes to the RWCA, said Mr. McColl. The Ryan White Work Group also is planning more meetings with Congressional representatives to educate them about the epidemic.

Discussion

Mr. Frost said that on the one hand, he does not want to see States that refuse to expand their Medicaid programs rewarded with extra funding, but at the same time, those States will not have Ryan White Part A funds to help PLWHA. Mr. McColl said that such States will receive \$20 million in Part B supplemental funds. If the changes resulting from the ACA pose further problems for AIDS service organizations, AIDS United and others will look for flexibility within the program rules. Some issues can be addressed by legislators, as there has always been bipartisan political support for PLWHA, said Mr. McColl. Despite opposition to the ACA by southern States, those who created the RWCA may be open to solutions.

Mr. Westmoreland noted that it may be too soon to fix Ryan White programs, because the impacts of the insurance exchanges and Medicaid expansion are not yet known, and Dr. Kates agreed.

Dr. Kates said Federal and State policymakers should conduct ongoing assessments of the impact of these changes in health care, tracking not just policy but individual outcomes. The continuum of care is the best rubric to capture outcomes. HIV is different from other conditions, Dr. Kates reiterated; current treatment options can mitigate harm to PLWHA and prevent transmission.

Several members expressed concern for PLWHA in the South. Although it may be too soon to pursue a fix for the legislation, it is clear that PLWHA in southern States will not benefit from Medicaid expansion. The Supreme Court's decision to allow States not to expand their Medicaid programs increased disparities, despite the goal of the ACA to reduce disparities. Dr. Kates said some States are expanding coverage without expanding their Medicaid programs, but she agreed that disparity may grow.

Regarding the potential for tying Ryan White funding to laws that criminalize HIV transmission, Mr. Westmoreland described biased, ignorant testimony before Congress about how HIV is spread when the RWCA was drafted. Some amendments suggested that PLWHA deserved their condition, but the legislation was "declawed," said Mr. Westmoreland. He believes the RWCA "dodged that bullet" successfully.

Mr. McColl acknowledged that Ryan White himself was not representative of the HIV epidemic, but he evoked much sympathy. Eventually, as the NHAS points out, PLWHA will be integrated into mainstream health care, possibly through the ACA, said Mr. McColl. He pointed to Federal efforts over the past 4 years to break down some of the silos. Mr. Westmoreland added that although many have forgotten who Ryan White was, the program is now a well-known "brand" with bipartisan support; changing the name could jeopardize that support.

Dr. Kates emphasized the importance of relating the stories of individual people and their needs. The "Greater Than AIDS" campaign has been a successful tool for engagement and empowerment. Mr. McColl added that Mr. Hopkins and others are working to tell the stories of Ryan White beneficiaries, for example, using State fact sheets that describe real people and reflect diversity. Mr. McColl said AIDS United and the Black AIDS Institute also are promoting campaigns to bring stories of real PLWHA to legislators and policymakers.

Rev. Vanessa D. Sharp, M.Div., M.A.C.M., M.A.T.M., suggested that all these entities come together in the name of raising awareness, perhaps pooling their materials in one place, as part of an effort to speak with a unified voice.

In terms of the program's structure, Mr. McColl said the RWCA incorporated some preexisting components as well as some efforts aimed at ramping up response. Overall, it focused on getting resources to individuals, not systems. Humberto Cruz, M.S., pointed out that the result

is a fragmented system, and it is time to think about how Ryan White programs work in conjunction with States. Dr. Kates agreed that better planning and streamlining within States is even more important with the implementation of the ACA. Mr. McColl said the Ryan White Work Group is interested in hearing practical suggestions about integration.

Mr. McColl noted that NASTAD and others are discussing how to provide technical assistance to States, particularly those in which public health departments are prohibited from doing anything that helps or promotes the ACA. Mr. Greenwald said the best way to leverage the potential of the ACA in States that do not expand their Medicaid programs is to maximize use of the insurance marketplaces by PLWHA, which only works if ADAP is aligned to assist with premiums and copays.

ACA and Ryan White—Meeting the Goals of the NHAS From the State HIV/AIDS Administrator and Health Provider Perspectives

Moderator: Patricia Garcia, M.D., M.P.H., PACHA Member

Dan O’Connell, Director, AIDS Institute, New York State Department of Health

The AIDS Institute provides the full range of services to PLWHA and those with other sexually transmitted infections (STIs), with a focus on health of the lesbian, gay, bisexual, and transgender (LGBT) community and drug users. The Institute’s rates of viral suppression are better than the national average, said Mr. O’Donnell.

New York spends \$2 billion per year on HIV-related care through Medicaid. A large portion of care is covered by Ryan White funds, and the State makes substantial contributions that help cover other costs, such as syringe exchange. Of the 2.7 million uninsured people in New York, about 1.1 million will gain coverage under the ACA. A small portion of those who receive ADAP support will benefit from the ACA, but ADAP funds will still be needed to cover medications, and Ryan White funds will still be needed to address service gaps. Mr. O’Connell emphasized that no one knows how the ACA will affect PLWHA and their programs.

Mr. O’Connell pointed out that prevalence drives the need for Ryan White services. If more of those who are currently undiagnosed move into care, costs will increase. Moreover, many PLWHA are over 50 and have other health needs related to aging. The system has many components that work together. States that contribute their own funds to HIV services should not be penalized for it with lower Ryan White funds, Mr. O’Connell noted.

Mr. O’Connell recommended leaving the RWCA as is until the ACA is fully implemented and its impact understood. Ending the epidemic for this infectious disease will not happen by tearing things down but rather by building them up, he said. We must look at the tools available and combine them in ways we think will have the best possible impact, he concluded.

Adaora Adimora, M.D., M.P.H., University of North Carolina at Chapel Hill, Professor of Medicine, School of Medicine, Professor of Epidemiology, Gillings School of Global Public Health, Division of Infectious Diseases

Speaking as a care provider on the front lines, Dr. Adimora stressed that Ryan White programs are essential to PLWHA and their care providers. In addition to health issues, PLWHA may be disproportionately affected by poor education, poverty, lack of health insurance, stigma, mental illness, and substance use; they may live far from HIV care centers and suffer from comorbidities. Many of these conditions are worse in the South, said Dr. Adimora. Ryan White funds help recruit and retain PLWHA into care and help them obtain and adhere to medications.

The system is far from perfect, said Dr. Adimora; eligibility issues and limited funds are causing real problems. But in her clinic, Ryan White funds support a benefits coordinator who helps with ADAP and insurance enrollment, which allows her to focus more on patients and decreases the risk of provider burnout. The clinic also has a social worker, a data collector, a research program coordinator, an addiction specialist, and a nurse interventionist. Thus, Ryan White dollars are critical for providers, because they support the workforce needed to address a broad array of issues.

Richard Moore, M.D., M.H.S., Professor of Medicine, Director, Johns Hopkins HIV Clinic, Johns Hopkins University School of Medicine

Dr. Moore said the HIV clinic that opened at Johns Hopkins University in 1984 could not have survived without the RWCA. He echoed Dr. Adimora, describing the many components of health care and social support that PLWHA need to thrive, all of which are at least partly funded by the RWCA. Even Maryland's generous Medicaid program does not support all the services that PLWHA and providers rely on, said Dr. Moore.

The RWCA has contributed to a foundation of HIV expertise in treatment and care and to the patient-centered medical home (PCMH) model that has become popular for managing chronic disease. HIV care expertise leads to better treatment and clinical outcomes, improved retention in care, better management of social issues, less stigma, and greater trust, said Dr. Moore. The success of antiretroviral therapy (ART) is based on the work of Ryan White programs that brought PLWHA into care, kept them in care, and provided supportive services.

Jeanne Keruly, M.S., C.R.N.P., Assistant Professor of Medicine, Johns Hopkins University School of Medicine, Division of Infectious Diseases

Ms. Keruly said that Baltimore's eligible metropolitan area (EMA) has good resources to assist uninsured and underinsured people, but Ryan White support remains critical for engaging people in care. Providers are concerned about how HRSA will redistribute funds to EMAs, especially in States that are expanding their Medicaid programs.

The need for Ryan White funding persists, because of clinical and psychosocial issues that impede continuous access to insurance, said Ms. Keruly. PLWHA have a high prevalence of substance and alcohol use and mental health disorders; they also are affected by life chaos (e.g., poverty) and low health literacy. Despite Medicaid expansion, Ryan White programs will still serve the uninsured and help PLWHA transition into Medicaid or private insurance.

Ms. Keruly expressed concern that expanding Medicaid might hurt the existing infrastructure if resources are insufficient to deliver core services and maintain comprehensive services. Planning councils are concerned that some jurisdictions will immediately shift funding from core services to support services. Ms. Keruly said Maryland has good coordination among stakeholders in

Part A, Part B, and Medicaid working to sort out what the programs will look like in the near future. Baltimore's EMA still allocates more than 75 percent of its funding to core services, including oral health. This year, it will spend more on outreach, noted Ms. Keruly.

Mildred Williamson, Ph.D., M.S.W., HIV/AIDS Section Chief, Illinois Department of Health

Dr. Williamson noted that Illinois just agreed to expand its Medicaid program. The ACA represents a paradigm shift, and it will be important and challenging to monitor outcomes to determine whether health is improving, she said. Dr. Williamson, noted, for example, that Illinois has different definitions for case management across programs. Efforts are underway to create standards for measuring outcomes that can assess quality of life. Dr. Williamson said all people have a right to respectful care and access to medical and supportive care. The goal is to improve care for everyone, she noted.

Chicago has a municipal safety net system, and Dr. Williamson is among those concerned about the continued needs of the system despite ACA implementation. We have much to learn from those systems that use the team approach or PCMH model, she said. The framework of care varies across the country, Dr. Williamson concluded, but the components of care are the same.

Discussion

Phill Wilson said the speakers identified gaps that ACA implementation will create for people currently getting services through Ryan White. He also noted that the ACA is a health care financing mechanism, not a delivery system. He called for recommendations on how to minimize the negative impact in the short term or at least to quantify the impact of the coming changes. Mr. O'Connell reiterated that there is so much we do not know. He is very concerned about the misperception that the ACA is comprehensive, so other programs will not be needed.

Dr. Williamson said the current overlap in services is critical, because we do not know how much programs differ in different places. Where there is good coordination, some PLWHA will become eligible for Medicaid and may not even need to change providers. In areas with a less extensive safety net, individuals may lack continuity of care. Dr. Williamson said we must address linkages across programs and forge robust agreements among State programs. We also must make sure standalone programs are included in coordination efforts.

Dr. Adimora stressed the primary importance of aggressive monitoring to identify the unintended consequences of the coming changes. Mr. Greenwald agreed on the need for monitoring and enforcement of ACA implementation and the RWCA, but he was concerned about the message from all of the panelists to wait and see how PLWHA manage the transition under the ACA. The RWCA is a discretionary, annual appropriation that is not sustainable, he noted. We need Medicaid expansion, along with all the other pieces of health care reform, because Ryan White programs have not been doing very well in recent years. Complicated issues related to costs and equity must be addressed, Mr. Greenwald stated. Programs will need to demonstrate they are doing all they can to maximize their resources.

Mr. Greenwald called for a list of all the components that must be effective to demonstrate that we are maximizing all the opportunities provided by the ACA, a clear explanation of what Ryan White resources are needed to fill the gaps, and a description of how Ryan White funds will be equitably distributed.

Ms. Keruly said her program's case managers guide clients to other programs when possible, but even case management requires funding. Mr. O'Connell agreed that equity and fairness are important issues, and he asked why those States that are not expanding their Medicaid programs are not doing more for their citizens. Kathie M. Hiers said poor States have fewer resources.

Mr. Cruz said we are poorly prepared for the upcoming transition, and he blamed the Federal and State entities that have failed to provide education and training for service providers and clients on how to engage in new health care programs. HRSA funding to provide technical assistance to community organizations will be awarded only after enrollment starts. More funding should be allocated for public education, and Federal navigators should be in place, said Mr. Cruz.

Christine Campbell of Housing Works said it is challenging to come up with State solutions at the Federal level. She asked how to incentivize States using Federal structures and how to help people in the South if their State governments do not prioritize their health care. We must consider how to use Ryan White funds to support equitable activities in States that choose not to work within the system. The solutions have to be about the people, said Ms. Campbell, and we need a common voice that does not create a regional war.

Carol Treston, R.N., of the Association of Nurses in AIDS Care, agreed with Mr. Cruz that providers and administrators do not understand how the ACA will be implemented or how it will affect their practices. Given the lack of awareness, she called for extending the open enrollment period. She also noted that as PLWHA age, they will face comorbidities and other conditions that require hospitalization. She asked PACHA to consider how the ACA will affect uncompensated hospital care. Dr. Moore responded that more people will be covered by Medicaid or by private insurance, both of which cover hospital care. However, even in States with generous Medicaid benefits that also embrace the ACA, PLWHA still need many of the

services that only Ryan White programs offer to keep them out of the hospital. We need to monitor the programs and get more data, Dr. Moore noted.

Asked about subpopulations of PLWHA, such as those in the criminal justice system, Mr. O'Connell said that New York has achieved 90 percent viral suppression among inmates who are treated, but one-third of the State's inmates are PLWHA who will not disclose their status. We have to address the issue of people who will not accept care, he noted. Dr. Adimora pointed out that North Carolina is not expanding Medicaid. The University of North Carolina's School of Medicine provides good care to prisoners who identify as HIV-positive, but once they leave prison, they often lose their benefits and stop taking their medications.

Looking Ahead

Moderator: Kathie M. Hiers, PACHA Member

Carolyn McAllaster, J.D., Director, AIDS Legal Project, Duke University School of Law, SASI

Ms. McAllaster provided data from SASI, which addresses nine Deep South States that share common characteristics (e.g., poor health outcomes and high poverty rates): Alabama, Florida, Georgia, Louisiana, Mississippi, South Carolina, North Carolina, Tennessee, and the eastern portion of Texas. These States have the highest rates of new HIV diagnoses and are home to 8 of the 10 U.S. cities with the highest new AIDS diagnoses. The nine States account for 22 percent of the U.S. population but one-third of new HIV diagnoses. The HIV fatality rates for the Deep South are even more disturbing, said Ms. McAllaster.

The disproportionate rates of HIV/AIDS in the South result from overall poorer health of the population in those States, higher rates of STIs, higher poverty levels, and stigma. The Ryan White funding inequities detected in the early 2000s have narrowed, but the nine Deep South States still receive about \$180 less per person than the U.S. average. In addition, a lower proportion of people are covered by Medicaid, and Medicaid eligibility is more restrictive.

Eight of the nine States are not expanding their Medicaid programs. (Tennessee is undecided.) Lack of Medicaid expansion will result in more inequities in the amount of Federal funds that southern States receive. These data support the continued need for Ryan White funds to address coverage gaps, particularly for those who qualify neither for Medicaid nor for subsidies to purchase insurance, said Ms. McAllaster. Many PLWHA will still need ADAP to pay for medications or to assist with insurance premiums; many also will still need clinic services.

Ryan White funds provide essential services to link and retain people in care. Many southern States have a large rural epidemic, and transportation services are key. Case management, counseling, and testing are needed to overcome stigma. Continued funding of Part C clinics is needed. Many Federally qualified health centers (FQHCs) do not have HIV specialists; Ms. McAllaster said she hears frequently about FQHCs that do not want to treat PLWHA.

Karen Pearl, President, God's Love We Deliver (GLWD)

Ms. Pearl said GLWD provides medically tailored meals to PLWHA and others to improve their health outcomes. Other organizations, such as food pantries, grocery delivery services, and congregant meal programs, also provide food and nutrition services (FNS) to people in need. Research demonstrates that food is medicine, said Ms. Pearl. FNS help PLWHA connect with care, stay in care, adhere to their medications, and benefit from their treatment. Food also is a major social determinant of health (SDH). PLWHA who are food-insecure have worse health outcomes and cost the health care system more (because of missed appointments, more ED use, and less drug treatment adherence) than those who are food-secure.

Furthermore, a study of an urban home meal delivery service found enormous cost savings with medically tailored meals: average costs fell 62 percent for 3 months after the service began, representing nearly \$30,000 per person. Clients who were hospitalized had reduced lengths of stay (37 percent decrease) and an increased likelihood of being discharged to home instead of another facility. Costs for PLWHA were \$20,000 less per month as a result of the meal service. Other studies confirm the association between food insecurity and poor health outcomes. In addition, one third of rehospitalizations are related to malnutrition, not the underlying illness. With all these data, we should be focusing on the potential cost savings of FNS, said Ms. Pearl.

In 2009, HRSA determined that FNS can be a core medical service under the RWCA. Ms. Pearl suggested that planning councils for the ACA consider including FNS as core medical services. Some structural issues pose barriers to integrating FNS into the ACA for PLWHA. For example, CMS will not assign Medicaid numbers to FNS programs, so programs cannot bill Medicaid directly. Many States are seeking waivers to work around the barriers.

Ms. Pearl called for continued funding of Ryan White to maintain the infrastructure for FNS. She said FNS should be integrated into the ACA, but it is a long road that requires an individual solution for each State. Food pantries and other services face more challenges, because it is harder to make the case for their impact on health. Ms. Pearl concluded that FNS should be recognized as a critical part of care for PLWHA, that roadblocks should be removed, and that advocacy should continue until we reach a world without AIDS.

Miriam Vega, Ph.D., Vice President, Latino Commission on AIDS

Dr. Vega reiterated that the ACA is a financing system, not a health care delivery system, and Latinos in particular are being left behind. Going forward, we must ensure that the organizations providing culturally competent services continue to fill gaps in care. The RWCA should not be a zero-sum game, said Dr. Vega, and it should not create infighting across States and regions.

From a public health framework, the RWCA has succeeded in making HIV/AIDS care available, accessible, and acceptable. When the ACA is implemented, we cannot be assured that care will be available, accessible, and acceptable, given the barriers described in the South, such as providers reluctant to serve PLWHA. The public health framework also takes into

account structural SDH, including stigma, availability of resources, laws and policies, and individual susceptibility.

Dr. Vega said 31 percent of Latinos are not insured. They often face structural barriers, such as language problems and discriminatory behavior or policies. A study found that Latino PLWHA are deterred by the mental and physical rigors of navigating the system, lack of culturally competent providers, lack of services customized to their needs, lack of supportive services (e.g., housing and transportation), and economic barriers to care. In the study, respondents also said mental health support would be helpful. Looking at the increasing rates of HIV and AIDS diagnoses among Latinos (especially in the South), the high number of uninsured Latinos, and proposed immigration reforms that would delay access to affordable health insurance, “you can see a perfect storm in the works for Latinos,” said Dr. Vega.

Organizations that serve Latinos should help people navigate the system and identify their coverage options. They should assess and address staff awareness of what the ACA involves, particularly for HIV services. Organizations should maintain the infrastructure that made them the vanguards of HIV care. They should develop and leverage partnerships, share resources, and learn from each other, said Dr. Vega. Finally, the expertise of HIV care providers should be integrated into the health care system, and the new HIV workforce should develop cultural competence.

Discussion

Ms. Pearl explained that research on food insecurity controls for income level, gender, and other factors, and studies continue to find that food insecurity is an enormous predictor of poorer health outcomes and higher costs of care (and that food security is associated with better outcomes and less costly care). Mr. Wilson suggested that the benefits of food security be highlighted to policymakers, because it is easier to address than the larger issue of poverty.

A. Cornelius Baker pointed out that the high rates of HIV/AIDS in the South are complicated by racism and political resistance to taxation that puts the burden of care for southern PLWHA on the rest of the country. Given the historic disparities, even if southern States received all of the Ryan White funding, blacks would probably still have poor outcomes, said Mr. Baker.

Ms. McAllaster agreed that southern States would likely continue to have poorer outcomes, even with a greater proportion of Ryan White funds, but we cannot allow the gap to widen even more, she said. We should consider supplemental Ryan White funding for areas of great need, she continued, but Ryan White funding will not eradicate poverty and racism.

Ms. McAllaster noted that HHS’ Care and Prevention of HIV in the United States (CAPUS) project has funded demonstrations to improve HIV testing and treatment for racial and ethnic minorities. She added that efforts to address HIV/AIDS in the South must go through the RWCA, because it is the only source of care for a huge swath of the population.

Ms. Hiers said Medicaid in the South has always been complicated. For example, Alabama has an impoverished population with a small tax base. It also has no property taxes and high sales taxes, and these factors affect the poorest people in the State.

Ms. McAllaster agreed with the suggestion that providers and consumers be better educated about legal rights involving health care, and she said small efforts are underway to advocate for those who face discrimination.

Mr. Brooks asked how to better emphasize the moral imperative to care for those in need, how to frame the discussion in a less adversarial way, and how advocates could form new alliances with those outside the HIV/AIDS community (such as the National Association of Social Workers). Dr. Adimora said the problems in the South are perpetuated by State legislatures run by Republicans with an agenda who do not care about people, are driven by the Tea Party, are suppressing voter rights to retain power, and are ignoring fiscal responsibility. She recommended focusing on 2014 and 2016 elections.

Mr. Wilson hoped to focus on improving outcomes. If southern States need more funding to improve outcomes, programs must make the case that the funds will be well spent. It may not feel good to provide funding to States that are undermining ACA implementation, Mr. Wilson said, but the beauty of the RWCA is that it allows grantees to deliver services to people in need, no matter how hostile the environment. We should focus resources where we can create a positive outcome, said Mr. Wilson. Ms. McAllaster noted that CAPUS grantees have demonstrated impressive results despite the atmosphere.

Cecilia C. Chung suggested looking at PLWHA in the South who are doing well and determine what sustains them. Mr. Greenwald agreed, noting that more administrators from the South should talk with PACHA about the options available to improve outcomes for PLWHA. PACHA should pinpoint initiatives that work under the RWCA, such as FNS programs.

Rev. Sharp described the challenges of getting black churches involved in raising awareness about HIV testing. She also expressed frustration that some nonprofit agencies are only now considering becoming involved in helping PLWHA because funding is available through the ACA—not because they care deeply about health outcomes. Dr. Vega agreed that building trust and gaining buy-in from faith-based organizations (FBOs) can take a very long time. She said focusing on health disparities and appealing to social justice issues is effective. Her organization offers the Stigma Institute, a customizable curriculum for FBOs about stigma.

Key Take-Away Messages and Recommendations for the Future

Moderators: Robert Greenwald, J.D., and Mario Perez, M.P.H., PACHA Members

Mr. Perez summarized his observations of the day's presentations:

- The RWCA is already complicated, and ACA implementation, which varies by State, complicates it further. The RWCA is likely to remain stable for those not eligible for other care.
- In States that expand their Medicaid programs, the RWCA will probably serve the role of coverage completion, paying for services that Medicaid does not cover.
- In some States, Ryan White funds may help make private insurance affordable.
- The RWCA has supported a network of HIV specialists and high-quality HIV care that may be eroded as the universe of providers for PLWHA increases. Quality will likely be a topic of discussion at the local and municipal levels.
- The menu of services for PLWHA offered by new managed care plans is not yet known.

Mr. Perez suggested the following topics for PACHA consideration:

- Despite Federal pressure to encourage State Medicaid and AIDS directors to coordinate, some States have pushed the issues down to the local level, so State-level pressure is not sufficient.
- It would be useful to have an inventory of providers available for each category of consumer (e.g., Medicaid-eligible, RWCA only).
- Technical assistance and public education efforts should be increased.
- The timeline should be reviewed. Experience suggests that it takes about 5 years of lead time to get programs off to a good start.
- If RWCA reauthorization is postponed until 2015 or 2016, there is an opportunity to address problems with the current structure.
- Those who thrive under the RWCA do so because of a holistic approach. The ideal mix of case management and supportive services to meet NHAS goals should be considered.
- The RWCA has a long history of pushing HIV performance metrics, but Medicaid expansion plans and new insurance plans do not seem to reflect that momentum. Metrics should be addressed.

Discussion

Ernest Darkoh, M.D., M.P.H., M.B.A., said advocates should emphasize that the RWCA is the best model for care; otherwise, the funding structure determines the model. Cost-effectiveness and other health economics studies are critical to make the case in support of the Ryan White model. HRSA data demonstrate that Ryan White programs improve outcomes across the continuum of care. The South represents a special circumstance, Dr. Darkoh noted, and may require specialized strategies and tactics to address PLWHA.

Dawn Averitt agreed with others that it is necessary to monitor ACA implementation, but she advocated for a more aggressive approach, rather than waiting years before crafting a solution to the gaps and challenges we already expect to see. There should be a mechanism not only for monitoring but also for responding rapidly, she said. For example, Federal funds could support a team of State Medicaid and AIDS directors to capture and present data.

Ms. Hiers pointed out that advocates have often advised PLWHA to keep their incomes low so they remain eligible for treatment, but the ACA model encourages them to earn money so they can purchase insurance. PACHA should discuss employment issues for PLWHA.

Mr. Wilson suggested that PACHA make a recommendation to lengthen the open enrollment period. Mr. Greenwald was skeptical that the enrollment period could be expanded, but it may be possible to add some flexibility—for example, allowing people to enroll off-cycle when they experience a major life event. He said a State’s ability to offer ADAP funds to assist with insurance premiums could qualify as a life-changing event that triggers open enrollment for PLWHA. The current open enrollment period is dictated by the insurance companies and is seen as an incentive to drive enrollment, because there is a penalty for not enrolling.

Asked about the essential health benefits (EHB) package, Mr. Greenwald noted that the benefits are set, but the Secretary has the authority to step in if a State’s EHB package discriminates against PLWHA.

Mr. Cruz pointed out that Ryan White programs and ACA implementation differ in each State. Also, while monitoring is necessary, Mr. Cruz worried that some in Congress would use the results to destroy the ACA before it has time to succeed. He anticipates that Ryan White programs and ACA reforms will be integrated in stages. Using ADAP funds for insurance premiums is one step toward integration and serves as a mechanism for managing a complex law. Mr. Cruz supported using some Ryan White funds now to educate more people about how the program will be integrated with health care reform. While Ryan White and the ACA are parallel systems now, the ACA is supposed to take over; a phased approach is needed.

Ms. Chung emphasized that private funding is crucial. We should revisit the concept of charity care, in which community foundations assist when public dollars are not sufficient. She also suggested that HRSA Special Projects of National Significance (SPNS) address how to move forward with Ryan White programs in States that are not expanding Medicaid to provide evidence demonstrating the need to protect Ryan White funding. In addition, Ms. Chung called for gathering more and better data about subpopulations at risk.

Rev. Sharp said Ryan White programs are not well known outside of the HIV community. Also, insurance companies are infiltrating communities with advertising but not explaining how the ACA will work or what benefits will be provided. Ms. Hiers said that the navigators should take the lead in letting people know what the ACA offers, and Federal agencies have provided information to CHCs and others to assist with navigation. She noted that not all plans are open to PLWHA, and those receiving tax subsidies will have some limits on the plans available. Mr. Cruz added that some States have put up barriers, such as requiring navigators to be certified, as a way to prevent implementation of the ACA.

In terms of next steps, Mr. Greenwald said many of the issues raised are being addressed by the Access to Care Subcommittee. Ms. Hiers and Mr. Perez suggested establishing a short-term working group to inventory and tackle the issues raised.

Action Item

A short-term working group will be established to review and address the issues raised at today's meeting.

Ms. Hiers also recommended paring resolutions down to no more than three critical issues that the Administration should address. She also suggested tracking the impact of PACHA resolutions.

Action Item

An inventory will be taken of all PACHA resolutions and recommendations to HHS and Secretary Kathleen Sebelius, along with their status and suggested next steps.

Closing Remarks and Adjournment

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

In concluding for the day, Ms. Hayes thanked Caroline Talev of PACHA and the new members of PACHA in particular for their contributions to the meeting. Ms. Hayes adjourned the meeting for the day at 5:06 p.m.

Day 2—September 19, 2013

Call to Order and Roll Call

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

Ms. Hayes called the meeting to order at 9:08 a.m. and called the roll.

Black MSM Update

Moderator: A. Cornelius Baker, PACHA Member

Mr. Baker reminded the participants that PACHA passed a resolution in 2011 requesting Federal activities to eliminate HIV health disparities among black MSM in light of the mountain of evidence describing the issue. He acknowledged that focusing on a subpopulation in the context of HIV resources can be fraught, but we have reached an extreme, where nearly half of all those infected come from one small population. If we do nothing to cut off the spigot of infection and ensure that the infected have care, we are committing them to death, said Mr. Baker, and we risk the genocide of a small population.

Greg Millett, M.P.H., Senior Behavioral Scientist, Division of HIV/AIDS Prevention, CDC

The HIV epidemic in the United States affects young black MSM disproportionately, Mr. Millett said. Along the continuum of care, black MSM fare worse than whites at every stage. To eliminate the disparity in viral suppression, nearly 40,000 more black MSM would need to be on treatment.

Structural issues, such as low income or lack of health insurance, pose substantial barriers to testing and treatment. Among black and Latino MSM, even having insurance and disclosing their sexual orientation to their health care providers does not necessarily lead to testing and diagnosis. Thus, providers are not even reaching the so-called low-hanging fruit, Mr. Millett noted. Moreover, among black and Latino MSM, beliefs (including conspiracy theories about HIV and the belief that homosexuality is wrong) and a lack of social support correlate with low rates of HIV testing, diagnosis, and medication adherence. Attitudes toward homosexuality have barely changed in the black community, said Mr. Millett, while they have changed substantially among whites.

Little research has focused on MSM, partly because of attitudes about homosexuality. The fact that any studies of young MSM are funded is testament to the commitment of Federal agencies to address the issue, given the lack of public support for such research, Mr. Millett emphasized. More interventions studies are underway, but it is clear that interventions addressing risk behaviors only are not effective. An analysis of the probability of exposure shows that even reducing the number of partners does not significantly reduce HIV risk among black MSM. Mr. Millett summarized the effectiveness of available interventions for preventing HIV among MSM, noting that health education and risk reduction are not very effective. A program in place

since 2006 has helped identify factors driving HIV infection among black MSM, including STIs, undiagnosed HIV, disparities across the continuum of care, sexual networks, and SDH. Despite poor SDH, black MSM demonstrate more resilience than others, Mr. Millett noted.

Mr. Millett suggested looking more closely at black MSM compared with others to determine how much HIV risk is attributable to specific factors. Now that we see the impact of multiple risk factors beyond unprotected sex, we need a more complex model, he said. Such research should be paired with cost analyses to identify where to focus funding to have the biggest impact on black MSM. In addition, we need interventions that focus on keeping HIV-positive black MSM in care, said Mr. Millett. (The HRSA SPNS provided some good demonstration projects.) There are no social marketing efforts aimed at HIV-positive MSM describing the benefits of ART or the options for making ART more tolerable. Along those lines, Mr. Millett suggested studying the potential for monthly or semiannual dosing of ART or pre-exposure prophylaxis to increase medication adherence.

Victoria Cargill, M.D., M.S.C.E., Director, Minority Research and Clinical Studies, Office of AIDS Research, NIH

Dr. Cargill focused attention on those portions of the NIH research portfolio where studies of HIV, the black community, and MSM converge. Black MSM can be engaged in HIV research, as demonstrated by a study that included peer navigators to promote HIV testing, among other components. Structural, behavioral, and biological factors were associated with the high rates of undiagnosed HIV among black MSM in this study.

Dr. Cargill gave some examples from among the hundreds of NIH-funded studies that involve specific, unique HIV prevention approaches for black MSM. They include peer health educators, targeted interventions, and technology-based approaches, sometimes further narrowing the focus to youth or substance users. Understanding that biomedical prevention is important for black MSM, NIH studies have engaged more black men in research on microbicides and vaccines in development. Biomedical research is now paying more attention to the qualities of a product to better address the acceptability and likely use of that product.

NIH efforts recognize that black communities need to see more investigators from their communities. It supports the professional development of minority investigators, who in turn have addressed topics such as black MSM and incarceration, HIV testing patterns among black MSM, and differences in various risk behaviors among black MSM compared with black bisexual men.

Dr. Cargill said black MSM confront numerous health, social, and economic challenges that compound those challenges presented by HIV. NIH supports a large, comprehensive portfolio of relevant research as well as training for minority scholars who contribute to the scope of research. Dr. Cargill concluded that addressing these issues will take time and persistence.

Timothy Harrison, Ph.D., Senior Policy Advisor, OHAIDP, ASH, HHS

Dr. Harrison outlined some efforts across HHS to address HIV among black MSM, such as a meeting on HIV prevention, care, and research for black MSM and black bisexual men.

The meeting participants recommended the following:

- Increase outreach, education, and technical assistance to improve access to biomedical advances
- Increase research on the impact of stigma and SDH, strategies and interventions to address stigma and SDH, and methods for evaluating strategies
- Fund and support tools, education, technical assistance, and capacity-building targeted at black MSM and black bisexual men.

The Secretary's Minority AIDS Initiative (MAI) Fund has an annual budget of \$52 million to address racial and ethnic disparities in HIV/AIDS. Dr. Harrison highlighted some of its competitively funded projects aimed at black MSM, which represent efforts across the continuum of care and incorporate new technology and tools.

The MAI Fund also supports the CAPUS projects, which seek to increase testing, treatment, and retention in care of racial and ethnic minorities with HIV. The CAPUS awards were designed to promote large-scale, cross-agency projects with greater impact than smaller awards. Six of the eight awards went to projects in southern States, and all focus on SDH. Some CAPUS activities are aimed specifically at black MSM, such as an anti-stigma campaign, a partnership with community-based organizations (CBOs) that successfully serve black MSM, a comprehensive men's HIV clinic, workshops to address stigma and improve health literacy, campaigns to improve linkages to care and treatment adherence, and social marketing/social network strategies. Dr. Harrison concluded that HHS is revisiting the way the MAI Fund is used; agencies that receive the funds are stepping up to the plate and thinking about how to better use them, he said.

Kali Lindsey, Director of Legislative and Public Affairs, NMAC

Mr. Lindsey said that although the alarm was sounded in 2005 and despite having the tools to prevent HIV transmission, black MSM continue to be diagnosed later, less engaged in care, and less likely to achieve viral suppression. We have not yet even touched on many factors that affect risk and make black MSM more vulnerable, such as a history of trauma, he said. Some efforts have sought to make the PCMH model—embraced by the RWCA and encouraged under the ACA—work better for black MSM. Even with advocates working in black communities to identify black MSM who would benefit, stigma from within the community, poor family support systems, and structural barriers such as transportation funding thwarted efforts to engage black MSM in care.

The RISE Proud Initiative is a partnership between NMAC and Resources To Improve, Strengthen, and Empower (RISE) that created an action plan for SDH and structural barriers for black MSM and black bisexual men. Mr. Lindsey called on the Federal Government to provide

the \$2.4 billion needed to respond to the unmet needs of black MSM. Of that amount, \$2 billion will come immediately through the ACA and Medicaid expansion, but services must reach the black MSM who need them. If we targeted investment, said Mr. Lindsey, we could avert at least 6,000 cases of HIV infection among black MSM per year, surpassing NHAS goals.

Mr. Lindsey suggested that PACHA reaffirm its resolution to eliminate disparities that affect black MSM. NMAC has asked the HHS Secretary to perform two activities: form an interdepartmental group to seek out innovative models and synthesize the evidence related to HIV health disparities, and make clear recommendations to address them. Across HHS, said Mr. Lindsey, NMAC sees roadblocks to a heightened response, such as a lack of diversity among the senior leadership, although there does appear to be some support in Congress to address structural racism.

Finally, Mr. Lindsey said, we must invest in tackling HIV among black MSM not only at the Federal level but also at the State level. We cannot accept States' claims that they do not have the funds to invest, because they are putting the funds they do have into jails where they can incarcerate more black and Latino men. States must spend less on incarceration and more on HIV prevention and care, he concluded.

Discussion

Mr. Wilson pointed out that the funding required to address black MSM with HIV is not that large, yet we seem to lack the will to pursue the matter. The continuum of care demonstrates that we are not holding our investments accountable for progress. We know where the epidemic is, but we are not connecting the dots, said Mr. Wilson. The only population in which HIV infection rates are increasing is black MSM, yet our actions do not reflect that knowledge.

Dr. Horberg said that for black MSM, we must address issues beyond medication and address them in the context of the medical home. He called for more efforts to improve the diversity of the workforce and to engage national associations focused on minority health care, such as the National Medical Association and the HIV Medicine Association. We need better multidisciplinary care teams to address not just HIV but specific populations, said Dr. Horberg. We also need more systematic expansion of successful efforts. Dr. Cargill added that providers should consider hiring care retention specialists.

Mr. Lindsey noted that as the RWCA becomes integrated into the ACA environment, we should keep in mind that the Ryan White approach has not worked well for all populations. We should consider what services should be incorporated into the PCMH model so that it works better for black MSM and what Federal investment is needed. Mr. Baker pointed to one study underway that will provide more information about care coordination.

Asked about efforts to raise awareness among young people, Dr. Cargill said numerous projects across HHS divisions focus on youth. For example, the NIH has a network of researchers addressing HIV-positive and at-risk adolescents and teens, evaluating interventions such as a

mobile van test site to reach young people where they are. Dr. Harrison added that portions of some CAPUS-funded projects target youth, including peer education efforts. Mr. Millett said CDC recently awarded \$50 million to CBOs serving young black MSM to support linkages to care. Mr. Lindsey noted that there has been a lot of Federal support for more testing of black MSM; the real challenge has been getting black MSM to accept testing.

Asked what it would take to categorize HIV among black MSM as a true emergency, Dr. Colfax said that policymakers have been aware of the challenges for a decade. For example, the ACA will increase access to insurance, but insurance is not enough to get people into care. Insurance enrollment is an abstract concept to young people, and support from CBOs and families is needed to engage LGBT youth. Regarding the need for investment, the HIV CCI will assess the allocation of resources by population and evaluate redistribution according to the needs of those hardest hit by the epidemic. Dr. Colfax said that not all interventions have equivalent effect; despite all the efforts underway, we must consider whether we are implementing programs strategically, investing resources as well as possible, collecting data, and assessing effectiveness. We must scale up recommendations, said Dr. Colfax; if even black MSM engaged in the health care system are not getting tested, the accountability of providers comes into question.

Dr. Colfax agreed that the situation requires a sustained response and resources that can be focused more effectively. He agreed with Mr. Wilson that we know the right things to do, but said we have to increase our sense of urgency. With the ACA and the HIV CCI, the Administration is committed to getting the response right, said Dr. Colfax. Dr. Garcia called on PACHA to hold providers accountable for giving appropriate care. In addition, PACHA should push to prioritize HIV testing and treatment for black MSM.

Mr. Perez said the data show that biomedical treatment approaches are the most effective, while health education and risk-reduction messages have the least impact. We need dramatic, drastic changes now, he said. He wondered whether the political will exists to sound the alarm again in the name of shifting resources to meet the needs of young black MSM. Where Ryan White programs do not address the structural barriers that increase risk for young black MSM, Mr. Perez called for a major departure from current policy. For example, he said, consider expanding Ryan White programs to cover services for black MSM and transgender people who are HIV-negative. Mr. Perez added that significant funds are going to social marketing, but there is no consistent messaging.

Rev. Sharp expressed concern about the lack of knowledge of risk among young black MSM. She called for a stronger marketing component to raise awareness. However, she also noted the need for support and counseling to allay fears when people do get tested.

Asked how women can be more involved in messaging to better reach men, Dr. Cargill said some studies and pilot programs are focusing on mothers and daughters, for example. Mr. Baker added that some young black MSM would benefit from messages that better reflect the strong influences of grandmothers and mothers. Mr. Brooks called for immediate action from

PACHA, noting that many more young black MSM will be infected or die between now and the next time PACHA meets.

HHS Teen Pregnancy Prevention Programs and Evidence Review

Moderator: Kathie M. Hiers, PACHA Member

Barbara Broman, Associate Deputy Assistant Secretary for Human Services Policy, ASPE, HHS

Ms. Broman explained that in 2009, HHS contracted with Mathematica to systematically review the evidence base on teen pregnancy prevention programs. Following review using a detailed, defined protocol, Mathematica published a list in 2010 of 28 models identified as evidence-based programs. Mathematica updated the list in 2012, adding three more models. The Heritage Keepers abstinence-only curriculum did not meet the criteria of the initial review, but additional data from original studies were submitted for the second review. The Heritage Keepers curriculum met the criteria during the second review and was determined to be of moderate quality. The criteria require evidence that the curriculum reduces high-risk sexual behavior among teens.

Evelyn Kappeler, Director, OAH, HHS

Ms. Kappeler further explained that in 2010, the President proposed a new teen pregnancy prevention program using evidence-based models. The OAH awarded \$75 million in grants to organizations to replicate proven prevention models, and through a joint funding announcement with the ACYF, awarded \$25 million for research and demonstration projects to evaluate new models. The OAH reviews grantees' materials for medical accuracy. Of the 28 evidence-based models that Mathematica determined met the criteria for inclusion (in its first review), OAH grantees are using 23. They include a range of approaches, including youth development, comprehensive sex education, and abstinence education. Information about the review and the models is available online.

Ms. Kappeler emphasized that the models were selected on the basis of research evidence; the content was not reviewed for medical accuracy. Grantees are required to submit the materials they use (e.g., core curriculum and other educational materials) and demonstrate that they are age-appropriate and medically accurate, but the review of medical accuracy by the OAH takes place after the grant is awarded. Each submission goes through two reviews that address issues such as contraception, STIs, reproductive anatomy, and pregnancy. Information must not be inaccurate, outdated, poorly referenced, or confusing. A courtesy copy of the review findings is shared with the curriculum developer. Once they receive the report, grantees have 30 days to respond to any recommendations and send revised materials back to the OAH for further review. Grantees and curricula developers may not include in their materials any statements that can be perceived as an endorsement of the materials by HHS.

Debbie A. Powell, Deputy Associate Commissioner, ACYF, FYSB, HHS

Ms. Powell said that part of FYSB's core mission is preventing pregnancy and the spread of STIs among adolescents. FYSB supports State, tribal, and community efforts to promote comprehensive sex education, adulthood preparation programs, and abstinence education. The Personal Responsibility Education Program awards grants to State agencies, tribal entities, and CBOs to educate young people on both abstinence and contraception as effective methods of preventing pregnancy. The Personal Responsibility Education Innovative Strategies Program supports research and demonstration projects that implement innovative strategies for preventing pregnancy among youth. Models used by grantees must provide medically accurate information tailored to the age of the population served.

The Title V State Abstinence Education Grant Program provides funding to States and territories for abstinence education, mentoring, counseling, and adult supervision. It promotes abstinence to prevent teen pregnancy in youth, especially for those from minority groups, in foster care, or who are homeless. States are encouraged to use evidence-based abstinence education models, and the materials used must be medically accurate. Across all FYSB programs, grantees must certify that the educational materials are grounded in scientific research. The agency applies a consistent definition of medical accuracy as follows: Medical information must be verified or supported by the weight of research conducted in compliance with accepted scientific methods and published in peer-reviewed journals, where applicable, or be composed of information that leading professional organizations and agencies with relevant expertise in the field recognize as accurate, objective, and complete.

Discussion

Dr. Garcia pointed out that in the evidence review, only one curriculum demonstrated efficacy across more than one outcome measure. She expressed concern that Federally funded programs are not held to a higher standard—one in which programs demonstrate effectiveness not just in terms of self-reported sexual behaviors but also in terms of the health outcomes, specifically pregnancy and STI prevention. Ms. Broman responded that the outcomes were described in the authorizing legislation, which explicitly states that any program demonstrating a positive, statistically significant finding on one outcome measure meets the criteria.

Ms. Kappeler added that grantees are testing innovative approaches, and HHS is hoping to build up the evidence base in this area. As the evidence base becomes richer, said Ms. Broman, the OAH will review the criteria. Dr. Garcia countered that programs are not compelled to demonstrate evidence of STI prevention and so the evidence will never be collected.

Ms. Hiers read excerpts from a previous version of the Heritage Keepers curriculum that used fear and shame to promote abstinence. Ms. Broman noted that the contractor was not asked to review the content of the curriculum. Ms. Kappeler said none of the programs her office funds are using the Heritage Keepers curriculum, so she does not have it. Ms. Powell said one grantee is using the curriculum, but she has not seen a copy. She is trying to learn from the grantee whether there are prohibitions on sharing the curriculum outside of the program.

Several PACHA members expressed disbelief that any curriculum used in a federally funded program would be considered acceptable even though no Federal official has read it. Mr. Perez pointed out that in 2012, PACHA passed a resolution supporting comprehensive sex education for youth. On the basis of public comments, he believes that the Heritage Keepers curriculum promotes gender bias and perpetuates stigma of LGBT and queer/questioning (LGBTQ) youth and thus should not be supported. As the Administration strives to promote equality of women, it cannot include a curriculum that competes with that goal. Mr. Perez requested that PACHA urge HHS to remove the Heritage Keepers curriculum from its list of evidence-based models until it is determined to be congruent with PACHA's proposed criteria for appropriate sex education.

Mr. Greenwald added that HHS cannot abdicate its responsibility for developing the protocol around which model programs are reviewed. Through the Teen Pregnancy Prevention Initiative, the Federal Government is essentially sponsoring the education programs used by grantees. The review protocol must be revised in light of the unintended consequences of its application.

Asked what the OAH is doing about HIV prevention among young black MSM, Ms. Kappeler said the OAH primarily focuses on teen pregnancy prevention but also provides technical assistance to programs supported by the MAI Fund. Ms. Powell said HIV prevention is an indirect goal of the FYSB mission, so it provides technical assistance and materials to grantees that have LGBTQ youth within their target population.

Public Comments

Lindsey Dawson of the AIDS Institute focused on the importance of transparency and data collection in Ryan White programs as the ACA is implemented. Only after the ACA is implemented and data are analyzed and collected can the future needs of Ryan White programs be assessed and plans made to improve outcomes. The AIDS Institute asks that CDC release the HIV and AIDS case counts used by HRSA to formulate Part A and B grant awards, which it has not released in years. While the total award for each Part A jurisdiction has been released, it would be helpful to know how much of the award is formula-driven and how much is supplemental. Additionally, for Parts A and B, HRSA should release the extent to which each jurisdiction is protected by the "hold harmless" provision. Having these baseline data will be a critical first step to better evaluating the RWCA and planning for the future.

The AIDS Institute is eagerly awaiting the results of the ASPE–Mathematica study examining the service needs under the RWCA as the ACA is implemented and identifying strategies to direct Federal resources to areas of greatest need. The AIDS Institute supports the two HRSA studies proposed in the President's budget examining coverage completion services offered by payers that do not receive Ryan White funds and assessing the impact of the ACA on the RWCA. Data from these studies should be released on an ongoing and timely basis.

As these and other studies are undertaken, the AIDS Institute urges Federal partners to work together—particularly CDC and HRSA, both of which collect data on viral load and CD4 counts,

among other things. The AIDS Institute notes that the analysis of the impact of health reform on the RWCA should include analysis of diverse communities across different regions to address health disparities.

Data collection will be especially useful in tracking how States use their ADAP dollars now and after ACA implementation in both expansion and nonexpansion States, particularly how much of ADAP dollars are used to cover premiums and copays compared with drugs and for how many people. Data examining the costs and content of coverage completion services and tracking Ryan White client enrollment in private insurance and Medicaid also will be important.

There is no doubt that the demand for Ryan White services and funding will continue, but it also is certain that as millions of individuals gain access to coverage, Ryan White programs will need to adapt. Before we make changes, we must scrutinize the data to ensure that any reforms are evidence-based and do not jeopardize clients' well-being, Ms. Dawson concluded.

Ms. Treston of the Association of Nurses in AIDS Care suggested that PACHA establish a report card on the status of its resolutions and recommendations. She appreciated the rich panel discussions and the opportunity for public participants to ask questions throughout the meeting. She wondered how PACHA would move from discussion to resolutions that advocates can use, such as the resolution on HIV criminalization. Ms. Treston noted that nurses are in a good position to talk with young people about enrolling in Medicaid if they want to avoid joining their parents' insurance because they do not want to disclose their status.

Ron Simmons of Us Helping Us, People Into Living stressed the important role of CBOs that are not medical clinics. Researchers estimate that 30,000 black MSM in need do not get care because of homophobia and stigma. Culturally competent organizations are needed to engage and retain black MSM in care with social supports and navigators. New technology, such as social media, also requires a culturally competent approach. In addition, capacity-building is needed. HIV prevention organizations must be integrated as respected and funded partners in the overall system developed under the ACA. Mr. Simmons feared that as HIV care becomes mainstream, efforts will center on doctors and leave out CBOs.

Mr. Hopkins referred to a letter to HHS Secretary Sebelius and a press release written by the National Black Gay Men's Advocacy Coalition calling for a more robust response to the increasing rate of HIV infection among black MSM.

Mr. Hopkins read a statement from **Barbara Joseph** of the National Black Women's HIV/AIDS Network (NBWHAN). Ms. Joseph wrote that her organization stands in solidarity with black MSM in the quest to achieve the goals of the NHAS and to become active agents of education in the communities and CBOs that serve black people with HIV. The NBWHAN and the Heterosexual Men of Color Coalition have joined together to address the shared concerns of black people with HIV. On World AIDS Day, President Obama called on all of us to do more to show that the lives of black gay men matter. However, the Government is doing less, not more, and our black heterosexual brothers are invisible in this epidemic. Ms. Joseph requested that

the NHAS coordinating agencies and State health departments develop plans that include community-drive strategies addressing each segment of the population disproportionately affected by this disease. Ms. Joseph requested that PACHA follow up on its resolution to eliminate health disparities among black MSM. She also requested that PACHA recommend that the HHS Secretary create an intra-agency task force to develop strategies to address the SDH (e.g., unemployment, housing, and incarceration) that contribute to high rates of HIV for many, particularly for black people.

In response, Ms. Chung raised concerns about building silos around the black community. Efforts to address HIV/AIDS should focus on patients, not labels, she said.

Venton Jones of the National Black Gay Men’s Advocacy Coalition shared a letter he received that described the plight of a young black Haitian gay man hospitalized with AIDS. The author wrote, “He was so stigmatized by the harmful impact of homophobia and HIV that he expressed how he saw himself as unworthy to treat his health as a priority and he accepts the worst possible outcomes as deserved. He stopped taking his medications and failed to remain in care and had virtually no support system in place, fearing disclosure and being an outcast.” With treatment, the man’s condition improved, but he lost his job and health insurance because the hospital failed to link him to the AIDS Insurance Continuation Program. He was linked to Ryan White services and received mental health counseling. However, he was forced to change counselors when his Medicaid benefits kicked in, which drove him out of counseling, and he continues to keep his sexual orientation secret. The author wrote, “Our LGBT culture in South Florida is not immune to the lingering undercurrent and sinkholes caused by bigotry and racism. I’m pleased to observe and witness efforts for our community to better embrace and value the diversity within our community. We still have a long journey ahead, but thankfully, it is a journey moving forward.” Mr. Jones said his organization hears many such stories, and his personal story is similar. The health care system needs help, he said, and information needs to penetrate at all levels.

Dan Nugent of NMAC said that his organization recently issued an action plan to address HIV among black gay/bisexual men, “RISE Proud: Combatting HIV Among Black Gay and Bisexual Men.” This document presents recommendations and action steps for the Administration and Congress to address HIV in young gay men of color. It was developed in concert with organizations with missions similar to NMAC and informed by the HIV Prevention Trials Network study 061, which found high levels of HIV infection, incarceration, and unemployment among black gay men.

For too many young gay men of color, HIV is a rite of passage to adulthood. While they represent less than one-half of 1 percent of the general population, young black MSM accounted for approximately 4,800 new HIV infections in 2010, more than any other age or ethnic group of MSM. They account for one-half of new infections among young MSM.

PACHA must ensure that efforts to address the HIV epidemic commit to the health and lives of young gay and bisexual men. The RISE Proud action plan encourages a more comprehensive

approach to addressing this demographic and highlights key actions for response among policymakers, community leaders, physicians, researchers, corporations, private funders, families, educators, faith communities, and young gay men of color. The plan acknowledges that SDH, such as stigma, family rejection, social isolation, and homophobia, play significant roles in keeping these young men vulnerable to health and other disparities. The goal of the action plan is to galvanize and mobilize the response of broad parts of American society to quell the rising tide of infections among young gay and bisexual men.

Mr. Nugent highlighted three recommendations in the action plan specifically aimed at HHS:

- HHS must prepare, in advance, to create U.S. Public Health Service duty stations (which provide health care for underserved populations) in areas with high rates of HIV incidence that do not expand their Medicaid programs (especially in the rural South, which is home to many black MSM).
- HHS must form a plan to specifically address enrollment of black gay men into ACA plans to help build the capacity of black gay men to manage their own health.
- HHS and the Department of Labor should engage State and Federal prisons to create a program for released prisoners to gain employment as health navigators in the ACA, which would assist with ACA registration within their respective communities while also offering a source of income to the formerly incarcerated.

PACHA members reviewed various written comments:

- **Jean Public** expressed the opinion that HIV is a self-inflicted disease and that taxpayer dollars should not be used for a meeting about HIV or to address HIV.
- **Ivy Turnbull** of the AIDS Alliance for Women, Infants, Children, Youth, and Families described the dire consequences of Federal sequestration (mandatory budget cuts for fiscal year 2012–2013) on Ryan White Part D programs.
- **Ms. Campbell** of Housing Works asked that PACHA support updating the NHAS to reflect new realities about ending AIDS, particularly research demonstrating that housing is effective as both HIV treatment and prevention and the need for proportionate allocation of effort and resources to women and youth.

Closing Remarks and Adjournment

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

Ms. Hayes thanked all the participants. She adjourned the meeting at 12:15 p.m.