ENDING
THE HIV/AIDS
EPIDEMIC

Summary of Findings from Regional Dialogues Conducted in Louisiana, Los Angeles County, and Washington, DC

April and May 2012
INTRODUCTION

In April and May 2012, the National Minority AIDS Council (NMAC) convened regional dialogues in New Orleans, Louisiana; Los Angeles, California; and Washington, DC, to discuss ending the HIV/AIDS epidemic.

The goal of the dialogues was to ensure effective translation of recent research and policy developments and identify critical issues, barriers, and potential solutions. This summary combines findings from the regional dialogues in the context of policies, legislation, and medical advances that position the United States to augment efforts to end the HIV epidemic in this country.

At the time of the dialogues, the U.S. Department of Health and Human Services (HHS) had just released new HIV treatment guidelines, while the fate of the Patient Protection and Affordable Care Act (ACA) and the future of the Ryan White CARE Act (RWCA) were both in question. Thus, the dialogues represent a snapshot of a system in flux. In June, the Supreme Court ruled the ACA constitutional but left to the states the decision as to whether to expand Medicaid. Thus, the ruling resolved some questions but added new questions in many cases.

Participants at the dialogues included local and regional stakeholders representing people living with HIV/AIDS (PLWHA), community-based organizations (CBOs), local and state service provider organizations, health care providers, health researchers, private foundations, pharmacies, local and state governments, and others. The aim of the meetings was not to reach consensus but rather to bring stakeholders together for an open discussion about the challenges and opportunities that each region faces in addressing and ending the HIV epidemic.

Through background materials and presentations, NMAC representatives and others outlined key issues for consideration and prompted discussion among the participants. A summary of each regional dialogue, including the names of participants, the background materials, and presentations provided at the meetings, are available online. These summaries compile the participants’ discussion in some detail and highlight the take-home messages from each dialogue. It should be emphasized that no effort was made to guide the participants toward consensus. Opinions varied, and some statements contradict others, as they represent the wide-ranging perspectives of the stakeholders. The value of the dialogues lay in the variety of perspectives that stakeholders brought to the table.
Estimates of New HIV Infections in the United States, 2009, for the Most‑Affected Subpopulations*

NOTE: Subpopulations representing 2% or less of the overall U.S. epidemic are not reflected in this chart.

Background

This summary explores common issues discussed at each dialogue, as well as the range of regionally specific issues cited by each locale. It provides an overview of the priorities and concerns identified among all the participants related to bringing the epidemic to an end while also addressing the unique challenges and opportunities articulated in each region.

Additionally, this document describes regional innovations and key questions to consider in bringing an end to the epidemic through the development of local implementation plans.

At the time of the dialogues, the Supreme Court had yet to rule on the fate of the ACA. In turn, considerable confusion and conjecture pervaded the discussion of health care reform because the future of the legislation remained uncertain. With the Court’s June 2012 decision, it became clear that the individual mandate will stand along with the following key provisions:

- Prohibit insurance companies from withholding coverage because of preexisting conditions
- Prohibit lifetime coverage limits
- Restrict annual dollar limits on coverage
- Provide rebates and subsidies to purchase coverage for those unable to afford plans sold through a state’s health care exchange

Furthermore, although Medicaid expansion is not compulsory, residents of states that choose to participate in the expansion are eligible for Medicaid based solely on their income level (i.e., at or below 133 percent of the federal poverty level). The ACA promises to increase access to more affordable insurance, through private health plans and Medicaid expansion, for thousands of PLWHA, albeit through a patchwork of covered services and treatments across the country.

Similarly, uncertainty about the RWCA and its future in light of health care reform affected the discussion. As a designated payer of last resort, the RWCA’s primary funding purpose—to provide affordable access to treatment and care—was called into question. Further, the saliency of equally critical auxiliary services funded by the RWCA, such as case management, mental health care, substance abuse treatment, transportation, and dental care, also was questioned. Concern remains about the continued provision of resources adequate to support the comprehensive array of services that have enabled RWCA-funded programs to play a key role in linking, engaging, and retaining thousands of uninsured and underinsured PLWHA with services necessary for care and treatment.

The National HIV/AIDS Strategy (NHAS) offered a means to frame the discussion about the interplay between the ACA and the RWCA through its goals to reduce incidence, increase access to care, improve health outcomes, and reduce HIV-related health disparities. The NHAS goals exemplify the continued need for a robust RWCA program to increase access to care and improve health outcomes for PLWHA. Each jurisdiction articulated the challenges to accomplishing the
NHAS goals, particularly those goals that are keyed to the initial NHAS assessment in 2015 and the availability of new resources.

The results of the HIV Prevention Trials Network (HPTN) Study 052 were released in the months preceding the dialogues. HPTN 052 found that heterosexual PLWHA reduced the risk of transmitting the virus to their sexual partners by 96 percent through initiation of antiretroviral therapy, a phenomenon known as treatment as prevention (TasP).

When used in conjunction with traditional evidence-based prevention strategies, TasP shows considerable promise in slowing the spread of HIV. The results of this clinical trial significantly informed the participants’ discussion about local, state, and federal policies contributing to, or inhibiting, the scale-up of TasP and high-impact prevention.

Finally, biomedical advances informed the discussions in New Orleans, Los Angeles, and the District of Columbia. The Food and Drug Administration’s consideration of preexposure prophylaxis was under way at the outset of the dialogues and spurred numerous conversations around prevention modalities. The topic of microbicides similarly presented an opportunity for participants to weigh in on how best to scale up innovative prevention tools and strategies. The consideration of biomedical interventions during the dialogues underscored the common priority to augment combination prevention efforts by introducing additional tools for use in concert with other evidence-based strategies.

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Of the 1.1 million Americans living with HIV, only 25% are virally suppressed.

Shared Issues and Concerns

The dialogues revealed a number of considerations that were common across all three locales. These topics were not necessarily the most pressing concerns—and, again, they do not necessarily represent a consensus among participants within or across regions. Later sections of this document describe the unique or region-specific issues that arose at each dialogue.

Lack of Resources Tops the List of Challenges Across Regions

Ideally, the ACA and other policy changes will begin to address the largest concern that all of the dialogue participants raised: the lack of resources available for prevention and treatment. Participants in California and Louisiana indicated that state and local entities lack the resources to meet current health care needs of PLWHA. They also expressed concerns about the expanded role that federally qualified health centers (FQHCs) will play under the ACA, as well as the lack of clarity about the role of CBOs and their relationship with FQHCs. In Louisiana, some participants said resources are insufficient in every aspect, so community partners are needed to make programs work.

In Washington, DC, which has made tremendous strides in providing access to care for nearly all of its citizens, participants still worried about future funding. A Washington, DC, participant said, however, that stakeholders cannot take the attitude that there is no more money and the only option is to “re-slice the pie.” Rather, stakeholders must fight at the local and national levels for the money to provide services so that current gains will not be eroded.

Uncertainty About Future Policy Raises Concerns

Many participants emphasized that the uncertainty surrounding ACA implementation, increased focus on FQHCs, the future of the RWCA, and formula changes to Housing Opportunities for Persons with AIDS (HOPWA)/U.S. Department of Housing and Urban Development (HUD) programs make it difficult to plan and move forward. Prevention and access to wraparound services such as mental health and substance abuse treatment remain vital components to ensuring a healthy community. More information is needed about how the ACA would either incorporate or complement RWCA services and, in turn, how a restructured RWCA would relate to HOPWA and other HUD programs. Additional information is needed to assess whether Medicaid expansion might be able to share supportive housing costs such as case management for housing services, as offered in New York Medicaid HIV Special Needs Plans. The essential health benefits package that will be included in the insurance plans offered in each state’s health exchanges, as well as the services to be provided in expanded Medicaid programs, must be defined before stakeholders can determine what wraparound services would be needed in a renewed (i.e., reauthorized) RWCA. Louisiana participants suggested that modeling the cost-effectiveness of the RWCA could be a step toward maintaining the program in concert with the ACA.
The specifics of ACA implementation remain somewhat vague. Participants noted that one challenge of the ACA is creating a mechanism that can pay for care from multiple sources, which Medicaid currently does. However, several people pointed out that Medicaid may not be the ideal model for cost reimbursement, as some physicians already do not accept Medicaid because of its insufficient reimbursement rate.

Participants expressed frustration about the lack of support and guidance from the federal government in light of the changing needs for HIV/AIDS services. In Louisiana, for example, the Health Resources and Services Administration (HRSA) has not provided resources to help CBOs achieve an FQHC-lookalike designation and that Medicaid fees for the highest-cost clients are so low that programs are losing money with every visit. Participants in Washington, DC, identified not only the need for resources but also for technical assistance to prepare for implementation of the ACA, especially for nonclinical programs, such as data collection efforts. Louisiana participants also sought meaningful technical assistance around housing in general and HOPWA in particular.

### Communication, Collaboration Needed at All Levels

Many participants believed that, with the rapidly changing landscape of health care, stakeholders need to communicate and work more closely with each other. There are efforts under way in all three regions to build partnerships that can address the gaps in HIV care. Participants recognize that more collaboration is needed across governments and among federal, state, and local agencies; community health centers (CHCs); and CBOs to provide coordinated care. They also are aware that collaboration requires planning and investment. In Louisiana, for example, FQHCs do not have a formal mechanism for collaboration with state CBOs serving PLWHA. However, there is optimism that promotion of the medical home model can incentivize discussion between FQHCs and the HIV/AIDS community.

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Across all risk groups, fewer than half are in ongoing care, and roughly a quarter have their virus in check.

* The term men who have sex with men (MSM) is used in CDC surveillance systems because it indicates the behaviors that transmit HIV infection, rather than how individuals self-identify in terms of their sexuality.

** IDU = injection drug user

Participants in Louisiana suggested some targeted solutions (e.g., developing and disseminating local resource fact sheets) but also called for broad steps to reinvigorate the PLWHA community, such as leadership training, national communication, and expanded education.

**Enthusiasm for TasP Is Mixed**
Participants acknowledged a clear need for treatment, and many expressed enthusiasm for the potential that TasP offers. TasP is a key selling point in seeking funding and a central theme around which new education and outreach efforts among stakeholders can be built. Participants in Louisiana pointed out that collaboration among organizations and a strong champion are needed to move TasP into regular practice.

However, a number of participants expressed skepticism about TasP as a broad policy, particularly in light of financial issues such as paying for long-term medications. There is concern about the influence of pharmaceutical companies in promoting TasP. Moreover, participants noted that TasP alone cannot succeed without addressing the social determinants of health, such as housing, employment, and access to mental health and substance abuse treatment. Many agreed that TasP should be considered one among several tools to prevent and treat HIV. Participants in California were particularly worried that overemphasis on TasP could deter from other prevention efforts and interventions. Some participants questioned the effectiveness of TasP, particularly because it hinges on adherence, as well as its appropriateness as a blanket approach to treatment.

Some participants highlighted the importance of communicating to consumers that TasP benefits the individual, not just the community. It was suggested that CBOs can remind providers and other stakeholders that TasP helps the individual first.

**More and Better Data Collection, Evaluation Needed**
In general, CBOs and public health departments recognize the need to collect more and better data and to use data to inform decision making, but these efforts require more education, training, funding, equipment, and staff to do so. Even small CBOs can benefit significantly from collecting and analyzing their own data.

Participants said CBOs and others collect data from a patchwork of data sources, most frequently for use in funding proposals. A system that aggregates data from multiple sources could be useful in planning and evaluation. Louisiana, for example, has some unique collaboration around data collection given the use of electronic health records in its largest-serving public health provider. Pharmacies have a rich database that could be mined. State health departments have information on state Medicaid and Medicare clients. Coordination among public and private providers, as well as new public health approaches to outreach and follow up, can target those who are hard to reach or retain in care.

Data are needed to better evaluate and demonstrate the impact of programs and interventions. Without key data (e.g., how many HIV-positive people are not getting regular care), programs cannot give legislators a firm description of the costs and return on investment to support TasP. Data collection and evaluation were highlighted as areas in critical need of more technical assistance and resources. In California, for example, it was suggested that more investment be made in evaluating the impact of homegrown interventions, which can be very effective but rarely have data to show their results. Participants in Louisiana pointed out that programs could get more resources if they did a better job collecting and analyzing data to understand more fully the impact and landscape of HIV in the community.

**HIV/AIDS Community Must Mobilize, Combat Broad Complacency**
There was consensus among participants that PLWHA leadership is essential for ending the HIV epidemic. However, the success of HIV treatment and civil rights gains have resulted in issue fatigue among PLWHA, leading to less active, organized efforts to address HIV than in the past. One participant explained, “I can’t be more outraged about your health than you are.”
Participants in Louisiana suggested some targeted solutions (e.g., developing and disseminating local resource fact sheets) but also called for broad steps to reinvigorate the PLWHA community, such as leadership training, national communication, and expanded education. In California, it was suggested that PLWHA coalitions take the lead in ensuring that TasP is implemented appropriately, because they can be a trusted source of support, advocacy, and information. Consumer groups in Louisiana are bringing consumers together to talk about TasP and to encourage PLWHA to take the lead in changing how HIV is treated.

Some participants pointed out that coalition politics offer an opportunity to advance the movement. At present, the discussion about preventing and ending HIV lacks focus on a universal issue around which various groups can work together to create a policy and articulate a message. Participants in California and Washington, DC, focused on the importance of identifying a clear, consistent message about prevention and treatment and communicating it with a sense of hope, not fear. Some participants suggested that pharmaceutical companies should be asked to provide financial support for messaging—for example, combating stigma.

The paradox of communicating about HIV/AIDS arose during the dialogues. On the one hand, it was noted that legislators should be educated about how HIV/AIDS is both an infectious disease and a chronic disease, thus different from cancer, diabetes, and other conditions, merit its own funding stream for treatment and management. On the other hand, some said messaging around HIV has been hampered by privacy concerns and “HIV exceptionalism.” The HIV/AIDS community often advocates for treating HIV as a mainstream disease yet also advocates for additional resources to access HIV specialists and RWCA services.

Stigma, Criminalization Pose Barriers to Treatment

Participants pointed out that stigma around HIV is overwhelming and may be increasing, in part because PLWHA coalitions that once provided social support have been dismantled. Stigma manifests in many forms and comes from within the lesbian, gay, bisexual, and transgender (LGBT) community, as well as from society as a whole. As long as stigma persists, it will be challenging to get large numbers of PLWHA to accept treatment and testing and thus reduce community viral load. Participants in California and Washington, DC, suggested creating a coordinated effort to address stigma with outreach, messaging, and a new “coming out” movement. It was noted that peer support and education remain crucial.

The extent of HIV criminalization is not widely recognized within the PLWHA community, and even those who are aware of it are reluctant to speak out about it because it may reflect badly on them. Some participants said that repealing HIV criminalization legislation is an important step toward getting PLWHA to accept testing and treatment. The criminalization of HIV may be a deterrent to testing, as people who do not know their status cannot be prosecuted.

Consumers and Providers Alike Need More Education

Participants noted that with health care reform, more HIV care will fall to primary care providers who may lack sufficient education and training to treat HIV-positive patients adequately. HIV poses challenges to most primary care providers because it requires a specialized intake approach, and patients may need extra care to overcome the fear, stigma, and barriers to care that may prevent PLWHA from full disclosure about all relevant health factors. Some participants said many doctors are afraid to test for HIV because they are not trained to give the diagnosis. Provider education is important to ensure that people get the right care.
Many participants agreed that consumers are not well informed about HIV/AIDS prevention or treatment or about the changing landscape of health care. Providers and PLWHAs alike lack information about legislation and policies affecting health care, such as the future of the ACA and RWCA. More efforts are needed to educate on new health care policies and to coordinate responses so that providers and PLWHA are not surprised by sudden changes in services. Louisiana participants said there are very few groups in Louisiana for PLWHA, and participants in California pointed out that there are now fewer advocates for health and civic engagement than there were in the past.

Role of Housing Must Be Considered
Participants said housing is integral to successful HIV treatment; it affects the health of the whole community. Some participants noted that when HOPWA was created, projected life spans for PLWHA were not as long as they currently are. In turn, some questioned the rationale for a program designed specifically for PLWHA when their housing needs are increasingly indistinguishable from those of other low-income people. The financing of HOPWA is structured to provide only short-term support. The discussion underscored the importance of taking a broad and holistic approach to prevention and treatment that includes wraparound services.

Housing is integral to successful HIV treatment; it affects the health of the whole community.

Spectrum of Domestic Engagement in Care by Race/Ethnicity

<table>
<thead>
<tr>
<th></th>
<th>White</th>
<th>Hispanic/Latino</th>
<th>Black/African American</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosed</td>
<td>85%</td>
<td>80%</td>
<td>81%</td>
</tr>
<tr>
<td>Linked to Care</td>
<td>71%</td>
<td>33%</td>
<td>29%</td>
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<tr>
<td>Retained in Care</td>
<td>38%</td>
<td>28%</td>
<td>21%</td>
</tr>
<tr>
<td>Prescribed ART</td>
<td>35%</td>
<td>33%</td>
<td>34%</td>
</tr>
<tr>
<td>Virally Suppressed</td>
<td>30%</td>
<td>21%</td>
<td>21%</td>
</tr>
</tbody>
</table>

African Americans are least likely to be in ongoing care or to have their virus under control.


Unique Issues and Concerns

At each regional dialogue, some topics were especially salient to that region, and the following section summarizes those issues. Again, it should be noted that each dialogue followed its own path, and the topics mentioned may not be unique to the region.
LOUISIANA

State Averse to ACA Implementation
Insufficient funding and the political climate in Louisiana have hampered the ability to prepare for the ACA and move forward on NHAS goals. Additionally, there is considerable confusion around the ACA in Louisiana, as state government has not moved to initiate its implementation.

Rural Areas Struggle to Compete for Funding
Health care disparities persist in Louisiana. Currently, people throughout Louisiana—especially in rural areas—do not have consistent, reliable, affordable access to high-quality care. However, the landscape is changing, and some efforts are under way to expand capacity, coordinate services, and foster partnerships. Transportation and access to care remain critical barriers to appropriate HIV treatment for people in rural areas.

Opportunities Exist for FQHCs
Throughout the state, the role of FQHCs in HIV care is unclear. However, the Louisiana Department of Health and Hospitals is trying to link FQHCs and CHCs that are interested in providing HIV services with medical mentors to increase access to HIV services. Louisiana recently moved to Medicaid managed care, and that program will serve as the basis for implementing the ACA. HIV providers and FQHCs will be part of the Medicaid plans. The state can partner with FQHCs to evaluate the resources available to address public health needs. Assessing the capacity of FQHCs to serve HIV-positive clients provides an opportunity to evaluate services offered by FQHCs and their current capacity to treat clients. In Baton Rouge, the Division of Human Development and Services is participating in information sessions to get a better sense of which community organizations, FQHCs, and CHCs need more information and training on the medical home model. It was suggested that FQHCs could form a central billing agency to alleviate some of their administrative burden.

Potential Solutions to Education, Collaboration Offered
Louisiana participants also identified opportunities to gather more information about programs and capacity, obtain assistance to facilitate planning and capacity development, collaborate across organizations, capitalize on the influence of the NHAS, and educate consumers. They suggested the following:

- The implementation of the preexisting condition insurance plans and Simply Healthcare’s HIV managed health care plan may provide useful lessons.
- To address concerns about provider education, Medicaid could require that health care providers complete at least one hour of continuing education on HIV treatment to receive reimbursement.
- HRSA’s Bureau of Health Professions (BHPR) could require providers who receive loans for medical or nursing training to complete some training on treating HIV-positive clients in the outpatient setting to qualify for loan forgiveness. The BHPR should include some sort of quality assurance and improvement effort. Health professional schools should be required to include HIV outpatient treatment in their curricula.
- PLWHA should be prepared through education and empowerment to communicate with their care providers to be more actively engaged in maintaining their health.
- Stakeholders should work with pharmacists and pharmaceutical companies to seek assistance with paying drug costs.
- After Hurricane Katrina, organizations built some momentum around collaboration, and it could be done again. A bold vision for ending the epidemic could galvanize organizations.
Transparency, Oversight of Funding Needed
CBOs, particularly those that focus on minority populations, partly rely on pharmaceutical industry funding to provide services. Pharmaceutical companies are willing to invest where private foundations are not. Transparency of funding is vital to maintaining credibility, so organizations should develop policies about taking money. Oversight mechanisms should be established, with PLWHA involved in that oversight and decision making.

Minority and Disenfranchised Populations Left Out of Discussion
Participants pointed out that promoting healthy sexuality (particularly among gay black men) too often is ignored. Black people feel left out of the discussion and distanced from the decision making. Very few health care providers understand the overall health care needs of the transgender community. Few medical providers focus on the needs of young people. Undocumented people may be adversely affected by changes in health care policy. It is not clear how the ACA will address the overall health care needs of PLWHA as they age and require concurrent care for other chronic health conditions. Participants emphasized the importance of acknowledging and addressing racial issues. Targeted interventions may be helpful in addressing population-specific issues.

Substance Use
Participants cited the role of substance abuse in fueling the epidemic throughout the region. The challenge to reach undiagnosed PLWHA who use methamphetamine and to retain them in care was raised. Conversation on this topic addressed a variety of behavioral approaches and incentives to address the complications that accompany substance use in the process of scaling up testing efforts and improving care and treatment outcomes.

Spectrum of Engagement in Care: Los Angeles County

Federal Assistance and Support Needed
Organizations need federal technical assistance to implement the ACA and meaningful data on which to base decisions. The community needs direct support from the national and state level in the form of technical assistance and funding, but also clear support for policies such as syringe exchange, combating stigma, and eliminating HIV criminalization. Access to providers is a barrier that all people face as the health care system changes.

CBOs Must Define Their Strengths in a Changing System
CBOs need mechanisms to help them evaluate their strengths and weaknesses, as well as to interface and collaborate with FQHCs. Many questions remain about how CBOs will be reimbursed for their services under the ACA and as part of collaborative efforts. Some health centers will have to partner with CBOs that provide nonmedical services, as well as with providers of more advanced medical care to ensure that patients achieve optimal treatment. Health centers are developing more formal agreements with such organizations but also seek to retain their independence. All of the players in the system must figure out what they do well and where they fit in the big picture.

Medical Home Model and Comprehensive Programs Effective
While the medical home concept may be effective for PLWHA, accreditation may be out of reach for programs that are not formally affiliated with providers of advanced medical care. There are models demonstrating that aggressive outreach and testing; linkage to coordinated, comprehensive, and easy-to-access care; and peer support together can bring the hardest-to-reach, hardest-to-treat populations into care and retain them.

Quality of Care Remains a Concern
Evidence shows that even well-insured minorities do not receive high-quality care. The ACA will not resolve the concerns about the quality of care for insured PLWHA. Washington, DC, is among the most progressive cities in the United States in terms of health care access and now recognizes that it needs to redesign the health care system to make effective, high-quality care available to all populations.

Continuum of HIV Care 2010: District of Columbia*

<table>
<thead>
<tr>
<th>Number of HIV Cases</th>
<th>Diagnosed HIV Cases</th>
<th>Linked to HIV Care as of 12/31/2010</th>
<th>Continuous HIV Care During 2010</th>
<th>Virally Suppressed During 2010</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>4,879</td>
<td>4,172</td>
<td>1,078</td>
<td>823</td>
</tr>
</tbody>
</table>

* This includes HIV/AIDS cases diagnosed in DC between 2005 and 2009 and living as of December 31, 2010.
† Continuous care is defined as having 2 viral load or CD4 test results reported to the District of Columbia Department of Health at least 2–4 months apart.
‡ Cases are considered virally suppressed if their last viral load test reported in 2010 was ≤400 copies/mL.
SOURCE: District of Columbia Department of Health.
NEXT STEPS

The findings from all the NMAC regional dialogues could form the basis for requests to local, state, and federal governments to fund new initiatives to address HIV/AIDS.

Further, NMAC will use the priorities identified by the regional dialogues to inform development of implementation toolkits to assess the opportunities and challenges other jurisdictions face in navigating ACA implementation, scaling up TasP, and addressing the unique conditions fueling the epidemic in their regions.

The findings, as well as the implementation toolkits, also will be used to foster dialogues among key stakeholders in communities throughout the United States.