

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

**51st Meeting**

**Hubert H. Humphrey Building**

**U.S. Department of Health and Human Services (HHS)**

**Washington, DC**

**April 22, 2013**

**Council Members—Present**

Nancy Mahon, J.D., PACHA Chair

A. Cornelius Baker

Dawn Averitt

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

Patricia Garcia, M.D., M.P.H. (by telephone)

Robert Greenwald, J.D.

Kathie M. Hiers

David Holtgrave, Ph.D. (by telephone)

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

Ejay L. Jack, M.S.W., M.P.A.

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

Naina Khanna

Mario Pérez, M.P.H.

Rev. Vanessa D. Sharp, M.Div., M.A.C.M., M.A.T.M.

Sandra Torres-Rivera

**Council Members—Absent**

Praveen Basaviah

Douglas Brooks, M.S.W.

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

Humberto Cruz, M.S.

Kevin Robert Frost

Anita McBride

Douglas A. Michels, M.B.A.

Rosie Perez

Phill Wilson

**Staff**

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

Caroline Talev, PACHA Public Health Assistant

## **Federal Liaison**

Wanda Jones, Dr.P.H., Principal Deputy Assistant Secretary for Health, HHS

## **Panelists**

Andrew J. Baskin, M.D., National Medical Director, Aetna

Laura W. Cheever, M.D., Sc.M., Acting Associate Administrator and Chief Medical Officer, HIV/AIDS Bureau, Health Resources and Services Administration (HRSA)

Gary Cohen, J.D., Deputy Administrator and Director, Center for Consumer Information and Insurance Oversight (CCIIO), Centers for Medicare and Medicaid Services (CMS)

Jeffrey Crowley, M.P.H., Distinguished Scholar/Program Director, National HIV/AIDS Initiative, O'Neill Institute for National and Global Health Law, Georgetown Law

H. Dawn Fukuda, Sc.M., Director, Office of HIV/AIDS, Massachusetts Department of Public Health

Amna Osman, M.P.A., Director, Division of Health, Wellness, and Disease Control, Michigan Department of Community Health

Cindy Mann, J.D., Deputy Administrator/Director, Center for Medicaid and Children's Health Insurance Program (CHIP) Services (CMCS), CMS

Murray Penner, Deputy Director, National Alliance of State and Territorial AIDS Directors (NASTAD)

Michael S. Saag, M.D., Jim Straley Chair in AIDS Research; Director, Center for AIDS Research, University of Alabama at Birmingham

Judy Solomon, J.D., Vice President for Health Policy, Center on Budget and Policy Priorities

## **SUMMARY**

### **Roll Call and Welcome**

PACHA Chair Nancy Mahon called the meeting to order at 9:22 a.m., and PACHA Executive Director Kaye Hayes called the roll. Ms. Mahon explained that unlike other PACHA meetings, this meeting would use a town hall format. Panelists representing various stakeholder groups would offer brief presentations and then respond to questions from PACHA members and the audience.

### **Remarks by Wanda Jones, Dr.P.H., Principal Deputy Assistant Secretary for Health, HHS**

Dr. Jones praised the power of PACHA, observing that many of its members have been part of the evolution of HIV/AIDS from initial research efforts to national policy. The positive changes being seen now in the health care system are the result of HIV/AIDS advocates who pointed out the shortfalls of the system and providers who worked to make sure that people living with HIV/AIDS (PLWHA) were not abandoned by the system, Dr. Jones said. We would not be here today without the muscle, commitment, and vision of PACHA, she added. The National HIV/AIDS Strategy (NHAS) furthers the efforts of PACHA and others by helping the Federal

Government and its partners align their efforts and move forward in an unprecedented way, Dr. Jones noted.

The Patient Protection and Affordable Care Act (ACA) is one of the most significant pieces of legislation in history and an enormous boon to PLWHA, many of whom have been denied insurance in the past on the basis of preexisting conditions, said Dr. Jones. The ACA will cover as many as 30 million more people, many with little experience with the health care system outside of emergency departments (EDs) and clinics. Thus, the first issue to address is helping people find plans and get enrolled. Dr. Jones called on PACHA and others to help educate people about their options. The HHS Web site *HealthCare.gov* will be frequently updated to provide information, and *AIDS.gov* also will provide critical, up-to-date information.

Dr. Jones said PACHA plays a crucial role in helping HHS move forward. On behalf of Howard Koh, M.D., Assistant Secretary for Health, and HHS Secretary Kathleen Sebelius, Dr. Jones thanked PACHA members for the work they do for their communities, States, Tribes, families, and country.

## **State and Local ACA Implementation Panel**

### **Moderator: Mario Pérez, M.P.H., PACHA Member**

Mr. Pérez said that lessons learned in his home State of California about Medicaid expansion and continuity of service for PLWHA will inform the rest of the country. We are in a period of excitement about the future of the ACA but also in a period of anxiety, especially when State and local partners are not on the same page, Mr. Pérez noted. Panelists were asked to provide the State perspective on such challenges as Medicaid expansion and the creation of State health insurance exchanges where individuals can shop for insurance plans. States can run their own exchanges, partner with the Federal Government, or cede operations to the Federal Government, Mr. Pérez clarified.

### **ACA: State Implementation Update**

*Murray Penner, Deputy Director, NASTAD*

With open enrollment for insurance plans beginning in October 2013 (and plans taking effect January 1, 2014), States are working frantically to get their exchanges in place, develop processes for certifying eligible insurance plans, and ensure that consumers are ready to enroll, said Mr. Penner. Sequestration—the mandatory, across-the-board, Federal budget cuts that took effect in March—threaten not only health care reform efforts but also core public health funding.

Although authorization of the Ryan White Care Act (RWCA) expires in September 2013, Mr. Penner stressed that Ryan White programs will not end at that time. The President's 2014 budget calls for continuing the RWCA through the implementation of the ACA. Ryan White-funded programs will be crucial over the short term to maintain health care access for PLWHA. In the long term, as more people are insured, stakeholders will reevaluate the role of the

RWCA, assess what is not covered by the ACA, and consider the affordability of care under the ACA.

Not all States have agreed to go forward with Medicaid expansion. Among Ryan White program clients, 14 percent earn 100–138 percent of the Federal poverty level (FPL) and therefore would be eligible for Medicaid in States that do expand. Further, 54 percent of Ryan White program clients earn 100–400 percent of FPL and therefore would be eligible for Federal subsidies to purchase insurance through their State health exchanges. Some States, especially those that are not expanding their Medicaid programs, are considering purchasing insurance for those who make less than 100 percent of FPL and are not eligible for Medicaid under the current guidelines.

NASTAD is assisting Ryan White programs in four key efforts:

- Preparing for client enrollment in new systems
- Preparing State HIV/AIDS programs for health care reform
- Preparing providers for a changing health care landscape
- Ensuring that the ACA advances public health goals.

### **The Promise of Health Care Reform: Opportunities for HIV/AIDS Prevention and Care**

*H. Dawn Fukuda, Sc.M., Director, Office of HIV/AIDS, Massachusetts Department of Public Health*

Ms. Fukuda stressed that Massachusetts has a unique combination of infrastructure, politics, State policies, and other factors contributing to the success of its health care reform efforts, which began more than 10 years ago. The core components of Massachusetts' reform are Medicaid expansion, an insurance exchange, and improved access to health insurance and providers. Medicaid expansion was vital to the State's success. In Massachusetts, Medicaid covers more than three-quarters of PLWHA. Continued investment in Ryan White programs is critical in areas without Medicaid expansion, said Ms. Fukuda. Massachusetts maintains a safety net system that provides care to those ineligible for insurance.

States must think long term. When Massachusetts first expanded Medicaid to PLWHA who earned up to 200 percent of FPL, only 225 people enrolled, because most PLWHA did not know they were eligible. Successful outreach takes time, investment, and training, said Ms. Fukuda, because navigating enrollment and eligibility is very complicated. In addition, if AIDS drug assistance program (ADAP) funds are used for plan premiums, the State should have some input to ensure that the plans provide sufficient coverage, manageable deductibles, and good value. Massachusetts worked closely with insurers, providers, and consumer advisory boards to reach agreement on a restricted subset of plans for which ADAP funds can be used.

Ms. Fukuda offered a planning checklist for health care reform:

- **Build connections with State Medicaid programs.** Develop personal relationships. Review the Medicaid application to ensure that it is consistent with the unique needs of PLWHA.
- **Anticipate cost-shifting realistically.** Ryan White programs provide essential services not covered by health plans. In States without a safety net, it is not clear who will provide care for the uninsured.
- **Review ADAP coverage components.** Massachusetts found that using ADAP funds to pay for insurance premiums is more cost-effective than just buying medications.
- **Educate providers and consumers.** Providers must deliver information in ways that people can digest. The presence of a wide variety of stakeholders should help get the word out.

Ms. Fukuda pointed out that communicable diseases of public health significance—particularly those like HIV/AIDS that disproportionately affect vulnerable populations and contribute to health inequities—require a governmental response.

### **A Glimpse Into Michigan**

*Amna Osman, M.P.A., Director, Division of Health, Wellness, and Disease Control, Michigan Department of Community Health*

The Michigan legislature is debating Medicaid expansion, which could cover as many as 500,000 of the State's 1.2 million uninsured, said Ms. Osman. Looking at the cascade from HIV diagnosis to treatment to viral suppression for Michigan, Ms. Osman believes her State should invest more in linking those newly diagnosed with HIV to care. Community care in Michigan is evolving into a system that offers integrated health care within the context of a multidisciplinary provider team. Collaboration is key to providing high-quality services, said Ms. Osman, and the needs of the client must be at the center of every effort. As the system evolves further, we must consider how to train and equip public health departments to bill third-party payers and how to exchange information captured in electronic medical records (EMRs). Through a pilot project on sexually transmitted disease (STD) testing and billing, Michigan found that many services were covered by insurers, so the State began working harder to expand its billing options.

Michigan has a transformation plan that includes training internal staff to support the transition to the ACA, empowering clients to ensure access to services under the ACA, and enhancing providers' capacity to continue and sustain services. For example, the State is working closely with AIDS service organizations (ASOs), which are trusted sources that can reach PLWHA. Ms. Osman stressed the importance of engaging in meaningful discussions at every step with all those involved in providing care and services and measuring success.

The State also is focused on restructuring its ADAP in the context of a rapidly changing health care environment, seeking technical assistance from HRSA for third-party billing, developing partnerships to establish a State-wide navigator program, and ensuring availability of culturally and linguistically appropriate and competent services. Ms. Osman stressed that the State will

continue to keep the lines of communication open, identify what works and how to maintain it, sustain funding, and expand capacity. Ultimately, we are facing a great opportunity to provide health insurance for all and improve health outcomes, she concluded.

## **Questions and Answers (Q&A)**

### ***What happens if States decide not to expand their Medicaid programs?***

Ms. Fukuda said the costs of caring for PLWHA are already being borne somewhere in the system. States that do not expand will continue to bear those costs elsewhere in their systems. States that do expand gain a real understanding of how PLWHA are served. For those that do not expand, Ryan White will not be enough, and the cascade of care will worsen. Ms. Fukuda worried that States that do not expand will see reversals in the progress made toward stemming the transmission of HIV.

Mr. Penner said States already vary widely in how they care for PLWHA. The ACA is an important opportunity for transformation, but disparities among States will persist. Ryan White and other health programs should be considering innovative approaches to adapt, such as buying insurance for those who cannot get coverage through Medicaid expansion. It is not possible to generalize across States; each State is unique. The HIV community, providers, and other stakeholders should be advocating for Medicaid expansion. Mr. Penner worried about PLWHA in States that do not expand their Medicaid programs.

Ms. Osman said that it would be a problem if Michigan chooses not to expand Medicaid. Her office had hoped that 60 percent of those currently receiving ADAP funds—about 1,700 people—would move to the expanded Medicaid program. If they are not insured by Medicaid, the State will have to find a way to insure them. Ms. Osman wondered whether the State also could afford to provide care for those who are not already accounted for in the health care system. Contingency plans are needed, she said. It is critical that Ryan White funds be available to fill in the gaps if Michigan does not expand its Medicaid program.

### ***Medical case management is crucial to PLWHA. What is the impact if medical case management is not covered by Medicaid expansion?***

Ms. Fukuda responded that there would be a considerable negative impact. The term “medical case management” generally refers to services provided by a qualified professional or a peer who understands how to navigate insurance and health care delivery systems. The health care system is never good at providing case management services broadly, Ms. Fukuda noted; the system works when it is directed at certain populations or conditions (e.g., pregnant women, children, and people with diabetes). She did not have faith that case management services would ever be sufficient under Medicaid, and additional funding is therefore critical. We cannot abandon PLWHA because we think others will take care of them, Ms. Fukuda concluded.

Ms. Osman said Oregon has a good model of care coordination that looks at what is manageable and what can be covered, what services medical case management provides, and how those services can be reimbursed. Mental health services are a core service funded by

Ryan White, and there are billing codes that enable others to offer and bill for such services. Ms. Osman suggested dissecting the components of medical case management and learning how to bill for more services.

Mr. Penner underscored the need to maintain Ryan White funding to fill gaps in care. Already, we can see a lot of the gaps, but we will know more once the ACA is fully in place, he said.

***How can we eliminate health care disparities in States that do not have the political will to expand their Medicaid programs, such as those southern States that have indicated they will not expand?***

Mr. Penner pointed out that disparities are embedded in existing Medicaid programs, especially in those States with more restrictive programs. The burden of disease is clearly evolving in the South, where long ADAP waiting lists and other markers indicate problems meeting the needs of PLWHA. The question highlights the need for flexibility within the RWCA so that resources can be moved to where they are most needed. These are difficult financial times for States and the Federal Government, Mr. Penner added. We should think about our options to improve health care in the future, when times are not so bad. There are people all over the country with health care needs, so we cannot focus on one region, but we do need to recognize that we must address disparities.

Flexibility is key, Dr. Fukuda agreed. The Centers for Disease Control and Prevention (CDC) has resources for prevention, and its 12 Cities Project recognized the importance of prioritizing investment in areas with the most need. We need Federal Government incentives that spur States to address disparities, she said.

Ms. Osman called for more investment in health equity. In addition to flexibility, we should think about a dedicated stream of funding, as well as different expectations and metrics to address health disparities. We need to build the infrastructure and capacity to provide health equity. We need to think differently and get State, local, and Federal partners working in that direction, said Ms. Osman.

***What is critical to ensure an adequate workforce to address the needs of PLWHA in the changing health care environment?***

Ms. Osman said multidisciplinary teams are critical. Community service providers who have been involved in helping PLWHA for years must be at the table, because they are vital to successful navigation and access. Providers should build relationships with community health centers (CHCs) around the medical model. Chronic disease management has been successful in navigating the system and creating certifications that enable billing for service. We need to take the same multidisciplinary team approach, Ms. Osman concluded.

Mr. Penner said educating organizations at the local level is important, especially those community-based organizations (CBOs) and ASOs that used to receive Ryan White funding and provided services within their own networks. The Ryan White program has served PLWHA well; the cascade is better for Ryan White clients when compared with the nation overall. But CBOs

and ASOs are struggling. Some work well with CHCs; others do not. CBOs and ASOs need to be prepared to understand billing and eligibility issues for their insured clients. The lack of education among Ryan White-funded ASOs and CBOs at the local level is a significant gap. We need to set up networks and improve communication, Mr. Penner said.

Ms. Fukuda said Massachusetts struggles with conflicts among CHCs, nonmedical ASOs, and hospitals. Her office set up a meeting among those stakeholders, who together recommended that the State require the medical and nonmedical ASOs to collaborate, because it was too hard for them to do so without some State enforcement mechanism. As a result, the State has a hybrid model of organizations working together and billing for services. Regarding workforce capacity, Ms. Fukuda was uncertain about staff capabilities. Medical and case management services are provided by separate entities, she said, but she was not sure how the entities could work together, let alone bill for their services.

***How did Massachusetts' health care reform affect the quality of HIV medical care?***

Ms. Fukuda said Massachusetts measures the quality of services for PLWHA through chart review (which has been ongoing for over a decade) by nurse practitioners in Ryan White-funded provider organizations. These services have reached high benchmarks of quality in areas such as the proportion of clients prescribed treatment. Massachusetts' clinical outcomes and process measures demonstrate high quality, and with reform, more people are using and benefitting from services. Ryan White support of the infrastructure was essential, said Ms. Fukuda. Ensuring that States have the tools and resources to monitor quality can be costly, and sometimes it is forgotten, she noted.

***How have CBOs adjusted to new ways of doing business, such as third-party billing?***

Mr. Penner said States are beginning to think differently about CBOs and ASOs, recognizing that they provide more than support groups and transportation. They also can provide the one-on-one guidance needed to help clients navigate the health care system. NASTAD is working with health departments so the departments can help their CBOs, and many city Ryan White programs are working with their local CBOs.

Ms. Fukuda pointed out that the New Orleans AIDS Task Force in Louisiana transformed into a medicalized model. No single approach will work for all areas. She encouraged States to set up demonstration projects to try new approaches and to move quickly. There will always be services that PLWHA need that are not reimbursed. At the moment, we should think about the short- and long-term investments needed and focus on the most urgent needs, Ms. Fukuda suggested.

Mr. Penner added that ASOs and CBOs not only need to adjust to new billing processes but also must adjust to being part of a network of service providers.

***What should community planning look like during the transformation period?***

Ms. Osman said community planning should prepare for a different approach. The best place to begin discussions about the ACA is within community planning groups. Those groups need

education and technical assistance to incorporate the ACA changes into planning related to HIV. It also is important to bring new and different stakeholders to the table. One approach will not work for all areas, and we need to look at different models, said Ms. Osman.

Mr. Penner expressed the hope that Federal, State, and local governments would take this opportunity to cooperate and streamline planning efforts. All plans should require meaningful community engagement (although not necessarily as prescriptive as in the past regarding issues such as parity, inclusion, and representation) and streamlined plans to ensure that all effort is not being expended on planning. Individuals and communities should be involved at each step of the cascade.

Ms. Fukuda said way too much planning is going on; she called it “ridiculous, wasteful, and dangerous,” because resources that should be going to caring for PLWHA are instead focused on planning, paperwork, and completing checkboxes. She called for more flexibility, pointing to the NHAS, which requires State plans but gives no guidance or template. Massachusetts took advantage of that extraordinary flexibility to conduct its own planning. States should do it their own way; they will then do it fast and well, Ms. Fukuda said.

***Is complete coverage of all services necessary to move PLWHA along the continuum of care? Should we prioritize specific interventions? If so, which are most important right now that insurance should cover?***

Mr. Penner said that linkage and retention are the most critical issues. Although we all agree that everyone with HIV should be able to get drug treatment that suppresses viral load, we have not reached that point yet, he said. Even with great improvements at each step in the cascade, we would not achieve full suppression—each step is important. Under the ACA, coverage for treatment and medication is critical, so ADAP funds are needed to fill the gaps and keep people in care.

Ms. Fukuda said Massachusetts has a 99 percent retention rate, yet only 72 percent of PLWHA achieve viral suppression. These findings demonstrate how hard it is to make progress.

Ms. Fukuda added that some States are looking at population-specific cascades (e.g., women with HIV and injecting drug users), which can help identify where to focus investments. Understanding subpopulations within a State is important, she concluded.

Ms. Osman said achieving health equity and eliminating disparities are critical issues. Interventions aiming at the social determinants of health and focused on linkage and retention are important, she said. Ms. Fukuda pointed out that social determinants of health should be considered long before an individual is diagnosed with HIV.

***How does Massachusetts maximize its funding sources, and how does the State use Part A, C, and D resources in the current environment?***

Ms. Fukuda responded that the Community Research Initiative of New England administers the State’s ADAP; monitors the programs; and collects data on client income, housing, health care costs, and other factors. The organization helps the State maximize its coverage (e.g., by

identifying clients who qualify for other programs). Also, in Massachusetts, most ADAP enrollees have health insurance, and the clients cover their own copays. In addition, the State benefits from pharmaceutical company rebates.

Regarding parts A, C, and D, Mr. Fukuda explained that, thanks to the State's early reform efforts, it realized it could redirect resources as needed. Part A and D programs jointly request funding, and the State can make award decisions at the same time, knowing that ADAP will cover the basic needs of PLWHA. Part A programs always have a waiver, so the State does not need to spend 75 percent on medications, because ADAP covers some of those costs. Part C programs are challenging, Ms. Fukuda said.

***Is there a breakdown of PLWHA eligible for insurance by State?***

Mr. Penner said NASTAD is collecting data and working on a specific breakdown to get a sense of how many eligible and ineligible PLWHA each State has.

***Can Ryan White funds pay for insurance premiums in the marketplace if the client's FPL is below the ADAP FPL?***

Ms. Fukuda and Mr. Penner said yes.

***What do we do if we build a new system to support PLWHA and they do not use it (e.g., because they have no experience navigating the health care system)?***

Mr. Penner emphasized the need to build a bridge to the health care system. Often, Ryan White and ADAP programs serve as navigators that help clients understand their options. That role is more complicated with the ACA (e.g., understanding eligibility requires tax forms). However, it is important that case managers in Ryan White programs understand that their roles will change dramatically under the ACA as they become navigators. Mr. Penner also noted that even those who already have insurance find it difficult to navigate the system.

Ms. Fukuda emphasized the importance of having a blended system of medical and nonmedical providers and case managers and investing in both sides of the equation. Together, these providers have considerable expertise with support and resources to educate, engage, and serve clients. The best approach depends on the population and its specific needs. States should identify and coordinate multidisciplinary teams, partnerships, and collaborations at various levels.

Ms. Osman said a coordinated approach works well. Conversations in communities are effective, especially for targeted populations. Michigan officials used the ACA as the basis for initial discussions and are now returning to the same communities to follow up. The State also is working to mobilize those communities. CDC and HRSA are doing a good job of developing information, but State and local entities must translate and disseminate that information into their communities. Conversations are needed to educate and empower stakeholders, and those conversations should not stop in 5 years when the ACA is fully implemented, said Ms. Osman.

***Is it possible that the connection between Ryan White programs and the 340B pharmacy program will dissolve?***

Mr. Penner noted that the 340B pharmacy program is part of the Veterans Health Care Act and addresses drug pricing. It is not related to the ACA. The 340B program enables ADAP programs to negotiate additional discounts and rebates on drugs, in addition to the discounts that other organizations already receive using the 340B program. The 340B program is under close scrutiny now; Congress is reviewing reports of hospitals using it inappropriately. Mr. Penner was not sure whether the program is in jeopardy, but he said it is important to have a system that enables public entities to purchase drugs at lower costs. It is not clear how the ACA and the 340B program will interact in the future, said Mr. Penner.

## **Federal Government Panel**

**Moderator: Robert Greenwald, J.D., PACHA Member**

### **Medicaid Expansion, Essential Health Benefits (EHBs), and Antidiscrimination Provisions**

*Cindy Mann, J.D., Deputy Administrator/Director, CMCS, CMS*

Together, Medicaid and CHIP cover about 60 million people. About half of all PLWHA are covered by Medicaid. In some States, 30 percent of Medicaid beneficiaries are PLWHA. Medicaid expansion would be a major advance for PLWHA, allowing individuals to qualify on the basis of income instead of meeting categorical requirements. Ms. Mann expressed surprise that some States are debating expansion, given that the Federal Government will cover 100 percent of the cost for the first 3 years. States can enact expansion—and reverse the expansion—at their own discretion. Ms. Mann pointed out that not all States took part in the original Medicaid program when it rolled out. Sometimes the consequences of a decision become clear over time, she said.

Expanded Medicaid programs are required to provide benchmark coverage subject to the 10 EHBs in statute. CMS issued proposed regulations on the EHBs for Medicaid and is finalizing regulations now. Some changes have been made to the EHBs to make them fit better into Medicaid plans. The proposed EHB regulations state that the full Medicaid prescription benefit will apply, and that is a point of contention, said Ms. Mann. Discriminatory benefit design is not permitted in any plans, she added.

Those seeking insurance will complete one application, and the health exchange system will determine eligibility for Medicaid, CHIP, or private plans. CMS and HRSA are working with community partners to ensure consistent coordination of coverage. CMS initiated a webinar series to provide more information and is eager to get input on how to engage communities and better disseminate information.

To provide better coverage and care and improve outcomes, the ACA offers tools, such as health homes to emphasize coordination of care, matching funds for coordinated care, and some efforts specifically targeting people with chronic illness and PLWHA. The ACA encourages integrated care models, which are based on the Ryan White model. Some States have received funding from CMS to transform their systems and to focus on people with chronic diseases and

PLWHA. The Center for Medicare and Medicaid Innovation provided grants to design and test models for multipayer integrated care systems. Ms. Mann concluded that CMS wants to demonstrate that it can incorporate the lessons learned from the past 20 years into future systems.

### **Marketplace Update, Patient Navigation, and Outreach**

*Gary Cohen, J.D., Deputy Administrator and Director, CCIIO, CMS*

Mr. Cohen said that HHS needs help from PACHA and other stakeholders to get the word out about the ACA and to identify what is working, what is not working, and how to improve programs. As Ms. Mann explained, there is “no wrong door” to coverage. Individuals will access the marketplace via a single stream. CCIIO hopes to simplify the process, but because financial information is involved, the process will not be that simple. Some people will be eligible for tax credits (or subsidies) or reduced cost-sharing. The Federal Government will pay tax credits to the insurance company, and the covered individual will pay the difference (with their annual income taxes). For cost-sharing, the insurance company will estimate the reduction, and the Federal Government will pay the insurer directly (again, with a reconciliation process at the end of the year for the client).

CCIIO is working on defining qualified health plans that can be offered in the exchanges. The ACA directed CCIIO to define EHBs on the basis of a current, typical small employer’s plan. CCIIO set up benchmarks, and States can choose which benchmarks to use to determine their EHBs. Consumers can choose among four tiers of plans, each with different levels of coverage, out-of-pocket expenses, and premiums. The qualified health plans are required to contract with essential community providers (ECPs) or provide a rationale for not doing so.

The application form for individuals will be available online. It relies on self-attestation of income but is linked to a Federal data hub that can verify information in real time using data from the Internal Revenue Service, the Social Security Administration, the Department of Homeland Security, and others. In the first year, open enrollment continues through March 2014.

HHS recently released a funding opportunity announcement for navigators—people and organizations that will provide education, outreach, and assistance with the application process. Beginning in June, a call center will be available 24/7 to help with applications. The Web site *HealthCare.gov* is increasingly consumer-focused and will provide more details about information needed to complete the application. When open enrollment starts, HealthCare.gov will have an online chat function to answer questions. There also will be a special enrollment option for people who become eligible after the open enrollment period closes (e.g., because they had a child or changed jobs).

## **Ryan White Program and the ACA**

*Laura W. Cheever, M.D., Sc.M., Acting Associate Administrator and Chief Medical Officer, HIV/AIDS Bureau, HRSA*

HRSA and CMS are working closely to ensure a smooth transition to the ACA for Ryan White clients. The Administration strongly supports the continuation of Ryan White services, said Dr. Cheever, and it is clear that Ryan White programs will continue to play a critical role in the cascade.

Dr. Cheever reiterated that authorization for RWCA ends in September 2013, but the program does not end. The decision to reauthorize relies on Congress. In the meantime, HRSA aims to maximize the flexibility of Ryan White to support the transition to new programs under the ACA.

HRSA is communicating with Ryan White grantees, developing policies, offering training, and developing technical assistance tools. The HIV/AIDS Bureau Web site is collecting questions via e-mail that will be answered online in a frequently-asked-questions format, which is helping the Bureau identify areas of concern. The Web site also provides information about the ACA for Ryan White providers. HRSA staff is meeting regularly with national stakeholders to discuss community concerns.

HRSA is reviewing existing policies, e.g., the use of Ryan White funding to help clients enroll in ACA programs. It is explaining the roles of ECPs and providing lists of ECPs. HRSA reissued its Medicaid eligibility policy to remind programs that Ryan White is the payer of last resort. HRSA also better articulated how Ryan White services wrap around Medicaid services. Additional guidance is under development.

HRSA and CMS are working closely on training project officers and grantees. The two entities are cohosting webinars to help grantees better understand the integration of Ryan White programs and the ACA. HRSA is developing tools to assist with outreach and enrollment, using funds from the Secretary's Minority AIDS Initiative.

Dr. Cheever said HRSA has learned much from States that are already moving ahead with health care reform. HRSA aims to build on the millions of dollars of Ryan White and Medicaid funding already invested in infrastructure. HRSA has mechanisms in place to evaluate the quality of care provided. To succeed in retaining PLWHA in care, we need to significantly expand the provider base, said Dr. Cheever, and the ACA can help build on existing programs.

## **Q&A**

### ***What are the key metrics that will affect 2015 and 2016?***

Mr. Cohen described metrics measuring how well programs are working (e.g., call center response times and application processing times) and the number and demographics of people enrolled. Ultimately, quality of care is the most important measure. Insurance is just a means to an end. We all recognize that reforming the health care system will take time, said Mr. Cohen.

Ms. Mann said the evolution of the systems is happening fast. CMS provided States with 90 percent matching funds to modernize their information technology (IT) systems, which allowed many States to streamline application processes. Those matching dollars are available until the end of 2015, at which time, Ms. Mann believes, States will have completed their upgrades, and matching funds will be available for maintaining IT systems. She emphasized that HHS needs strong feedback from all the stakeholders to identify priority areas for improvement.

***Under the proposed rule, Medicaid would provide expansive benefits, but can States restrict their Medicaid offerings?***

Ms. Mann said rules are still being finalized, but the current prescription drug benefit for Medicaid is broad and takes advantage of manufacturer rebates. Some States could still place limits on the number of drugs covered per month for a beneficiary. CMS does plan to review drug coverage, which has been optional and which is evaluated differently from other components of coverage. Drug coverage will not be optional in new plans. Some States place limits in the form of prior authorization. Ms. Mann expressed the hope that stakeholders would keep CMS informed about State policies of concern—as well as policies that work well.

***How confident are you that the electronic databases used to assess eligibility are reliable?***

Mr. Cohen acknowledged that problems may arise, but CCIIO is doing what it can to ensure that applicants can see health care providers and get prescriptions filled while they are in the process of switching insurance coverage (through a 90-day exception coverage policy).

***How would the adjustment for subsidized insurance work? Are the penalties for individuals too low?***

Mr. Cohen reiterated that the Federal Government will pay the insurance company directly, and the beneficiary will pay the remaining amount owed following a reconciliation process. If an individual's income increases and he or she is no longer eligible for the subsidy, a fine will be levied. Those who are unemployed or working part time should amend their information to avoid being fined. We will see whether the penalty for not purchasing insurance motivates people, said Mr. Cohen. One challenge will be reaching young, healthy people and encouraging them to join the insurance pool. In focus groups, even healthy people recognize the benefits of insurance coverage. People under 30 can choose high-deductible, catastrophic coverage plans that may be more affordable.

***Will States be attracted to the basic plans as a way to avoid reconciliation?***

Ms. Mann said the basic plan will be an option. More outreach is needed. Many people who are eligible may face significant barriers that prevent them from knowing they are eligible and from completing the enrollment process, Ms. Mann noted.

***How do we ensure retention?***

Dr. Cheever said California's efforts provide some insight. Work is underway to educate providers, and some Ryan White programs provide excellent case management. HRSA must

ensure that clients are aware of their options. Ryan White clients may select new providers, and HRSA wants to ensure a “warm handoff,” said Dr. Cheever.

***Clearly there will be workforce shortages. How can we make sure there are enough providers?***

Dr. Cheever said there is no clear definition of “providers.” We need people who can respond quickly to simple matters as well as service providers. The Office of HIV/AIDS Policy has refined its indicators and is looking at different models of care, said Dr. Cheever.

Ms. Mann said some Medicaid funding is available to address system design in an effort to provide better care. Incentives to provide-high quality care can help and can be established within Medicaid.

***What role will housing play? Is there a measure? How will CMS review housing?***

Ms. Mann acknowledged that housing is an enormous issue, and CMS is working on it with the Department of Housing and Urban Development (HUD). She noted that CMS pays for housing when a beneficiary is in a nursing home.

***Has there been any movement on PACHA’s recommendation to designate a coordinator for the integration of Ryan White programs within the ACA under CMS?***

Dr. Cheever said there are individuals in HRSA and CMS with technical experience who are working to engage people.

***How will Ryan White programs offer services to undocumented people? Will Ryan White programs serve people who are penalized for not buying insurance?***

Dr. Cheever said that Ryan White programs can continue to serve the undocumented and ineligible. HRSA is working on a policy to address those who opt not to buy insurance or cannot afford it. She reiterated that the Ryan White program is a payer of last resort.

***The current benchmark plans have limits and exclusions that affect PLWHA. Will there be additional guidance on identifying and eliminating discriminatory benefit design?***

Mr. Cohen said that plans are being submitted through the end of this month for the federally operated marketplaces. CCIIO is reviewing the plans and will ask insurers to revise and resubmit plans if problems are identified. Mr. Cohen then said that the public would probably not have an opportunity to review the proposed plans before they are fully processed by CCIIO. He urged stakeholders to contact CCIIO if they already know of potential problems with the existing benchmark plans. Mr. Cohen said he would further consider how much information about the submitted plans should be available before they are approved.

***How many new patients may enter care because of the ACA? Of the 30 percent of Ryan White clients currently uninsured, how many will actually receive coverage? What is the real impact of cost-shifting if only a portion of those are eligible for coverage?***

Steve Cha, M.D., chief medical officer for CMCS (speaking for Ms. Mann), responded 16 million roughly between the CCIIO and Medicaid, but the projections change annually. Mr. Cohen said

approximately 7 million new people would be insured in 2014. Dr. Cheever said HRSA has not projected how many PLWHA will be newly covered under the ACA. Eligibility varies by State, and CDC and Ryan White programs do not collect such data.

***People with chronic diseases tend to use infectious disease specialists as their primary care providers. How can we ensure that those people do not have to change providers and do not lose access to the expert care they have now?***

Dr. Cha said the issue is one of network adequacy, and there are challenges to CMS' ability to enforce adequacy. Medicaid is already a joint program, and the addition of managed care organizations means that there are three different views of what constitutes adequate care. CMS will host a webinar in May dealing with managed care plans. Medicaid mainly relies on managed care plans to determine which providers can offer primary care. Dr. Cha said the answer might not be in regulation. He said CMS is seeking best practices and would like to know what States have to do to respond to regulations. We are moving toward a system that holds all providers accountable for the quality of care of beneficiaries, said Dr. Cha. Instead of a regulatory model, we could use an outcomes model and create incentives to do better, he added.

***Numerous studies show that specialized, experienced care is best for PLWHA. Why create a new model instead of integrating what we know works?***

Dr. Cha said CMS wants to focus on areas that it knows work. Mr. Greenwald pointed out that the system does not work the same for HIV as for other conditions. Plans could engage in cherry-picking by limiting the number of specialists available, because such specialists might attract more PLWHA to a plan.

***While Alabama will not expand its Medicaid program in 2014, it does use Medicaid targeted case management. Will that program continue?***

Dr. Cha said the decision whether to expand Medicaid has no bearing on services that are part of a State's essential programs.

***How do we combat the homophobia and discrimination against PLWHA that persist in health care?***

Mr. Cohen said navigators are the best way to combat such problems. We need to rely on organizations already serving PLWHA who have built relationships of trust to reach out and help PLWHA navigate the system. We also expect that clinics, hospitals, and other places where people get care now will have staff at the point of care to help with enrollment, said Mr. Cohen. However, to be effective, we need a community-based effort, he added. HHS can promote the ACA through advertising and media, but those do not get to the hard-to-reach people.

***There will be a need for more providers as more people are insured. Federally qualified health centers (FQHCs) are geographically based now; could they expand to focus on special populations, such as PLWHA?***

Dr. Cheever said she was unsure how much flexibility the legislation supporting FQHCs offers, but she would take the question back to HRSA for further consideration.

***For States that rely on ADAP to pay for insurance premiums, what is HRSA doing to ensure that States get the best value from the plans, that clients select plans that work, and that premiums do not exceed ADAP funds?***

Dr. Cheever said those issues are under discussion now, and HRSA has already learned much from the Massachusetts model.

***There is pressure for Ryan White dollars to cover a lot, but funding has been flat (or declining, if inflation and caseload are considered). How will HRSA allocate Ryan White dollars in the face of competing demands?***

Dr. Cheever acknowledged that allocating funding is difficult at the broad national level. Most Ryan White funding uses formulas based on living cases of HIV, and there are already significant disparities. In the most recent reauthorization, HRSA was asked to look at allocation according to the severity of need. However, it is important not to create perverse incentives; that is, States that are doing more for PLWHA (successfully) should not get less money as a result, said Dr. Cheever. HRSA is assessing the situation, and funding will be discussed further with the next reauthorization, she said.

## **Community and Stakeholder Panel**

**Moderator: Michael Horberg, M.D., M.A.S., PACHA Member**

### **Perspective of the Center on Budget and Policy Priorities**

*Judy Solomon, J.D., Vice President for Health Policy, Center on Budget and Policy Priorities*

Ms. Solomon described the current coverage by Medicaid and CHIP on the basis of FPL, pointing out that the ACA intended for Medicaid in all States to cover all people who earn up to 133 percent of FPL. As a result of the Supreme Court decision allowing States to choose whether to expand their Medicaid programs, those with incomes between 133 percent and 400 percent of FPL will be able to purchase subsidized insurance through an exchange, but a gap remains for those below 133 percent of FPL in States that do not expand. In these States, low-income people may attempt to purchase insurance only to learn they do not make enough money to qualify for subsidies, nor do they qualify for Medicaid.

So far, 34 States have set up a health insurance exchange that is either federally operated or a State–Federal partnership. As with the current Medicaid program, every State is unique. States are at different levels of readiness in terms of systems. Federal funding for IT expansion was needed to help States upgrade to modern systems that can verify eligibility at the time of enrollment and provide data to support complex new rules. The connection between exchanges—especially federally operated exchanges and State Medicaid programs—is challenging and critical. Not all States will be ready by January 2014.

Navigators will not be enough to ensure successful enrollment and a smooth transition, said Ms. Solomon. The Federal funding to support navigators is insufficient, and navigators will need a considerable amount of education about State rules. Questions remain about State choices on benefit packages. Affordability of plans will vary, and cost-sharing may pose some barriers.

Assessing the adequacy of provider networks is an important consideration. Medicaid personnel in States that do not expand are worried that they will have to turn people away, despite the law that was supposed to provide health insurance access to everyone. Ms. Solomon said these concerns must be reiterated in the fight to get all States to expand.

Organizations like the Center on Budget and Policy Priorities are working to help with implementation but also keeping an eye on the long-term goal of fixing an imperfect law. Developing an early-warning system is critical to fixing legislation. More effort is needed to integrate Ryan White services with newly available Medicaid and private plans. All stakeholders should be engaged, and all levels of knowledge and expertise are needed. We should monitor programs and celebrate successes when we find them, Ms. Solomon concluded.

### **Commercial Health Plan Perspective: HIV**

*Andrew J. Baskin, M.D., National Medical Director, Aetna*

Dr. Baskin explained that private commercial plans determine coverage policies on the basis of medical necessity and the benefit to the plan's clients. Cost is not a factor in determining medical necessity, he emphasized. However, the interpretation of medical necessity can vary in the details, and cost-sharing varies as well. For example, in 2005, the U.S. Preventive Services Task Force (USPSTF) recommended screening those at high risk for HIV. In 2006, CDC recommended routine HIV screening. Shortly thereafter, the USPSTF reviewed the same evidence as CDC, yet reiterated its recommendation for screening those at high risk. Aetna adopted routine HIV screening as a policy, but the inconsistency between the two authoritative sources demonstrates the complexity of setting medical policy.

The ACA relies on the USPSTF recommendations to determine which preventive services should be covered by insurers. However, said Dr. Baskin, the USPSTF recommendations are evidence-based reviews of medical necessity. They are not written as coverage documents and lack the details needed by plans to establish policies, leaving room for interpretation. The inconsistency in coverage across plans leads to dissatisfaction among patients and health care providers, said Dr. Baskin. If USPSTF recommendations are to form the basis of coverage policies, he added, they should be more detailed, so that companies, providers, patients, and others are all on the same page. Coding for billing (e.g., for HIV screening) also varies and offers another target to improve consistency.

For PLWHA, as for those with other chronic conditions, Aetna invests in supportive programs to encourage consistent use of medications, such as a pharmacist outreach effort through the company's mail-order delivery (MOD) program for PLWHA. Pharmacists review patient records to identify potential drug interactions and to ensure that the correct medications are used. They also seek out the optimal drug regimen for the individual patient—but cost does not factor into that decision, Dr. Baskin insisted. The MOD program has been successful, with a high rate of engagement and a good opt-in rate among those selected for the case management component.

The inconsistency of regulations across the States poses a significant barrier to health information exchange, Dr. Baskin noted. Each State has its own laws about the confidentiality of personal health information, some specific to HIV. Some providers do not fully understand these laws and refuse to share information with insurance companies, even when it is legal to do so and would be helpful in caring for patients. Information exchange guidelines are another area for potential improvement, said Dr. Baskin.

### **Impact of the ACA on HIV Clinics**

*Michael S. Saag, M.D., Jim Straley Chair in AIDS Research; Director, Center for AIDS Research, University of Alabama at Birmingham*

Dr. Saag described the 1917 Outpatient, Research, and Dental Clinic in Birmingham, Alabama, which offers a variety of specialty and subspecialty medical care as well as social and support services. It also identifies clients eligible for clinical trials and enrolls them instantly. In-house navigators help clients find needed services. Alabama's Medicaid system is broken, said Dr. Saag, and the State fears that expanding it now would lead to a collapse.

At the request of the Office of Management and Budget, Dr. Saag and colleagues analyzed the cost structure of the 1917 Clinic. They calculated the expenses and revenues for 2,100 patients in 2012 as a basis for estimating how much Ryan White funding would be needed to fill the gaps once the ACA is implemented. Dr. Saag emphasized that the results are preliminary and have not yet been published. The analysis revealed that the clinic would run an annual deficit of about \$1 million. The clinic recently absorbed 800 new clients from another Part C Ryan White clinic and will receive that clinic's \$1.4 million in funding.

Dr. Saag championed the comprehensive care that clinics like his provide, saying he would love to receive his own primary care in such a system. However, his analysis of the 1917 Clinic's costs has several implications. First, the ACA will not be enough to sustain high-functioning medical homes under the current reimbursement. The fee-for-service arena is not taking advantage of primary care for its clients (because specialists and procedures are valued over primary care and prevention). Finally, PLWHA are fortunate to have Ryan White, and we could not face our current health care challenges without it. Dr. Saag offered the following recommendations:

- Wherever possible, let clinics provide medical care and medical case management.
- Allow CBOs and ASOs to partner with clinics to provide "community" case management; these organization should link clients to care and help facilitate retention.
- Make the whole Ryan White program patient-centered, not city- or region-centered, and direct all Ryan White funds to medical clinics, with capitation. The clinics would be responsible for contracting with CBOs and ASOs as appropriate and for ensuring accountability.
- Make Ryan White clinics the model for primary care.

## The Continuing Role of the Ryan White HIV/AIDS Program

*Jeffrey Crowley, M.P.H., Distinguished Scholar/Program Director, National HIV/AIDS Initiative, O'Neill Institute for National and Global Health Law, Georgetown Law*

Despite the challenges it poses, the ACA is an opportunity to improve HIV care and make it more stable, said Mr. Crowley. The RWCA is likely to remain critically necessary to the HIV response. The context for the RWCA is changing, which raises anxiety but should be viewed as an opportunity to improve. The program has never been static, but the new environment may require larger changes than Ryan White programs have been through in the past. We need a short-term strategy to support the transition for PLWHA and a long-term vision for integration of the RWCA and the ACA. Most importantly, said Mr. Crowley, we have more time than many think to make thoughtful decisions about the future and to work with policymakers to chart a new course over the next few years.

About 30 percent of Ryan White clients are uninsured. That means that even before the ACA is implemented, 70 percent have some form of insurance, but it does not meet all their needs. Under the ACA, the role of Ryan White will only intensify, said Mr. Crowley. In considering the future of the RWCA, Mr. Crowley identified four key questions.

- **How do we support PLWHA at every stage of the treatment cascade, from diagnosis to viral suppression?** Ryan White programs are not set up to focus on the cascade. How can we update the program to instill more accountability for improving specific measures along the cascade? How can we better integrate prevention and care?
- **How do we build HIV care networks in underserved communities?** We do not have the medical capacity to care for all PLWHA, even if all were insured. Building the infrastructure is critical. The RWCA has mechanisms for targeting resources, so we need to ask whether we are targeting the right populations, how we can integrate PLWHA in the solutions (e.g., as navigators), and what roles CBOs should play.
- **How do we integrate HIV care expertise into the mainstream health care system?** PLWHA make up less than 1 percent of the total U.S. population, so the broader system may not have much experience caring for them. How can we continue to support HIV providers so that their expertise is translated into the mainstream system? We must integrate medical care and support in smart ways so that all sides are working together to serve clients.
- **How do we fairly and effectively allocate resources?** We have already taken some steps, such as developing new funding formulas based on living HIV cases and changes to related HUD programs, but we still do not have equity. The RWCA has a variety of funding approaches, and they should be considered as a whole. Neither a system of all competitive funding nor one of all formula-based funding is completely fair.

Finally, Mr. Crowley said we are poised to make major progress for PLWHA. Clearly, the Administration supports continuation of the RWCA. The 2014 budget request recognizes that coverage under the ACA may not be adequate for PLWHA. Mr. Crowley concluded that the RWCA is likely to have a central role in moving us closer to ending the HIV epidemic.

## Q&A

### ***What challenges does the 1917 Clinic face in absorbing 800 new clients?***

Dr. Saag said his clinic immediately set up urgent/walk-in care teams to ensure that all of those clients had access to care and medications. It also held a series of intake sessions. All of the clinic's providers worked overtime to accommodate the new clients. The informatics team worked hard to integrate the new clients' records (from two EMR systems as well as paper records) into the clinic's recordkeeping system, even before providers saw the new clients. It takes a village, and thanks to the RWCA, the clinics have one, said Dr. Saag.

### ***How do the sequestration cuts and funding uncertainty affect infrastructure during the transition?***

Mr. Crowley said the budget cuts have a serious impact and have added pressure on an already strained system. NASTAD and others are working to get resources restored through administrative transfers. Mr. Crowley cautioned providers and others to avoid sending the message that care is not available. He added that there is no magic solution, and we will just have to weather this storm and hope we reach a place with more certainty.

### ***Who will make decisions about substituting generic medications for proprietary ones? Do other chronic diseases provide a model for maximizing efficiency while ensuring that high-quality medications are available?***

Dr. Baskin said that generic drugs are theoretically the same as their proprietary counterparts, so there is not a lot of pushback. Companies are not interested in pushing customers to use a generic drug that is different or less efficacious than the proprietary drugs they are already taking. When drugs are clearly equivalent, companies may require use of the generic product first. That scenario is probably a long way off for antiretroviral therapy (ART), said Dr. Baskin.

### ***Some fixed-dose drug combinations are commonly used. Is it likely that insurers will try to break those out in an effort to use more generics?***

Dr. Baskin replied that simpler medication regimens are so much better that there is no inclination to break down regimens to use more generic medications. As of now, there is no real value to such an approach in the long run.

Mr. Crowley added that generic substitution is not necessarily a bad thing. Most plans are not managing PLWHA aggressively, and there are good clinical guidelines in place for HIV treatment. The generics that are coming into the market now are not considered first-line drug regimens, said Mr. Crowley, so we should watch that they are not used as such. However, providers and plans will need to discuss dosing and medication specifics with new products.

### ***A distinction was made between nonmedical and medical care management. What does that distinction mean for Ryan White providers who are not working in FQHCs?***

Dr. Saag said that medical care provided by ASOs that have medical clinics and receive Ryan White funding is on target. Those that are not part of the medical delivery system find it hard to perform medical case management efficiently because of information confidentiality issues.

Dr. Saag said a different approach should be taken, such as partnerships that incorporate community-level management.

***How would you implement the radical suggestion of making clinics the sole capitated source of funding? There have always been charges that clinics overcharge the uninsured. Also, would you redistribute the 25 percent of Ryan White funds allocated for support services?***

Dr. Saag said that any institution that provides free care overcharges its privately insured clients. Ideally, the ACA would fix that problem, because all patients would have some form of insurance to pay for care. The current requirement to allot 25 percent of Ryan White to support services is anachronistic, said Dr. Saag. It should be possible to sort out what is covered by Medicare and cover the rest through Ryan White funding, he noted.

Dr. Baskin agreed that more transparency about the costs of care is needed. If everyone were a paying customer, there would be no cost-shifting, he said.

***What are the next steps for Ryan White, and where do clinics need to improve?***

Mr. Crowley suggested focusing on better integration between support and medical care providers, especially in the service of linkage and retention.

Ms. Solomon said the same conversation is occurring among providers of mental health and substance abuse services. At the State level, some believe that expanding Medicaid would allow the State to cut dollars elsewhere, which makes providers of mental health and substance abuse services nervous. Those providers are also underfunded, and the HIV community should be sensitive to their concerns, said Ms. Solomon.

Dr. Saag suggested that over the next 5 years, clinics should forge links with the community to fix the cascade. In Alabama, once in care, 75 percent of PLWHA achieve suppression, and that takes resources. Also, we should collect data uniformly and study outcomes. At present, we report but are not required to analyze our operations or assess the outcomes, said Dr. Saag.

Dr. Baskin added that fragmentation of the system is among the biggest problems, but there are some good models to improve quality through partnerships. There are opportunities not just to create more links to community resources but also to improve information exchange and connectivity with commercial and private insurers.

***What are other model Ryan White clinics like?***

Dr. Saag said the providers and staff at these clinics share a similar spirit—a desire to be there that you may not see in a primary care provider’s office. Ryan White clinics provide most of the services their clients need, sometimes on a shoestring. The 1917 Clinic has an academic health care system to fall back on, but other Ryan White clinics do not, Dr. Saag stated.

***Although the RWCA may continue for a while, it may face cuts, especially if the House does not support it. Do we need a clear, concise, consensus statement on the importance of the RWCA right now?***

Mr. Crowley reiterated that we need both short- and long-term plans. In the short term, we need to facilitate the transition and continue Ryan White programs. There is clear consensus in the community that it is too late for a legislative fix to the RWCA. There is broad, bipartisan support for continuing the RWCA and ADAP because they have been successful.

Bill McColl of AIDS United said his organization's Ryan White Working Group would like to work with PACHA on a formal statement supporting the RWCA.

***How can we use Ryan White and other funding to bring down the infection rates among those populations where rates are rising and bring those individuals into a system that works? The RWCA was created in part because of the stigma around the epidemic and some fear of returning to a system that has already failed PLWHA once.***

Mr. Crowley said that building the infrastructure for care is critical. Part D programs and the Minority AIDS Initiative are some mechanisms for reaching target populations. HIV rates are increasing among young gay men, and they are the least likely to transition into good, integrated care. Ryan White programs have the best chance of reaching hard-to-reach populations. We need to step back and look at all the gaps, said Mr. Crowley, and ask what we are building to serve those populations most in need. Ryan White programs focus on high-need populations, but we do not break down the data to identify high-need, high-cost populations. Maybe if we focused on a small subset of patients, we could bring down infection rates, Mr. Crowley said.

Ms. Fukuda added that Massachusetts focused on acuity, which then raised questions about other STDs and communicable diseases. HIV care is too expensive for primary care providers to offer, but there may be an opportunity to focus on specialty care for people with communicable diseases. Mr. Crowley cautioned that we have learned a lot from Ryan White programs that can be translated to people with hepatitis, but we should be careful about suggesting that Ryan White programs are not needed or could expand to include people with hepatitis. He suggested taking small steps to fund some integration of services across STDs and learning from them.

Dr. Saag disagreed with the notion that treating HIV is too expensive for primary care providers. We spend a lot on specialty care and relatively little on wellness, he said, and we rank low in every international health outcome measure. We need to invest in primary care and deemphasize fee-for-service specialty payment, Dr. Saag stated.

***Clearly, decisions about Medicaid expansion are not being made by States on the basis of data. What is effective, and what can the HIV community do to promote expansion?***

Ms. Solomon said use of data is expanding, and some Governors have changed their minds when they see, for example, the amount of money that other programs could save as a result of expansion. Focusing on subgroups, such as uninsured veterans, is an effective tactic. Massachusetts has data demonstrating the cost-effectiveness of treating PLWHA. Insuring women of childbearing age means they will have coverage before they become pregnant, which may improve birth outcomes. Policymakers in favor of expansion appreciate data, so draw on the examples that already exist, Ms. Solomon advised.

***If navigators are not the answer for outreach, what should we do?***

Ms. Solomon clarified that she believes navigators are important, but they can only do so much. Organizations that already have navigators will have to train them about, for example, how to transition people from Medicaid to private insurance and vice versa, the impact of changes on coverage, and other services available. Ms. Solomon questioned where navigators would get support for such extensive training. She suggested a huge effort to support enrollment similar to that of the CHIP program rollout in 1997. In addition, a tiered system of expertise is needed, in which front-line staff knows where to get answers. Such a tiered system lays the groundwork for an early-warning system. Ms. Solomon said navigators are just one part of an enormous system, so organizations should not think that hiring navigators is all they need to do.

**Public Comments**

**Jenny Collier** of the Ryan White Medical Providers Coalition (RWMPC) said the meeting format was helpful in framing the challenges ahead. The meeting only touched on the seriousness of fiscal challenges, however. We are at a critical juncture. Through the RWCA and other programs, we built an amazing infrastructure, and there are many concerns about continuation of Ryan White funding and possible threats to World AIDS Day funding as well. The RWMPC surveyed Ryan White programs last year, before sequestration became a reality, and more than half had already cut services and staff and frozen patient rolls. If Part C programs suffer the 10 percent cut that is being discussed, 66 percent of Ryan White programs will cut more services, and 13 percent more will freeze their patient load. Ms. Collier urged PACHA and others to keep their eyes on the prize: RWCA reauthorization, ACA implementation, and sufficient funding for critical services.

**David Martin** of the American Psychological Association (APA) said the HIV Costs and Services Utilization Study found that PLWHA had high rates of mental health and substance abuse issues, and those with such issues were more likely to experience problems with compliance and to engage in risky behaviors. Limited attention has been given to behavioral interventions in treating PLWHA. Current HIV treatment points to the need for integrated strategies that include behavioral, biomedical, and structural approaches to reduce HIV transmission and slow disease progression. Psychological and behavioral interventions can improve treatment uptake and medication adherence. The APA strongly endorses the value of integrated behavioral–biomedical interventions to reduce HIV transmission, improve the mental health of PLWHA, and reduce HIV-related disparities.

The APA supports four priority areas: 1) Ryan White program continuation alongside full implementation of the ACA, with integration of health care and mental health care for PLWHA; 2) combination HIV prevention that includes behavioral and psychological approaches and expansion of ART to promote uptake and maximize adherence; 3) planning and increased resources for PLWHA who are able to work and need assistance entering or reentering the workforce; and 4) greater inclusion of psychologists on Federal advisory boards such as PACHA to ensure that behavioral science and approaches are integrated into national HIV/AIDS policy.

**Sarah Audelo** of Advocates for Youth thanked PACHA for its support of the first national Youth HIV/AIDS Awareness Day on April 10. The day was an incredible success, with events across the country that reached many in an audience that is typically hard to reach. Ms. Audelo also thanked PACHA for the resolution on comprehensive sex education that it passed a year ago. However, there has been no discussion since then about the inclusion of the Heritage Keepers abstinence-only sex education curriculum on HHS' list of evidence-based interventions. There is no review process for curricula included on HHS' list, and no determination of whether included curricula deny the effectiveness of condoms, promote homophobia or transphobia, or use fear- or shame-based tactics. HHS recently called for additional curricula to add to the list, so it is possible that more programs like Heritage Keepers could be added. In 2015, the HHS Teen Pregnancy Prevention Initiative (TPPI) will send out a new funding opportunity announcement, and grantees will be able to select curricula from HHS' evidence-based list. As a result, the Heritage Keepers curriculum could be implemented using Federal dollars.

Ms. Audelo urged PACHA to make time at its next meeting to discuss why Heritage Keepers is included on HHS' list of evidence-based curricula and to propose some kind of content review of curricula that goes beyond outcomes data. She said that when the 2015 funding announcement for TPPI is released, it will be clear whether grantees are using the Heritage Keepers curriculum. Ms. Audelo noted that her organization still has not been able to obtain a copy of this curriculum, and HHS says it does not have a copy. Finally, Ms. Audelo requested that more young people be represented in future PACHA membership.

**Michael Smirlock** of Iris House, a center for women living with HIV in New York City, asked that PACHA and others not lose sight of the specific populations served. The best medical care is useless if no one uses it. The impact of HIV on women should be properly considered and addressed through funding. Women received very little attention in the NHAS. About 25 percent of those affected by HIV are women, and most are minority women. Helping women helps men, as 25 percent of all transmission occurs through heterosexual contact. Women are the loci of care for their families. Women face unique barriers to care, such as low socioeconomic status, intimate partner violence, and the competing needs of other family members. Most HIV-positive women are caregivers, and HIV makes it harder for them to fulfill their caregiving roles. They often put the needs of other family members before their own, which may be why it is so difficult to retain women in care or maintain viral suppression. Mr. Smirlock emphasized the importance of providing resources to women, including gender-specific programs and services such as case management, safe housing, and transportation access. HIV prevention should target both women and men. Not providing sufficient resources to address HIV in women is a catastrophe, Mr. Smirlock concluded.

**Nancy Bernstine** of the National AIDS Housing Coalition said her organization is encouraged that PACHA's Incidence Subcommittee is discussing the housing needs of PLWHA, as it is critical to move as quickly as possible to protect the most vulnerable populations. Housing is a proven intervention for PLWHA. Lack of housing is linked to inadequate HIV care, high viral load, poor health status, increased use of ED care, and early death. Unmet subsistence needs have as

great an effect as failure of ART adherence on overall mental and physical health. Homeless PLWHA are more likely to transmit HIV and more likely to have a detectable viral load. Housing assistance is a powerful, cost-effective way to improve outcomes. As Grant Colfax, M.D., director of the White House Office of National AIDS Policy, said at the February 2013 PACHA meeting, housing is HIV prevention. As we move forward with ACA implementation, the role of housing in health care should be increased to ensure that PLWHA fully benefit. The ACA should increase access to all kinds of care, but housing insecurity is a barrier to effective treatment. Ms. Bernstine said she is pleased that HHS and the Institute of Medicine both identified housing as a core indicator for monitoring HIV and health outcomes, but CMS does not collect data on housing status, nor do EMRs. Ms. Bernstine urged PACHA to pass a resolution acknowledging that housing is a cost-effective way to help end the HIV epidemic.

**Christine Campbell** of Housing Works also urged PACHA to pass a resolution on housing for PLWHA and people at risk as soon as possible. Housing is an effective treatment for HIV/AIDS that is positively associated with effective ART, viral suppression, lack of co-infection, reductions in avoidable ED care, and decreased early mortality. Housing is effective HIV prevention. Infection rates are as much as 16 times higher among those with unstable housing than those with stable housing. Daily survival needs make homeless people more vulnerable to HIV infection. There is solid evidence that housing saves health care costs. In the District of Columbia, the Housing Opportunities for Persons With AIDS program has a backlog of 1,000 applications. The lack of safe, stable housing impedes our ability to progress toward an AIDS-free generation. The best medical treatment is ineffective if patients are homeless or have unstable housing. Ms. Campbell said she hoped that PACHA would pass a resolution that housing-related support services should be part of evidence-based HIV prevention and treatment programs.

**Kenneth Pinkela**, a lieutenant colonel in the U.S. Army, said that he has HIV and was recently released from an Army prison, having served 272 days in prison for aggravated assault on the basis that he exposed someone to HIV. He thanked PACHA for passing the resolution against HIV criminalization at its February 2013 meeting. LTC Pinkela said that the Army was not concerned about what happened between him and his accuser, only that he was accused and he is HIV-positive. The court did not allow him to introduce critical physical and medical evidence in his defense. As a result, LTC Pinkela is a convicted felon and a registered sex offender. His 26 years of service and sacrifice are gone. He has no job, no retirement benefits, and no access to medical care for his combat injuries or other health needs, including HIV. His case is pending in the military appeals process, and he prays that this process will right the wrong. But the damage has been inflicted, and his reputation can never be corrected.

LTC Pinkela said the Uniform Code of Military Justice does not have an HIV-specific article or statute, but individual convening authorities and military prosecutors can and do use HIV as the reason to prosecute under other articles. He asked PACHA to join him in questioning whether prosecutions such as his reflect the will of Congress, the Commander in Chief, or the Nation. He further asked that PACHA use its bully pulpit and send its resolution to Secretary Sebelius and the Chairman of the Joint Chiefs of Staff, urging their immediate attention to this injustice

to those serving in the armed forces and to the Nation. He asked PACHA to urge President Obama to use an executive order to prohibit the use of HIV as justification for prosecution of men and women in the armed forces. In addition, PACHA should ask for review of all military prosecutions based on HIV status and consider executive clemency, pardons, or sentence reconsiderations. LTC Pinkela said he is committed to helping PACHA and Congress members like Representative Barbara Lee in the fight for meaningful legislation that will protect the nation and not discriminate against PLWHA.

**Carol Treston, R.N.**, of the Association of Nurses in AIDS Care noted that decriminalization of HIV and homosexuality is one of her organization's four policy priorities. She asked that PACHA appoint a highly qualified nurse to one of its open positions and said at least four such individuals have been nominated. Nurses in HIV/AIDS care have a deep recognition of the social determinants of HIV and are concerned not only with clinical advances and retaining patients in high-quality, accessible care but also with the intersection between human rights, HIV, poverty, and other structural factors driving the epidemic. Nurses witness the daily impact that public policies have on individuals living with and at risk for HIV infection. With the expansion of health care due to the ACA, the role of nurses in HIV care will grow, said Ms. Treston.

**Bridget Verrette** of the AIDS Institute thanked PACHA for focusing on ACA implementation but also requested immediate attention to continued funding for ADAPs and medical care provided by Part C clinics. In the past few years, ADAPs have been unable to keep up with demand that was fueled by a combination of increased HIV screening and a poor economic environment. At one point, the ADAP waiting list had more than 9,000 people. Thanks to emergency funds transferred by President Obama to support ADAPs and Part C programs and assistance from pharmaceutical companies, the waiting list was reduced to 50 people. However, in late March, Congress passed a continuing budget resolution that did not preserve the emergency funding. It is estimated that 8,000 ADAP clients will be affected by the cut. We know that PLWHA taking ART must continue their treatment without interruption or risk developing resistance to their medications, Ms. Verrette said. Without continuous treatment, patients are likely to have increased viral load and lower CD4 counts, causing progression of disease, reducing quality of life, and adding costs to the health care system. In addition, RWCA Part C clinics may be forced to reduce services, cut staff, and close enrollment to new patients without continued funding. In addition, sequestration would take an estimated \$45 million away from ADAP alone, leaving even more people at risk of losing services. Ms. Verrette asked that PACHA join the AIDS Institute and others in urging the President to transfer \$35 million to ADAP and \$10 million to Part C clinics to prevent the loss of services over the next several months.

## **Conclusion**

On the basis of today's discussion, said Ms. Mahon, she identified two key areas in which PACHA can make a difference. First, it should continue to inform people about the ACA and work to maximize enrollment among eligible individuals. Second, the feedback loop is a vital part of implementation, and PACHA should think through mechanisms to ensure consistent feedback.

Ms. Mahon thanked all the commenters and participants, especially Dr. Horberg, Mr. Greenwald, and Mr. Pérez for their work in organizing the panels. She thanked the participants for their patience, engagement, respectfulness, and thoughtful questions. Ms. Mahon applauded PACHA staff members Kaye Hayes and Caroline Talev for their concerted efforts.

Ms. Mahon noted that PACHA has received 200 nominations for its five or six open seats. The number of nominations is a testament to how interested and engaged the community is in moving forward with HIV policy.

### **Adjournment**

In closing, Ms. Mahon thanked the participants for all that they do every day to increase the quality and the length of the lives of PLWHA. She adjourned the meeting at 5:05 p.m.