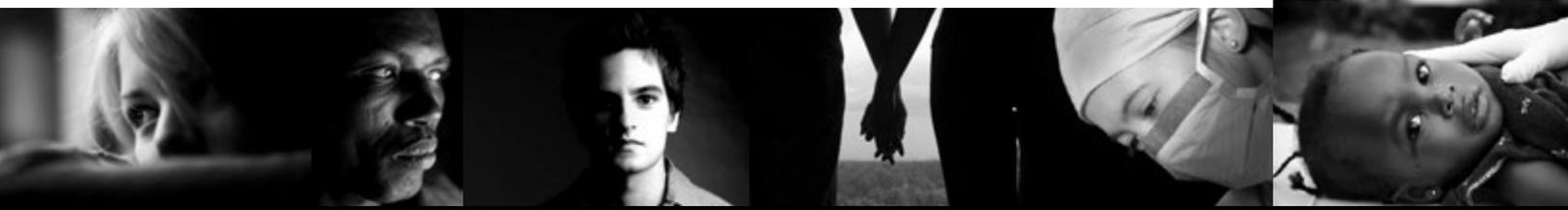


*Achieving An*  
**AIDS-FREE GENERATION**

*Presidential Advisory Council on HIV/AIDS*



RELEASED SEPTEMBER 2013 | NANCY MAHON, J.D., CHAIR





PACHA members convened a meeting during the XIX International AIDS Conference (AIDS 2012) in Washington, DC, July 25, 2012.

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# Achieving An AIDS-FREE GENERATION

## INTRODUCTION

*The Presidential Advisory Council on HIV/AIDS (PACHA) was established to provide advice, information, and recommendations to the Secretary of the U.S. Department of Health and Human Services (HHS) regarding programs and policies intended to improve the U.S. response to the HIV/AIDS epidemic—including the promotion of effective prevention of HIV disease and improved delivery of HIV care, treatment, and housing services—and to advance a progressive HIV/AIDS research agenda.*

On July 13, 2010, the White House released the National HIV/AIDS Strategy (NHAS or Strategy) and charged PACHA with two tasks: 1) establishing a mechanism to monitor progress toward achieving the NHAS goals, and 2) developing recommendations for ways to promote and normalize safe and voluntary disclosure of HIV status in various contexts and circumstances.

**Through this Strategy, an HIV/AIDS-specific vision for the United States was outlined for the first time:**

*“The United States will become a place where new HIV infections are rare and when they do occur, every person regardless of age, gender, race/ethnicity, sexual orientation, gender identity or socio-economic circumstance, will have unfettered access to high quality, life-extending care, free from stigma and discrimination.”*

In addition, the NHAS established three ambitious goals for the Nation to work toward by 2015:

- Reducing the number of people who become infected with HIV;
- Increasing access to care and improving health outcomes for people living with HIV; and
- Reducing HIV-related health disparities.

Over the last several years, PACHA has been working diligently on recommendations to help achieve the goals set forth in the Strategy. PACHA recommendations and resolutions adopted to date are highlighted in this progress report. Furthermore, this report outlines both NHAS progress and challenges identified thus far and, more importantly, outlines specific issues and areas that require further attention and action in the immediate term.

# BACKGROUND

PACHA has four standing subcommittees that reflect the main components of the NHAS:

- 1. Access to Care Subcommittee**—charged with developing recommendations to improve access to lifesaving care and treatment services for hundreds of thousands of Americans living with HIV
- 2. Incidence Subcommittee**—charged with advancing recommendations to reduce the number of new HIV infections domestically
- 3. Disparities Subcommittee**—charged with advancing recommendations to eliminate troubling HIV-related disparities
- 4. Global Subcommittee**—charged with advancing recommendations to improve the U.S. response to the international HIV epidemic.

PACHA established an additional subcommittee, Expanding Access to HIV Care, which held its first meeting in July 2012. This new subcommittee is charged with providing advice to and developing recommendations for HHS related to planning for changes in the categorical Ryan White HIV/AIDS Program (RWHAP) in light of the full implementation of the Patient Protection and Affordable Care Act (ACA).

Over the last 3 years, PACHA has deliberated on a broad cross section of programmatic, strategic, fiscal, policy, and legal issues affecting America's response to HIV/AIDS. Since June 2010, PACHA has passed several resolutions and has sent letters to the President and Secretary with recommendations for improving the Nation's domestic response to HIV. These documents include the following:

## Resolution Regarding Timely Access to Lifesaving Care and Treatment

PACHA passed a resolution at its June 2010 meeting requesting the President and Secretary to work



closely with Congress to provide adequate Federal emergency AIDS Drug Assistance Program (ADAP) funding in FY 2010 (\$126 million) to eliminate wait lists, reverse cost containment measures, and meet anticipated increased demand for lifesaving treatment. PACHA also requested adequate Federal RWHAP funding in FY 2011 and beyond to meet the growing demand for RWHAP-provided care, treatment, and essential support services. Additionally, PACHA requested that States be provided with the ability to immediately expand access to Medicaid for people living with HIV and AIDS through the enactment of the Early Treatment for HIV Act.

## Resolution on HIV Testing

On January 28, 2011, PACHA recommended that the U.S. Preventive Services Task Force (USPSTF) launch immediately a new review of its rating for routine population-based screening for adults and adolescents in clinical care settings. Further, PACHA recommended that HHS convene the Centers for Medicare and Medicaid Services (CMS), Health Resources and Services Administration (HRSA), and Centers for Disease Control and Prevention (CDC) to undertake a joint HIV testing initiative and a provider education campaign to ensure that providers understand the breadth of the already existing Grade A recommendation and to ease reimbursement difficulties for HIV testing among individuals at increased risk for

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HIV. The USPSTF issued a final recommendation in April 2013 in strong support of routine HIV testing for ALL adolescents and adults aged 15 to 65.

### Resolution in Support of Increased Funding Toward HIV/AIDS Prevention

On January 28, 2011, PACHA passed a resolution urging the Administration and Congress to achieve the following: (a) as rapidly as possible, fully fund the HIV prevention efforts in the United States at levels previously described as necessary in Congressional testimony and peer-reviewed publications so as to assure attainment of the goals of the National HIV/AIDS Strategy; (b) by June 2011 develop a system of annual reporting whereby all HIV prevention funding in the Federal Government is described in a publicly available document containing all funding amounts, uses, and measured or estimated outcomes; and (c) by July 2011 develop and implement a set of recommendations for any necessary redirection of current Federal HIV and other Federal prevention funding from its existing use to more impactful utilization in partnering with PACHA.

### Letters to the President and Secretary Regarding Successes Over the Prior Year and Challenges for the Upcoming Year

On August 8, 2011, PACHA sent letters to President Obama and HHS Secretary Kathleen Sebelius with recommendations for advancing implementation of the NHAS. In the letters, PACHA members described what they viewed as “some of the major successes over the prior year as well as the major challenges for the upcoming year which must be addressed to make NHAS goal achievement a reality.”

### Resolution Requesting Federal Activities To Eliminate HIV Health Disparities Among Black Men Who Have Sex With Men (MSM)

On September 30, 2011, PACHA requested that the Secretary convene a high-level summit (including Government and non-Government stakeholders) on the HIV epidemic and its impact on young Black men who have sex with men (YBMSM) and to create a Department-wide task force charged with developing a comprehensive plan to address all aspects of the epidemic among YBMSM.

Additionally, PACHA requested that the Secretary ensure the following: 1) that HIV prevention, care, and treatment funding distribution methodologies are aligned with the epidemic in ways that adequately support the needs of populations disproportionately affected by HIV, including YBMSM; and 2) that knowledge gained from studies of social determinants of health are integrated into all interventions that might help to reduce inequalities in health.

Further, PACHA called on the National Institutes of Health (NIH) to develop and issue a high-priority research plan by March 31, 2012, that addresses HIV among YBMSM, including evaluating the potential benefits of biomedical interventions (such as pre-exposure prophylaxis [PrEP] and treatment as prevention) and the use of novel technologies and other strategies to engage YBMSM in care and treatment and combination prevention strategies. *HHS hosted a Black Gay and Bisexual Men’s HIV/AIDS Summit on November 15–16, 2012, in Washington, DC.*

### Letter on Implementation of a Public Health Approach To Advance Sexual Health

On March 14, 2012, PACHA, along with the CDC/HRSA Advisory Committee on HIV, Viral Hepatitis, and STD Prevention and Treatment (CHAC), recommended that HHS’s Office of the Secretary, the CDC, and HRSA leadership support the development and implementation of a public health approach to advancing sexual health in the United States.

### Resolution on the Needs of Women Living With HIV

On May 17, 2012, PACHA approved a resolution addressing the needs of women at risk for and living with HIV. PACHA requested participation in the newly created White House Working Group on the Intersection of HIV/AIDS, Violence Against Women and Girls and Gender-Related Health Disparities. PACHA also recommended that the Secretary request all relevant Federal agencies, the new working group, and the Office of HIV/AIDS and Infectious Disease Policy (OHAIDP) to amend the Strategy and its implementation plan to include specific, targeted, and measureable goals for women and to achieve continued progress in that direction.

### Resolution To Support Comprehensive Sex Education for Youth

On May 17, 2012, PACHA approved a resolution to support comprehensive sex education for our Nation's youth. PACHA resolved that no Federal funds should be used for health education programs that withhold lifesaving information about HIV; are medically inaccurate or lack compelling empirical support; promote gender stereotypes; are insensitive and unresponsive to the needs of sexually active adolescents; are insensitive and unresponsive to the needs of lesbian, gay, bisexual, or transgender youth; or are inconsistent with the ethical imperatives of medicine and public health. PACHA also supports the expansion of adolescent sexual health efforts in the CDC's National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention and maintaining a strong programmatic and policy focus on adolescent school health.

### Letter on Federal Support for Syringe Services Programs

On May 17, 2012, PACHA sent a letter to President Obama supporting the fiscal year (FY) 2013 HHS budget language that would allow for the use of Federal funds to support syringe services programs. The language is consistent with PACHA's longstanding position on this issue and is further amplified by a statement by PACHA reiterating strong community



support for evidence-based efforts. The letter encouraged the Administration to prioritize restoring local flexibility in funding syringe services programs during negotiations around the FY 2013 appropriations bills and to clearly convey the priority to Congress.

### Resolution on Implementation of the Patient Protection and Affordable Care Act (ACA) in Ways That Meet the National HIV/AIDS Strategy (NHAS) Goals

On January 7, 2013, PACHA recommended that the implementation of the ACA be used in ways that promote the goals of the NHAS; limit geographic disparities with regard to access to insurance and scope of benefits; and ensure access to HIV/AIDS prevention, care, and treatment that meets the HIV standard of care. Also, PACHA recommended that Ryan White grantees and providers help develop plans for transitioning and adapting to the new health care financing environment, grow workforce capacity, and ensure that information is available to Ryan White grantees to support clients as they transition to health care coverage.

### Resolution on Ending Federal and State HIV-Specific Criminal Laws, Prosecutions, and Civil Commitments

On February 7, 2013, PACHA resolved that the U.S. Department of Justice should complete a written review regarding opportunities for the creation of specific guidance and incentives to State attorneys

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general and State departments of health for the elimination of HIV-specific criminal laws and for the development of recommendations for approaches to HIV within the civil and criminal justice systems that are consistent with the treatment of similar health and safety risks and that support legislation, such as the REPEAL HIV Discrimination Act, which advances these objectives. The resolution recommends that U.S. law should be consistent with current medical and scientific knowledge and accepted human rights-based approaches to disease control and prevention and should avoid imposition of unwarranted punishment based on health and disability status.

#### Resolution on the Needs of Male-Bodied American Indian/Alaska Native Individuals Living With or At Risk for HIV

On February 7, 2013, PACHA passed a resolution focusing on the needs of the two-spirit community. “Two-spirit” is the term used to describe lesbian, gay, bisexual, transgender, and third- and fourth-gender American Indian/Alaska Native individuals. One recommendation from this resolution is that HHS should provide current Native epidemiological, mental health, and behavioral health data and impanel Native research and epidemiological workgroups to augment information on community viral load and social determinants to the Native epidemic, with a focus on the male-bodied, two-spirit community.



#### Resolution on Effectively Addressing the HIV/AIDS Epidemic in Transgender Populations

On February 7, 2013, PACHA passed a resolution pertaining to the needs of the transgender community and the HIV/AIDS epidemic. PACHA recommended relevant HHS operating divisions should dedicate grant funds to projects that focus specifically on HIV prevention and treatment in transgender populations.

The resolutions and letters are included in Appendix B.

In addition, PACHA again partnered with the CHAC to sponsor a *Safe and Voluntary HIV Disclosure Summit*, June 28–29, 2012, to solicit public input and make recommendations for normalizing and promoting safe and voluntary disclosure of HIV status for individuals.

# INCREASING ACCESS TO CARE

Although increasing access to care is only one of the three NHAS goals, it is essential to meeting the HIV incidence and HIV disparity goals. Recent scientific evidence confirms that access to care and effective combination antiretroviral (ARV) treatment greatly reduce HIV transmission.<sup>1</sup> It is clear to PACHA that as a Nation we are not likely to meet the NHAS goal for reducing HIV incidence (lowering the annual number of new HIV infections by 25 percent) unless we meet the NHAS access to care benchmarks. Similarly, we are not likely to reach the NHAS goals for reducing HIV-related health disparities (increasing the proportion of gay and bisexual men, Blacks, and Latinos with undetectable viral load by 20 percent), unless we meet these associated access and incidence benchmarks. Improving access to critical HIV care is a cornerstone of the NHAS. Given its importance, the NHAS has set three main benchmarks for improving access to and retention in care by 2015:

1. Increase the proportion of newly diagnosed patients linked to clinical care within 3 months of their HIV diagnosis from 65 percent to 85 percent;
2. Increase the proportion of RWHAP clients who are in continuous care (at least two visits for routine HIV medical care in 12 months at least 3 months apart) from 73 percent to 80 percent; and
3. Increase the percentage of RWHAP clients with permanent housing from 82 percent to 86 percent.

As a Nation, we have made progress toward realizing the NHAS access to care goals. To name a few key accomplishments: Pre-Existing Condition Insurance Plans (PCIPs) created by the ACA are now available in every State to people living with HIV, including persons who have traditionally been excluded from the individual insurance market; HRSA has awarded

<sup>1</sup> Cohen MS, Chen YQ, McCauley M, et al. Prevention of HIV-1 infection with early antiretroviral therapy. *N Engl J Med*. 2011;365:493–505. doi: 10.1056/NEJMoal105243.



contracts to increase training of primary care physicians in HIV care; and, HHS has made significant progress in actively engaging Federal partners to critically review, and ultimately synergize, existing process and outcome indicators of HIV health care performance.

Achieving the NHAS access to care goals will require that all public, private, and civil society partners work together to fully realize the reforms made possible through the ACA. Specifically, fully realizing the NHAS access to care goals will require meeting three distinct, but interrelated, objectives: fully implementing ACA reforms; adequately maintaining the RWHAP to ensure access to critical nonclinical services; and eventually retooling the RWHAP to address outstanding gaps in coverage and affordability that will continue to exist after full implementation of the ACA.

## Maximizing the Impact of the Patient Protection and Affordable Care Act and Supporting Ryan White HIV/AIDS Program Reforms

To make significant progress in meeting the NHAS goals, the ACA must be implemented in ways that most successfully increase engagement and retention in HIV care as well as increase and manage ARV therapy, ultimately leading to viral suppression. The widely cited article by Gardner et al, *The Spectrum of Engagement in HIV Care and its Relevance to Test-and-Treat Strategies for Prevention of HIV Infection*,<sup>2</sup> established the original “care cascade” for the United States, demonstrating the shortcomings in keeping people living with HIV retained in care, on treatment, and virally suppressed. The CDC subsequently released an updated cascade (see Figure 1), which illustrates the limited progress we have made domestically in this area, and, more importantly, outlines the work that needs to be done to improve access to care and health outcomes for people living with HIV.<sup>3</sup>

It is estimated that 18 percent of persons living with HIV are unaware of their seropositive status. Thirty-four percent of persons living with HIV have not been linked to care, and 63 percent have not been retained in care. For people living with HIV, it is estimated that only 33 percent are on ARVs, and only 25 percent have achieved viral suppression. Put simply, achieving the NHAS access to care goals will require marked improvement in each one of these stages of health care engagement.

Both the ACA and the RWHAP offer excellent opportunities for improving access to care and health outcomes for people living with HIV and, if properly implemented, will play an important role in reaching our Nation’s



access to HIV care goals. The overwhelming majority of persons living with HIV in the United States will receive their care through the expansion efforts, subsidized private health insurance, and/or the RWHAP. The ACA eliminates Medicaid’s current system of categorical eligibility, which, in the context of HIV, generally requires a person to become fully disabled by AIDS before becoming eligible for Medicaid-based care. In its place, Medicaid eligibility will be granted to most individuals who meet a singular requirement: income of no more than 133 percent of the Federal poverty level (FPL). For those with incomes between 133 percent and 400 percent FPL, the ACA provides subsidized private health insurance. The ACA also provides for the development of an essential health benefits package—a set of 10 essential health services, including access to prescription drugs; mental health and substance use services; habilitative and rehabilitative care; maternity, childbirth, and pediatric care; and chronic disease management—which must be provided to all newly eligible Medicaid and subsidized private insurance beneficiaries and can be utilized to meet the standard of health care needed by people living with HIV. It is important to note, however, that neither the Medicaid expansion nor the provision of subsidized private health insurance will benefit everyone. Undocumented residents are barred both from Medicaid and from purchasing insurance through State Health Insurance Marketplaces (with or without subsidies). Residents with documented immigration status are barred from Medicaid for the first 5 years of their legal residence in

2 Gardner EM, McLees MP, Steiner JF, Del Rio C, Burman WJ. The spectrum of engagement in HIV care and its relevance to test-and-treat strategies for prevention of HIV infection. *Clin Infect Dis*. 2011;52(6):793-800.

3 Hall HI, Frazier EL, Rhodes P, Holtgrave DR, Furlow-Parmley C, Tang T, Mahle Gray K, Cohen SM, Mermin J, Skarbinski J. *JAMA Intern Med*. Published online June 17, 2013. doi:10.1001/jamainternmed.2013.6841.

the United States, but are eligible to receive subsidies to purchase insurance through State Marketplaces, regardless of how long they have been in the United States. The ACA also invests in strengthening and growing our primary care workforce. Among other initiatives, in the first allocation of funds in the new Prevention and Public Health fund, one-half of the funds (\$250 million) were used to boost the supply of primary care providers. The Act also increases Medicaid payments made to primary care providers for services during 2013 and 2014 to Medicare payment rates.

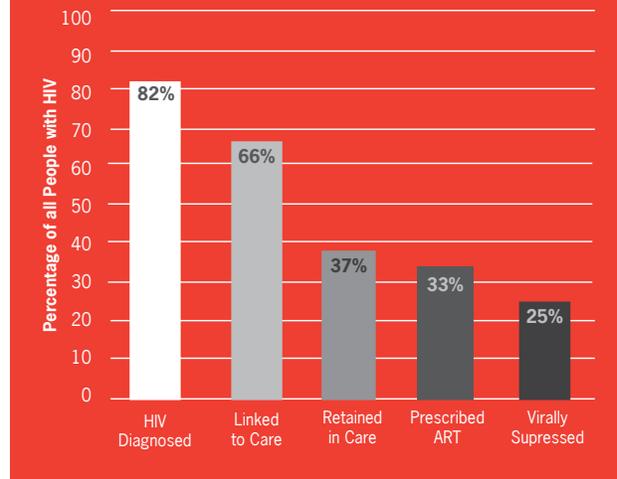
These and other ACA reforms are necessary components for meeting the health care needs of people living with HIV. Nonetheless, “the devil is in the details”—and only sound implementation of the reforms will guarantee success. To maximize the effectiveness of reforms, three key Federal strategies are recommended:

1. Create Federal standards to promote the NHAS and HIV standard of care goals by developing explicit regulations and guidance to States.<sup>4</sup> Additionally, implement appropriate oversight mechanisms to ensure successful enactment of the new Federal standards.

- ▶ Explicit guidance from HHS and the Centers for Medicare and Medicaid Services (CMS) to States will support proper Federal oversight of both the Medicaid expansion and Marketplace design and implementation, as well as the successful integration of people living with HIV, their providers, and models of care into health care reforms. A model health benefits package will ensure that essential health benefits provisions are implemented in ways that meet HIV care and treatment needs. There are three primary statutory requirements that together mandate that essential health benefits meet the HIV standard of care: (1) ACA

4 If properly implemented, these ACA provisions provide the opportunity to better integrate HIV, primary, sexual, and reproductive care in ways that meet the multiple needs of people living with HIV—needs too often poorly addressed by the existing fragmented systems of health care.

**Figure 1:  
The HIV Care Cascade in the United States, 2011**



Source: Hall HI, Frazier EL, Rhodes P, Holtgrave DR, Furlow-Parmley C, Tang T, Mahle Gray K, Cohen SM, Mermin J, Skarbinski. *J. JAMA Intern Med.* Published online June 17, 2013. doi:10.1001/jamainternmed.2013.6841.

Essential Health Benefits Mandates; (2) § 1937 Benchmark Mandates—for Medicaid only; and (3) ACA Anti-Discrimination Mandates.

2. Establish a high-level official at CMS charged with coordinating Federal and State Medicaid reform implementation.

- ▶ A high-level Federal HIV health care reform official will help to maximize the potential that States will implement both the Medicaid expansion and newly created private insurance Marketplaces in ways that best meet the care and treatment needs of people living with HIV. In addition, the official will help States understand and implement important optional programs, including the Medicaid Health Home Program that allows for enhanced and coordinated care and services for individuals living with a chronic health condition, including people living with HIV.

3. Maintain the RWHAP throughout the development and implementation of ACA reforms. Once successful integration of HIV care, treatment,

and service models is achieved, we recommend retooling the program to ensure it has the capacity to fill ongoing gaps in core health and support services and to address gaps in affordability.

- ▶ Providing high-quality, continuous health care to individuals living with HIV improves health outcomes and results in viral suppression, meeting significant individual and public health objectives. Achieving these objectives also requires explicit and ongoing Federal support of the RWHAP. Efforts to meet the retention in care and viral suppression goals of the HIV Care Cascade (see Figure 1; updated U.S. cascade by CDC as developed by Gardner et al.), as well to meet the NHAS goals, depend on the Federal Government’s support of a RWHAP that has the ability to address gaps in core health and support services (including, but not limited to, vision and dental care, transportation, case management, and housing services) as well as gaps in affordability (associated with insurance premium and copayment obligations).

### **Case Studies: Massachusetts and California**

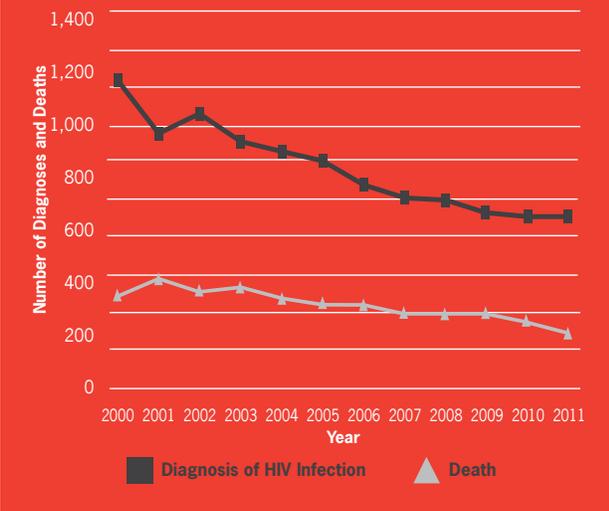
Massachusetts and California illustrate the importance of properly managing ACA reforms to ensure adequate health benefits for people living with HIV. Health care reform in Massachusetts provides a snapshot of a post-health care reform State in a pre-reform country—a State that has greatly improved HIV health outcomes and dramatically reduced HIV incidence, health disparities, and deaths. Conversely, California’s Medicaid §1115 waiver process demonstrates that when not adequately planned, health care reform can cause disruptions in HIV care and ultimately undermine the NHAS goals.

Massachusetts provides strong evidence that health care reforms and the RWHAP can work together to meet the NHAS goals—access to care and otherwise. In 2001, Massachusetts expanded Medicaid



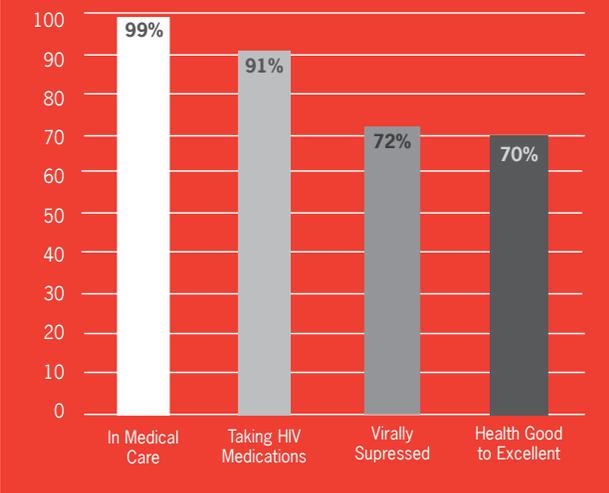
coverage to people living with HIV with incomes up to 200 percent FPL. Since its inception, coverage has included a robust benefits package and a broad exemption for HIV medications from utilization management. Massachusetts also subsidized private insurance for those with incomes between 200 percent and 300 percent FPL. These health care reforms are similar to the ACA’s Medicaid expansion and subsidized private insurance program. Massachusetts reforms have been coordinated with a retooled RWHAP to address coverage gaps in vital health and support services and gaps in insurance affordability. Ultimately, Massachusetts health care reforms have translated

**Figure 2:  
Trends in HIV Infection and Death  
Among People Reported with HIV/AIDS  
by Year: Massachusetts, 2000–2011**



Data source: Massachusetts Department of Public Health HIV/AIDS Surveillance Program; data as of January 1, 2013.

**Figure 3:  
Massachusetts Consumer Survey  
Experience of Medical Care**



Source: Massachusetts and Southern New Hampshire HIV/AIDS Consumer Study Final Report, December 2011. JSI Research and Training, Inc.

into dramatically improved individual and public health outcomes—successes that can be replicated in Federal ACA reforms if properly implemented.<sup>5</sup>

Massachusetts has experienced significant decreases in both HIV diagnoses and deaths among HIV-positive individuals. From 2000 to 2011, the number of HIV infection diagnoses decreased 44 percent, and deaths declined 41 percent (see Figure 2).<sup>6</sup> Of note is that new HIV diagnoses decreased equivalently across all races and ethnicities. In contrast, nationally, both new HIV diagnoses and deaths among persons with HIV have remained stable.<sup>7</sup> In addition to the individual and public health benefits of reducing the number of HIV diagnoses, averting new infections saves money. The Massachusetts Department of Public Health estimates that more than 5,500 HIV infections have been averted over the past decade, saving \$2.1 billion in health care costs.<sup>8</sup>

5 Massachusetts is but one of several States that have developed health care reforms well before the ACA. Through pre-ACA reforms, these States have maximized the use of both Federal and State resources to effectively address the complex care, treatment, and service needs of people living with HIV. Many of these State initiatives provide strong “lessons learned” and insights as to how to develop excellent systems of care for people living with HIV under the ACA. States must now move forward quickly in implementing the ACA, and, in doing so, they should consider the range of highly effective implementation strategies that have proven to work. Although there are national statutory standards that must be met, States also have the flexibility to build upon their existing health systems, as well as adapt proven effective strategies from other States, to meet the needs of their residents who are living with HIV.

6 Figure 2 used courtesy of H. Dawn Fukuda. *HIV/AIDS in Massachusetts: Challenges and Opportunities to Enhance the Public Health Response*. [PowerPoint slides]; Fenway Community Health Center, May 14, 2013. See also Massachusetts Department of Public Health, Office of HIV/AIDS, Massachusetts HIV/AIDS Data Fact Sheet: *The Massachusetts HIV/AIDS Epidemic at a Glance*, April 2013.

7 Centers for Disease Control and Prevention. HIV Surveillance Report, 2011; vol. 23. <http://www.cdc.gov/hiv/topics/surveillance/resources/reports/>. Published February 2013. Accessed August 18, 2013.

8 H. Dawn Fukuda, *HIV/AIDS in Massachusetts: Challenges and Opportunities to Enhance the Public Health Response* [PowerPoint slides]; Fenway Community Health Center, May 14, 2013.

Among people living with HIV in Massachusetts, the overwhelming majority have access to and are engaged in care and treatment. A recent survey of more than 1,000 people living with HIV reported 99 percent in medical care, 91 percent taking HIV medications, and 72 percent to be virally suppressed. Seventy percent of survey respondents rated their health as “good to excellent” (see Figure 3).<sup>9</sup> Similarly, an extensive 2010–2011 review of charts from medical management sites found 93 percent of people to be in care (using the HRSA definition of two or more medical visits at least 3 months apart) and 98 percent on antiretroviral treatment. Viral suppression rates ranged from 76 percent to 84 percent.<sup>10</sup> The survey and chart review results, along with the drop in HIV diagnoses and deaths, illustrate the powerful impact well-implemented health care reforms can have on improving access to care and health outcomes for people living with HIV in Massachusetts.

California, by contrast, illustrates how poorly implemented reforms can impede progress in improving access to care for people living with HIV. California’s §1115 waiver process failed to adequately account for people living with HIV who became newly eligible for Medicaid through the waiver. Federal and State government officials failed to develop an implementation plan to successfully integrate people living with HIV, their health and social service providers, and HIV models of care delivery into the reform effort; they also failed to coordinate reforms with the RWHAP. This lack of adequate planning and oversight of the California waiver process had a devastating impact on many people living with HIV, particularly the most vulnerable and disabled. Many people living with



HIV were unaware of changes to their health care providers and eligibility status and consequently fell through the cracks. Providers struggled to patch together care, treatment, and support plans to address the complex health care needs of these individuals. Finally, many people living with HIV and their health and social service providers continue to expend limited resources to resolve issues that should have been addressed early in the health care reform planning process.

### Access to Care Conclusion

We have made important progress reaching the NHAS access to care and retention in care goals, but continued Federal action and oversight are needed to ensure that health care reforms provide adequate access to high-quality, comprehensive health care for people living with HIV. As demonstrated in Massachusetts, the impact that thoughtfully implemented ACA health care reforms and utilization of the RWHAP can have on health outcomes for people living with HIV is considerable. Conversely, poorly implemented ACA health care reforms and inadequate integration with the RWHAP can have a potentially devastating negative impact on people living with HIV. The recommendations in this report, in tandem with the continued development of a set of standardized metrics—including behavioral metrics—by which the HIV epidemic can be thoroughly monitored, will help ensure that we meet the NHAS access to care, prevention, and health disparity goals for people living with HIV.

9 JSI Research and Training Inc. *Massachusetts and Southern New Hampshire HIV/AIDS Consumer Study* Final Report, December 2011 (Massachusetts outcomes N=1,004).

10 H. Dawn Fukuda, *HIV/AIDS in Massachusetts: Challenges and Opportunities to Enhance the Public Health Response* [PowerPoint slides]; Fenway Community Health Center, May 14, 2013. The viral suppression rate for people with two or more medical visits more than 60 days apart was 76 percent; for people with one or more medical visits, it was 84 percent. Higher viral suppression in the one-visit cohort may indicate that people were adhering to treatment regimens, feeling well, and not seeing the need to go for a medical visit.

# REDUCING HIV INCIDENCE

## Prevention Goals

The NHAS set out three major HIV prevention goals in July 2010: (a) to reduce HIV incidence by 25 percent by 2015; (b) to reduce the HIV transmission rate by 30 percent by the same year; and (c) to increase the percentage of persons living with HIV who are aware they are living with the virus to 90 percent in the same timeframe.

## Baseline and Current Measures

As of now, there is not a complete set of measures of HIV incidence, prevalence, transmission rate, and awareness of seropositivity for the baseline year 2010 or any more recent year (though an estimate of incidence alone is now available for 2010). Therefore, progress on the three main goals cannot yet be directly measured. For 2009, the CDC estimated HIV incidence to be 48,100 (42,200 to 54,000; 95 percent CI), HIV prevalence to be 1,148,200 (1,117,800 to 1,178,500; 95 percent CI), HIV transmission rate from 100 persons living with HIV to seronegative partners in a given year to be 4.19, and awareness of HIV seropositivity to be 81.9 percent. Of the roughly 207,600 persons living with HIV but not yet diagnosed in the United States (as of 2009), there are clear disparities with the lowest rates of seropositivity awareness among young persons, racial and ethnic minority communities, MSM, and heterosexual women and men.<sup>11</sup>

Over the next year, we believe that the following HIV prevention issues need special attention by the Administration, Congress, public health officials, and the private sector.

## Maximize Accountability and Effectiveness by Overhauling HIV-Related Performance Metrics

HHS, the White House Office of National AIDS Policy (ONAP), and other partners (in conjunction with PACHA) have worked to develop a streamlined, practical, and prioritized set of HIV measures and reporting requirements. We applaud the near finalization of this process and encourage implementation in the field as soon as possible. Identifying a smaller number of strategically chosen metrics to be collected across agencies is critical to help the Nation focus on central outcomes and impacts; set the stage for cross-agency and intra-agency reallocation of resources to achieve optimal HIV care and prevention impact; alleviate current burdensome and uninformative reporting requirements on grantees; and allow for identification of specific ways in which HIV programs can be strategically coordinated with sexually transmitted infections services, hepatitis programs, and substance abuse treatment interventions. We note that HHS and ONAP chose to develop this set of metrics before devising a clear strategy to reduce the overwhelming number of existing measures currently required of health department HIV prevention grantees; this strategy for reducing the overlapping and less relevant measures should be urgently developed as well (and, notably, this work has now begun). Also, unlike global HIV prevention evaluation efforts, HHS and ONAP have chosen to exclude any behavioral measures in their core set of indicators due to concerns about data quality and representativeness. This is remarkably dissimilar to international HIV monitoring efforts and seems to compromise the ability to manage HIV prevention programs if there are no measures of the modes of viral transmission. We urge attention be given to at least one behavioral measure in the upcoming year.

<sup>11</sup> Centers for Disease Control and Prevention. HIV Surveillance Report, Supplemental Report, Vol. 17, No. 3, Part A: Monitoring Selected National HIV Prevention and Care Objectives by Using HIV Surveillance Data—United States and 6 U.S. Dependent Areas—2010. Published June 2012.

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## **Refine Evidence-Based Prevention Programs**

Scientific findings released in 2011 have provided further evidence that HIV treatment not only plays a major role in improved health outcomes but also is crucial in preventing the forward transmission of HIV. To maximize the full potential of these findings, we urge HHS to immediately convene and sponsor a landmark “state of the science” conference, which would include researchers, advocates, and people living with HIV, to examine and recommend interventions for facilitating the aggressive movement across the care continuum of persons living with HIV.

Further, in the selection of HIV prevention services to be funded, we encourage the explicit consideration of HIV prevention programs that combine the best behavioral and biomedical interventions available into a synergistic, client-centered, impactful, and cost-effective service delivery bundle. Unfortunately, “combination prevention” is sometimes giving way to “substitution prevention” in which only behavioral or biomedical services are considered; truly both are necessary and are indeed mutually reinforcing.

## **Invest in and Target Prevention as a Cost-Saving Public Health Strategy**

To truly bend the HIV cost curve, we must dramatically bend the HIV incidence curve, and this requires an increased investment in prevention funding. In addition, funding allocations must be aligned with both the current distribution of HIV and emerging HIV epicenters (such as the Southeastern United States). We also must address the infrastructure needs of “communities” hardest hit by the epidemic, especially Black gay men, Latinos, people living in the Southeast, women of color, and transgender persons.

The peer-reviewed literature contains a very recent estimate of the cost of achieving the goals of the NHAS by 2015. It demonstrates via careful mathematical modeling that without a very substantial and rapid scale-up of, at a minimum, HIV care and treatment,

housing, testing, and prevention services for persons living with HIV, the goals of the NHAS would appear impossible to meet by 2015. We urge that sufficient new, redirected, and/or private-sector funds be identified to cover a substantial portion of these services to ensure that the 2015 goals are met successfully.

## **Avoid Backsliding on the Administration's Key HIV Prevention Policy Victories**

As a signal to its commitment to science and to achieving the NHAS prevention goals, it is crucial that the Administration uphold all evidence-based policies, including making ongoing, clear, public statements (especially to Congress) in full support of Federal funding for syringe exchange, and investment in comprehensive sexual education (rather than abstinence-only education that is not science-based).

## **Evaluate CDC Geographic Reallocation of HIV Prevention Resources**

Recently, the CDC reallocated a large amount of its HIV prevention funding to State, local, and territorial health departments ostensibly to better track the epidemic. This resulted in very large losses of funding to some jurisdictions and very large gains in funding to others. To date, we know of no comprehensive evaluation of the impact this reallocation has had. Some jurisdictions that lost funds have made clear in the media that a number of their key HIV prevention services are being shut down, but few reports have been made about what is being done with the new funding in jurisdictions receiving additional resources. Further, no national mathematical modeling has been published demonstrating whether or how this reallocation will lead to achievement of the goals of the NHAS. These statements are not intended to be critical, but rather to point out that without any empirical evaluation, we cannot know if this movement of funding made an improvement in the response to the epidemic, and, if so, to what extent.

# REDUCING HIV-RELATED DISPARITIES

The NHAS recognizes that communities are not equally affected by HIV disease. Traditionally underserved and historically marginalized communities (including racial, ethnic, and sexual orientation minorities) bear a disproportionate share of the U.S. HIV epidemic. Although these communities have diverse prevention and care needs, they are alike in experiencing higher rates of HIV incidence and prevalence, poorer health outcomes, and higher mortality than their White or heterosexual counterparts.

The disparities that exist among Black, Latino, and/or gay and bisexual men are significant. In 2010, Black men accounted for 70 percent (14,700) of the estimated 20,900 new HIV infections among all adult and adolescent Blacks. The estimated rate of new HIV infection for Black men (103.6/100,000 population) was seven times as high as that of White men, twice as high as that of Latino men, and nearly three times as high as among Black women.<sup>12</sup> Disparities persist in the estimated rate of new HIV infections in Hispanics/Latinos. In 2010, the rate of new HIV infections for Latino males was 2.9 times that for White males, and the rate of new infections for Latinas was 4.2 times that for White females.<sup>13</sup>

HIV is a serious public health issue among American Indians/Alaska Natives (AI/AN), who make up about 1.2 percent of the U.S. population. AI/AN men accounted for 76 percent (161) and AI/AN women accounted for 24 percent (51) of the estimated 212 AI/AN diagnosed with HIV in 2011. In addition, 75 percent (120) of the estimated 161 HIV diagnoses among AI/AN men in 2011 were attributed to male-to-male sexual contact. Sixty-three percent (32) of the estimated 51 HIV infections among AI/AN women were attributed to heterosexual sex. In 2011, an estimated



146 AI/AN were diagnosed with AIDS, a number that has remained relatively stable since 2008.<sup>14</sup>

Disparities also are present among the AI/AN population. In 2011, the rate of newly diagnosed HIV infections among AI/AN was 9.3 per 100,000 population in all 50 States and the District of Columbia. The newly diagnosed AIDS case rate for AI/AN was 6.4 per 100,000 population (greater than Whites and Asian/Pacific Islanders). The AIDS mortality rate in 2010 was 3.0 per 100,000 population. However, based on data published in 2011, the proportion of persons surviving 36 months after AIDS diagnosis for AI/AN is lower (0.88) compared with Whites (0.92), Blacks (0.90), Hispanics (0.92), and Asian/Pacific Islanders (0.94).<sup>15</sup>

Overall, approximately 20 percent of HIV-infected Americans do not know they are infected, while among AI/AN this figure is 26 percent. AI/AN diagnosed with HIV infection or AIDS have one of the shortest survival times of all ethnic or racial groups, suggesting that they may be diagnosed late in the course of their

12 Centers for Disease Control and Prevention. Fact Sheet, HIV Among African Americans. Available at <http://www.cdc.gov/hiv/risk/raciaethnic/aa/facts/index.html>.

13 Centers for Disease Control and Prevention. HIV in the United States: At a Glance. Available at <http://www.cdc.gov/hiv/statistics/basics/ataglance.html>.

14 Centers for Disease Control and Prevention. HIV Surveillance Report, 2011; vol. 23. Published February 2013. Retrieved on June 25, 2013 from <http://www.cdc.gov/hiv/library/reports/surveillance/index.html>.

15 Centers for Disease Control and Prevention. HIV Surveillance Report, 2011; vol. 23. <http://www.cdc.gov/hiv/topics/surveillance/resources/reports/>. Published February 2013. Accessed August 18, 2013.



infection or have limited access to care.<sup>16, 17</sup>

Among sexual minorities, gay and bisexual men are 55 to 75 times more likely to be diagnosed with HIV than are heterosexual men and 52 to 65 times more likely to become infected than are all women.<sup>18</sup> In addition, data show that HIV-positive women who have experienced trauma within the last 30 days are four times more likely to fail treatment<sup>19</sup>, and national samples of American women demonstrate that women living with HIV are twice as likely to have been the victim of intimate partner violence.<sup>20</sup>

Along with disparities in infection rates, Blacks, Latinos, and gay and bisexual men also experience higher rates of HIV-related mortality, despite overall

national decreases due to improved access to care and treatment. Compared with Whites, Black and Latino women, men, and gay and bisexual men are more likely to die earlier from AIDS.<sup>21</sup>

The NHAS proposed the following steps, with accompanying recommended actions, to help reduce HIV-related health inequities and health disparities among Blacks, Latinos, and gay and bisexual men:

1. Reduce HIV-related mortality in communities at high risk for HIV infection;
2. Adopt community-level approaches to reduce HIV infection in high-risk communities; and
3. Reduce stigma and discrimination against people living with HIV.

The NHAS anticipated that the results of its proposed efforts to reduce health disparities would be to increase the proportion of HIV-diagnosed Blacks, Latinos, and gay and bisexual men with undetectable viral loads by 20 percent by 2015. Although the NHAS proposed specific actions to reduce HIV-related health disparities, this remains an uphill battle, with health and health care inequities persisting across the HIV prevention and care continuum. For example, the CDC promotes the use of more than 60 HIV behavioral interventions for communities at disproportionate risk for HIV infection through its Diffusion of Effective Behavioral Interventions (DEBI) project. These programs aim to decrease rates of unprotected sex and encourage regular HIV testing, build positive social connections, and improve communication skills. However, despite the availability of effective prevention programs, disparities still exist among racial, ethnic, and sexual orientation minority populations.<sup>22</sup>

In order to increase the proportion of Black, Latino, and gay and bisexual HIV-positive individuals with

16 Centers for Disease Control and Prevention. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 U.S. dependent areas—2010. HIV Surveillance Supplemental Report 2012;17 (No. 3, part A). [http://www.cdc.gov/hiv/library/reports/surveillance/2010/surveillance\\_Report\\_vol\\_17\\_no\\_3.html](http://www.cdc.gov/hiv/library/reports/surveillance/2010/surveillance_Report_vol_17_no_3.html). Accessed April 2, 2013.

17 Centers for Disease Control and Prevention. HIV Surveillance Report, 2010; vol. 22. Published March 2012. Retrieved on August 31, 2012 from <http://www.cdc.gov/hiv/surveillance/resources/reports/2010report/index.htm>. <http://www.cdc.gov/Features/NativeHIVAIDS/>.

18 Purcell DW, Johnson CH, Lansky A, Prejean J, Stein R, Denning P, Gaul Z, Weinstock H, Su J, Crepaz N. Estimating the population size of men who have sex with men in the United States to obtain HIV and syphilis rates. *Open AIDS*. 2012; 6 (Suppl 1: M4): 98-107.

19 Machtinger EL, Haberer JE, Wilson TC, Weiss DS. Recent trauma is associated with antiretroviral failure and HIV transmission risk behavior among HIV-positive women and female-identified transgenders. *AIDS Behav*. 2012 Nov;16(8):2160-70. doi: 10.1007/s10461-012-0158-5.

20 Machtinger EL, Wilson TC, Haberer JE, Weiss DS. Psychological trauma and PTSD in HIV-positive women: a meta-analysis. *AIDS Behav*. 2012 Nov;16(8):2091-100. doi: 10.1007/s10461-011-0127-4.

21 Losina E, Schackman BR, Sadownik SN, et al. Racial and sex disparities in life expectancy losses among HIV-infected persons in the United States: impact of risk behavior, late initiation, and early discontinuation of antiretroviral therapy. *Clin Infect Dis*. 2009 Nov 15;49(10):1570-8. doi: 10.1086/644772.

22 More information is available at [http://www.effectiveinterventions.org/Libraries/General\\_Docs/11-1007-DEBI\\_overview\\_factsheet.sflb.ashx](http://www.effectiveinterventions.org/Libraries/General_Docs/11-1007-DEBI_overview_factsheet.sflb.ashx).

undetectable viral loads, specific benchmarks must be put in place. These benchmarks relate directly to access to care and successful implementation of health care reform. Benchmarks also are needed within targeted behavioral interventions to address current disparities.

The NHAS Federal Implementation Plan calls on the Federal Government to review methods utilized to distribute formula grants to ensure that resources go to the areas of greatest need, thereby reducing disparities. One call to action is for the U. S. Department of Housing and Urban Development (HUD) to work with Congress to evolve to HIV/AIDS case reporting as the basis for the Housing Opportunities for Persons with AIDS (HOPWA) legislation and funding decisions. The current funding methodology bases 75 percent of funding allocations on cumulative AIDS cases since 1981, including using more than 600,000 deceased persons. The PACHA Disparities Subcommittee has been resolute in urging the HHS Secretary to work directly with the Secretary of HUD and Congress to modernize the funding methodology used for this critical program. In order to more successfully address health disparities, improve health outcomes, and reduce risk behaviors, scarce HOPWA resources must be allocated more effectively, and at a minimum, shifting to an approach based on cases of people living with HIV and AIDS.

Since the release of the NHAS, the Administration has made some progress toward the Strategy's health disparities goals, including endorsement of various CDC initiatives:

- *Act Against AIDS campaign—provides MSM with culturally appropriate messages about HIV prevention;*
- *Testing Makes Us Stronger program—supports increased testing among Black gay and bisexual men; and*
- *Prevention funding for States and territories (based on HIV prevalence rather than AIDS prevalence).*

There also are efforts focusing on the unique needs of women and transgender women at risk for or affected by HIV. PACHA offered several concrete recommendations to its Federal partners charged with shepherding



the NHAS Federal Implementation Plan. In addition, PACHA passed a resolution addressing the needs of women at risk for or living with HIV, including a substantial focus on racial, ethnic, and sexual minority health disparities. PACHA is looking forward to remaining involved in the specific goals and activities of the White House Working Group on the Intersection of HIV/AIDS, Violence Against Women and Girls, and Gender-Related Health Disparities. Recommendations in the May 2012 resolution on women also include amending the NHAS Federal Implementation Plan to address the needs of women by making gender-sensitive care for women living with HIV more widely and readily available. The resolution recommends the integration of HIV care and prevention services with sexual and reproductive health care and intimate partner violence prevention and counseling.

Similarly, PACHA advocates for increased efforts to address disparities among gay and bisexual men. By having a specific focus on Black and Latino gay and bisexual men, we will target a significant part of the population in which there are major health disparities. PACHA passed a resolution that recommends a number of specific Federal activities to eliminate HIV health disparities among Black MSM. Based on rising HIV and STD incidence rates among YBMSM, stigma-based barriers to care, and trauma-related disorders within communities of MSM, PACHA recommends the following:

- *Actions for the HHS Secretary*
  - ▶ Convene a summit that includes Government and non-Government stakeholders on the HIV epidemic and its impact on YBMSM.

- ▶ Create a task force across HHS charged with developing a comprehensive plan to address the specific needs and impact of the epidemic among YBMSM.
- ▶ Ensure that the knowledge gained from extensive research conducted on social determinants of health is integrated into every intervention that could substantially reduce inequalities in health.
- *Actions for the National Institutes of Health*
  - ▶ Develop and issue a high-priority research initiative addressing HIV prevalence among YBMSM. This initiative should include evaluating the potential benefits of biomedical interventions and the use of new technology to engage YBMSM in care and treatment, as well as the potential benefits of combination prevention methods.
- *Additional actions and activities*
  - ▶ Mandate continuing HIV medical education requirements for physicians practicing at publicly funded organizations or receiving public medical reimbursement to ensure that qualified HIV providers are accessible in all communities.
  - ▶ Continue to develop research and recommendations focused on health inequities faced by HIV-positive and at-risk transgender populations.
  - ▶ Assess current funding levels to geographic areas most disproportionately affected by HIV—particularly the South and Northeast—as well as the impact of geographic redistribution of resources on other regions.

The NHAS also provides guidance for PACHA and the Centers for Disease Control and Prevention (CDC)/Health Resources and Services Administration (HRSA) Advisory Committee on HIV, Viral Hepatitis, and STD Prevention and Treatment (CHAC) to reduce stigma and discrimination against people living with HIV by tasking the two advisory committees with soliciting public input in developing recommendations for ways to promote and normalize safe and voluntary disclosure of HIV status in various contexts and circumstances.

The PACHA/CHAC HIV Disclosure Workgroup convened a 2-day HIV Disclosure Summit in June 2012 with thought leaders from cross-cutting and diverse public and private partners (e.g., people living with HIV and community advocates, social scientists, medical ethicists, researchers, health providers, education leaders, lawyers, policy makers, and others). The workgroup created guiding principles and policy recommendations for Federal officials to consider adopting.

The PACHA/CHAC HIV Disclosure Workgroup recommends the following:

- *HHS and other Federal funders should devote a portion of currently funded programs to facilitate campaigns and education on safe and voluntary HIV disclosure.*
- *Federal funders should develop and/or disseminate a quantitative and qualitative research agenda and fund studies on the benefits and challenges of HIV disclosure.*
- *The Surgeon General should write a letter to the American people containing up-to-date information about HIV/AIDS.*
- *The Secretary of Health and Human Services should appoint an HHS representative to work with the Associate Attorney General to create a working group to examine laws and policies that discriminate against people with HIV.*
- *Establish a dedicated position within the office of the Associate Attorney General for HIV Law and Policy.*
- *HHS and medical providers should prioritize disclosure support as a component of mental health services within clinical settings.*
- *HHS should develop sex-positive prevention messages rooted in evidence-based research, but that are also reflecting and tailored to people's real lives.*
- *HHS should develop ways to encourage and incentivize States to address State and local laws that create barriers to disclosure of HIV status and access to care.*

# THE GLOBAL AGENDA

The past 3 years have seen tremendous breakthroughs in HIV prevention, treatment, and research. Since 2009, we have seen the first vaccine to show effectiveness, a microbicide that was found to be modestly efficacious, and two studies demonstrating that an HIV medication could be used as pre-exposure prophylaxis or could reduce new infections by treating those with HIV earlier. These advances have led many to herald a new era in our 30-year campaign to end the epidemic. In November 2011, Secretary of State Hillary Rodham Clinton signaled a new era in her landmark speech at the NIH in which she noted: “America must also continue its leadership role in global health. Our efforts advance our national interests. They help make other countries more stable and the United States more secure. And they are an expression of our values—of who we are as a people.”

The progress of the past few years, however, is now threatened by a significant reduction in support on the part of donor nations in a time of restrained budgets and fiscal austerity. These reductions risk rolling back the successes achieved and will undermine the ability of collaborating with partners to take advantage of our advances.

The intersection of the global epidemic and the domestic U.S. epidemic means that any efforts to achieve an AIDS-free generation in the United States are inextricably linked to our efforts to fight AIDS globally. The U.S. Government remains the single largest donor to the global fight against AIDS, providing support through the United States President’s Emergency Plan for AIDS Relief (PEPFAR) and the Global Fund to Fight AIDS, Tuberculosis and Malaria. America’s efforts in this regard have achieved important successes, including the massive undertaking to provide treatment access to millions of people living with HIV in the developing world. However, additional resources and programmatic realignment are critical to build upon recent new research findings related to



treatment as prevention and the scale-up of proven evidenced-based approaches.

The necessary program realignment will require U.S. Government agencies to select proven interventions for scale-up in countries with generalized epidemics because those efforts cannot and should not attempt to do all things in all places. In countries with concentrated epidemics, programs will need to focus on vulnerable populations, including MSM, and on harm reduction.

There is an important need to set measurable goals for these efforts and to require accountability in achieving goals. The measurement of these goals must have timelines and include transparent reporting on progress with real-time assessments of the outcomes.

Among the proven interventions that should be prioritized are the prevention of mother-to-child transmission, treatment according to antiretroviral therapy (ART) guidelines to maximize the benefits of treatment and prevention, and evidenced-based programs for vulnerable populations.

Additionally, there is a continuing need to build a knowledge base for proven interventions, particularly those necessary to serve vulnerable populations that are contextualized and specific to the different cultural

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needs of the populations to be served. Operations research on the scale-up of these interventions will continue to be an important area requiring additional support.

The return of the International AIDS Conference to the United States in July 2012 represented a significant victory for public health and human rights. Bringing the conference to Washington, DC, was the result of years of advocacy to end the Nation's entry restrictions for people living with HIV and a triumph of science over prejudice. PACHA continues to be diligent in providing advice, information, and recommendations to the Secretary of the U.S. Department of Health and Human Services regarding U.S. Government programs and policies to address the HIV epidemic. We believe that we are at a critical moment to change the course of the HIV epidemic at home and abroad by advancing human rights, public health, and science.

In recognizing World AIDS Day in December 2011, President Obama issued this call to action:

*"To the global community—we ask you to join us. Countries that have committed to the Global Fund need to give the money that they promised. Countries that haven't made a pledge, they need to do so. That includes countries that in the past might have been recipients, but now are in a position to step up as major donors. China and other major economies are in a position now to transition in a way that can help more people.*

*To Congress—keep working together and keep the commitments you've made intact. At a time when so much in Washington divides us, the fight against this disease has united us across parties and across presidents. And it shows that we can do big things when Republicans and Democrats put their common humanity before politics. So we need to carry that spirit forward.*



*And to all Americans—we've got to keep fighting. Fight for every person who needs our help today, but also fight for every person who didn't live to see this moment; for the Rock Hudsons and the Arthur Ashes, and every person who woke us up to the reality of HIV/AIDS. We've got to fight for Ryan White and his mother Jeanne, and the Ray brothers, and every person who forced us to confront our destructive prejudices and our misguided fears. Fight for Magic Johnson and Mary Fisher, and every man, woman and child, who, when told they were going to die from this disease, they said, "No, we're not. We're going to live."*

*Keep fighting for all of them because we can end this pandemic. We can beat this disease. We can win this fight. We just have to keep at it, steady, persistent—today, tomorrow, every day until we get to zero."*

Although there are challenges in reaching the goals set forth in the National HIV/AIDS Strategy, PACHA is optimistic that if we all focus our efforts we will indeed *Achieve An AIDS-Free Generation*.

# PACHA RECOMMENDATIONS AT A GLANCE

PACHA believes that implementation of the following policy recommendations is imperative to achieving the National HIV/AIDS Strategy (NHAS) goals:

- In implementing the Patient Protection and Affordable Care Act (ACA), explicit Federal regulations and guidance to States should be promulgated to promote the NHAS and HIV standard of care goals as well as the successful integration of people living with HIV, their providers, and models of care into health care reforms. Additionally, the U.S. Department of Health and Human Services (HHS) should implement appropriate oversight mechanisms to ensure successful enactment of the new Federal standards.
- The Centers for Medicare and Medicaid Services should be charged with coordinating Federal and State Medicaid reform implementation.
- The Ryan White HIV/AIDS Program should be maintained throughout the development and implementation of ACA reforms, and once successful integration of HIV care, treatment, and service models is achieved, then the program should be retooled to ensure it has the capacity to fill ongoing gaps in core health and support services, as well as to address gaps in affordability.
- HHS should immediately convene and sponsor a landmark “state of the science” conference for researchers, advocates, and people living with HIV to examine and recommend interventions to facilitate the aggressive movement of persons living with HIV across the care continuum.
- HHS and the Office of National AIDS Policy (ONAP) should complete current efforts to strategically refocus metrics used to gauge progress in the fight against HIV in the United States (and give attention to behavioral measures in the coming year).
- ONAP and relevant Federal departments should amend the National HIV/AIDS Strategy Federal Implementation Plan to include specific and measurable goals and targets for women.
- HHS should ensure the needs of women are met by making gender-sensitive care for women living with HIV more widely and readily available through the integration of HIV care and prevention services with sexual and reproductive health care and intimate partner violence prevention and counseling.
- The Administration and Congress should make the necessary financial investments (new, directed, and/or private-sector resources) in HIV prevention, care, and housing to meet the 2015 NHAS goals.
- HHS should convene a summit that includes Government and non-Government stakeholders on the HIV epidemic and its impact on young Black men who have sex with men (YBMSM).
- HHS should create a task force across HHS charged with developing a comprehensive plan to address the specific needs of YBMSM and the impact of the epidemic on this population.
- Knowledge gained from extensive research conducted on social determinants of health should be integrated into every intervention strategy to substantially reduce inequalities in health.
- NIH should develop and issue a high-priority research initiative addressing HIV prevalence among YBMSM. This initiative should include evaluating the potential benefits of biomedical intervention and the use of new technology to engage YBMSM in care and treatment, as well as evaluating the potential benefits of combination prevention methods.
- HHS should mandate continuing HIV medical education requirements for physicians who practice at publicly funded organizations or receive public medical reimbursement to ensure that HIV providers are accessible in all communities.
- HHS should continue to develop research and recommendations focused on health inequities faced by HIV-positive and at-risk transgender populations. Further, HHS should assess current funding to geographic areas most disproportionately affected—particularly the South and Northeast.
- HHS should focus on global efforts that promote prevention of mother-to-child transmission, treatment according to antiretroviral therapy guidelines, maximization of the benefits of treatment and the implementation of prevention, and evidenced-based programs for vulnerable populations.

# APPENDIX A: PACHA MEMBERSHIP, SUBCOMMITTEES, CHAIRS, AND STAFF

## PACHA Membership

### Nancy Mahon, J.D.

**PACHA Chair—Sworn in December 2, 2011**  
**Senior Vice President, M•A•C Cosmetics**  
**Global Executive Director, M•A•C AIDS Fund**  
**New York, New York**



As a senior vice president at M•A•C and Global Executive Director of the M•A•C AIDS Fund, Ms. Mahon serves as a member of the brand's senior management team while overseeing the strategic direction and day-to-day

operation of the M•A•C AIDS Fund. Under her leadership, the Fund has further refined and enhanced its giving, taking on larger grant initiatives including the Caribbean Initiative, while at the same time continuing to fund the grassroots service-based charities that the Fund has supported in the past. Currently, the Fund gives away over \$18 million annually throughout the world, particularly the 65 countries in which M•A•C has affiliates.

### Dawn Averitt



Ms. Averitt was diagnosed with HIV in 1988. She founded the Well Project, which is a not-for-profit organization that works to change the course of the HIV/AIDS pandemic through a unique and comprehensive focus on women.

The organization works to develop new resources to educate, nurture, and support the community of HIV-positive women, their caregivers, and their health care providers.

### Cornelius Baker

**Senior Policy Advisor**  
**National Black Gay Men's Advocacy Coalition**  
**Washington, DC**



Mr. Baker also serves as a Technical Advisor at FHI 360. For the past two decades, Mr. Baker has worked in the local and Federal Government sectors, local and national community-based advocacy and service delivery, and on a variety of workgroups to advance the nation's response to the HIV epidemic. Mr. Baker is a person living with AIDS; he was diagnosed with HIV in 1985.

### Praveen Basaviah



Mr. Basaviah most recently completed serving for 1 year as a Bill Clinton fellow in India through the American Indian Foundation (AIF). He worked in the HIV/AIDS sector in South India with the South India AIDS Action Program.

Prior to joining the AIF, Mr. Basaviah worked as a program manager at the National Centers on Sexuality in San Francisco; he also worked with the Speakers Bureau of Communities United Against Violence.

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**Douglas M. Brooks, M.S.W.**

**Senior Vice President for Community, Health,  
and Public Policy**

**Justice Resource Institute (JRI)  
Boston, Massachusetts**



Mr. Brooks directs community and government relations across JRI, which is a multi-site regional health and human service agency with a variety of educational, residential, and community-based services. He also oversees JRI

Health, a division of JRI with residential, peer, legal, case management, and other supportive services for people living with HIV/AIDS and other disabilities; HIV, viral hepatitis, and TB prevention services; a LGBT youth community center; and curriculum development, training, and organizational development assistance.

Mr. Brooks holds a master of social work degree and is a licensed clinical social worker. He represents JRI in local, State, and national health and human service arenas and has served as a consultant to national and international government and nongovernmental organizations. Mr. Brooks is a Visiting Fellow at the McCormack School Center for Social Policy at the University of Massachusetts, Boston, and is Chair of the Board of Trustees of AIDS United in Washington, DC. He was appointed to PACHA in 2010. Mr. Brooks is a person living with HIV.

**Calvin Butts III, D. Min.**

**Pastor**

**Abyssinian Baptist Church  
New York, New York**



Dr. Butts is the pastor of one of the largest churches in Harlem, New York. He also is president of the State University of New York (SUNY) College at Old Westbury. Dr. Butts is considered a community leader. Under his leadership,

the community development and outreach efforts of his church include homelessness, senior citizen and youth empowerment, and cultural awareness.

**Humberto Cruz**

**Director, AIDS Institute**

**New York State Department of Health  
New York, New York**



Mr. Cruz has been employed in progressively responsible positions in the AIDS Institute for approximately 20 years. He assumed responsibility for the leadership position approximately 2 years ago. In his current position,

Mr. Cruz provides oversight for the development, evaluation, and delivery of prevention programs; health care and support services; the establishment of clinical standards for care; education of health providers and the public; and guidance for regional and statewide planning. Mr. Cruz is a person living with AIDS.

**Ernest Darkoh, M.D., M.P.H.**

**Founding Partner**

**BroadReach Healthcare, LLC  
Washington, DC**



Dr. Darkoh is an internationally recognized expert in global health program management, strategic planning, health systems development, and large-scale treatment program implementation. Dr.

Darkoh has served as an advisor to numerous governments, including Botswana, China, Ethiopia, and South Africa, in the development of their public and private-sector HIV/AIDS programs.

**Kevin Frost**

**Chief Executive Officer**

**The Foundation for AIDS Research (amfAR)  
New York, New York**



Mr. Frost joined the staff of amfAR in 1994; he has occupied his current position since 2007. Prior to joining amfAR, Mr. Frost worked as an inpatient care coordinator of the AIDS program at Bellevue Hospital in New York City.

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**Patricia Garcia, M.D.**  
**Professor, Department of Obstetrics  
and Gynecology**  
**Northwestern University**  
**Chicago, Illinois**



Dr. Garcia is specialized in maternal and fetal medicine. Her research interests include epidemiology of and interventions in sexually transmitted diseases and HIV/AIDS.

**Robert Greenwald, J.D.**  
**Clinical Professor of Law**  
**Director**  
**Center for Health Law and Policy Innovation**  
**Harvard Law School**  
**Cambridge, Massachusetts**



Robert Greenwald has more than 20 years of experience in the fields of health, public health, and HIV law and policy. Mr. Greenwald and his staff at the Center for Health Law and Policy Innovation of Harvard Law School

are engaged in State and national research, policy development, and advocacy on health initiatives. Since 1998, he also has served as Director of the Treatment Access Expansion Project, working to improve access to care for people living with HIV. Mr. Greenwald has served as an advisor to the President's National Commission on AIDS and the HRSA/CDC Community Advisory Committee, and as a board member of AIDS Action Council of Washington, DC, and the National Lesbian and Gay Bar Association.

**Kathie Hiers**  
**Chief Executive Officer**  
**AIDS Alabama**  
**Birmingham, Alabama**



AIDS Alabama is a nonprofit organization that provides housing and supportive services, as well as education, outreach, and testing to low-income persons with HIV/AIDS. Ms. Hiers' employment history includes serving as

Executive Director of Mobile AIDS Support Services and as a founder of the Lee Simmons Fund for People Living with AIDS in Mobile, Alabama. Ms. Hiers has worked for more than 15 years to serve the HIV/AIDS populations through Alabama's service organizations.

**David Holtgrave, Ph.D.**  
**Professor and Chair**  
**Department of Health, Behavior and Society**  
**Johns Hopkins Bloomberg School of Public Health**  
**Baltimore, Maryland**



While much of Dr. Holtgrave's efforts have been directed toward prevention, he also has knowledge and expertise of HIV/AIDS issues that impact treatment and housing. Dr. Holtgrave was previously employed by the

Centers for Disease Control and Prevention (CDC) as Director, Division of HIV/AIDS Prevention—Intervention Research and Support. While employed in this position, Dr. Holtgrave worked on the first comprehensive evaluation strategy for HIV prevention programs; coordinated the first review paper on HIV prevention intervention science; helped to establish HIV prevention community planning; and improved working relationships with health departments, community-based organizations, private-sector partners, and others Federal agencies.

**Michael Horberg, M.D., MAS, FACP, FIDSA**  
**Executive Director Research and Community Benefit**

**Mid-Atlantic Permanente Medical Group**  
**Director, HIV/AIDS**  
**Kaiser Permanente**  
**Rockville, Maryland**



Dr. Horberg is responsible for all research activities in Kaiser Permanente Mid-Atlantic States. He serves as director of HIV/AIDS program-wide for Kaiser Permanente. He is a Fellow of the American College of Physicians

and the Infectious Disease Society of America, and he serves as Chairperson of the Board of Directors of the HIV Medicine Association of the Infectious Disease Society of America. He has co-chaired the NCQA/AMA/HRSA/IDSA-sponsored expert panel on HIV-related provider performance measures. He is Assistant Clinical Professor at Stanford University Medical School. Dr. Horberg is past president of the national Gay and Lesbian Medical Association. His HIV research interests are health service outcomes for HIV-infected patients (including HIV quality measures and care improvement, and determinants of optimized multidisciplinary care for maximized HIV outcomes), medication adherence issues in these patients, and epidemiology of the disease. Dr. Horberg has published more than 40 peer-reviewed manuscripts and delivered more than 100 scientific presentations.

**Ejay Jack, M.S.W., M.P.A.**  
**Health Education Manager**  
**Planned Parenthood of the Heartland**  
**Council Bluffs, Iowa**



Mr. Jack is a trained social worker who conducts educational programs on holistic sexuality with adolescents, parents, and professionals for Planned Parenthood of the Heartland, primarily in southwest Iowa and

the Omaha community. Mr. Jack has been involved with LGBTQ education, outreach, and advocacy for 14 years. He currently facilitates a transgender support group and links transgender people to appropriate care in the Midwest. Mr. Jack has worked both internationally and domestically to ensure sex workers have access to syringe exchanges and promoted risk-reduction strategies on the street level.

**Jack Jackson Jr.**  
**Senator**  
**Arizona State Legislature**  
**Window Rock, Arizona**



Mr. Jackson has been involved with matters concerning the impact of HIV/AIDS on American Indians and Alaska Natives living in tribal and urban communities. Mr. Jackson previously served on the Board of the National Native

American AIDS Prevention Center (NNAAPC) and also served as one of the organization's public policy consultants.

**Naina Khanna**  
**Policy Director**  
**Women Organized to Respond to Life-threatening Disease (WORLD)**  
**Oakland, California**



Ms. Khanna coordinates the U.S. Positive Women's Network (PWN), a national membership body of more than 2,500 HIV-positive women, inclusive of transgender women, which advocates for policies and programs at local, State,

and national levels that reflect the needs of women affected by HIV. She has spoken, presented, and advised nationally and internationally about achieving gender-sensitive, human-rights-grounded policies informed by people living with HIV, and about women's rights. Prior to working in the HIV field, Ms. Khanna co-founded and served as National Field Director for

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the League of Pissed Off Voters, a progressive electoral organizing project focused on increasing political participation by young people and communities of color. Ms. Khanna was diagnosed with HIV in 2002.

### **Anita McBride**



Anita McBride served as Assistant to President George W. Bush and Chief of Staff to First Lady Laura Bush from 2005 to 2009. She directed the staff's work on the wide variety of issues in which Mrs. Bush was involved—educa-

tion, global literacy, youth development, women's rights and health, historic preservation and conservation, the arts, and global health issues, including efforts to end pandemic diseases like malaria and HIV/AIDS.

### **Douglas Michels** **President and Chief Executive Officer** **OraSure Technologies, Inc.** **Bethlehem, Pennsylvania**



Mr. Michels joined OraSure Technologies, Inc., in June 2004, as President and Chief Executive Officer. He is a member of the company's Board of Directors. Since joining OraSure, Mr. Michels has led the company to become

a global leader in oral fluid diagnostics for infectious disease and drugs of abuse. Prior to joining the company, Mr. Michels spent 19 years with Johnson & Johnson and 7 years with Abbott Laboratories. At Johnson and Johnson, he was President, International, for Ortho-Clinical Diagnostics, Inc., and President of Johnson & Johnson Health Care Systems, Inc.

### **Mario J. Pérez, M.P.H.** **Director, Division of HIV and STD Programs** **County of Los Angeles, Department of** **Public Health** **Los Angeles, California**



Mr. Pérez is responsible for managing, planning, and guiding the annual investment of more than \$100 million in local, State, and Federal resources that support a responsive and comprehensive local HIV and STD

service delivery system. He is extremely active in the HIV/AIDS community both locally and nationally, and is a leader on State, local, and national HIV policy issues, serving as a member of the National Minority AIDS Council Board of Directors, the Urban Coalition for HIV/AIDS Prevention Services, and the Los Angeles County Commission on HIV. Mr. Pérez began providing HIV/AIDS services in 1990 while still a student at UC Berkeley. On numerous occasions over the last 20 years, he has testified before members of Congress, the Los Angeles County Board of Supervisors, and the Los Angeles City Council to address a range of HIV/AIDS issues, including support for scientifically proven interventions, and adequate resources to meet broad HIV/AIDS goals. Mr. Pérez has received recognition for his leadership in the fight against HIV/AIDS by then Assemblyman Antonio Villaraigosa, State Senator Hilda Solis, the Los Angeles City Council, Los Angeles County Supervisor Mark Ridley-Thomas, and multiple local organizations. He was born and raised and currently lives in Los Angeles.

**Rosie Perez**  
**Actor, Choreographer, Director**



Ms. Perez was born Rosa Maria Perez on September 6, 1964, in New York, New York. Originally Ms. Perez wanted to be a marine biologist, and she got into acting by accident. Director Spike Lee saw her in a nightclub and

hired her for the 1989 film *Do the Right Thing*, which explored what could happen when racial tensions explode on a hot summer day. More film roles and television guest spots soon followed. She appeared on *21 Jump Street* and became the choreographer for the show *In Living Color*, which earned her three Emmy nominations. She also starred in *White Men Can't Jump* (1992) with Woody Harrelson and Wesley Snipes and *Untamed Heart* (1993) with Marisa Tomei and Christian Slater. It was her dramatic turn in *Fearless* (1993) that earned her first Oscar nomination. Starring with Jeff Bridges, Ms. Perez played a plane crash survivor wracked with guilt of the death of her child, also in the crash. She has also lent her distinctive voice to a number of different projects, including *The Road to El Dorado* (2000).

**Vanessa D. Sharp (Cephas), M.Div.,  
MACM, MATM  
Pastor  
Worldwide Outreach for Higher Hope  
Christian Ministries  
Atlanta, Georgia**



Rev. Sharp was diagnosed with HIV in 1990, breaking her silence as a World AIDS Day speaker in December 1997. A strong advocate for HIV/AIDS, Rev. Sharp (Cephas) recently married, is Coordinator for the BLCA Metro

Atlanta Affiliate of the National Black Leadership Commission on AIDS (NBLCA); SisterLove, Inc.'s Board Chair; ChangeOneLife, Inc.'s consultant in Kenya, East Africa; and Ghana, West Africa; and founder

of LINC Worldwide Outreach, Inc. (Love Integrates Nurture & Care), a "Girls to Women Empowerment Initiative" outreach that serves both locally and globally. Rev. Sharp's advocacy in the area of HIV and AIDS has spanned some 15 years.

**Sandra Torres**  
**Executive Director  
Bill's Kitchen, Inc.**



Mrs. Torres is a tireless advocate for the rights of people with HIV/AIDS. Based in Puerto Rico, she has been recognized as an exceptional leader in the areas of public health and human rights, and services for HIV/AIDS-infected and -affected populations, homeless persons, and the substance abuse population, among others. She has an ample understanding of the area of nutritional and support services for persons living with HIV and at high risk. She is been involved for the last 17 years in advocacy efforts to change policies at local government structural barriers to improve or eliminate delay of funding for HIV/AIDS service providers to the social justice and human rights issues that impact PLWHA. She has been a board member of the Ryan White Part A Planning Council, the Puerto Rico Health Task Force, the Puerto Rico Alliance Against AIDS, *Unidos dando Cara al SIDA*, and the internationally focused Association of Nutrition Services Agencies, among others affiliations. She is currently a consultant for the Puerto Rico Department of Housing on HOPWA and Shelter Plus Care and has served as the Executive Director for Bill's Kitchen, Inc., for the last 17 years.

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**Phill Wilson**  
**President and CEO**  
**The Black AIDS Institute**  
**Los Angeles, California**



Founded in May of 1999, The Black AIDS Institute is the only national HIV/AIDS think tank focused exclusively on Black people. The Institute's mission is to stop the AIDS pandemic in Black communities by engaging

and mobilizing Black institutions and individuals in efforts to confront HIV. The Institute interprets public and private-sector HIV policies, conducts trainings, offers technical assistance, disseminates information, and provides advocacy mobilization from a uniquely and unapologetically Black point of view.

Our motto describes a commitment to self-preservation: "Our People, Our Problem, Our Solution."

## PACHA Subcommittees

### Access to Care Subcommittee

- Robert Greenwald (Co-Chair)
- Michael Horberg (Co-Chair)
- Humberto Cruz
- Pat Garcia
- Naina Khanna
- Sandra Torres-Rivera

### Incidence Subcommittee

- David Holtgrave (Co-Chair)
- Mario Pérez (Co-Chair)
- Cornelius Baker
- Naina Khanna
- Douglas Michels
- Rosie Perez

### Disparities Subcommittee

- Douglas Brooks (Co-Chair)
- Kathie Hiers (Co-Chair)
- Calvin Butts
- Ejay Jacks
- Jack Jackson
- Phill Wilson

### Global Subcommittee

- Dawn Averitt (Co-Chair)
- Kevin Frost (Co-Chair)
- Praveen Basaviah
- Ernest Darkoh
- Anita McBride
- Vanessa Sharp

### Expanding Access to HIV Care Subcommittee

- Nancy Mahon, PACHA Chair
- Humberto Cruz, (Co-Chair), PACHA member
- Mario Pérez, (Co-Chair), PACHA member
- Robert Greenwald, PACHA member
- Kathie Hiers, PACHA member
- Michael Horberg, PACHA member
- Jen Kates, Kaiser Family Foundation
- Jeff Levi, Trust for America's Health
- Julie Scofield, National Alliance of State and Territorial AIDS Directors (NASTAD)
- Andrea Weddle, HIV Medicine Association

### U.S. Department of Health and Human Services (HHS) Federal Liaisons/Subject Matter Experts

- Mayra Alvarez, Office of Health Reform, HHS
- Chantelle Britton-Faison, Health Resources and Services Administration (HRSA)
- Barbara Edwards, Centers for Medicare and Medicaid Services (CMS)
- Cindy Mann, CMS
- Jonathan Mermin, CDC
- Deborah Parham Hopson, HRSA
- Jeremy Sharp, Office of the Assistant Secretary for Legislation, HHS
- Adelle Simmons, Office of the Assistant Secretary for Planning and Evaluation, HHS

### CDC/HRSA Advisory Committee on HIV, Viral Hepatitis, and STD Prevention and Treatment (CHAC)

- Antigone H. Dempsey, Co-Chair and Liaison to PACHA

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## **PACHA Current and Former Chairs and Staff**

### **Nancy Mahon, J.D.**

PACHA Chair  
December 2011–present

### **Helene Gayle, M.D., M.P.H.**

PACHA Chair  
August 2009–September 2011

### **Ronald Valdiserri, M.D., M.P.H.**

Deputy Assistant Secretary for Health, Infectious Diseases, and  
Director, Office of HIV/AIDS and Infectious Disease Policy  
U.S. Department of Health and Human Services  
June 2010–present

### **B. Kaye Hayes, M.P.A.**

Executive Director  
March 2012–present

### **Christopher Bates, M.P.A.**

Executive Director  
February 2009–March 2012

### **Caroline Talev, M.P.A.**

Public Health Analyst  
August 2012–present

### **Melvin Joppy**

Committee Manager  
August 2008–August 2012

# APPENDIX B: PACHA RECOMMENDATIONS, RESOLUTIONS, AND LETTERS

## Resolution Regarding Timely Access to Lifesaving Care and Treatment

June 2010

The Patient Protection and Affordable Care Act of 2010 will greatly improve access to affordable, high quality health care for many people living with HIV and AIDS. Key reforms in the new law include elimination of the Medicaid disability requirement, which will provide access to Medicaid to individuals and families with income below 133 percent of the Federal poverty level beginning in 2014. The Act also provides for counting ADAP contributions toward Medicare Part D's true out of pocket spending limit ("TrOOP") starting in 2011 and eliminating the Medicare Part D "donut hole" by 2020. In addition, the Act contains provisions that will increase access to private health insurance by eliminating pre-existing condition exclusions, ending the practice of charging higher premiums based on gender or health status, increasing affordability through subsidies for people with income up to 400 percent of the Federal poverty level, and increasing portability.

However, many of these and other important reforms do not go into effect until 2014 or beyond. While health care reform will significantly improve access to care, people living with HIV and AIDS will likely continue to face challenges even after implementation. In the meantime, people living with HIV and AIDS confront significant barriers to access to care and treatment right now. For instance, current practices in the private insurance sector often preclude individuals from purchasing private health insurance. Medicaid remains largely out of reach other than to those disabled with AIDS. Medicare Part D co-payment obligations continue to limit access to drugs for many Part D beneficiaries. And, the increased demand for Ryan White Program services and ADAP benefits

is contributing to growing wait lists, leaving many people unable to access care, treatment and essential support services.

Individual and public health goals demand that the Federal government, in partnership with State governments, do all that it can to address the significant gaps in access to care and treatment that will exist until health care reform is fully implemented in 2014 and beyond. Uninsured, low-income people living with HIV and AIDS cannot wait until 2014 for access to Medicaid. Similarly, ADAP wait lists and cost containment measures, including restrictive income eligibility requirements and drug formularies, must be eliminated. The Centers for Medicare and Medicaid Services and Health Resources and Services Administration must have the financial resources and programmatic tools necessary to adequately identify and meet existing and ongoing need for care and treatment.

WHEREAS people living with HIV in the United States experience multiple barriers to care and treatment leading to unnecessary and greater morbidity and mortality;

WHEREAS there is increasing evidence that earlier care and treatment helps improve HIV-related survival and prevent the spread of HIV infection;

WHEREAS the Patient Protection and Affordable Care Act of 2010 will greatly improve access to care and treatment for low-income uninsured people living with HIV and AIDS when the Medicaid expansion goes into effect in 2014;

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WHEREAS from now until 2014 an increasing number of people living with HIV and AIDS will lack access to care, lifesaving medications and essential support services;

WHEREAS emergency and ongoing adequate Federal Ryan White Program funding, including AIDS Drug Assistance Program (ADAP) funding, will eliminate growing waiting lists and other recently implemented access restrictions, and will allow states to provide lifesaving care, treatment and support services to people living with HIV; and

WHEREAS the Early Treatment for HIV Act, with its enhanced Federal medical assistance percentage (FMAP), will support Federal-State partnerships in efforts to extend Medicaid coverage to pre-disabled, low-income, uninsured people living with HIV --

BE IT RESOLVED that the Presidential Advisory Council on HIV/AIDS recommends that the President and the Secretary of Health and Human Services work closely with Congress to:

1. Provide adequate emergency Federal ADAP funding in FY 2010 (\$126,000,000) to eliminate wait lists, reverse cost containment measures, and meet anticipated increased demand for live-saving treatment in FY 2010.
2. Provide adequate Federal Ryan White Program funding in FY 2011 and beyond to meet growing demand for Ryan White Program provided care, treatment and essential support services.
3. Provide states with the ability to immediately expand access to Medicaid for people living with HIV and AIDS through the enactment of the Early Treatment for HIV Act.

## Resolution on HIV Testing

January 28, 2011

An individual's ability to benefit from the great strides that have been made in the treatment and care of HIV largely depends upon timely diagnosis, effective treatment, and attention to co-morbidities and co-conditions (including mental health, substance use, and housing). Further, reducing the potential for HIV transmission in our communities, through reduced viral load and behavior change, also depends upon timely diagnosis and effective treatment. The benefits of early diagnosis and linkage to care are only realized if individuals know their status through HIV testing.

The U. S. Preventive Services Task Force (USPSTF) recommends routine HIV screening for those persons at "increased risk" of HIV infection (a "Grade A" recommendation). USPSTF also recommends testing of all pregnant women (Grade "A"), which should continue and be promoted. However, for persons not clearly identified as increased risk or pregnant, the USPSTF conferred only a "Grade C" recommendation. The USPSTF recommendation is important because coverage and reimbursement for preventive services under Medicare, Medicaid, and most private insurance under the Affordable Care Act depend on an "A" or "B" level USPSTF recommendation, and adequate reimbursement supports clinicians' efforts to increase health screening.

WHEREAS, the USPSTF clinical considerations defining "increased risk" for HIV infection include: (1) one or more individual risk factors; (2) receipt of health care in a high-risk clinical setting; or (3) receipt of health care in a high-prevalence clinical setting (defined by the Centers for Disease Control and Prevention as those with a 1 percent or greater prevalence of infection among the patient population being served);

WHEREAS, "increased risk" covered under the Grade A USPSTF recommendation includes: 1) men who have sex with men after 1975; men and women having unprotected sex with multiple partners; past or present injection drug users; men and women who

exchange sex for money or drugs or who have sex partners who do; individuals whose past or present sex partners were HIV-infected, bisexual, or injection drug users; individuals being treated for sexually transmitted diseases; individuals with a history of blood transfusion between 1978-1985; and individuals who request an HIV test: 2) and high-risk clinical settings includes STD clinics, correctional facilities, homeless shelters, tuberculosis clinics, clinics serving men who have sex with men, and adolescent health clinics with a high prevalence of STDs; and 3) high prevalence settings includes those with a 1 percent or greater prevalence of infection among the patient population being served;

WHEREAS, even with the broad definition of "increased risk" under current Grade "A" USPSTF recommendations, there are still people who fall outside of the "increased risk" category who will benefit from testing, and numerous studies document that risk-based HIV screening in health care settings fails to identify up to half the patients infected with HIV;

WHEREAS, many health care providers often do not take detailed sexual or substance use history or may simply assume their patients are not at risk for HIV disease and/or are unaware of the broad definition of "increased risk";

WHEREAS, numerous studies also document that routine screening of patients without specific risk factors is well-accepted by patients;

WHEREAS, the USPSTF last considered HIV routine testing in 2007, updating a 2005 evidence review; and the evidence model that led to their "C" level recommendation for routine HIV testing was based on preventing clinical progression or death within three years, assuming treatment would be initiated only at CD4 T-cell counts <200/ $\mu$ L, but subsequent evidence of increased survival and improved health outcomes with earlier treatment and decreased infectiousness among horizontal transmissions with effective anti-retroviral treatment has accumulated; and, the DHHS

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and other professional societies recommend initiation of antiretroviral therapy at CD4 levels of 350-500/ $\mu$ L (A/B II), if not sooner;

WHEREAS, both public and private insurance reimbursement often relies on health care providers' full understanding of the definition of "at increased risk," but many health care providers are unaware of the scope of this definition;

Therefore:

BE IT RESOLVED that the Presidential Advisory Council on HIV/AIDS recommends that: the U.S. Preventive Services Task Force immediately launch a new review regarding its rating for routine population-based screening for adults and adolescents in clinical care settings; and the Department of Health and Human Services convene the Centers for Medicare and Medicaid Services, the Health Resources and Services Administration, and the Centers for Disease Control and Prevention undertake a joint HIV testing initiative and provider education campaign to ensure that providers understand the breadth of the already existing Grade A recommendation and to ease reimbursement difficulties for increased risk HIV testing.

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## Resolution in Support of Increased Funding Toward HIV/AIDS Prevention

January 28, 2011

WHEREAS, the HIV prevention funding investment is far too small in the U.S. to truly change the course of the epidemic according to the 2008 sworn testimony of the Director of the Centers for Disease Control and Prevention and other witnesses, as well as according to peer-reviewed published articles;

WHEREAS, the current level of investment continues to shrink when adjusted for inflation (dropping over 20 percent since FY 2002) and the purchasing power of the HIV prevention investment in the U.S. is now approximately only what it was in 1993;

WHEREAS, the HIV prevention funding in the U.S. only accounts for about 3 percent of the total HIV/AIDS investment and is insufficient to meet the goals of the NHAS;

WHEREAS, all HIV prevention funding (be it current or future) must be subjected to the highest standards of transparency, effectiveness and efficiency so as to be fully accountable, maximally impact the epidemic in the U.S., and assure attainment of the goals of the President's National HIV/AIDS Strategy;

BE IT RESOLVED that PACHA urges the Administration and Congress to achieve the following: (a) as rapidly as possible, fully fund the HIV prevention efforts in the U.S. at levels previously described as necessary in Congressional testimony and peer-reviewed publications so as to assure attainment of the goals of the National HIV/AIDS Strategy; (b) by June 2011, develop a system of annual reporting whereby all HIV prevention funding in the Federal Government is described in a publicly available document containing all funding amounts, uses, and measured or estimated outcomes; and (c) work closely with PACHA by July 2011 to develop and implement a set of recommendations for any necessary redirection of current Federal HIV and other Federal prevention funding from its existing use to more impactful utilization.

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Presidential Advisory Council on  
**HIV/AIDS**

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AUG - 8 2011

The Honorable Barack H. Obama  
The White House  
1600 Pennsylvania Avenue, NW  
Washington, DC 20500

Dear Mr. President:

As members of the Presidential Advisory Council on HIV/AIDS (PACHA), we would like to thank you for the wonderful opportunity to serve the nation in addressing the HIV/AIDS epidemic, and to congratulate you for your outstanding leadership in releasing the National HIV/AIDS Strategy (NHAS) in July 2010. The NHAS has done much to reenergize the HIV/AIDS efforts in the U.S. and to promote a shared vision of where the nation needs to be by 2015.

While there is great support of the NHAS goals regarding HIV incidence reduction, treatment access expansion, disparities alleviation, and service coordination improvement, a tremendous amount of work must be done by 2015 to achieve these goals. PACHA respectfully requests that you indulge us an annual letter to describe what we see as some of the major successes over the prior year as well as the major challenges for the upcoming year which must be addressed to make NHAS goal achievement a reality. We have sent a more detailed letter to Secretary Sebelius (a copy of which is attached).

***Situational Analysis.*** Since the beginning of the epidemic and through 2006, HIV prevention efforts in the U.S. have averted at least 350,000 infections and saved over \$129 billion in healthcare costs. In a given year in the U.S., over 95% of all persons living with HIV do not transmit the virus to anyone else (down from very high transmission rates early in the epidemic), thanks to testing, prevention and treatment efforts. Advances in HIV treatment have resulted in substantial reductions in death rates, and HIV may now rightly be considered a chronic disease. As of 2008, there were nearly 1.2 million persons living with HIV. Unfortunately, there are still approximately 50,000 HIV infections per year in the U.S. and there is still a death among persons living with HIV roughly every 33 minutes in the nation.

The HIV-related disparities are stunning with men who have sex with men (especially Black men who have sex with men), African-American, and Latino/Latina communities profoundly disproportionately shouldering the burden of this epidemic. Many women delay entry into care, and are less likely to begin antiretroviral therapy due in part to insufficient women-centered services, missed opportunities for linkages between various service delivery programs, and socioeconomic barriers to care (such as poverty). The financial consequences of the epidemic are also daunting as HIV care costs roughly \$20,000 to \$34,000 per client per year, depending on disease stage and provider.

Of course, the NHAS does an outstanding job of pointing us in a number of key directions that must be taken to more effectively address the prevention, care, disparities and program coordination aspects of the epidemic. We believe that in the coming year, the following areas are in need of priority attention:

**Supporting Full Access to Testing, Care and Prevention Services.** Approximately 20% of persons living with HIV are not aware of their HIV serostatus. Of persons diagnosed with HIV, only 75% are linked to HIV care, and only one-half are retained in care. Therefore, the AIDS Drug Assistance Program (ADAP) waiting lists (which now include over 8,650 people living with HIV) are just a small fraction of the unmet needs for HIV care in the U.S. We believe that additional efforts are urgently needed to ensure comprehensive access to testing, treatment, and prevention services in the U.S. (including protecting the Medicaid program from budget cuts given its critical role in meeting the care and treatment needs of low-income people living with HIV and other chronic medical conditions). It has been estimated in the literature that supporting the services necessary to meet the prevention goals of the NHAS would have an \$8:\$1 return on investment, sufficient to pay for the NHAS treatment expansion goals. We are grateful that you have worked hard to enact and implement the Affordable Care Act (ACA); yet we need additional short-term responses to ADAP waiting lists until 2014, and then longer-term efforts to address the other barriers such as inadequate engagement in care, late initiation of treatment, lack of sufficient support services, and poor adherence, many of which will become easier to address once insurance coverage is expanded by the ACA.

**Identifying Optimal Resource Allocation for Evidence-based Prevention Strategies.** The National Institutes of Health (NIH) and CDC have previously identified an array of evidence-based HIV prevention strategies (including HIV testing, behavioral interventions, condom distribution, syringe exchange, and structural interventions including housing). **We now have the very recent and critical findings from an NIH trial (called "HPTN 052") that early HIV treatment in HIV serostatus discordant couples can nearly eliminate transmission of the virus.** As a nation, we must make optimal use of this landmark finding of "treatment as prevention." However, given that so many people living with HIV in the U.S. do not have access to treatment (or do not know their HIV status), reaping the full potential of the HPTN 052 findings will be challenging. Indeed, over one-half million people living with HIV in the U.S. are not in HIV care, and therefore the translation of a finding from a landmark clinical trial on "treatment as prevention" into a population level effect poses substantial operational and resource allocation challenges that must be addressed in the coming year.

**Transforming Expensive Reporting Requirements Into a Strategic Management Dashboard.** Health Departments receiving federal HIV/AIDS funding are now burdened with nearly ninety separate reporting requirements (including reporting on hundreds of specific variables). Sadly, the large quantity of this information has not yielded the optimal quality data needed for program evaluation and management. Therefore, we urge that a streamlined, strategic dashboard be finalized over the coming year. Utilizing just a handful of very well-chosen metrics that are relevant and comparable across federal funding sources, this dashboard should emphasize

Page 3 – The Honorable Barack H. Obama

program transparency, accountability, and allow for strategic mid-course corrections to ensure achievement of the NHAS goals.

**Support of Transfer Authority for Strategy Implementation Fund.** We applaud your seeking of Congressional approval for transfer authority to create a Strategy Implementation Fund to be used at the discretion of the Secretary. This fund will address critical unmet needs, and support the gathering of information and conducting of analyses necessary to ensure that *all* federal HIV/AIDS efforts make their maximum contribution to the NHAS goals. We support the fund's maintenance and potential expansion.

**Addressing HIV-Related Health Disparities in the U.S.** The NHAS rightly decries the substantial stigma and discrimination faced by persons living with HIV. It is shocking that thirty years into the epidemic, we still see such social injustices in the nation. While we believe that addressing inequities in funding patterns is key to lessening HIV-related disparities, even more profound progress will be made when the root causes of HIV-related stigma are also confronted. Addressing stigma will also require tackling HIV criminalization - the use of the criminal law to target and punish those who are HIV seropositive for consensual sex and conduct that poses no risk of HIV transmission.

**The Domestic/Global Interface of the HIV Epidemic.** The U.S. HIV epidemic is inextricably woven into the global epidemic. America's efforts to tackle the global AIDS epidemic through PEPFAR and the Global Fund have had profound impact and laid the foundation for the Administration's Global Health Initiative. However, new resources and portfolio realignment are necessary to take advantage of the connection between HIV treatment and prevention and to scale up these proven evidence-based approaches in our international efforts. We have a moral imperative to turn the tide of the AIDS pandemic globally as it devastates individuals, families, communities, and society at large – possibly threatening our national security as 50 million children worldwide could be left parentless by 2020 without bold action.

We thank you most sincerely for taking the time to consider our reflections and recommendations, and would be pleased to hear from you on how we might be of optimal service to your Administration. We take very seriously our roles as members of PACHA and are eager to tackle tasks that you would find informative and useful. We all share your intense commitment to addressing the HIV epidemic in the U.S. and across the globe; indeed, we have all devoted our lives to ending this epidemic.

With greatest respect and appreciation,

*David Halperin, for*

Helene Gayle, MD, MPH  
Chairperson

Presidential Advisory Council on HIV/AIDS

Enclosure

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Presidential Advisory Council on  
**HIV/AIDS**



AUG - 8 2011

The Honorable Kathleen Sebelius  
Secretary of the Department of Health and Human Services  
Hubert H. Humphrey Building  
200 Independence Ave., SW  
Washington, DC 20101

Dear Madame Secretary:

As members of the Presidential Advisory Council on HIV/AIDS (PACHA), we would like to thank you for this wonderful opportunity to serve the nation in addressing the HIV/AIDS epidemic, and to congratulate you for your outstanding leadership in releasing the National HIV/AIDS Strategy (NHAS) in July 2010. The NHAS has done a great deal to reenergize HIV/AIDS efforts in the U.S., and to promote a shared vision of where the nation needs to be by 2015.

While there is great support of the NHAS goals regarding HIV incidence reduction, treatment access expansion, disparities alleviation, and service coordination improvement, a tremendous amount of work must be done by 2015 to achieve these goals. PACHA respectfully requests that you indulge us an annual letter describing what we see as the major successes over the prior year as well as the major challenges for the upcoming year which must be addressed to make the NHAS goals a reality (we are sending a briefer summary of this letter to President Obama). We also plan a press release every World AIDS Day describing for the American people what we see as the major domestic and global challenges and highlighting how everyone in the U.S. might become more involved.

***SITUATIONAL ANALYSIS.*** Since the beginning of the epidemic and through 2006, HIV prevention efforts have averted at least 350,000 infections in the United States and saved over \$129 billion in healthcare costs. In a small number of areas (such as San Francisco), HIV incidence appears to be decreasing. In a given year in the U.S., over 95% of all persons living with HIV do not transmit the virus to anyone else (down from very high transmission rates early in the epidemic), thanks to testing, prevention and treatment efforts. Advances in HIV treatment have resulted in very substantial reductions in death rates, and HIV may now rightly be considered a chronic disease. Further, recent scientific findings have helped us to understand the prevention potential of HIV testing and antiretroviral drugs (and we have long known that HIV drugs can be highly successful in preventing mother to child transmission of HIV). In addition syringe exchange programs and other services for persons who inject drugs have led to substantial reductions in HIV incidence attributed to non-sterile injection practices. According to the National Institutes of Health (NIH), other proven interventions include behavior modification

Page 2 -- The Honorable Kathleen Sebelius

strategies, condom distribution, blood supply screening, and male circumcision. We recognize and applaud the Administration's very important initial steps to better coordinate and prioritize the diversity of HIV/AIDS efforts across the federal government.

Unfortunately, despite these tremendous successes much work remains to be done, and we must honor the memory of over 617,000 friends, partners, relatives and neighbors who died with an AIDS diagnosis. There are still approximately 50,000 HIV infections per year in the U.S. According to the Centers for Disease Control and Prevention (CDC), there were nearly 1.2 million persons living with HIV as of 2008 (a number that grows daily). Sadly, even now in 2011, there is still a death among persons living with HIV roughly every 33 minutes in the nation. The financial consequences of the epidemic are also daunting as HIV care costs roughly \$20,000 to \$34,000 per client per year, depending on disease stage and provider.

The HIV-related disparities are stunning for gay men (especially Black gay men), African-American, and Latino/Latina communities profoundly disproportionately shouldering the burden of this epidemic. Many women experience poor health outcomes as a result of delayed entry into care and poor retention once in care, and are less likely to begin antiretroviral therapy due in part to insufficient women-centered services, missed opportunities for linkage between services for sexual and reproductive health and HIV, inadequate supportive services, and socioeconomic barriers to care (such as poverty).

Approximately 20% of persons living with HIV are not aware of their HIV serostatus. Of persons diagnosed with HIV, only 75% are linked to HIV care, and only one-half are retained in care. Therefore, the AIDS Drug Assistance Program (ADAP) waiting lists (which now include over 8,650 people living with HIV) are just a small fraction of the unmet needs for HIV care in the U.S.

Of course, the NHAS does an outstanding job of pointing us in a number of key directions that must be taken to address prevention, care, disparities and program coordination aspects of the epidemic. Below, we recognize recent successes and urge new and greater efforts in the four major areas of the NHAS.

**REDUCING NEW INFECTIONS.** We applaud the NHAS goals of reducing new HIV infections, decreasing the HIV transmission rate, and promoting awareness of HIV serostatus. To make continued progress toward these goals, we believe that the following points need special attention in the coming year.

**Refine Evidence-Based Prevention Programs.** First, there must be a continued and ever strengthened commitment to evidence-based prevention programs. Recent, exciting scientific findings have provided further evidence that HIV treatment can have not only a major role in HIV care but also in prevention; the full potential of this important finding must be realized. Unfortunately, too many media outlets incorrectly reported that we now have an "end to AIDS"; we wish this were the case but sadly it is not. Indeed, over one-half million people living with HIV in the U.S. are not in HIV care, and therefore the translation of a finding from a landmark clinical trial on "treatment as prevention" into a population level effect poses substantial operational and resource challenges. We suggest that over the coming year, federal and private

sector partners engage in a vigorous discussion that results in a shared approach to maximize the effect of such findings at the population level, that ensures the optimal array of evidence-based prevention programs (such as HIV counseling and testing, treatment as prevention, condom provision, behavior change services, comprehensive sexual education, and structural interventions such as syringe exchange and housing programs) in the best possible combination prevention package, and that determines the requisite level of human and fiscal resources to make the delivery of such optimized services sufficient to achieve the goals of the NHAS. The adoption of an Implementation Science framework as now employed by PEPFAR offers a promising path forward and is one way that global and domestic HIV prevention efforts can draw the best from each other.

**Invest in Prevention as a Cost-Saving Public Health Strategy.** Second, we recognize that we live in very difficult fiscal times and that public resources are scarce. But according to the published literature, underinvestment in HIV prevention efforts will actually result in *higher* medical costs for the nation in the long term. To truly bend the HIV care cost curve, we must bend the HIV incidence curve. Fully funding prevention serves not only to save lives but also to save scarce public sector resources, and should rightfully be considered a cost-saving strategy. Indeed, the choice not to fully fund HIV prevention efforts is actually a choice to increase federal costs associated with the care of HIV by billions of dollars in the coming years (it has been estimated that the rate of return for new investments in prevention sufficient to achieve the NHAS goals will be over \$8 saved for each dollar spent).

Of course, appropriate levels of prevention and care funding should be aligned with where the epidemic is now and where it is headed in the U.S., and should be subjected to the very highest standards of accountability and transparency. We appreciate CDC's and the Department of Health and Human Services' (HHS') focus on the Twelve Cities project that aimed to determine how to realign and optimize current resources, clearly articulate unmet needs and better coordinate services in a dozen jurisdictions heavily impacted by HIV. We appreciate the fact that HIV prevention base funding was increased by \$31 million at CDC in FY11 (a year in which CDC's budget was cut heavily by Congress), and we appreciate the HIV prevention increases proposed in the Administration's FY12 budget. However, even these promising events do not result in a fully funded prevention program sufficient to meet the goals of the NHAS. Further, we are concerned that the core prevention service delivery funding for health departments supported by CDC was cut by \$20M in the recent FY12 funding announcement and urge its immediate restoration.

**Maximize Accountability and Effectiveness by Overhauling HIV-related Metrics.** Third, as PACHA, we have appreciated the federal agencies' willingness to review with us their HIV prevention budgets and the initial steps taken to move toward better coordination of these investments (including HHS' initial attempts at ensuring that HIV prevention resources are congruent with the epidemic and serve populations most in need of services). However, more work remains to be done. For example, the number of reporting requirements for Health Departments now receiving federal HIV/AIDS funding approaches ninety separate requirements, and several hundred variables are tracked. We believe strongly in complete accountability and transparency of the use of public sector HIV prevention resources, but clearly such reporting requirements must be better coordinated and streamlined. Further, they must be better prioritized

as the current myriad of requirements has not yielded a comprehensive "dashboard" by which the epidemic can be thoroughly monitored and "managed." Identifying a smaller number of critical metrics to be collected across agencies will help the nation keep its eyes focused on the central outcomes and impacts identified in the NHAS.

We suggest that metric prioritization would better set the stage for cross-agency and intra-agency reallocation of existing resources to achieve optimal HIV prevention impact, and allow for identification of specific ways in which HIV programs can be strategically coordinated with sexually transmitted infections services, hepatitis programs, and substance abuse treatment interventions. PACHA has already begun a very productive dialogue with the HHS Departmental Working Group on HIV/AIDS Metrics; over the next year, we encourage HHS, Office of National AIDS Policy (ONAP), and other partners (in conjunction with PACHA) to finalize work on a streamlined, practical and prioritized set of HIV/AIDS measures and reporting requirements that will both save administrative resources and also allow for the construction of a highly strategic dashboard that will help the nation make annual mid-course corrections necessary to achieve the goals of the NHAS.

**IMPROVING ACCESS TO CARE.** Pure and simple (and as noted in the Vision Statement of the NHAS), every American living with HIV should have access to high quality care and treatment, and the resources to make this a reality must be identified. As a starting point, this means fully funding the AIDS Drug Assistance Program to eliminate waiting lists, denials of care, and formulary caps that result in suboptimal care and HIV-related disparities. It also means protecting the Medicaid program from budget cuts given its critical role in meeting the care and treatment needs of low-income people living with HIV and other chronic medical conditions.

Recent science (NIH-sponsored HPTN study #052) confirms what many people living with HIV and their providers long suspected – aggressive HIV medication treatment not only extends the lives of HIV seropositive Americans, it also helps to decrease the transmission of the virus. As the NHAS calls for increased access to care (including medications) and lowering transmission rates, achieving these goals will rely heavily on the nation's public health care systems. In particular, Medicaid and Medicare account for approximately 75% of federal spending on HIV and AIDS-related care; along with Ryan White Programs, Veterans Administration and Indian Health Services, they serve the vast majority of people living with HIV and AIDS in the United States. We believe that the following action steps are necessary in the next year to successfully meet the goals of the NHAS and to make real headway against the HIV epidemic.

**Ensuring Successful Integration of HIV Care as the Affordable Care Act is Implemented and Creating a Healthy Bridge to 2014:**

**Provide all necessary support for a full-time senior-level advisor on HIV at the Centers for Medicare and Medicaid Services (CMS).** We appreciate CMS's commitment to increasing access to HIV prevention, care, and treatment by urging state Medicaid Directors to cover routine testing, identifying HIV/AIDS as a chronic condition eligible for the new Medicaid health home benefit, and developing guidance for states to facilitate applications for section 1115 waivers to expand access to "pre-disabled" people living with HIV. However, many states and other federal agencies find it difficult to engage with CMS to respond quickly and effectively to

these opportunities. We appreciate the fact that a senior level advisor has been designated who reports directly to the CMS Administrator, but this advisor has a portfolio of responsibilities broader than this task alone. To facilitate outcome-oriented action on these opportunities and to meet the goals of the NHAS, we recommend that the senior advisor be a full-time appointment with sufficient resources to implement the NHAS-related tasks at hand.

**Provide support of state efforts to prepare and submit section 1115 waiver applications.** CMS has worked diligently to make the 1115 Medicaid waiver a viable option for states to create a bridge to 2014 for people living with HIV. However, states struggling with understaffed Medicaid offices lack the resources to gather data and conduct budget analyses to develop a successful waiver application. We urge CMS and HHS to develop mechanisms to support states to develop plans that meet budget neutrality requirements and the needs of “pre-disabled” people living with HIV. This includes ensuring that all costs of treating persons living with HIV are considered (including pharmaceutical costs) before transferring eligible persons to local Low Income Health Plans to avoid bankrupting local and State health systems. Finally, CMS must also contribute to the successful implementation of the “12 Cities Initiative,” and help meet the immediate goals of the NHAS.

**Initiate demonstration projects to evaluate quality and outcomes of the HIV “health home” (Ryan White) care model.** The Center for Medicare and Medicaid Innovation should deploy a collaborative CMS/HRSA (Health Resources and Services Administration) pilot project to evaluate the Ryan White Program’s (and similar program’s) model of comprehensive and coordinated care, treatment, and supportive services, and develop payment mechanisms to support this level of care under Medicaid and Medicare, as called for in the NHAS Implementation Plan.

**Ensuring Successful Implementation of the Findings of IPTN 052 and Meeting the Goals of the NHAS:**

**Ensure adequate resources and guideline development that incorporate the latest scientific breakthroughs.** As noted above, the HIV scientific and clinical community view IPTN 052 as a true “game changer”; with full implementation of the lessons learned through this study, we can not only improve the health of all HIV seropositive patients, but also help to prevent the transmission of the virus and lower incidence rates in the U.S. – all goals of NHAS. To ensure comprehensive implementation of these findings, HHS-supported HIV clinical treatment guidelines must be revised to reflect these findings, followed by adequate funding to allow every HIV seropositive American access to these medications (a recommendation already made by the Institute of Medicine in its 2004 report on public financing of HIV care).

**Adopt HIV harmonized quality measures that encourage increased HIV testing and access to care.** The U.S. Preventive Services Task Force (USPSTF) has already given a rating of A to routine HIV screening done in which any of the following conditions apply: (a) the geographic area is one of high HIV prevalence; (b) the venue is one of high HIV prevalence (even if the geographic area has low prevalence); or (c) the presenting client may be at risk of infection regardless of the HIV prevalence in the venue or the geographic area. (It is useful to note that CDC’s entire Expanded Testing Initiative to further promote routine testing would meet

the conditions to earn an A recommendation.) We believe that CMS should immediately move to reimburse such routine testing. Further, the USPSTF is presently reviewing its previous HIV testing recommendations for circumstances in which none of the three conditions above are met, and we believe recent scientific data may well support elevation of such HIV testing to an A or B level recommendation even in such circumstances. We believe that quality measures employed by both public and private healthcare institutions should be adopted that measure such testing efforts and an HIV seropositive American's ability to access HIV testing and quality care.

**Develop data sharing protocols between federal, state and other jurisdictions to ensure accurate measurement of NHAS progress and to ensure persons living with HIV are getting the care they need.** NHAS access to care goals intended to both address unmet need and reduce health disparities must be predicated on an accurate baseline and the ongoing sound measurement of unmet need and health disparities. We recommend the establishment of an HHS-led task force to develop and implement consistent data collection. We also recommend sharing protocols among CMS, HRSA, state Medicaid directors and State and local AIDS Directors, as well as among other stakeholders, so as to establish these baselines and measurement strategies. These actions should serve to improve service delivery as well as achieve the additional goal of reducing the reporting burden on the states, tribal and local jurisdictions.

**REDUCING HIV-RELATED DISPARITIES.** The NHAS rightly decries the substantial stigma and active discrimination faced by persons living with HIV in the U.S. It is shocking that thirty years into the epidemic, we still see such social injustices in the nation. This section of the NHAS directs attention toward alleviating the disparities in detectability of viral load in men who have sex with men, African Americans, and Latinos/Latinas living with HIV (relative to the broader population of persons living with HIV). There also are disparities in how the government uses the criminal law to target and punish people with HIV for consensual sex or conduct posing no risk of HIV transmission, based in part on outdated beliefs about the routes and actual risks of HIV transmission, and current realities of living with HIV that reinforce stigma and discrimination.

**Improve Equity and Impact in Funding Distributions.** Consistent with the tenets of the NHAS, we believe that it is critical that federal HIV/AIDS funding be based on living HIV cases in as close to real time as possible. The recent CDC health department prevention funding opportunity announcement takes an important step in this direction. However, it must be recognized that no jurisdiction is seeing a reduction in persons living with HIV, and it must be recognized that HIV prevention services are seriously underfunded in the U.S. overall. This has created a situation in which resources have been reduced in some jurisdictions, thereby disrupting services, in order to shift funds to other jurisdictions (who must be prepared to quickly and strategically invest these new resources so that they maximally contribute to achieving the goals of the NHAS). We believe that managing this very challenging circumstance will require much analysis, evaluation, vigilance, and community engagement in the coming months. PACHA's members have a wide variety of experiences relevant to this situation, we respectfully request the opportunity to engage in ongoing dialogue with HHS to review the myriad issues associated with resource distribution and attainment of the NHAS goals.

In addition, just ensuring that the "money follows the epidemic" is not sufficient; once the resources are allocated, the best possible interventions must be delivered at the appropriate scale so as to maximally impact the epidemic. This means delivering evidence-based interventions that are customized to the particular social circumstances and needs of the clients and communities being served (for instance, ensuring that critical programs serving youth are based on the best evidence available and incorporate an understanding of the challenging life circumstances facing many young people). Further, this means quickly developing the organizational and institutional capacity among populations where HIV is spreading most rapidly and disproportionately; this is especially true of organizations serving Black gay men and those serving poor Black women and men in the South and elsewhere. Additionally, it means directly addressing human and civil rights issues that contribute to the stigmatization and marginalization of some of the most highly impacted populations (such work should lead HHS to even stronger partnerships with the Departments of Justice, Labor and Education). These partnerships should produce government leadership on pressing issues of stigma and discrimination, and should inform efforts to address critical ongoing issues such as state laws that criminalize HIV status. As stated in the NHAS, CDC data and other studies tell us that intentional HIV transmission is atypical and uncommon. This requires clear statements from CDC about the routes and relative risks of HIV transmission, as well as other affirmative leadership. For instance, it also will require the identification and evaluation of best practices to support jurisdictions that have taken constructive steps to alleviate such discrimination from HIV-specific criminal law, and to support the transfer of these findings to other jurisdictions. This is an important area for ongoing dialogue between PACHA and federal partners.

**Improve Access to Health Care to Alleviate Health Disparities.** As also noted in the care section above, it is urgent and vital that we eliminate the AIDS Drug Assistance Program waiting list through a combination approach, including the implementation of programs through Medicaid to bridge the gap to 2014 and significantly increased federal appropriations to immediately eliminate waiting lists. Additionally, federal standards should be set to prevent exclusionary program thresholds, such as income eligibility levels, and to ensure an acceptable formulary of medications. Further, we must not stop with ADAP waiting lists but must also attempt to address the entire cascade of unmet HIV care needs described above. Moreover, as we look to 2014, it must be acknowledged that a range of Ryan White-funded support services is essential to assure access to care and must be continued.

**Expand HHS 12 Cities Project.** CDC's Enhanced Comprehensive HIV Prevention Planning (ECHPP) and HHS' Twelve Cities demonstration projects have been outstanding opportunities to re-examine HIV/AIDS efforts at a local level in a number of very disproportionately impacted locales. We applaud these efforts, and call for their expansion with additional funding. In particular, we recommend that the Twelve Cities project be expanded to include areas with high rates of new transmissions, as well as highly impacted rural areas. Through this expansion lessons learned throughout the demonstration project can be appropriately applied to additional areas of rapidly expanding epidemics, smaller cities and to

rural America. Such an expansion might include a mix of replications of the 12 Cities Projects in some jurisdictions, as well as a much broader delivery of technical assistance services across the country (including capacity building services on emerging topics such as resource allocation)

**COORDINATION.** A very important but unsung section of the NHAS rightly calls for increased public/private- sector interface. We applaud the White House for its forum on public/private sector initiatives, and congratulate HHS for its outstanding efforts to bring together federal agencies working on HIV issues in ways never seen before. There is an increase in communication across agencies that can be clearly noticed. However, we believe there are further opportunities in this area.

**Coordinate Funding Announcements, Reporting Requirements, and Evaluation.** As noted above, Health Departments that are grantees of federal agencies now face dozens of uncoordinated reporting requirements, and must report on hundreds of variables as a condition of funding. It is vital that these requirements and evaluation metrics be streamlined to a small, strategically chosen set that will not only save administrative resources but allow for increased, more targeted, and more effective service delivery to clients. Further, this set of reporting requirements metrics should be directly tied to annual measurement of progress toward the achievement of the goals of the NHAS.

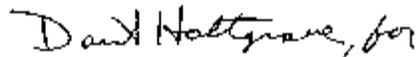
**Continue Support of Transfer Authority for Strategy Implementation Funds.** We applaud the Administration for including in the FY12 Presidential Budget Request a plan to build a Strategy Implementation Fund to be used by the Secretary to address key unmet needs and that will help garner information and provide analyses to make optimal use of the entirety of federal HIV/AIDS efforts. Such cross-agency reallocation is crucial to improve our response to the epidemic, and in the future, we believe that such a fund must be maintained and potentially even expanded. We support your efforts to obtain the transfer authority necessary to make this critical fund a reality.

**DOMESTIC/GLOBAL EPIDEMIC INTERFACE.** Although this letter focuses primarily on the NHAS and the epidemic in the U.S., it is important to recognize the much larger global epidemic and consider that the domestic epidemic exists within and interfaces epidemiologically with the global epidemic. There are important lessons to be learned in both directions and key strategies which can be utilized to confront the challenges of the epidemic both at home and abroad. America's efforts to tackle the global AIDS epidemic through PEPFAR and the Global Fund have had profound impact and laid the foundation for the Administration's Global Health Initiative. However, new resources and portfolio realignment are necessary to take advantage of the connection between HIV treatment and prevention and to scale up these proven evidence-based approaches in our international efforts. We therefore urge targeted new resources for the domestic and global AIDS response -- beyond those proposed in your FY12 budget -- that are designed to take advantage of the new opportunities at hand. We have a moral imperative to turn the tide of the AIDS pandemic globally as it devastates individuals, families, communities, and society at large -- possibly threatening our national security as 50 million children worldwide could be left parentless by 2020 without bold action.

**CONCLUSION.** In summary, we find ourselves collectively at the thirtieth anniversary of the HIV epidemic in the U.S., it is clear that progress has been made and it is no longer the same epidemic it was previously. However, as the NHAS rightly points out, this epidemic is far from over in our nation, and much work must be done in the most urgent fashion possible. We have attempted here to highlight some areas that we believe are in need of greatest attention in the coming year. We gratefully point out that in many cases, your teams in the White House and HHS have already anticipated these issues and are working diligently on them. Hence our points may not be unique, but given our charge as PACHA, we felt it was our responsibility to underscore the importance of these key issues so that you would know directly what we collectively felt are some of the most critical activities needing near term attention.

We thank you most sincerely for taking the time to consider our reflections and recommendations, and would be pleased to hear from you on how we might be of continued and optimal service to the Administration. We take very seriously our roles as members of PACHA and are eager to tackle tasks that you would find informative and useful. We all share your intense commitment to addressing the HIV epidemic in the U.S. and across the globe; indeed, we have all devoted our lives to ending this epidemic.

With greatest respect and appreciation,



Helene Gayle, M.D., M.P.H.  
Chairperson  
Presidential Advisory Council on HIV/AIDS

## Resolution Requesting Federal Activities To Eliminate HIV Health Disparities Among Black MSM

September 30, 2011

WHEREAS, the Centers for Disease Control and Prevention (CDC) HIV surveillance report, released on August 3, 2011, underscored the significant health disparities that exist for Black gay and other men who have sex with men (BMSM) in general and young Black gay and other men who have sex with men (YBMSM) in particular, showing that while the overall number of new HIV infections in the United States has remained fairly stable from 2006–2009, there continues to be an increase in new infections among BMSM; most alarming was the 48 percent growth of new HIV infections among YBMSM, ages 13-29, with a statistically significant estimated annual increase of 12.2 percent and,

WHEREAS, the CDC reported in the *Annals of Internal Medicine* on August 1, 2011, that rates of primary and secondary syphilis, an indicator of elevated risk for HIV transmission and acquisition, disproportionately increased in recent years among Black and Hispanic young men who have sex with men and,

WHEREAS, a study presented at the National Medical Association 12th Annual Colloquium on March 31, 2011, reported that social stigmatization is still the largest barrier keeping African American frontline physicians from routinely testing their patients for HIV and,

WHEREAS, a study published in the *American Journal of Public Health* in December 2010 reported on the disproportionately pervasive trauma exposure histories and post-traumatic stress disorder risk in a large survey of sexual minorities, including MSM, and,

WHEREAS, a September 2011 special supplement to *Public Health Reports* underscores a need to address social determinants of health (SDH)—the underlying economic and social conditions that influence the health of individuals and communities as a whole.

BE IT RESOLVED that the Presidential Advisory Council on HIV/AIDS calls on the Secretary of Health and Human Services to convene a high-level summit (including government and nongovernment stakeholders) on the HIV epidemic and its impact on YBMSM and to create a department-wide task force charged with developing a comprehensive plan to address all aspects of the epidemic among YBMSM.

We also call on the Secretary to ensure the following: 1) that HIV prevention, care and treatment funding distribution methodologies are aligned with the epidemic in ways that adequately support the needs of populations disproportionately impacted by HIV, including YBMSM; and 2) that knowledge gained from studies of social determinants of health are integrated into all interventions that might help to reduce inequalities in health.

We further call on the NIH to develop and issue a high priority research plan, by March 31, 2012, that addresses HIV among YBMSM, including evaluating the potential benefits of biomedical interventions (such as PrEP and treatment as prevention) and the use of novel technologies and other strategies to engage YBMSM in care and treatment and combination preventions strategies.

We call on HRSA and the CMS to require all physicians practicing at publicly funded institutions or receiving public reimbursement for the delivery of health care services to undergo continuing medical education (and where available certification) in HIV testing, care and treatment.

In conclusion, the National HIV/AIDS Strategy visions a nation where HIV infections are rare and that all those in need of care are granted it without exception. Providing prevention, care and treatment, and all social services that are culturally structured and of high quality to Black MSM at all stages of life is a key milestone to ending the HIV epidemic in the United States.

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## Presidential Advisory Council on **HIV/AIDS**

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March 14, 2012

The Honorable Kathleen Sebelius  
U.S. Department of Health and Human Services  
200 Independence Avenue, SW  
Washington, DC 20201

Dear Secretary Sebelius:

We are writing on behalf of the **Presidential Advisory Council on HIV/AIDS (PACHA)** and the **Centers for Disease Control and Prevention (CDC)/Health Resources and Services Administration (HRSA) Advisory Committee on HIV, STD, and Viral Hepatitis Prevention and Treatment (CHAC)** to update and request your support with addressing the broad area of sexual health in the United States (U.S.). Our committees believe that sexual health is an important element of health across the lifespan and that its promotion has great potential to enhance the impact of core public health programs focused on preventing adverse outcomes with which we are concerned – HIV, STD, and viral hepatitis – as well as other public health issues facing the nation such as teen and unintended pregnancy, and sexual violence. While none of these adverse outcomes are new challenges in the U.S., we believe that a **sexual health framework** provides a unifying theme with a focus on health, rather than on disease, that may counter the forces of stigma and provide a positive, life-affirming approach.

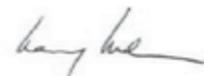
In 2009, the National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP) at the CDC established a Steering Committee to explore the potential role of public health entities at the federal and local level in advancing sexual health as an essential component of overall individual health. In 2010, NCHHSTP held a technical consultation to gain input from partners and stakeholders <http://www.cdc.gov/sexualhealth/docs/SexualHealthReport-2011-508.pdf> on sexual health. CHAC was briefed on these efforts at its May 2010 bi-annual meeting and in November, 2010 created a Sexual Health Workgroup of the CHAC to provide a forum for developing recommendations for CDC and HRSA in this area. The CHAC Workgroup developed a new definition of sexual health in 2011 to provide greater clarity to the effort. The Workgroup has also reviewed the development of a set of sexual health indicators and a draft policy statement on a *Public Health Approach for Advancing Sexual Health in the United States*. The importance of sexual health as a framework was initially articulated in 2001 by the *Surgeon General's Call to Action to Promote Sexual Health and Responsible Sexual Behavior* and has been recently endorsed by the National Prevention Strategy with its emphasis on prevention and wellness rather than sickness and disease and with its selection of Reproductive and Sexual Health as one of its seven highest priority areas of focus. In 2012, eleven years after the Surgeon General's *Call to Action*, attaining sexual health remains a challenge for Americans. For example, more than 1.3 million cases of Chlamydia were reported to the CDC in 2010, the largest number of infections ever reported domestically, at a rate well beyond that reported by other industrialized countries worldwide. Chlamydia is of particular concern for young women who have the highest rates of infection between the ages of 15-24 years old, placing them at risk for infertility. Syphilis is re-emerging as a major problem, particularly among men who have sex with men, and antibiotic-resistant gonorrhea is a critical threat. Even more alarming is the fact that new HIV infections among young black men who have sex with men, increased 48% from 2006 through 2009. These challenges continue to undermine the health of our nation.

We recognize that the political environment of an election year is charged with many external constraints, but we believe that the health of Americans, especially for young men and women, we cannot wait to support the promotion and endorsement of a mature national dialogue on issues of sexuality, sexual health, and respectful and responsible sexual behavior. **Given this, PACHA and CHAC recommend that HHS, CDC and HRSA leadership support the development and implementation of a public health approach to advancing sexual health in the United States through the following:**

- expand efforts by CDC, HRSA, and other entities within HHS (e.g. OHAP, OMH, OWH, OAH) to address sexual health including a focus by the leadership of these organizations on supporting and disseminating messages regarding the importance of this issue; continue and
- to enhance educating young people with comprehensive, medically accurate, age-appropriate sexual health information and to create measurable standards; ensure efforts
- Division of Adolescent and School Health in advancing its efforts to implement evidence-based sexual health education for prevention of HIV, STD and teen pregnancy by ensuring sufficient funding for current and future activities; support the
- plan for increased training of health professional students and health care providers in comprehensive understanding of human sexuality and their ability to provide effective sexual health services; develop a
- monitor a comprehensive set of national indicators for sexual health and to address important research priorities; develop and
- approved policy statements promoting a sexual health approach; and create HHS
- report from the Institute of Medicine on gaps and priorities in addressing sexual health in the U.S. commission a

In closing, we understand that societal discussions on sexuality can be challenging and that there are many levels of sensitivities and complexities associated with dialogues around sexual health. However as your federally appointed advisors on HIV/AIDS, STD, and viral hepatitis, we feel compelled by the urgency of this issue and the need to reframe how we address sexually transmitted diseases, unintended pregnancies and partner violence, we needed to raise it to the highest levels. The chairs of each committee are willing and happy to meet with you at anytime to discuss this further. Finally, we thank you for your ongoing efforts towards improving health for all Americans, we appreciate your review and consideration of this issues outlined in this letter.

Sincerely,



PACHA Chair  
Nancy Mahon



CHAC co-Chair  
Antigone H. Dempsey



CHAC co-Chair  
Jeanne Marrasso

cc: Thomas R. Frieden, Director, CDC and Mary Wakefield, Administrator, HRSA

## Resolution on the Needs of Women Living With HIV

May 17, 2012

WHEREAS we are at a critical moment in the HIV epidemic and cannot end the epidemic without addressing the specific needs of all affected communities;

WHEREAS women bear more than a quarter of the domestic HIV burden and women of color represent over three-quarters of women living with HIV;

WHEREAS women living with HIV enter later into HIV care, have a lower likelihood of receiving antiretroviral therapy, have twice as many HIV-related illnesses, and have higher mortality rates, than men;

WHEREAS accessing care and essential support services, including housing, are particularly complicated for women living with HIV as they are disproportionately low-income, and are more likely to have caretaking responsibilities, than men;

WHEREAS the primary mode of HIV acquisition for woman is heterosexual contact and female-controlled prevention methods are not yet available;

WHEREAS transgender women living with HIV face unique challenges in accessing and adhering to HIV and HCV care and treatment regimens;

WHEREAS women most at risk for or living with HIV are more likely to experience sexual or intimate partner violence one or more times in their lives;

WHEREAS the Affordable Care Act (ACA) provides numerous opportunities to increase access to care for women living with and at risk for HIV, including expanding access to private and public insurance coverage;

WHEREAS sustained success in perinatal prevention efforts requires unfettered access to prenatal care;

WHEREAS access to reproductive health services is essential to decrease the occurrence of unplanned pregnancies and to promote safe conception;

BE IT RESOLVED, the PACHA recommends that the Secretary of Health and Human Services (HHS) request all relevant Federal agencies work with the White House Office of National AIDS Policy and the HHS Office of HIV/AIDS Policy to develop amendments to the National HIV/AIDS Strategy and its implementation plan to ensure they include specific, targeted and measurable goals and objectives for reducing HIV incidence and HIV-related health disparities and improving health care access and health outcomes for women living with HIV.

BE IT FURTHER RESOLVED, the PACHA recommends that the National HIV/AIDS Policy (NHAS) implementation plan be amended to address the needs of women in the following ways:

- 1) To evaluate the effectiveness of the first two years of the National HIV/AIDS strategy in addressing the needs of women living with HIV, including those co-infected with HCV;
- 2) To make gender-sensitive care for women living with HIV more widely and readily available through the integration of HIV care and prevention services with sexual and reproductive health care and intimate partner violence prevention and counseling;
- 3) To expand and expedite the provision of housing and services that facilitate linkage to and retention in care for women with HIV;
- 4) To produce and make available in a timely manner more refined data that analyzes the unique health and service needs of women with HIV; and
- 5) To produce expanded research into the development of women-controlled prevention methods.

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BE IT FURTHER RESOLVED that the PACHA recommends that routine HIV testing, screening and counseling for intimate partner violence and sexually transmitted infections be covered as required Medicaid preventive services for women, just as these services are now required to be covered by private insurance plans without cost sharing.

BE IT FURTHER RESOLVED that the PACHA recommends that ONAP work with HHS, the Health Resources and Services Administration (HRSA), and the Centers for Medicare and Medicaid Services (CMS) to develop an Affordable Care Act implementation plan that ensures that the full prevention, care, and treatment needs of women living with and at risk for HIV are met.

## Resolution To Support Comprehensive Sex Education for Our Nation's Youth

May 17, 2012

WHEREAS young people ages 13 – 29 make up one third of new HIV infections, the largest share of any age group;

WHEREAS data released in August 2011 from the Centers for Disease Control and Prevention (CDC) show that the only age group where HIV incidence is increasing is young people ages 13–29, driven by an increase in new infections among young men who have sex with men, primarily young black men;

WHEREAS the National HIV/AIDS Strategy goal of reducing new infections by 25 percent cannot be reached without addressing the age group most impacted by new HIV infections;

WHEREAS comprehensive sex education programs give young people the information and tools they need to make healthy and responsible decisions about their sexual health, not only in their adolescence, but throughout their lifetimes;

WHEREAS the finalized Fiscal Year (FY) 2012 funding included a devastating \$10 million cut to the CDC's Division of Adolescent and School Health (DASH), the only Federal funding dedicated to HIV, sexually transmitted infection (STI), and unintended pregnancy prevention in our nation's schools;

WHEREAS DASH funding helps to provide educators the tools they need to instruct students in preventing STIs, including HIV, and unintended pregnancy;

WHEREAS the FY 2012 budget also includes \$5 million in funding for abstinence only until marriage programs that a preponderance of studies has shown are ineffective and that do not meet the HIV prevention needs of young people or HIV positive young people;

WHEREAS abstinence only until marriage programs were zeroed out in FY 2010 and FY 2011, as well as in the President's Request for the FY 2013 budget, after more than \$1.5 billion in Federal and state funding have been spent on these ineffective programs;

WHEREAS the Teen Pregnancy Prevention Initiative was created in FY 2010 to implement evidence based teen pregnancy prevention interventions and to build upon the existing body of evidence of teen pregnancy prevention programs by funding innovative approaches;

WHEREAS the Personal Responsibility Education Program was created through the Affordable Care Act to provide states with funding to implement sex education programs that educate young people about abstinence, contraception, and adult preparation subjects, such as healthy relationships and communication and decision-making skills;

WHEREAS the Title V Abstinence Only Program was reauthorized in the Affordable Care Act even though a 2007 Congressionally mandated study of Title V abstinence only until marriage programs show funded programs to have no impact on delay of sexual activity—the entire supposed purpose of the programs;

WHEREAS leading medical, scientific, and public health organizations, including the American Medical Association, American Academy of Pediatrics, American Congress of Obstetricians and Gynecologists, and the Society for Adolescent Health and Medicine support comprehensive sex education and have called for an end to Federal funding for abstinence only until marriage programs;

WHEREAS evidence-based and medically accurate interventions give states and organizations a starting point to find the best programs for their communities but are not held to comprehensive sex education content standards;

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WHEREAS this past World AIDS Day, the President boldly announced his Administration's commitment "...to ending the AIDS pandemic once and for all..." and pledged to fight HIV "...today, tomorrow, every day until we get to zero";

WHEREAS as a nation we will not be able to achieve the commendable goal of zero new infections without stemming the tide of new infections among young people; and

WHEREAS each day presents our nation's schools and community based organizations with the opportunity to play a critical role in reaching 56 million young people, providing them with information about health, and giving them the opportunity to practice the skills that promote life long, healthy behaviors;

BE IT RESOLVED that the Presidential Advisory Council on HIV/AIDS requests that the Federal Government increase HIV prevention efforts with young people, not drastically cut funding and dismantle the programs that work on the ground where young people are – in our nation's schools.

BE IT RESOLVED that the PACHA supports the expansion of adolescent sexual health efforts in the National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP) at the CDC, including the continuation of DASH as a stand alone Division within NCHHSTP and for the funding to remain dedicated to State, Local, and Territorial Education Agencies as well as to the non governmental organizations that support their efforts.

BE IT RESOLVED that all federally funded sex education programs should aim to reduce unintended pregnancy and sexually transmitted infections, including HIV; promote safe and healthy relationships; and promote and uphold the rights of young people to have access to information in order to make healthy and responsible decisions about their sexual health.

BE IT FURTHER RESOLVED that all federally funded sex education programs should use and be informed by the best scientific information available; be built on characteristics of effective programs; and expand the existing body of evidence on comprehensive sex education programs through program evaluation.

BE IT FURTHER RESOLVED that no Federal funds should be used for health education programs that deliberately withhold lifesaving information about HIV; are medically inaccurate or have been scientifically shown to be ineffective; promote gender stereotypes; are insensitive and unresponsive to the needs of sexually active adolescents; are insensitive and unresponsive to the needs of lesbian, gay, bisexual, or transgender youth; or are inconsistent with the ethical imperatives of medicine and public health.

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Presidential Advisory Council on  
**HIV/AIDS**



**PACHA Syringe Exchange Letter to President Obama**

May 17, 2012

The Honorable Barack H. Obama  
The White House  
1600 Pennsylvania Ave., NW  
Washington, DC 20500

Dear Mr. President,

As members of the Presidential Advisory Council on HIV/AIDS, we would like to thank you for your previous support for use of federal funds for syringe services programs (SSPs), and we request your continued leadership on behalf of the critical role that SSPs play in achieving the goals of the National HIV/AIDS Strategy (Strategy).

As stated in the Strategy, "...studies show that comprehensive prevention and drug treatment programs, including needle exchange, have dramatically cut the number of new HIV infections among people who inject drugs by 80 percent since the mid-1990s." The Strategy additionally states that access to sterile needles and syringes is one of five "...scientifically-proven biomedical and behavioral approaches that reduce the probability of HIV transmission..." and further states that "...several studies have found that providing sterilized equipment to injection drug users substantially reduces risk of HIV infection, increases the probability that they will initiate drug treatment, and does not increase drug use."

In December 2009, you signed into law the Consolidated Appropriations Act 2010, ending a two-decade ban on federal funding for syringe exchange programs contained in the Labor, Health and Human Services, Education, and Related Agencies Appropriations bills. This policy allowed local jurisdictions to invest federal funds for syringe exchange as a component of comprehensive HIV/AIDS and viral hepatitis prevention services and substance abuse treatment and recovery programs. Unfortunately, Congress imposed a complete ban on use of federal funds for SSPs for FY 2012. This reversal represents a major setback in achieving the goals of the Strategy at a pivotal time in the course of the epidemic. The funding restriction also diminishes our credibility and leadership on HIV/AIDS globally and our advocacy efforts to support effective, evidence-based strategies to combat the HIV/AIDS epidemic internationally.

Page 2 – The Honorable Barack H. Obama

Ending the ban on the use of federal funds for syringe services programs remains an urgent priority for the public health, HIV/AIDS, viral hepatitis, and harm reduction communities. Sustaining and expanding access to sterile syringes and comprehensive services for people who inject drugs is of vital importance to disease control efforts, as state and local jurisdictions struggle to adequately resource these programs as they confront new challenges and growing demand. We are extremely concerned that the FY 2012 federal funding ban may worsen access to HIV testing and prevention interventions for this key risk group, exacerbate HIV-related racial and ethnic health disparities among injection drug users, and jeopardize our ability to meet the goals of the Strategy.

We support your FY 2013 budget language that would allow for the use of federal funds to support SSPs:

*“SEC. 505. None of the funds contained in this Act may be used to distribute any needle or syringe for the purpose of preventing the spread of blood borne pathogens in any location that has been determined by the local public health or local law enforcement authorities to be inappropriate for such distribution.”*

This language is consistent with our longstanding position on this issue and is further amplified by a recent statement made to the PACHA reiterating strong community support for evidence-based efforts.

We encourage the Administration to continue its support for this language, to prioritize restoring local flexibility in funding syringe services programs during negotiations around the FY 2013 Appropriations bills, and to clearly convey this priority to Congress.

Again we thank you for maintaining your Administration’s focus on syringe services programs.

Respectfully yours,



Nancy Mahon, Chair  
Presidential Advisory Council on HIV/AIDS

## **HIV Disclosure Summit**

June 28-29, 2012

### **I. Background**

In 2010, the White House released a National HIV/AIDS Strategy (NHAS), which established a new vision for our response to the HIV/AIDS crisis in the United States (US)—a response that turns the US into a place where new HIV infections are rare and every person living with HIV has “unfettered access to high quality, life-extending care, free from stigma and discrimination.” To achieve this vision, the NHAS sets out a number of action steps for federal agencies, including the two existing federal advisory bodies: the Presidential Advisory Council on HIV/AIDS (PACHA), and the Centers for Disease Control and Prevention (CDC)/Health Resources and Services Administration (HRSA) Advisory Committee on HIV, Viral Hepatitis, and STD Prevention and Treatment (CHAC). Under “Goal 3: Reduce HIV-Related Health Disparities; Step 3: Reduce stigma and discrimination against people living with HIV,” the Federal Implementation Plan put forth the following directives for PACHA and CHAC:

- PACHA will be tasked with developing recommendations for ways to promote and normalize safe and voluntary disclosure of HIV status in various contexts and circumstances.
- CHAC will solicit public input and make recommendations for normalizing and promoting individuals’ safe, voluntary disclosure of their HIV status. HRSA will publish the recommendations.

As advisors to the President, Secretary of Health and Human Services, HRSA Administrator and CDC Director, the Disclosure Workgroup held a 2-day HIV Disclosure Summit on June 28-29, 2012 with thought leaders from cross-cutting and diverse public and private partners, e.g. people living with HIV and community advocates, social scientists, medical ethicists, researchers, health providers, education leaders, lawyers, policy makers and others. The workgroup created guiding principles and policy recommendations to these Federal officials to consider adopting. The policy recommendations and guiding principles are outlined below and were created to address the structural barriers (federal, state and local) to safe and voluntary HIV disclosure in the US. We believe these recommendations are integral to meeting the broader goals of reducing new infections, increasing access to care, and reducing health disparities, as outlined in the NHAS.

### **II. Guiding Principles**

#### *Preamble*

**We are committed to ending the HIV/AIDS epidemic.** We are committed to honoring the strength and resilience of people living with HIV and their invaluable role in the nation’s ongoing fight against the epidemic. We are committed to ensuring and protecting the right and ability, of all people, to live full, healthy lives.

With these commitments firmly in mind, we recognize and respect:

- the ultimate autonomy of each individual faced with the opportunities and challenges of disclosing her or his HIV status;

- that disclosure of HIV status is not a single, discrete event, but rather an ongoing process that spans a lifetime and a myriad of contexts; and
- the disclosure process necessarily involves multiple parties.

These commitments and the recognition of the characteristics of the disclosure process informed the development of the guiding principles for our discussions and our ultimate recommendations. While this document is focused on the NHAS directives on HIV disclosure, the group also acknowledges that disclosure of all STIs promotes greater communication and sexual health.

Now, therefore, we set forth the following Guiding Principles:

**PRINCIPLE NO. 1:**

**SOCIETY HAS AN OBLIGATION TO CREATE A SAFE ENVIRONMENT FOR DISCLOSURE**

There is an obligation and a responsibility for society to create a safe environment for people to voluntarily disclose their HIV status as well as other sexually transmissible infections. Accordingly, any laws and policies that create disincentives to an individual's safe and voluntary disclosure of her or his HIV status, e.g., by increasing HIV stigma and discrimination, should be eliminated. All relevant Federal, state and local laws and policies should incorporate the current state of medical science, best-practices in public health, and evidence-based strategies and priorities for effectively addressing the HIV epidemic and should strive to create and maintain resources and environments conducive to safe and voluntary disclosure.

**PRINCIPLE NO. 2:**

**DISCUSSION OF HIV AND STI STATUS IS IMPORTANT**

Confidential and ongoing communication about HIV status and other relevant sexual health conditions (both for those living with HIV and those whose current status is negative or unknown) is essential for individual, family, and community health. An environment that allows for safe, voluntary disclosure empowers persons living with HIV to: 1) access support and care without fear of stigma or persecution; and 2) participate in the organizations and mechanisms of policy, to which they bring invaluable lived-experience. Ultimately, an environment that protects the ability to engage in safe and voluntary disclosure enables all community members to make informed decisions in regard to their own health and conduct.

**PRINCIPLE NO. 3:**

**THE CIRCUMSTANCES AND CONTEXT OF DISCLOSURE MUST BE RESPECTED**

A complex constellation of cultural and social factors influences every individual's ability to safely disclose her or his HIV status. These factors must be respected in order to create environments that facilitate safe and voluntary disclosure. Only if we understand and appreciate the external pressures militating against safe, voluntary disclosure, can we create solutions that allow for all people to access the support, treatment and education resources that they need and deserve.

**III. Policy Recommendations**

In light of the foregoing Guiding Principles, we make the following policy recommendations:

**Short-term recommendations**

1. **HHS and other federal funders should devote a portion of currently funded programs to facilitate campaigns and education** on safe and voluntary disclosure that encourages

an understanding of HIV in the context of a range of sexually-transmissible diseases that can have a profound impact on health and life. Infuse issues of disclosure in prevention campaigns. Encourage NIH to research what is already known related to effective programs and how to apply their research findings.

*This recommendation responds to each of our guiding principles by: 1) developing the research base to inform laws and policies (Principle #1); 2) educating Americans about safe and voluntary HIV disclosure and encourage their ongoing discussions (Principle #2); and 3) addressing the circumstances that may influence those discussions (Principle #3).*

2. **Federal funders should develop and/or disseminate a quantitative and qualitative research agenda** and fund studies on the benefits and challenges of disclosure.

*Developing a comprehensive research agenda on disclosure will: 1) help better inform laws and policies regarding HIV/AIDS (Principles #1 and #2); 2) develop strategies for encouraging safe and voluntary disclosure in a variety of contexts (Principles #2 and #3).*

3. **The Surgeon General should write a letter to the American People** containing up-to-date information about HIV/AIDS and the importance of frank discussions about maintaining sexual health. Much has changed since Surgeon General Koop's 1988 letter; a new letter will help correct many persistent misconceptions about HIV, its transmission, and the prognosis for those whose infection if detected early and are provided with appropriate access to HIV-related healthcare

*We envision this letter as addressing each of our guiding principles, by using the authority of the Surgeon General to provide up-to-date information about HIV that will: 1) inform laws and policies based on best evidence and best practices in 2012 (Principle #1); 2) encourage all Americans to discuss, as appropriate, HIV with their partners, families, friends, and medical professionals (Principle #2); and 3) identify the factors that may impede or facilitate those discussions (Principle #3).*

4. **The Secretary of Health and Human Services should appoint an HHS representative** to work with the associate attorney general to create a working group to examine laws and policies that discriminate against people with HIV and formulate recommendations for the elimination of those laws, and develop recommendations for laws and policies that would support and protect people living with and vulnerable to HIV.

*This recommendation is directly responsive to Principle #1. Such an analysis will enable policymakers to make the required changes to ensure that laws do not create disincentives to disclosure and suggest ways that laws might be reformed to create a supportive atmosphere for disclosure. Such efforts can also underscore the importance of safe and voluntary HIV disclosure, while recognizing how context may influence the ability to do so (Principles #2 and #3).*

5. **Establish a dedicated position within the office of the Associate Attorney General** for HIV Law and Policy.

*This recommendation is similarly responsive to Principle #1 and is intended to provide leadership on the role of law in fostering a supportive environment for safe and voluntary HIV disclosure. As such, this recommendation may also serve to support the recognition of the importance of HIV disclosure in a variety of contexts (Principles #2 and #3).*

#### **Long-term recommendations**

6. **HHS and medical providers should prioritize disclosure support as a component of mental health services within clinical settings.** Include disclosure education, training

and support under the definition of “peer navigator/support.” Recognizing that disclosure is a continuous and voluntary process, we need to fund the supportive work around disclosure in the clinical setting over a person’s lifespan. In addition, the following approaches should be supported:

- a. Part of the clinical care model should include a comprehensive discussion of HIV and STI disclosure outcomes with a trauma-informed approach to care. Approaches to disclosure in the clinical setting which merely involve informing the newly-diagnosed of the existence of a law mandating disclosure and/or advising and admonishing the person to disclose to all sexual partners should be discouraged.
- b. To support this, AETCs should be allowed to train peers and count peer training. In addition, medical professionals need to be trained. Accordingly, nursing and medical education should include skills building on supporting and facilitating disclosure.

*Providing this support recognizes the importance of HIV disclosure (Principle #2) and addresses some of the potential barriers to voluntary HIV disclosure (Principle #3). More disclosure education may ultimately help in creating a more supportive atmosphere for safe and voluntary HIV disclosure (Principle #1).*

7. **HHS should develop sex-positive prevention messages** rooted in evidence-based research but also reflecting and tailored to people’s real lives; create culturally relevant messages developed by people living with HIV.

*The recommendation responds to Principle #3 and seeks to address some of the factors that may facilitate or impede HIV discussions. Messages developed in accordance with this recommendation are also likely to advance Principle #2, by discussing the importance of HIV discussions.*

8. **HHS should develop ways to encourage and incentivize states to address state and local laws that create barriers to disclosure of HIV status and access to care.** To further support this, we recommend that HHS conduct an objective analysis on the impact of these laws on access to testing and care.

*These recommendations are directly responsive to Principle #1 by identifying a specific way to understand how state law may either support or discourage discussion of HIV status and by creating incentives to develop legal environments that are supportive of safe and voluntary disclosure.*

**Participants**

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Ahmadi, Halima  
Birnbaum, Jeffery  
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**HHS Federal Observers**

Cheever, Laura  
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## Resolution on Implementation of the Patient Protection and Affordable Care Act (ACA) in Ways That Meet the National HIV/AIDS Strategy (NHAS) Goals

January 7, 2013

WHEREAS current inequities in the health care system fuel HIV-related disparities and contribute to a public health crisis for people living with HIV in the U.S. as evidenced by nearly 30 percent being uninsured (versus 16 percent of the general population), and nearly 50 percent of people with HIV relying on Medicaid coverage, which is generally obtainable only after they become disabled;

WHEREAS recent studies have demonstrated that early access to care, treatment, and supportive services is important to ensuring treatment success, improving individual health outcomes, lowering the overall cost of treatment, and drastically reducing the risk of transmission;

WHEREAS the ACA provides critical opportunities to develop a health care system that will increase access to care, reduce HIV-related health disparities, and reduce new HIV infections;

WHEREAS the ACA also includes a number of optional state programs and initiatives which will improve the ability of Medicaid and other programs to meet the needs of low-income, underserved populations, including: the Medicaid Health Home Program for beneficiaries with chronic conditions; providing preventive services in Medicaid without cost-sharing; and the Basic Health Program to reduce health coverage “churn;”

WHEREAS the Supreme Court’s holding on the Medicaid expansion, as well as recent Federal guidance and regulations, increase state flexibility and discretion across a range of implementation activities (including Medicaid expansion, design of the essential health benefits package, and the design and implementation of exchanges), and create the potential for continued HIV geographic disparities;

WHEREAS the ACA’s potential to help achieve the NHAS goals and ultimately end the epidemic in this country is dependent on full and effective state and Federal implementation of the ACA, as well as an ongoing robust commitment to the Ryan White Program to address ongoing care, treatment, services, affordability and covered population gaps; and

WHEREAS efforts to meet the retention in care and viral suppression goals of the HIV Care Cascade, as well to meet the NHAS goals, depend upon the Federal Government’s support of a Ryan White Program that has the ability to address gaps in core health and support services (such as vision and dental care, transportation, case management, and housing services) as well as gaps in affordability (associated with insurance premium and co-payment obligations); therefore

BE IT RESOLVED, the PACHA recommends that the Secretary of Health and Human Services (HHS) exercise her broad discretion in implementing the ACA through Federal regulations and guidance in ways that promote the goals of the NHAS, limit geographic disparities with regard to access to insurance and scope of benefits, and ensure access to HIV/AIDS prevention, care, and treatment that meet the HIV standard of care, specifically through the following ways:

- 1) Ensure that essential health benefits requirements for plans sold in individual and small group markets in 2014 as well as for packages available to newly eligible Medicaid beneficiaries guarantee access to the HIV standard of care, including unrestricted access to anti-retroviral medications, comprehensive mental health and substance abuse services, and unfettered access to specialists trained in HIV care and treatment;

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- 2) Ensure that the ACA's non-discrimination requirements are defined and enforced in ways that explicitly prohibit plans from using utilization management techniques, service limits, and other discriminatory plan design options, such as high co-payments and cost-sharing, to limit coverage for people living with HIV and other complex conditions;
  - 3) Ensure that exchange requirements for both state-run and federally facilitated exchanges include provider network adequacy standards that mandate inclusion of HIV medical providers, as well as robust consumer outreach and enrollment standards and Patient Navigator Program standards that leverage the expertise of community-based organizations experienced in outreach to vulnerable populations;
  - 4) Ensure that states are aware of the ACA's optional programs and initiatives, including the Medicaid expansion, by providing guidance to states on implementation strategies as well as technical assistance to help states prepare their infrastructure and programs for the expansion; and
  - 5) Ensure that adequate data is available to monitor and evaluate outcomes for people with HIV across third-party payers by encouraging states to require reporting on HIV-related quality measures.

BE IT FURTHER RESOLVED, the PACHA recommends that the Secretary of HHS appoint a senior level advisor within HHS, who reports directly to both the Secretary and the Administrator for the Centers for Medicare and Medicaid Services (CMS), to help coordinate HIV-related Medicaid expansion implementation efforts with HRSA and the CDC, to ensure that as the Medicaid expansion is implemented people living with HIV have uninterrupted access to care, treatment and qualified medical providers, and to oversee the transition of people living with HIV to Medicaid in 2014 and beyond.

BE IT FURTHER RESOLVED, the PACHA recommends that the Ryan White Program be maintained throughout the development and implementation of ACA reforms and then, once successful integration of HIV care, treatment and service models is achieved, re-tool the program to ensure it has the capacity to fill ongoing gaps in core health and support services as well as to address gaps in affordability.

BE IT FURTHER RESOLVED, the PACHA recommends that the Health Resources and Services Administration HIV/AIDS Bureau work collaboratively with CMS to provide technical assistance to Ryan White grantees and providers to help develop plans for transitioning and adapting to the new health care financing environment, to grow workforce capacity, and to ensure that information is available to Ryan White Program grantees to support Ryan White clients as they transition to health care coverage.

## Resolution on Ending Federal and State HIV-Specific Criminal Laws, Prosecutions, and Civil Commitments

February 7, 2013

Despite the relatively low risk of transmission and significantly lowered level of harm, thirty-four U.S. states and territories have adopted criminal statutes based on perceived exposure to HIV. Most of these laws were adopted before the availability of effective antiretroviral therapy for HIV, which substantially reduces already low transmission risks and provides a pathway to highly successful HIV treatment. Clearly the use of HIV-specific criminal laws, of felony laws such as attempted murder and aggravated assault, and of sentence enhancements to prosecute HIV-positive individuals are based on outdated and erroneous beliefs about the routes, risks, and consequences of HIV transmission. Legal standards applied in HIV criminalization cases regarding intent, harm, and proportionality deviate from generally accepted criminal law principles and reflect stigma toward HIV and HIV-positive individuals. People living with HIV have been charged under aggravated assault, attempted murder, and even bioterrorism statutes, and they face more severe penalties because law enforcement, prosecutors, courts, and legislators continue to view and characterize people living with HIV and their bodily fluids as inherently dangerous, even as “deadly weapons.” Punishments imposed for non-disclosure of HIV status, exposure, or HIV transmission are grossly out of proportion to the actual harm inflicted and reinforce the fear and stigma associated with HIV. Public health leaders and global policy makers agree that HIV criminalization is unjust, bad public health policy and is fueling the epidemic rather than reducing it.

WHEREAS the National HIV/AIDS Strategy (NHAS) includes a statement on the problem and public health consequences of HIV criminalization and notes that many state HIV-specific criminal laws reflect long-outdated misperceptions of HIV’s modes and relative risks of transmission; that criminal law has been unjustly used in the United States to prosecute and disproportionately sentence people with HIV; and that

legislators reconsider whether these laws further the public interest and support public health approaches to preventing and treating HIV;

WHEREAS nearly all HIV-specific criminal laws do not consider correct and consistent condom use and effective antiretroviral therapy that reduces the risk of HIV transmission to near-zero as evidence of a lack of intent or ability to harm; and behaviors that according to the Centers for Disease Control and Prevention (CDC) have negligible risk of transmitting HIV, such as spitting and biting, have resulted in sentences as long as 35 years;

WHEREAS sound criminal justice and public health policy toward people living with HIV is consistent with an evidence-based approach to disease control and research demonstrates that HIV-specific laws do not reduce transmission or increase disclosure and may discourage HIV testing;

WHEREAS criminalization harms women and young people, as well as men, with HIV in many ways, because it:

1. Creates a tool for control by abusers who threaten prosecution of partners who want to leave abusive relationships;
2. Complicates custody disputes and pregnancies;
3. Imprisons women and young people for non-disclosure without regard for complex reasons such as fear of violence or other situations when disclosure may not be advisable or safe;
4. Over-targets sex workers, against whom condom possession has been used as evidence of intent to commit a crime;

WHEREAS punishments imposed for non-disclosure of HIV status, exposure, or HIV transmission, including the use of sex offender registries and indefinite civil



commitment, are out of proportion to the actual harm inflicted or intended and reinforce the fear and stigma associated with HIV;

WHEREAS singling out HIV or any other health condition or disability as a basis for prosecution or sentence enhancement is unjust and unwarranted from legal, ethical, and public health perspectives;

BE IT RESOLVED that the PACHA recommends that the Department of Justice (DOJ) and the Department of Health and Human Services (HHS)/CDC complete a written review regarding opportunities for the creation of specific guidance and incentives to state attorneys general and state departments of health for the elimination of HIV-specific criminal laws and to develop recommendations for approaches to HIV within the civil and criminal justice systems that are consistent with the treatment of similar health and safety risks; and supports legislation, such as the REPEAL HIV Discrimination Act, that advances these objectives;

BE IT FURTHER RESOLVED that current criminal laws require modernization to eliminate HIV-specific statutes or application of general criminal law that treats HIV status, or the use of condoms or other measure to prevent HIV transmission, as the basis for criminal prosecution or sentence enhancement;

BE IT FURTHER RESOLVED that Federal and state officials should review the HIV-specific convictions and related penalties, sentence enhancements, and other restrictions imposed on people living with HIV, such as mandated sex-offender registration and civil commitment. In the event that such convictions or sentence enhancements fail to conform to the principles outlined above, federal and state officials should take appropriate measures (e.g., executive clemency, pardon, sentence reconsideration, parole, probation) to mitigate the harm caused to individuals;

BE IT FURTHER RESOLVED that all U.S. law should be consistent with current medical and scientific knowledge and accepted human rights-based approaches

to disease control and prevention and avoid imposition of unwarranted punishment based on health and disability status;

BE IT FURTHER RESOLVED that the CDC should issue a clear statement addressing the growing evidence that HIV criminalization and punishments are counterproductive and undermine current HIV testing and prevention priorities.

## Resolution on the Needs of Male-Bodied American Indian/Alaska Native Individuals Living With or At Risk for HIV

February 7, 2013

WHEREAS many American Indian/Native Americans/Alaskan Native/Native Hawaiian (“Native Peoples”) have long and respected histories of respect and inclusion of those in their communities, who might now be described today as Two-Spirit (Lesbian, Gay, Bisexual, Transgender, Third and Fourth Gender); and

WHEREAS the current seventeen Two-Spirit community-based organizations in the United States recently formed the coalition of the National Confederacy of Two-Spirit Organizations, and the membership of the National Confederacy of Two-Spirit Organizations central mandate is to re-establish the Two-Spirit role and function to their rightful place of honor within their communities; and

WHEREAS the work of the members of the National Confederacy of Two-Spirit Organizations with the exception of three programs is done with little to no direct federal or state funding; and

WHEREAS we are at a critical moment in the HIV epidemic and cannot end the epidemic without addressing the specific needs of all affected communities;

WHEREAS the Native people of this land are indigenous and, as a result of over 500 years of colonization, many Native Nations have been wiped from the face of this earth and many more are teetering on extinction, and

WHEREAS by the end of 2009 a higher percentage of Native adults and adolescents living with HIV infection were male (73.9%) with the majority of HIV infections among males living with HIV in 2009 attributed to male-to-male sexual contact (64.8%);

WHEREAS the male-bodied, Two-Spirit community is disproportionately impacted by HIV/AIDS;

WHEREAS similar results for new HIV diagnoses, according to Table 3a of the 2010 Centers for Disease Control and Prevention Surveillance Report, 72.8% of American Indian/Alaska Native persons diagnosed in 2010 were male, of those males, 72.6% were attributed to men who have sex with men (MSM) and another 12.2% were MSM/injecting drug users (IDU), the highest percentage of all race/ethnicities;

WHEREAS the Honor Project, National Institute of Mental Health (NIMH)-funded health survey of Two-Spirit Native Americans (R01 MH 65871-05), showed that 30% of the male-bodied men who have sex with male-bodied men self-report living with HIV as well as one out of three transgender Two-Spirit, rates of infection are similar to sub-Saharan Africa as well as to those in African-American MSM, a community in which there is a declared AIDS crisis;

WHEREAS Native transgender women living with HIV face unique challenges in accessing and adhering to HIV and hepatitis C virus (HCV) care and treatment regimens; and

WHEREAS the Affordable Care Act (ACA) provides numerous opportunities to increase access to care for Native peoples living with and at risk for HIV, including expanding access to private and public insurance coverage; now, therefore:

- 1 BE IT RESOLVED that the United States Department of Health & Human Services (HHS) should provide current Native epidemiological, mental health, and behavior health data, as well as empanel Native Research and Epidemiological Workgroups to augment information on community viral load and social determinants to the Native epidemic with a focus on the male-bodied, Two-Spirit community;
- 2 BE IT FURTHER RESOLVED that HHS should solicit the counsel and commitment of both spiritual and community leaders to develop strategies for prevention, care, and outreach informed by Native

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values and leverage social marketing to target youth, particularly those identifying as Two-Spirit, to foster a sense of belonging and increased self-worth with the express intent to reduce stigma;

- 3 BE IT FURTHER RESOLVED that HHS should develop a consultation process to meet with tribal leadership to emphasize the need to augment testing and care linkage, as well as prioritize the immediacy of the epidemic among all Native communities and to also develop parallel confirming processes to ensure input and guidance from non-Tribal based Native community-based organizations; and,
- 4 BE IT FURTHER RESOLVED that HHS should develop a Care Navigation and Coordination Strategy to address the unique health needs of Natives. The goal of the Strategy is to institute a more comprehensive continuum of care for Native populations, including an increased culturally-competent provider base and the improved use of medical home models.
- 5 BE IT FURTHER RESOLVED that the Office of the Assistant Secretary for Health should conduct and disseminate an analysis of federal (and, to the extent possible, state-by- state) epidemiologic, programmatic, and budgetary data related to American Indian/Alaska Native individuals living with or at risk from HIV.

## Resolution on Effectively Addressing the HIV/AIDS Epidemic in Transgender Populations

February 7, 2013

Transgender people, like any group of people, come from a range of backgrounds. They live in cities and rural areas; are young, elderly, and middle-aged; begin to live as their true gender when they are children, young adults, or much later in life; and live in families of all varieties. Transgender people, and the communities they live in, are diverse in terms of factors such as race, income, and sexual orientation.

Unfortunately, transgender people from all backgrounds commonly face discrimination in a wide array of settings. Transgender people across the United States today encounter prejudice, violence, and institutionalized discrimination in areas of everyday life such as health care, housing, employment, education, and legal recognition in their true gender. These disparities multiply for transgender people who are also members of other disadvantaged groups, such as transgender people of color and transgender women.

The consequences of discrimination are deadly. According to the 2011 *National Healthcare Disparities Report*, transgender people are disproportionately likely to experience violence in the home, on the street, and even in health care settings.<sup>i</sup> They are four times as likely as the general population to live in extreme poverty, more likely to be uninsured, and less likely to get preventive care that can catch diseases such as cancer early in disease progression.<sup>ii</sup> Additionally, in a recent study of more than 6,400 transgender people in the United States, 41% of respondents reported attempting suicide—a rate 25 times higher than the general population.<sup>iii</sup>

Discrimination also helps drive an overwhelming burden of HIV infection among transgender populations. The same structural circumstances that marginalize transgender individuals by forcing them down through the gaps in America's social safety nets, health care systems, and standards for legal

citizenship also systematically place them at greater risk of HIV infection. Data from the Centers of Disease Control and Prevention (CDC) show that new HIV infections among transgender people occur at almost three times that of non-transgender men and almost nine times that of non-transgender women.<sup>iv</sup> While available data indicate that HIV prevalence among transgender men is currently low, transgender men who have sex with men report high rates of unprotected intercourse, exposing this population to heightened risk for contracting HIV and other sexually transmitted infections.<sup>v</sup> African-American and Latino/a transgender people, particularly transgender women, are at especially high risk of HIV infection.<sup>vi</sup>

The National HIV/AIDS Strategy provides an initial framework for efforts to collect more data on the scope of the HIV epidemic among transgender populations, to better understand the effect that discrimination related to gender identity and gender expression has on HIV risk and other health disparities, and to begin to develop initiatives to connect transgender individuals with lifesaving HIV prevention and treatment services. The Affordable Care Act also provides opportunities to gather relevant data, to expand public insurance coverage, and to end exclusionary private insurance industry practices that deny coverage and care to transgender people. Truly making progress in curbing the HIV epidemic among transgender populations, however, will require policymakers, researchers, health advocates, and health care providers to make long-term investments in the value of transgender lives and to commit to working with transgender community members to prioritize the fight against HIV and AIDS.

WHEREAS transgender populations experience some of the highest rates of HIV infection in the United States with estimates of HIV infection prevalence ranging from 14 to 69%;

WHEREAS transgender individuals who are also members of other disadvantaged populations, such as transgender people of color and transgender women, bear an extremely heavy burden of HIV infection;

WHEREAS discrimination against transgender people in areas of everyday life such as education, housing, and employment contributes to elevated rates of homelessness, poverty, recourse to underground economies such as sex work, and incarceration, all of which are known drivers of HIV risk;

WHEREAS transgender populations experience significant health disparities, including elevated rates of substance use, mental health concerns such as depression, encounters with violence, and sexually transmitted infections, that contribute to higher risk of HIV infection;

WHEREAS transgender people frequently encounter barriers to health care, including a lack of insurance, fear of discrimination, provider insensitivity or hostility, and lack of knowledge about transgender health;

WHEREAS these barriers prevent many transgender people from accessing effective HIV prevention services, learning their HIV status, taking steps to connect with care when they are HIV-positive, or staying in care to help manage their HIV status;

WHEREAS authoritative public health sources such as Healthy People 2020 and the Institute of Medicine reports *Monitoring HIV Care in the United States: Indicators and Data Systems* and *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding* note that a nationwide lack of appropriate data collection related to gender identity and transgender status severely hinders efforts to effectively address transgender health disparities, including HIV risk and prevalence;

WHEREAS the National HIV/AIDS Strategy recognizes that HIV prevention efforts specifically focusing on the transgender population have been minimal and are not differentiated from initiatives focusing on the population of men who have sex with men;

WHEREAS the Affordable Care Act provides unprecedented nondiscrimination protections for transgender people on the basis of sex, gender identity, health condition, and disability;

WHEREAS despite these protections and recognition from expert bodies such as the American Medical Association, the American Psychiatric Association, the American Psychological Association, the American College of Obstetricians and Gynecologists, the American Academy of Family Physicians, the National Association of Social Workers, the Endocrine Society, and the World Professional Association for Transgender Health that transition-related health care services are medically necessary for many transgender people, exclusions denying this care persist in both public and private insurance programs across the United States;

WHEREAS removing these exclusions does not drive up premium costs and improves outcomes for some of the most significant health disparities affecting the transgender population, including reduced suicide risk, lower rates of substance use, improved mental health outcomes, and increased adherence to HIV treatment regimens;

BE IT RESOLVED:

- 1) Relevant Health and Human Services (HHS) operating divisions should dedicate grant funds to projects specifically focusing on transgender health, particularly in the context of HIV prevention and treatment, such as the 2012 Health Resources and Services Administration (HRSA) Special Projects of National Significance (SPNS) grants focusing on retaining HIV-positive, transgender women in care and the inclusion of transgender

- women as a priority population in the 2012 Office of Minority Health grant program on re-entry services for recently incarcerated individuals;
- 2) The Indian Health Service (IHS) should develop a health services protocol specific to providing culturally and clinically appropriate care for male and female bodied, Two-Spirit individuals, including HIV prevention, education, outreach, and treatment;
  - 3) The Substance Abuse and Mental Health Services Administration (SAMHSA) should pilot initiatives for transgender-specific, community-driven HIV prevention programs regarding substance use and black market hormone use;
  - 4) The CDC should develop and fund a research portfolio on new community-driven prevention programs for transgender individuals;
  - 5) HHS should develop a measure for identifying transgender respondents on federally supported surveys, similar to the question for sexual orientation that was added to the National Health Interview Survey in 2013;
  - 6) All Federal agencies involved in implementing the National HIV/AIDS Strategy should use this measure to collect and report accurate and reliable statistics about the HIV/AIDS epidemic among transgender populations, including the effect of factors such as employment, insurance, socioeconomic status, geography, and race on HIV risk and prevalence;
  - 7) HHS should include appropriate transgender measures (as well as sexual orientation measures) as required functionality for all electronic health records systems as part of Stage 3 of the Electronic Health Records Incentive Program;
  - 8) All Federal agencies involved in implementing the National HIV/AIDS Strategy should require their grantees and contractors to deliver services in a manner that is culturally competent with regard to the needs and experiences of transgender populations and that does not discriminate on the basis of gender identity or expression;
  - 9) The National Institutes of Health (NIH) should establish a cross-NIH coordinating mechanism to develop an integrated approach to pursuing a range of research related to transgender health and LGBT health more broadly, including HIV/AIDS and the socioeconomic determinants of transgender health;
  - 10) NIH should adopt a policy encouraging grant applicants to explicitly address the inclusion or exclusion of sexual and gender minorities in their samples;
  - 11) HRSA should establish a training and technical assistance resource center for federally qualified health centers that specifically focuses on enhancing staff and provider cultural and clinical competence in transgender health;
  - 12) The Centers for Medicare and Medicaid Services (CMS) should require facilities and providers receiving any federal funding to undertake regular staff trainings on transgender cultural competency;
  - 13) The Office of Population Affairs at HHS should incorporate recognized protocols for treating transgender patients, such as the *Standards of Care for the Health of Transsexual, Transgender, and Gender-nonconforming People* developed by the World Professional Association for Transgender Health into the revised guidelines for Title X clinics;
  - 14) HHS should work to ensure that members of vulnerable populations living with HIV or AIDS, including transgender people, continue to be able to rely on the services and supports provided by the Ryan White Program and are protected from the loss of important wraparound services during the implementation of the Affordable Care Act;

- 15) The Center for Consumer Information and Insurance Oversight at CMS should issue guidance clarifying that transgender-specific exclusions violate federal nondiscrimination regulations that include protections on the basis of gender identity, health condition, and diagnosis and requiring that issuers of plans offering the essential health benefits must remove these exclusions from their Essential Health Benefits (EHB)-based plans.

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## References

<sup>i</sup> Agency for Healthcare Research and Quality. 2012. National Healthcare Disparities Report, available at <http://www.ahrq.gov/qual/nhdr11/nhdr11.pdf>.

<sup>ii</sup> Grant, J.M., L.A. Mottet, J. Tanis, J. Harrison, J.L. Herman, and M. Keisling. 2011. *Injustice at Every Turn: A Report of the National Transgender Discrimination Survey*. Washington, DC. National Center for Transgender Equality and National Gay and Lesbian Task Force, available at [http://www.thetaskforce.org/reports\\_and\\_research/ntds](http://www.thetaskforce.org/reports_and_research/ntds).

<sup>iii</sup> Ibid.

<sup>iv</sup> Centers for Disease Control and Prevention, *HIV Among Transgender People* (2011), <http://www.cdc.gov/hiv/transgender/pdf/transgender.pdf>

<sup>v</sup> S. Reisner, B. Perkovich & M.J. Mimiaga, A Mixed Methods Study of the Sexual Health Needs of New England Transmen Who Have Sex with Nontransgender Men, 24 *AIDS Patient Care & STDS* 501 (2010); J. Sevelius, "There's No Pamphlet for the Kind of Sex I Have": HIV-related Risk Factors and Protective Behaviors Among Transgender Men Who Have Sex with Non-transgender Men, 20 *J. Assoc. Nurses AIDS Care* 398–410 (2009).

<sup>vi</sup> See, e.g., L. Nuttbrock, S. Hwahng, W. Bockting, A. Rosenblum, M. Mason, M. Macri, J. Becker, *Lifetime Risk Factors for HIV/Sexually Transmitted Infections Among Male-to-Female Transgender Persons*, 52 *J. AIDS* 417 (2009); R. Garofalo, J. Deleon, E. Osmer, M. Doll, G.W. Harper, Overlooked, Misunderstood and At-Risk: Exploring the Lives and HIV Risk of Ethnic Minority Male-to-Female Transgender Youth, 38 *J. Adolescent Health* 230 (2006).

## APPENDIX C: LIST OF ACRONYMS

ACA	Patient Protection and Affordable Care Act	NHAS	National HIV/AIDS Strategy
ADAP	AIDS Drug Assistance Program	NIH	National Institutes of Health
AI/AN	American Indians/Alaska Natives	OHAIDP	Office of HIV/AIDS and Infectious Disease Policy
ART	antiretroviral therapy	ONAP	Office of National AIDS Policy
ARV	antiretroviral	PACHA	Presidential Advisory Council on HIV/AIDS
CDC	Centers for Disease Control and Prevention	PCIP	Pre-Existing Condition Insurance Plan
CHAC	CDC/HRSA Advisory Committee on HIV, Viral Hepatitis, and STD Prevention and Treatment	PEPFAR	United States President's Emergency Plan for AIDS Relief
CMS	Centers for Medicare and Medicaid Services	PrEP	pre-exposure prophylaxis
DEBI	Diffusion of Effective Behavioral Interventions	RWHAP	Ryan White HIV/AIDS Program
FPL	Federal poverty level	STI	sexually transmitted infection
HHS	U.S. Department of Health and Human Services	USPSTF	U.S. Preventive Services Task Force
HOPWA	Housing Opportunities for Persons with AIDS	YBMSM	young Black men who have sex with men
HRSA	Health Resources and Services Administration		
HUD	Department of Housing and Urban Development		
MSM	men who have sex with men		
NCHHSTP	National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention		



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