

U.S. Department of  
Health and Human Services

## National HIV/AIDS Strategy

# *Implementation Progress Report*

**2012**



This report was prepared under the direction of the Office of HIV/AIDS and Infectious Disease Policy (OHAIDP), Office of the Assistant Secretary for Health, U.S. Department of Health and Human Services (HHS). Information contained in the report was provided by HIV Leads in each of the HHS Operating Divisions and Staff Offices and assembled by Ms. Vera Yakovchenko, M.P.H., of OHAIDP. Mr. Steve Holman, M.B.A., and Ms. Eileen Frueh, M.A., working under contract to OHAIDP, assisted OHAIDP staff in writing the report.

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## Introduction

Throughout 2012, the U.S. Department of Health and Human Services (HHS) continued to make significant strides in implementing the National HIV/AIDS Strategy (NHAS). Working independently on some activities and collaboratively on many others, HHS operating divisions and offices were actively engaged in a wide variety of pursuits—from research, regulation, and policy making to training, public awareness, and grant making—that helped advance us toward the Strategy’s goals. This progress report, prepared by the Office of HIV/AIDS and Infectious Disease Policy (OHAIDP) with input from HHS agencies and offices, highlights some of the Department’s key accomplishments during calendar year 2012. It is, however, just a sampling of the myriad actions taken by the HHS operating divisions and staff offices to pursue the Strategy’s vision and goals.

These selected highlights include many actions specifically detailed in the NHAS Federal Implementation Plan and the HHS NHAS Operational Plan. In several instances, they also reflect significant achievements that go beyond actions detailed in the Strategy, its Federal Implementation Plan, and the HHS NHAS Operational Plan.

In addition to the achievements featured in this report, one of the notable highlights of 2012 involving all HHS agencies and offices and many other partners was the return of the International AIDS Conference to the United States after 22 years. The XIX International AIDS Conference, known as AIDS 2012, brought together more than 23,000 participants representing 183 countries for a week of information sharing on key issues across the range of HIV-related disciplines. Addressing the conference, both the Secretary of Health and Human Services and the Assistant Secretary for Health spoke of the importance of the NHAS in galvanizing and guiding our national response to HIV/AIDS and of the progress underway across HHS and other federal departments involved in implementing the Strategy. By putting the spotlight on HIV/AIDS in the United States, AIDS 2012 generated significant public awareness about HIV/AIDS, helped renew the sense of urgency around our response, and fueled increased support for addressing the HIV/AIDS epidemic domestically and abroad. HHS agencies, offices, and supported activities were well represented across the conference sessions, speeches, posters, exhibits, and other activities.

Among the many important findings shared by HHS agencies and offices at AIDS 2012, one that has proven particularly important in strengthening and accelerating our efforts to implement the NHAS, was the national estimate of the number of persons living with HIV at each step of the HIV treatment

cascade, from diagnosis to viral suppression, shared by the Centers for Disease Control and Prevention (CDC). CDC's analysis estimated that only 25 percent (down from an earlier estimate of 28 percent) of the more than 1 million individuals in the U.S. who are living with HIV/AIDS are getting the full benefits of the treatment they need to manage their disease, keep the virus under control, and reduce the risk of transmitting the virus to others. The new analysis also indicated that African Americans and younger people are the least likely to be in ongoing care and have their virus under control. Throughout 2012, HHS agencies, offices, and programs sharpened their focus on the HIV treatment cascade, using it as an important tool to assess and monitor their progress in implementing the Strategy at national, state, and local levels, and to inform discussions about how best to prioritize and target resources to intervene on those things impacting the cascade. Similarly, in 2012 the HIV treatment cascade—also known as the “care continuum”—was beginning to be used by more and more state and local HIV prevention and care program managers, policy makers, and providers who used locally informed cascade models to assess, tailor, and improve coordination of their HIV prevention, care, and treatment activities.

In the months and years ahead, the HIV care continuum will continue to serve as a helpful organizing construct for those working at all levels to end the HIV/AIDS epidemic, allowing individuals engaged in HIV prevention, treatment, and care to pinpoint potential gaps and areas for improvement, as well as to solidify and enhance areas of strength and success as they build on the solid foundation of progress made by HHS agencies and offices since the Strategy's release.

# Background

On July 13, 2010, the White House released the National HIV/AIDS Strategy for the United States. The Strategy is the nation's first-ever comprehensive, coordinated HIV/AIDS roadmap, with a clear vision for the future.

## Vision for the National HIV/AIDS Strategy

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.

The NHAS set forth three ambitious but achievable goals for the nation to work toward by 2015:

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

It also acknowledged that to accomplish the Strategy's goals, we must undertake a more coordinated national response to the epidemic involving greater coordination across all levels of government as well as more thoroughly engaging all sectors of society to build on and refocus our existing efforts to deliver better results.

Accompanying the NHAS was a *Federal Implementation Plan* that tasked specific actions to federal agencies in 2010 and 2011. Subsequently, the lead federal agencies for implementing the Strategy—the Departments of Health and Human Services, Housing and Urban Development, Justice, Labor, and Veterans Affairs, and the Social Security Administration—each developed and submitted to the White House's Office of National AIDS Policy (ONAP) and Office of Management and Budget (OMB) detailed operational plans for implementing the NHAS within their agencies. The HHS NHAS *Operational Plan* was submitted in December 2010 and served, along with the NHAS and the *Federal Implementation Plan*, as a blueprint for HHS actions since. In July 2012 HHS shared its first annual progress report featuring highlights of its progress implementing the NHAS in 2011.

Read more about the NHAS and access all the related documents at <http://www.AIDS.gov>.



# Highlights of 2012 Accomplishments

Operating divisions and staff offices across the U.S. Department of Health and Human Services contributed in many ways to our progress toward achieving the NHAS goals in 2012. The following overview highlights some of the key accomplishments and milestones in each of the Strategy's goals.

## GOAL 1 Reduce New HIV Infections

### NHAS Action Steps

- Intensify HIV prevention efforts in the communities where HIV is most heavily concentrated.
- Expand targeted efforts to prevent HIV infection using a combination of effective, evidence-based approaches.
- Educate all Americans about the threat of HIV and how to prevent it.

### Anticipated Results, by 2015

- Lower the annual number of new infections by 35% (from 56,300 to 42,225).\*
- Reduce the HIV transmission rate, which is a measure of annual transmissions in relation to the number of people living with HIV, by 30% (from 5 persons infected per 100 people with HIV to 3.5 persons infected per 100 with HIV).\*
- Increase from 79% to 90% the percentage of people living with HIV who know their serostatus (from 948,000 to 1,080,000 people).

\* In August 2011, CDC published new incidence estimates using a refined methodology that allowed for a more precise 2006 incidence estimate (48,600, rather than the previous 56,300). This new estimate has implications for published 2015 targets, including numbers of new infections and transmission rate. In 2012, CDC published updated HIV incidence estimates for 2007-2009 and provided the first 2010 incidence estimate.

In pursuit of the Strategy's first goal, HHS undertook numerous activities in 2012, including the following:

***Developing social marketing campaigns to educate Americans about HIV and promote HIV testing***—In 2012 CDC supported two national HIV prevention campaigns geared to two of the populations most disproportionately impacted by HIV. *Testing Makes Us Stronger* is CDC's national campaign to encourage HIV testing among black gay and bisexual men, with messages emphasizing that knowing one's HIV status is important and empowering information. Throughout 2012 *Testing Makes Us Stronger* continued its reach to the target audience through promotions in six U.S. cities where black gay and bisexual men are heavily affected by HIV (Atlanta, Baltimore, Houston, New York, Oakland, and Washington, DC), onsite outreach to attendees of Black Gay Pride events in 15 U.S. cities, the campaign website (<http://hivtest.cdc.gov/stronger>) and Facebook page ([www.facebook.com/TestingMakesUsStronger](http://www.facebook.com/TestingMakesUsStronger)), and the provision of campaign promotional materials to community-based organizations and health departments around the country. *Testing Makes Us Stronger* generated more than 514

million media impressions between the campaign launch in December 2011 and January 2013.

In March 2012 CDC launched *Take Charge. Take the Test.*, a multifaceted social marketing initiative designed to increase HIV testing among African American women ages 18–34. This effort, also part of CDC's national Act Against AIDS communications initiative, helps African American women recognize their risk of getting HIV and the need for HIV testing. It also empowers them with information, encourages them to get tested, and enables them to take charge of their lives—whatever their HIV test result. The campaign was launched in 10 U.S. cities where large numbers of black women are affected by HIV: Atlanta, Chicago, Detroit, Fort Lauderdale, Houston, Memphis, Newark, New Orleans, St. Louis, and Hyattsville, Maryland. *Take Charge. Take the Test.* generated more than 400 million media impressions between the campaign launch in March 2012 and September 2012. Additionally, the campaign generated more than 52,000 visits to its website (<http://hivtest.org/takecharge>), where users entered their ZIP Code to find nearby local testing sites.

***Coordinating HIV prevention activities targeting young men who have sex with men (MSM) of color and young transgender persons of color***—In 2012 CDC continued supporting grants to 34 community-based organizations (CBOs) that coordinate HIV prevention activities targeted to young MSM of color, young transgender persons of color, and their partners. The grants enable CBOs with strong links to these target populations to meet their specific HIV prevention needs. Key CBO activities in 2012 included providing HIV tests, linking individuals to care and prevention services, and implementing proven behavioral change HIV prevention programs. According to preliminary data, in 2012 grantees tested more than 11,000 clients, identified more than 400 previously undiagnosed HIV infections, and successfully linked 80 percent of those newly diagnosed to care. In addition, on World AIDS Day 2012, CDC released an issue of its monthly Vital Signs that highlighted the fact that, according to 2010 data, 1 in 4 new HIV infections in the U.S. occurs among young people ages 13–24. The issue underscored the disproportionate impact of HIV on young, black MSM, bringing renewed attention to the fact that the greatest number of new HIV infections occurred among gay and bisexual youth, with nearly half of all new infections among youth occurring in African American males.

***Implementing interventions with HIV-positive individuals to prevent the transmission of new infections***—Helping individuals who are living with HIV to reduce their risk of transmitting the virus to others is an important aspect of HIV prevention. Indeed, one of the anticipated outcomes of the NHAS is the reduction of the HIV transmission rate, which is a measure of annual transmissions in relation to the number of people living with HIV, by 30 percent (from 5 persons infected per 100 people with HIV to 3.5 persons infected per 100 with HIV). Toward that aim and with funding from the Secretary's Minority AIDS Initiative Fund (SMAIF), the Health Resources and Services Administration's HIV/AIDS Bureau (HRSA/HAB) continued supporting and

evaluating a three-year “prevention with positives” demonstration project. Ask, Screen, and Intervene (ASI), an HIV prevention intervention for HIV-positive individuals developed jointly by the CDC’s HIV/STD Prevention Training Centers and HRSA’s national network of AIDS Education and Training Centers, is being integrated into the care provided at Ryan White HIV/AIDS Program-funded clinics in Baltimore, Miami, Chicago, and Los Angeles, four of the jurisdictions with the heaviest HIV/AIDS burdens in the nation.

ASI is a brief, straightforward intervention in which clinicians ask patients about their HIV transmission risk behaviors and assess their readiness for change. Clinicians then screen the patients, testing and treating them, if indicated, for sexually transmitted infections (STIs) and hepatitis C virus (HCV). Finally, clinicians intervene by delivering brief behavioral risk reduction messages and identifying achievable first steps for individuals who express readiness for change. Clinician-delivered prevention messages have been demonstrated in research to be feasible and effective in reducing patients' risk of transmitting HIV to their partners. The intervention also facilitates service referrals for alcohol and/or drug counseling and other support services, as well as partner notification and counseling.

***Strengthening HIV screening activities***—The Food and Drug Administration (FDA) approved new HIV diagnostic tests to help address the issue of individuals knowing their HIV infection status. In July 2012, FDA approved the OraQuick® In-Home HIV Test, the first over-the-counter, self-administered HIV test kit to detect the presence of antibodies to human immunodeficiency virus type 1 (HIV-1) and type 2 (HIV-2). The OraQuick In-Home HIV Test is designed to allow individuals to obtain test results within 20 to 40 minutes using an oral fluid sample collected by swabbing the upper and lower gums inside the mouth, then placing that sample into a developer vial provided as part of the kit. The test has the potential to identify previously undiagnosed HIV infections, especially if used by those unlikely to access standard HIV screening.

***Engaging in targeted efforts to promote HIV prevention, treatment, and care in American Indian and Alaska Native communities***—HIV is a critical public health issue among the approximately 5.2 million American Indians and Alaska Natives (AI/AN) who represent approximately 1.7 percent of the U.S. population. Compared with other races/ethnicities, AI/AN populations have poorer survival rates after an AIDS diagnosis, and face additional HIV prevention challenges, including poverty and culturally based stigma. To promote HIV prevention, treatment, and care in AI/AN communities, the Indian Health Service (IHS) engaged in numerous efforts in 2012. For example, through the HIV Media Interventions in American Indian and Alaska Native Communities project, IHS supported efforts to research, create, disseminate, and evaluate tribal approaches to HIV testing, medication adherence, and stigma reduction using social marketing and new media technologies. These included the development of a social networking campaign to reduce HIV-related stigma and discrimination; a technology-based health intervention encouraging HIV testing and early diagnosis; and a technology-based health

intervention supporting improved HIV treatment adherence and care for AI/AN individuals living with HIV/AIDS.

***Piloting a resource allocation model to help local jurisdictions maximize their HIV prevention efforts***—Building on work previously done by CDC in partnership with Philadelphia’s Department of Public Health, CDC and OHAIDP—with encouragement and funding from ONAP—developed and initiated a one-year pilot project to test and refine an HIV prevention resource allocation model. Such models are designed to help policy makers and health department leaders make well-informed fiscal decisions on the optimal allocation of available funds across populations and evidence-based prevention interventions to maximize the number of new HIV infections averted.

Three jurisdictions that have different local profiles and HIV prevalence rates (Chicago, Nebraska, and Alabama) are participating in the pilot. The CDC model being tested and refined in these jurisdictions offers a projection of the expected number of new HIV cases in a community over one to five years and indicates the optimal allocation of an HIV prevention budget for each program and population. The model incorporates the annual HIV prevention budget for a community; the size and characteristics of populations with or at risk for HIV; the proportions of those populations that can be reached annually by each intervention; and characteristics of those interventions, including cost, efficacy, and duration of effect. In addition to piloting the model in those three jurisdictions, the CDC-OHAIDP collaboration is developing and testing an associated technical assistance protocol to support jurisdictions in using the model, and assessing the feasibility of a software or online version of the model that can be more broadly used by other health departments.

***Advancing HIV prevention science to reduce HIV transmission***—The National Institutes of Health (NIH) continued its support of basic and clinical research on HIV prevention, including critical studies of the use of antiretroviral drugs to prevent HIV transmission. A seminal study sponsored by the NIH-funded HIV Prevention Trials Network (HPTN 052) demonstrated that in sero-discordant heterosexual couples treatment with ART, known as “Treatment as Prevention,” decreased HIV acquisition in the uninfected partner by 96 percent. In December 2011 HPTN 052 was named *Science Magazine’s* “Breakthrough of the Year.” NIH is continuing this study in partnership with CDC to assess the durability of the HIV prevention benefit.

NIH also continued conducting studies on the provision of antiretroviral drugs to people who are not infected with HIV but who are at high risk of acquiring HIV infection—a prevention strategy called pre-exposure prophylaxis (PrEP). The NIH-sponsored iPrex study provided evidence that PrEP can reduce the risk of HIV acquisition among men who have sex with men by 43.8 percent; even higher rates of effectiveness result with greater adherence to the regimen. Based on this and other studies, in July 2012 FDA approved the use of Truvada® (emtricitabine/tenofovir disoproxil fumarate) as PrEP in combination with safe sex practices, risk reduction counseling, and regular HIV testing to

reduce the risk of sexually-acquired HIV infection in uninfected adults who are at high risk of HIV infection. In August 2012 CDC published interim guidance for clinicians considering use of PrEP for heterosexually active adults; this interim guidance updated the 2011 guidance for MSM and addressed pregnancy and safety issues.

Other NIH-supported studies are planned and underway on how to maximize the benefits of PrEP for different populations and under different conditions. For example, the demonstration study “PrEP Initiation and Adherence Among Black MSM in Three U.S. Cities,” known as HPTN 073, is designed to assess the willingness of black MSM to use Truvada® daily to reduce their risk of becoming HIV infected. HPTN 073 will enroll a total of 225 HIV-negative black MSM in 3 U.S. cities: Chapel Hill, North Carolina; Los Angeles, California; and Washington, DC. Another study, conducted with participation from CDC, “A Phase-II, Randomized, Open-Label Pharmacokinetic and Behavioral Study of the Use of Intermittent Oral Emtricitabine/Tenofovir Disoproxil Fumarate PrEP,” known as HPTN 067, is a behavioral study to evaluate the feasibility of non-daily PrEP dosing for individuals at high risk for HIV infection. The study is designed to identify PrEP pill-taking schedules that participants are more likely to follow and determine if these schedules influence healthier sexual practices.

NIH also continued to support a number of domestic studies examining the use of oral and topical PrEP in women, including studies to develop new PrEP and microbicide products and new formulations of those products that will enhance adherence and usability in women. These new formulations include intravaginal rings, intravaginal films, injectable medications, and formulations of gels for rectal use that do not cause local tissue damage.

In November 2010, NIH convened a panel of HIV obstetrical experts to develop a standardized approach to study the safety of PrEP and microbicide candidates during pregnancy. Subsequent safety studies of candidate biomedical HIV prevention interventions used during pregnancy have been conducted in the NIH-funded Microbicide Trials Network (MTN) using 1 percent tenofovir intra-vaginal gel during the different stages of fetal development. These studies have set the standard for pregnancy safety clinical trials of future biomedical prevention products.

The MTN also is conducting effectiveness and acceptability studies of an intravaginal ring containing the antiretroviral drug dapivirine to prevent HIV acquisition in women. NIH also is funding collaborative studies with external organizations, including studies with Contraceptive Research and Development (CONRAD) to determine the effects of sexual intercourse on the pharmacokinetics and pharmacodynamics of 1 percent tenofovir gel as an intravaginal microbicide candidate (MTN 011) and clinical studies with the International Partnership for Microbicides (IPM) to test the safety and pharmacokinetics of an intravaginal ring containing the antiretroviral drug combination of dapivirine and maraviroc (MTN 013/IPM 016).

NIH collaborated with other Federal agencies to investigate the social and behavioral factors that are likely to influence the roll-out, uptake, effectiveness and long-term impact

of biomedical interventions. For example, in partnership with CDC, the study “TLC-Plus: A Study to Evaluate the Feasibility of an Enhanced Test, Link to Care, Plus Treat Approach for HIV Prevention in the United States,” known as HPTN 065, is evaluating testing, linkage to care, and promotion of adherence (“test and treat”) strategies in pilot programs in the Bronx and Washington, DC, collecting information on social factors that influence an individual’s willingness to be tested for HIV.

***Strengthening efforts to increase rapid HIV testing in substance abuse treatment facilities and among those affected by substance abuse and behavioral disorders***

—In 2012 NIH’s National Institute on Drug Abuse (NIDA) released findings from its study, “HIV Rapid Testing and Counseling in Drug Abuse Treatment Programs in the U.S.,” a randomized controlled clinical trial that assessed the relative effectiveness of three HIV testing strategies: onsite rapid HIV testing with brief, participant-tailored prevention counseling; onsite rapid HIV testing with information only; and referral for offsite HIV testing, in reducing risky sexual and drug-using behaviors. The study demonstrated the value of onsite rapid HIV testing in drug treatment centers and found no additional benefit from HIV risk-reduction counseling. NIDA disseminated results through its Blending Initiative, a partnership between NIDA and the Substance Abuse and Mental Health Services Administration (SAMHSA) to help move findings from drug abuse research into practice in front-line clinical settings. Through the Blending Initiative, results were disseminated via several user-friendly tools, including video interviews with researchers, treatment providers, and others, and a fact sheet detailing the urgent need to provide HIV testing for people in substance abuse treatment programs due to high HIV prevalence among that population.

SAMHSA supported numerous HIV testing efforts targeting individuals affected by substance abuse and behavioral disorders at high risk for HIV through its Minority AIDS Initiative-Targeted Capacity Expansion (MAI-TCE) grant programs. For example, SAMHSA’s Center for Substance Abuse Prevention (CSAP) MAI-TCE initiative supported 122 organizations that provide substance abuse and HIV prevention in high-risk communities. In 2012, these grantees provided HIV testing for more than 2,400 individuals, including more than 800 individuals who were tested for the first time. Additionally, eight projects under the Center for Mental Health Services (CMHS) MAI-TCE initiative provided rapid HIV testing for individuals at high risk for HIV and/or with behavioral disorders in minority communities with high HIV prevalence. Rapid HIV testing was also an integral part of the Center for Substance Abuse Treatment’s (CSAT) Targeted Capacity Expansion (TCE-HIV) substance abuse program. Fifty-seven (57) new TCE-HIV grantees provided HIV testing to high-risk young minority MSM, aged 18-29; heterosexual men and women; and MSM over the age of 30 years as an essential part of substance abuse treatment. In addition, 21 rapid testing supplements were awarded to existing substance abuse prevention and treatment grantees with funds provided through the SMAIF.

## GOAL 2 Increase Access to Care and Improve Health Outcomes for People Living with HIV

### NHAS Action Steps

- Establish a seamless system to immediately link people to continuous and coordinated quality care when they are diagnosed with HIV.
- Take deliberate steps to increase the number and diversity of available providers of clinical care and related services for people living with HIV.
- Support people living with HIV with co-occurring health conditions and those who have challenges meeting their basic needs, such as housing.

### Anticipated Results, by 2015

- Increase the proportion of newly diagnosed patients linked to clinical care within three months of their HIV diagnosis from 65 percent to 85 percent.
- Increase the proportion of Ryan White HIV/AIDS Program clients who are in continuous care (at least 2 visits for routine HIV medical care in 12 months at least 3 months apart) from 73 percent to 80 percent.
- Increase the percentage of Ryan White HIV/AIDS Program clients with permanent housing from 82 percent to 86 percent. (This serves as a measurable proxy of our efforts to expand access to HUD and other housing supports to all needy people living with HIV.)

In pursuit of the Strategy's second goal, HHS undertook numerous activities in 2012, including the following:

#### ***Leveraging public health data to support engagement and retention in care—***

HRSA/HAB initiated a capacity building demonstration project supporting the development of statewide health information exchanges (HIE) that confidentially link public health HIV/AIDS surveillance data with patient-level electronic medical record (EMR) data from inpatient, outpatient, and emergency healthcare settings such as hospitals and community-based clinics. The three-year project, Replication of a Public Health Exchange to Support Engagement in HIV Care, seeks to increase the rates of linkage, engagement, and retention in HIV care for racial and ethnic minorities who have tested positive for HIV but never received their test results and thus remain unaware of their infection, as well as those who have confirmed diagnoses, but have never been engaged in care, have refused referral to care, or have dropped out of care.

With funds from SMAIF, the demonstration project supports three sites (Georgia, North Carolina, and the Virgin Islands) in the replication of the Louisiana Public Health Information Exchange (LaPHIE), whose development was previously funded, in part, by HRSA/HAB's Special Projects of National Significance (SPNS) Electronic Networks of Care Initiative. LaPHIE, a collaboration between the Louisiana Office of Public Health and the Louisiana State University Health Care Services Division, is a secure bi-directional public health information exchange that links statewide public health HIV surveillance data with patient-level EMR data. By linking this data and supporting its

timely transfer to healthcare providers, providers are then able to track patients as they move from one point of service to another, and help ensure that individuals living with HIV are linked to and retained in HIV care. In its first 24 months of operation, the system identified and linked back to care over 400 Louisianans with untreated HIV. Using this model, the three funded sites will design, develop, implement, and evaluate their own comprehensive statewide public health HIEs, allowing HRSA/HAB to learn about how HIEs work in other jurisdictions with different levels of health information technology infrastructure, administrative structures and funding streams, and legal and privacy requirements.

***Supporting jurisdictions in using HIV surveillance data to monitor and improve linkage to and retention in care***—In March 2012 CDC awarded an additional \$20 million through Category C of CDC’s flagship five-year HIV prevention cooperative agreement to health departments to implement and evaluate innovative HIV prevention demonstration projects. More than half of the 30 health departments selected through a competitive process to receive those funds are implementing demonstration projects focused on better using HIV surveillance data to improve jurisdiction-wide linkage to and retention in care rates. In addition, CDC released formal guidance in February 2012, “Using Viral Load Data to Monitor HIV Burden and Treatment Outcomes in the United States,” providing the conceptual clarity and measurement standards necessary to foster broader uptake, application, and comparison of results across jurisdictions. CDC also developed and supplied to jurisdictions several data analysis programs that can be used with HIV surveillance data to develop estimates of and monitor progress towards key indicators, as well as to generate tools that support public health action (e.g., identifying HIV-infected persons who, based on available viral load and CD4 data, appear to not be engaged in HIV care).

***Addressing viral hepatitis co-infections to improve health outcomes***—Among the co-occurring conditions that must be addressed to improve health outcomes for people living with HIV is viral hepatitis. Hepatitis C virus (HCV) is a leading cause of morbidity and mortality among people living with HIV. On average, one-third of people living with HIV (PLWH) are co-infected with HCV, and rates are even higher among persons who inject drugs. In addition, an estimated 10 percent of PLWH are co-infected with chronic hepatitis B virus (HBV).

One important initiative addressing this issue is HRSA/HAB’s Hepatitis C Treatment Expansion Initiative. Funded as one of HAB’s SPNS, this initiative supported 29 Ryan White HIV/AIDS Program grantees in 2012. Each had received funding for two years to test new models of integrating HCV treatment into their clinical practice. The overall goal of the initiative is to enable sites to increase the number of co-infected patients treated for HCV. This initiative will evaluate the effectiveness of the interventions to deliver HCV treatment among HIV-positive populations, and share best practice models with Ryan White grantees and other HIV medical providers to improve access to and the quality of HCV services for HIV patients.

At the November 2012 Ryan White HIV/AIDS Program Grantee Meeting, two participants in this initiative—the AIDS Care Group of Chester, Pennsylvania, and the Siouxland Community Health Center of Sioux City, Iowa—shared their rationales for integrating HCV treatment into their practices, highlighted steps they took to develop and begin delivering these services, discussed clinical issues related to HCV treatment, and shared lessons learned. The University of South Florida, which has a cooperative agreement to serve as the training and evaluation center for this SPNS initiative, also presented at the grantee meeting. Their presentation, “Implementing HCV Treatment Programs in Comprehensive HIV Clinics,” provided an overview of HCV and HIV co-infection, addressed elements of a successful HIV/HCV program, and highlighted four models of care delivery being used by the SPNS grantees: primary care delivery with expert back-up; integrated care without a designated HCV clinic (expert consultation used for severe complications); integrated care with a designated internal HCV clinic; and co-located care with specialist who manages treatment at Ryan White clinical site. Outcomes to be measured across all sites include the number of HIV/HCV co-infected patients treated or not treated for HCV, barriers to HCV treatment, sustained virologic response, services utilization, and cost. Grantees are also encouraged to conduct projects designed to investigate local issues that affect HCV treatment in their populations.

SAMHSA initiated a project to enhance delivery of substance abuse treatment services to address viral hepatitis infection among intravenous drug users (IDUs). The purpose of the project is to demonstrate the cost-effective delivery of recommended hepatitis vaccination and testing to minority populations receiving interventions for opioid dependence within a treatment setting. The populations served in this project include African Americans, Hispanics/Latinos, Asian Americans, Native Hawaiians/Other Pacific Islanders, and AI/AN. The project includes hepatitis testing, vaccination, referral to treatment for those with evidence of infection, and risk reduction counseling.

***Improving the integration of behavioral health screening and services delivery with HIV prevention and care***—Working to improve the coordination of behavioral health services with HIV prevention, diagnosis, and care in minority communities for those at risk for and living with HIV and co-occurring mental health and/or substance use problems, SAMHSA supported 11 new grantees in 2012 in the first year of a three-year initiative. These cooperative agreements seek to facilitate the development and expansion of effective, culturally competent care networks that integrate behavioral health services, primary care, and HIV care and treatment. As part of SAMHSA’s involvement in the HHS 12 Cities Project, awards were made to 11 of the 12 jurisdictions with the highest HIV/AIDS burden in the United States: Atlanta; Baltimore; Chicago; Dallas; Los Angeles; Miami; New York City; Philadelphia; San Juan, Puerto Rico; San Francisco; and Washington, DC. SAMHSA’s MAI-TCE Integrated Behavioral Health/Primary Care Network Program is supported by funds from the SMAIF.

Early results from the first year of activity show that 4,966 individuals in the 11 cities were screened for behavioral health needs, 2,056 individuals were referred to other

community resources and 693 individuals were newly engaged in behavioral health services. At the local level, screening for behavioral health needs in conjunction with HIV testing increased among clients in primary care settings. In eight projects, grantees increased rapid HIV testing in substance abuse treatment, prevention, and primary care settings. In one project, care management increased for persons newly diagnosed with HIV, and substance abuse treatment and HIV care services were provided contemporaneously.

Other grantee activities included the initiation of peer coaching and mentoring for HIV-positive clients at a Federally Qualified Health Center (FQHC) and infectious disease clinics to help support client well being, reduce substance use, and improve retention in care; the introduction of behavioral health screening at STD clinics and infectious disease clinics, with onsite support and linkage to follow up care, as needed; and the establishment of a local Behavioral Health/Primary Care Network Committee to engage community partners in a dialogue to identify and address service or coordination gaps and to work toward building a seamless care network.

***Expanding linkage to care for AI/AN individuals living with HIV***—As part of its Improving Health Outcomes through Enhanced Medical Information Technology and Patient-Centered Delivery of Medical Services project, in 2012 IHS increased efforts to document and share best practices for linkage to HIV care. Activities included the implementation of a standardized electronic notification and referral process for patients with positive HIV test results; development of a database to monitor receipt of annual preventive care screenings; monthly adherence clinics for patients living with HIV/AIDS, HCV, and tuberculosis; implementation of a standard collaborative protocol for ensuring evaluation of patients by optometry, audiology, and mental health service providers; enrollment of qualified patients in federal and state assistance programs; and increased staff development and credentialing of providers to enable their further expansion of patient services.

While IHS has enjoyed significant success in several sites, there have been barriers to full implementation of the Improving Health Outcomes through Enhanced Medical Information Technology and Patient-Centered Delivery of Medical Services project across sites as IHS is mainly a primary care system, which means many HIV patients are referred to specialty care outside the system for HIV treatment. To help ensure quality, IHS is improving the monitoring of external referrals and working with HRSA to support the enrollment of AI/AN clients in Ryan White programs. Finally, IHS is encouraging primary care providers to take a larger role in HIV care by offering training and telemedicine opportunities. IHS technical assistance teams are reaching out via pharmacists, who often assume a case management role in AI/AN communities, helping patients to navigate the system to meet their medical and social needs.

***Enhancing HIV care through implementation of the Affordable Care Act***—HHS took steps in 2012 to both improve access to HIV care and enhance the quality of such care by implementing provisions of the Affordable Care Act. Activities included the following:

- ***Increasing access to home and community-based HIV care for individuals living with HIV/AIDS:*** In 2012 the Centers for Medicare & Medicaid Services (CMS) renewed three of the existing 1915(c) waiver programs authorized in 11 states that identified people living with HIV/AIDS as a specific target population for the waiver programs. 1915(c) waiver programs permit a state to furnish an array of home and community-based services that assist Medicaid beneficiaries to live in the community and avoid institutionalization. The Affordable Care Act has expanded the opportunities for the growth of home and community-based services. The state has broad discretion to design its 1915(c) waiver program(s) to address the needs of the waiver’s target population. Waiver program services complement and/or supplement the services that are available to participants through the Medicaid state plan and other federal, state, and local public programs as well as the supports that families and communities provide.

The year 2012 saw an increase of close to five percent in the number of individuals states had proposed to serve in these waiver programs. Under these waivers, the 11 states served more than 16,000 individuals living with HIV/AIDS by offering a variety of standard medical and non-medical services, including case management, homemaker services, home health aide support, personal care and adult day health services, habilitation services, and respite care, as well as other types of services to assist in diverting and/or transitioning individuals living with HIV/AIDS from institutional settings into their homes and communities. Medicaid community-based care has been found to be related to improved outcomes and reduced costs of care; thus renewal and expansion of such waiver programs are among the ways to increase access to care for PLWHA.

- ***Improving the provision of continuous quality HIV care for Medicaid-eligible adults living with HIV/AIDS:*** As required by Section 1139B of the Affordable Care Act, in January 2012 HHS published its initial core set of health care quality measures for Medicaid-eligible adults. This initial core set, for voluntary use by state Medicaid programs, includes a measure for “annual HIV/AIDS medical visits.” This quality measure allows states to track the percentage of Medicaid enrollees with a diagnosis of HIV/AIDS who received at least two medical visits per year, with a minimum of 90 to 180 days between each visit, thus ensuring that these individuals are linked to and retained in medical care that can help them stay healthy. States will have the option to report on this measure by January 2014.

In December 2012 CMS launched the Adult Medicaid Quality Grant Program: Measuring and Improving the Quality of Care in Medicaid. This two-year grant program is designed to support state Medicaid agencies in developing staff capacity

to collect, report, and analyze data on the core set of health quality measures for Medicaid-eligible adults. CMS selected 26 states to participate, and eight (Arkansas, California, Connecticut, Minnesota, Montana, New York, Oklahoma, and Oregon) have indicated the intent to report on the HIV/AIDS quality measure. The data collected from this measure will help CMS to better understand the quality of health care that HIV-positive adults enrolled in Medicaid receive. In turn, this data will provide important new information that will help in monitoring and evaluating the HIV care continuum nationally and in the participating states, aiding in efforts improve the quality of HIV care by addressing the fall-offs between steps in the cascade.

- *Ensuring healthcare coverage for low-income adults living with HIV/AIDS:* CMS also engaged in other efforts to support the transition of low-income adults living with HIV/AIDS into healthcare coverage programs. In 2012 CMS launched a series of webinars in collaboration with HRSA to help providers and states make transitions from the Ryan White HIV/AIDS program to Medicaid. The first joint webinar, “The Affordable Care Act and the Ryan White HIV/AIDS Program: New Opportunities for People Living with HIV/AIDS,” was jointly conducted by the CMS Center for Consumer Information and Insurance Oversight and HRSA and was attended by some 680 participants. Further webinars and resources to support transition planning are underway.

***Addressing the needs of adolescents who are living with HIV or at risk of HIV infection***—NIH’s Adolescent Medicine Trials Network for HIV/AIDS Interventions (ATN) is the only national, multisite research network devoted to the health and well-being of young people, ages 12–24, who are living with HIV or at risk of HIV infection. ATN activities encompass the full spectrum of research needs for youth, from primary prevention, including HIV preventive vaccine, microbicide and PrEP trials for youth at risk for HIV infection, to the clinical management of youth who are living with HIV, including treatment strategies and regimens, drug adherence, risk reduction, and linkage and engagement to care. In 2012 NIH established a program linking the existing ATN to CDC-funded HIV counseling and testing programs that target adolescents and young adults who are potentially infected with HIV. This new NIH/CDC collaboration seeks to enhance methods of linking these youth to treatment and encouraging them to remain in care so they can continue to receive life-saving therapy and manage any co-occurring conditions they may have.

***Increasing collaborative efforts to address homelessness and housing insecurity experienced by individuals living with HIV/AIDS***—In 2012, the office of the HHS Assistant Secretary for Planning and Evaluation (ASPE) funded and initiated a study on housing and care services for people living with HIV. In this study, “Analysis of Integrated Housing and Care Services,” researchers are conducting a quantitative analysis of national HIV housing assistance data and a qualitative study of Integrated HIV/AIDS Housing Plan (IHHP) projects funded by the U.S. Department of Housing and Urban Development (HUD). Findings from this study will inform federal policy makers

about innovative program integration models that address both housing and health to improve outcomes for people living with HIV.

In 2012 HRSA/HAB began Building a Medical Home for Multiply Diagnosed HIV-positive Homeless Populations, a multisite, multiyear SPNS project to support organizations in the design of focused, innovative, and potentially replicable interventions to address the complex care needs of homeless and unstably housed individuals living with HIV and co-occurring mental illness and/or substance use. The goal of the initiative is to improve the timely entry, engagement in, and retention in HIV care and supportive services for HIV-positive, multiply diagnosed homeless and unstably housed populations. Nine demonstration sites were funded; in addition to an evaluation and technical assistance center for this initiative. Demonstration site organizations are expected to provide intensive coordination of care and service needs to ensure retention and adherence to care. For the purposes of this initiative, integrated services will be broadly defined to include the management and delivery of HIV primary care and substance abuse and mental health treatment that assure homeless and unstably housed people living with HIV receive a continuum of care according to their specific needs. Awardees also will be expected to include access to housing resources and services for their target population.

**Supporting research to improve HIV treatment outcomes**—One of NIH’s central priorities is to advance the discovery and validation of therapeutic strategies to prevent the progression of HIV and its associated co-morbidities, co-infections, and other clinical complications in individuals who are living with HIV, across the lifespan. While ART has resulted in improved immune function in patients who are able to adhere to their treatment regimens and tolerate the toxicities and side effects associated with antiretroviral drugs, treatment failures and subsequent drug resistance are seen in an increasing number of patients who have been on ART. In 2012 NIH continued support for basic and clinical research to develop improved, less toxic HIV treatments and to investigate how genetic determinants, sex, gender, race, age, nutritional status, treatment during pregnancy, and other factors interact to affect treatment success or failure and/or disease progression.

Studies are also addressing the malignancies, cardiovascular, neurologic, and metabolic complications, and issues of premature aging associated with long-term HIV disease and antiretroviral therapy. For example, NIH research to develop new regimens for the treatment of AIDS-related lymphoma and the tailoring of these regimens to specific tumor types has markedly improved the therapeutic outcome and survival of patients with this malignancy. NIH is also focused on developing drugs and other innovative strategies that can target and eradicate persistent viral reservoirs in various cells, tissues, and organ systems, including the central nervous system that may lead to a functional cure for HIV disease. Importantly, NIH sponsored research initiatives address the critical issue of adherence to treatment focusing on promoting engagement in care and compliance with treatment regimens, including studies to improve HIV treatment outcomes in racial and ethnic minorities. NIH also is supporting studies to advance the

assessment of HIV treatment adherence and to incorporate measures into routine care to improve the identification of individuals in need of adherence support.

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## GOAL 3 Reduce HIV-related Disparities and Health Inequities

### NHAS Action Steps

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

### Anticipated Results, by 2015

- Increase the proportion of HIV diagnosed gay and bisexual men with undetectable viral load by 20 percent.
- Increase the proportion of HIV diagnosed Blacks with undetectable viral load by 20 percent.
- Increase the proportion of HIV diagnosed Latinos with undetectable viral load by 20 percent.

In pursuit of the Strategy's third goal, HHS undertook numerous activities in 2012, including the following:

***Funding new HIV care and prevention demonstration project targeting racial and ethnic minorities***—In September 2012, through a CDC funding announcement, HHS awarded \$14.2 million from the SMAIF to eight state health departments— Georgia, Illinois, Louisiana, Mississippi, Missouri, North Carolina, Tennessee, and Virginia—to support the first-year of a new, innovative, three-year cross-agency demonstration project. The Care and Prevention of HIV in the United States (CAPUS) Demonstration Project is designed to reduce HIV-related morbidity, mortality, and related health disparities among racial and ethnic minorities by addressing the individual social, economic, clinical, and structural factors that impede early HIV diagnosis and retention in HIV care.

The awards were made through a competitive process open to 18 state/territorial health departments in the United States with disproportionately high burdens of HIV/AIDS among minority communities—many of which are located in the Southern United States. Specifically, the eligible jurisdictions had more than 5,000 HIV cases among African Americans and Latinos and an AIDS diagnosis rate higher than 6 per 100,000, which focuses this initiative on disproportionately affected geographic areas. The primary goals of the CAPUS Demonstration Project are to increase the proportion of racial and ethnic minorities with HIV who are diagnosed by expanding HIV testing capacity; optimize linkage to, retention in, and re-engagement with care and prevention services for newly diagnosed and previously diagnosed racial and ethnic minorities who are living with HIV; and address social, economic, clinical, and structural factors influencing HIV health outcomes. CAPUS was developed collaboratively by OHAIDP, CDC, HRSA, and SAMHSA as part of ongoing efforts to foster a more integrated approach to HIV across

federally supported activities, and these agencies all continue to be involved in supporting the eight grantees by engaging in multi-agency site visits and coordinating cross-agency technical assistance.

***Reducing HIV disparities among African Americans, particularly gay and bisexual men***—As part of its ongoing work to intensify HIV prevention efforts in the communities where HIV is most heavily concentrated and reduce HIV-related health disparities, HHS engaged in a number of efforts to enhance the response to HIV among African American gay and bisexual men and other MSM. The need for such efforts was once again reinforced by findings released in 2012 from the NIH-supported study, “Feasibility of a Community-Level Multi-Component Intervention for Black MSM in Preparation for a Phase IIB Community-Level Randomized Trial to Test the Efficacy of the Intervention in Reducing HIV Incidence among Black MSM.” The study, known as HPTN 061, involved 1,553 black gay, bisexual and other MSM in six U.S. cities and was the first study to determine the rate of new HIV infections among such a large prospective cohort of U.S. black MSM. Study results presented at AIDS 2012 showed greatly elevated infection rates among black gay, bisexual, and other MSM, particularly younger men. The overall rate of new HIV infection among black MSM in this study was 2.8 percent per year, a rate that is nearly 50 percent higher than in white MSM in the United States. Even more alarming, HPTN 061 found that young black MSM—those age 30 and younger—acquired HIV infection at a rate of 5.9 percent per year, three times the rate among U.S. white MSM.

To address the needs of this population at such high risk of HIV infection, OHAIDP convened a two-day technical consultation in November 2012. Bringing together representatives from national and community-based organizations; healthcare providers; researchers; and federal, state, and local government leaders, the meeting explored how to best address the HIV prevention, treatment, and care needs of black MSM and the health disparities that put them at greater risk for both acquiring HIV and for experiencing poorer health outcomes when living with HIV and AIDS. Specific attention was given to three domains during the consultation and the policy and programmatic challenges and opportunities each presents: biomedical advances, stigma and structural determinants of health, and capacity building. The recommendations and ideas generated at the consultation continue to inform policy and program planning among HHS agencies and offices.

Other activities to address HIV among African Americans included OHAIDP’s October 2012 release of *An Inventory of HIV Prevention Programs Serving African Americans Funded by the U.S. Department of Health and Human Services*, a report describing the findings of an interagency collaboration to identify, review, and assess the effectiveness of HHS-funded discretionary programs and initiatives aimed at reducing HIV infections among African Americans. One of the NHAS tasks assigned to HHS, the inventory found preliminary evidence suggesting that more focused prevention program development and targeting of services may be warranted, particularly in

disproportionately affected subpopulations, including young black MSM and women, and African Americans living in hard-hit U.S. regions (e.g. South, Northeast). Finally, as noted previously in this report, CDC also supported the *Testing Makes Us Stronger* campaign, encouraging HIV testing among black MSM.

**Reducing HIV disparities and health inequities among women**—HHS engaged in numerous efforts in 2012 to address women and girls' unique risks and vulnerabilities related to HIV/AIDS. One in four people living with a diagnosis of HIV infection in the United States are women and Black/African American women and Latinas are disproportionately affected by HIV infection compared with women of other races/ethnicities. Shedding more light on this disparity, in March 2012 results were released from an NIH-funded study, HPTN 064, also known as the Women's HIV SeroIncidence Study (ISIS). This long-term, multisite observational study was designed to help determine the HIV incidence among women living in areas hardest hit by the epidemic, as well as to identify steps that women can take to lower their HIV-infection risk. Among the 2,099 women enrolled in the study, 88 percent were African American. At enrollment, 32 women (1.5 percent of all the participants) were newly diagnosed and two more were found to have acute HIV infection. The incidence rate during study follow-up was substantially higher, which indicates the ongoing need for concerted efforts to improve HIV prevention strategies for women.

Two HRSA/HAB SPNS initiatives focused on women-specific issues related to HIV care. HRSA's Enhancing Access to and Retention in Quality HIV/AIDS Care for Women of Color Initiative funds 10 demonstration sites for up to five years to design, implement, and evaluate innovative methods for enhancing access to and retaining women of color living with HIV/AIDS in primary medical care and ancillary services. Interventions, including those implemented in 2012, address community-based outreach, patient education, intensive case management, and patient navigation strategies that promote access to HIV care.

The Enhancing Engagement and Retention in Quality HIV Care for Transgender Women of Color Initiative, funded in 2012 and running through 2016, is a multisite demonstration project focused on identifying, engaging, and retaining in care transgender women of color who are at high risk of HIV infection or who are infected with HIV but are unaware of their status; those who are aware of their HIV infection but have never been engaged in care; and those who are aware but have either refused referral to care or have dropped out of care. Transgender people experience significant difficulties when attempting to access all types of health care due to fears of discrimination, provider insensitivity and lack of knowledge about transgender health, and other issues, and data from urban needs assessments and risk behavioral studies have shown high rates of HIV infection in this traditionally underserved population. The interventions of this initiative are addressing many of the barriers faced by transgender women of color who are living with HIV infection when they attempt to access HIV primary care.

Also in 2012, the Office on Women's Health (OWH) continued to train their grantees on gender-responsive programming and to pilot test the *HIV Prevention Gender Toolkit for*

*Women.* This toolkit was designed to help public health officials, program coordinators, community- and faith-based providers, and clinicians increase their understanding of gender as a social determinant of health and essential component of HIV programming.

The OWH and the Office of the HHS Assistant Secretary for Planning and Evaluation (ASPE), in conjunction with other Federal Interagency Reentry Council members and community partners, sponsored a 2012 conference on improving outcomes for women reentering the community from prison or jail. Both the conference and the subsequently developed action plan included HIV among the topics specifically covered while also addressing broader issues that contribute to increased HIV risk among these women.

The release of CDC's HIV incidence estimates in December 2012 ended the year on a hopeful note for women. While new HIV infections among black women remain high, for the first time this analysis found indications of an encouraging trend. Comparing 2008 to 2010, new HIV infections among black women decreased 21 percent, from 7,700 in 2008 to 6,100 in 2010. This decrease contributed to a 21 percent decline in new infections among women overall during the same time period. Additional years of data will be needed to determine if the decrease among black women is the beginning of a longer-term trend.

***Reducing/Eliminating stigma and discrimination against people living with HIV—*** HIV-related stigma and discrimination create barriers to HIV testing, treatment, and care. In July 2012, CDC launched *Let's Stop HIV Together*, a broadly targeted general campaign that raises awareness about HIV and its impact on the lives of all Americans, and fights stigma by giving voice to people living with HIV from all walks of life. As part of the campaign, people living with HIV, their friends, and family members share their personal stories, calling on everyone to join the fight against the disease. *Let's Stop HIV Together* encourages everyone to learn the facts about HIV transmission and prevention, get tested for HIV, and speak out against the stigma and complacency that helps fuel the spread of HIV.

*Let's Stop HIV Together* has been featured in local and national print ads, online ads, television and radio public service announcements, billboards, airports and other outdoor advertising venues. The campaign has a dedicated website (<http://www.cdc.gov/actagainstaids/together/index.html>) and Facebook page as well as a presence on You Tube with 15 videos and more digital stories to be added. Outdoor and transit ads began running in July 2012 in six cities heavily affected by HIV—Atlanta, Dallas, Los Angeles, New Orleans, New York City and Washington, DC—and extended to 21 other cities with more than 493 million impressions. Campaign videos on YouTube generated more than 603,000 views in 2012, and the campaign garnered nearly 67,000 Facebook page likes and more than 1,100 tweets using the campaign hashtag #StopHIVTogether. There has also been extensive media coverage of the campaign in more than 40 different print, online and broadcast outlets, including multiple top tier consumer outlets, such as ABCNews.com, CNews.com and USA

Today. The reach of the campaign has been further extended with over \$950,000 in donated ad space through billboards and public service announcement placements throughout the country. Based on the positive feedback received about this campaign, CDC began developing additional stories and materials, including several Spanish language stories, for release in 2013.

***Strengthening enforcement of civil rights laws affecting people living with HIV/AIDS***—The Office of Civil Rights (OCR), the Department's civil rights and health privacy rights law enforcement agency, continued to investigate and take action on complaints alleging discrimination against people living with HIV/AIDS by health care providers and human service agencies. For example, in August 2012, OCR secured an order terminating Medicaid payments to a California surgeon who discriminated against an HIV-positive patient by refusing to perform back surgery on him. The order was issued by the HHS Departmental Appeals Board, which concluded that the surgeon violated Section 504 of the Rehabilitation Act of 1973, which prohibits disability discrimination by health care providers who receive federal funds.

The OCR and the New York State Department of Health (NYSDOH) collaborated to address reports that some nursing homes in the state were denying admission to patients who have HIV/AIDS due to the cost of HIV medications. Such expenses, however, are not solely the responsibility of the nursing homes. Nursing home care is a critically important service for approximately 120,000 New Yorkers living with HIV/AIDS, and denying admission to individuals based on their HIV status (including based on the cost of their medications) may constitute discrimination that is prohibited by the Americans with Disabilities Act of 1990 and Section 504 of the Rehabilitation Act of 1973, as well as New York state statutes and regulations. As such, in October 2012 OCR and NYSDOH sent a joint letter to all New York nursing home administrators focusing on the requirement to provide equal access to health care for individuals with HIV/AIDS. In the letter, OCR and NYSDOH offered to provide technical assistance to facilities to ensure compliance with anti-discrimination statutes and regulations.

***Making recommendations regarding safe and voluntary disclosure of HIV status***—As part of efforts to reduce stigma and discrimination against people living with HIV, the Presidential Advisory Council on HIV/AIDS (PACHA) and the CDC-HRSA Advisory Committee on HIV, Viral Hepatitis, and STD Prevention and Care (CHAC) collaborated in 2012 to make recommendations for ways to promote and normalize safe and voluntary self-disclosure of HIV status in various contexts and circumstances. Through a process that involved input from both bodies as well as a two-day summit with various leaders including PLWH, medical ethicists, healthcare providers, lawyers, and others, PACHA and CHAC developed a set of principles for safe and voluntary disclosure of one's HIV status as well as short and long-term policy recommendations related to such disclosure. These principles and recommendations recognize and respect the ultimate autonomy of each individual faced with the opportunities and challenges of disclosing her or his HIV status and acknowledge that disclosure of HIV status is not a single,

discrete event, but rather an ongoing process that spans a lifetime and many contexts. The principles and recommendations were presented at the December 2012 PACHA meeting and subsequently sent to the Secretary for consideration.



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## Achieving a More Coordinated National Response to the HIV Epidemic

The Strategy clearly states that in order to achieve the goals it sets forth, emphasis must be placed on greater coordination of activities among agencies and across all levels of government. It specifically calls for:

- Increasing the coordination of HIV programs across the federal government and between federal agencies and state, territorial, local, and tribal governments.
- Developing improved mechanisms to monitor and report on progress toward achieving national goals.

Highlights of progress within HHS during 2012 on both these priorities include the following:

***Streamlining and standardizing indicators for monitoring HHS-funded HIV/AIDS prevention, treatment, and care services and reducing grantee reporting burden—***

On July 24, 2012, Secretary Sebelius approved a package of seven common core indicators to be widely used across HHS programs to monitor and report on HIV/AIDS prevention, treatment, and care services. These common core indicators, developed through a process of multiple consultations with a group of federal and non-federal stakeholders and informed by relevant treatment guidelines and empirical evidence, are as follows: HIV diagnosis, late HIV diagnosis, initial linkage to care, sustained engagement in care, initiation of antiretroviral treatment, viral load suppression, and housing status. By using this reduced, standardized set of core indicators across programs, HHS will be able to better focus its HIV data collection and reporting activities.

The HHS Office of the National Coordinator for Health Information Technology (ONC), CDC, CMS, HRSA/HAB, and OHAIDP are working collaboratively to facilitate the inclusion of several of the core indicators in Stage 3 of the CMS/ONC Meaningful Use Program, a program that governs the use of electronic health records and allows eligible providers and hospitals to earn incentive payments by meeting specific criteria. Through this program, the collaborating agencies and offices are seeking to integrate the HIV indicators into electronic health record systems beginning in 2016. These efforts are intended to increase transparency and interoperability of data management systems, improve accountability and data exchange, and simplify data input, flow, and coordination.

In 2012 HHS also made significant progress toward streamlining and standardizing grantee reporting requirements for grantees providing HIV/AIDS services. This has included an agency-by-agency review of reporting requirements and the identification and elimination of duplicative, under-utilized, or consistently poor quality data. As a result, by the beginning of FY 2014 HHS will have initiated changes that will reduce

grantee reporting of domestic HIV program data elements and reporting frequency by at least 20–25 percent. By the end of 2012, HHS operating divisions and staff offices that support HIV services had each developed and submitted to the Secretary draft operational plans to implement these core indicators and reporting changes across their funded programs. Further data harmonization and simplification are expected to result as the indicators work continues.

***Improving HIV data collection, reporting and use***—As well as working collaboratively on the development and implementation of common HIV indicators and reduction of grantee reporting burden, several HHS agencies and offices engaged in 2012 activities designed to support states and other jurisdictions as well as particular program grantees in collecting, analyzing, and utilizing key data to assess and improve HIV services as well as to monitor implementation of the NHAS. Activities included the following:

- ***Enhancing HIV surveillance data reporting:*** CDC is helping to lead a national shift in the use of data for program improvement and accountability by focusing its data collection and reporting activities on a reduced slate of core indicators that better reflect the state of prevention science and closely align with major transition points along the HIV care continuum (e.g., linkage to care and durable viral load suppression), and by publishing programmatic and surveillance reports that detail jurisdiction-specific performance on key process (e.g., lab-based reporting for all viral load and CD4 test values) and outcome indicators (e.g., viral load suppression at most recently reported viral load test, and the proportion of CDC funded tests that result in new HIV diagnoses). Beginning with 2011 HIV surveillance data, all states and territories now have mature, confidential name-based surveillance systems to report HIV infections. Confidential, name-based HIV reporting provides an accurate and reliable picture of the size and distribution of the HIV epidemic in the U.S.—information that is critical to the optimal allocation of scarce prevention resources.
- ***Improving HIV data collection in health centers:*** HRSA's Bureau of Primary Health Care (BPHC) continued to promote integration of routine HIV testing in health centers. Since the release of the Strategy in 2010, health centers have increased the number of HIV tests conducted by 28 percent, with nearly one million people receiving tests in 2012. To strengthen data collection on linkage to care, in 2012 HRSA/BPHC requested the addition of the new common HHS Linkage to HIV Medical Care indicator to its clinical performance measures. Once implemented in 2014, the use of this indicator will encourage activities related to linkage and care coordination and help evaluate these activities, thus supporting efforts to improve the health outcomes of people living with HIV/AIDS. Implementing this additional HIV core indicator will help HRSA/BPHC to align its HIV metrics with other HHS agencies and facilitate the interoperability of reporting systems across HHS.

***Improving access to benefit programs for persons at risk for or living with HIV/AIDS***—As part of their ongoing efforts to improve information sharing, program coordination, and collaboration, in 2012 the NHAS Federal Leads Work Group—composed of representatives from the Departments of Health and Human Services, Housing and Urban Development, Justice, Labor, and Veterans Affairs, and the Social Security Administration—completed a review and update of the HIV/AIDS information available on Benefits.gov. The mission of Benefits.gov is to reduce the expense and difficulty of interacting with the government while increasing citizen access to benefits information. The site’s core function is its Benefits Finder, an eligibility prescreening questionnaire. Answers to the questionnaire are used to evaluate a visitor’s situation and compare it to eligibility criteria for more than 1,000 federally funded benefit and assistance programs.

The Federal Leads facilitated a review of all the HIV-related programs featured on Benefits.gov, identified enhancements that could be made to better serve users seeking information about HIV-related services and benefits, and compiled information about seven additional programs to be added to the site. In addition, they collaborated with the site’s administrators to create an HIV/AIDS benefits page—available in English and Spanish—listing these and other relevant benefits available to people living with, at risk for, and/or affected by HIV/AIDS, and expanded the Benefits Finder to include several HIV-specific questions to assess individual eligibility and more effectively direct users to the appropriate programs. These efforts were bolstered by outreach activities conducted by Benefits.gov to several key populations, including low-income individuals and families, caseworkers serving at-risk populations, Veterans, students, and educators as well as a blog post on [blog.aids.gov](http://blog.aids.gov).

***Reporting on progress toward achieving national goals***—During a satellite session at AIDS 2012, HHS released its first progress report highlighting progress made in 2011 by the Department in pursuing the NHAS goals. The report featured key accomplishments from across the Department on each of the three NHAS goals as well as its call for a more coordinated national response to the HIV epidemic. In addition, throughout 2012 HHS and other federal partners shared developments about the implementation of the NHAS through AIDS.gov, which is managed by OHAIDP. Known as a “vehicle for transparency” for public reporting on the implementation of the Strategy and the federal government’s progress toward achieving the Strategy’s goals, AIDS.gov published 310 blog posts in 2012, 51 of which were focused specifically on some aspect of the Strategy and other related federal policies. In addition, AIDS.gov redesigned and updated the content provided on nine pages within its website specifically about the NHAS as well as disseminated information about Strategy implementation to the general public through its various social media channels.





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## Epilogue

The activities outlined in this report, along with the many others undertaken across HHS agencies and offices, have expanded the solid foundation for our ongoing efforts to pursue the NHAS vision and goals. In the coming months and years, it will be essential to sustain this momentum and continue to thoughtfully assess and innovate as well as engage, more intensively, various nonfederal partners in these efforts, including partners from across sectors such as state and local government, science, philanthropy, entertainment and media, education, and faith communities.

A key activity in the coming years will be assisting people at risk for and living with HIV/AIDS to access the full benefits of prevention, testing, treatment, and care as we move into the full implementation of the Affordable Care Act and the opening of the Health Insurance Marketplace on October 1, 2013. One of the most important pieces of legislation in the fight against HIV/AIDS in our history, the Affordable Care Act helps ensure that all Americans have secure, stable, affordable health insurance, something many people living with HIV/AIDS have had a difficult time accessing over the more than 30-year history of this disease. HHS agencies and offices will continue to be engaged in efforts to help people at risk for and living with HIV/AIDS take advantage of the opportunities for improved health and well-being afforded by the Act as we continue to work to realize the vision of the National HIV/AIDS Strategy:

*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.*

## Appendix: List of Acronyms

<b>AI/AN</b>	American Indian/Alaska Native	<b>IDU</b>	Intravenous (or Injection) Drug User
<b>AIDS</b>	Acquired Immune Deficiency Syndrome	<b>IHHP</b>	Integrated HIV/AIDS Housing Plan
<b>ASI</b>	Ask, Screen, and Intervene	<b>IHS</b>	Indian Health Service
<b>ASPE</b>	Assistant Secretary for Planning and Evaluation	<b>ISIS</b>	Women's HIV Seroprevalence Study, NIH
<b>ATN</b>	Adolescent Medicine Trials Network for HIV/AIDS Interventions, NIH	<b>LaPHIE</b>	Louisiana Public Health Information Exchange
<b>BPHC</b>	Bureau of Primary Health Care, HRSA	<b>MAI</b>	Minority AIDS Initiative
<b>CAPUS</b>	Care and Prevention in the United States	<b>MAI-TCE</b>	Minority AIDS Initiative-Targeted Capacity Expansion, SAMHSA
<b>CBO</b>	Community-based organization	<b>MSM</b>	Men who have sex with men
<b>CDC</b>	Centers for Disease Control and Prevention	<b>MTN</b>	Microbicide Trials Network
<b>CHAC</b>	CDC-HRSA Advisory Committee on HIV, Viral Hepatitis and STD Prevention and Care	<b>NHAS</b>	National HIV/AIDS Strategy
<b>CHIP</b>	Children's Health Insurance Program	<b>NIDA</b>	National Institute on Drug Abuse, NIH
<b>CMHS</b>	Center for Mental Health Services, SAMHSA	<b>NIH</b>	National Institutes of Health
<b>CMS</b>	Centers for Medicare & Medicaid Services	<b>OASH</b>	Office of the Assistant Secretary for Health, HHS
<b>CSAP</b>	Center for Substance Abuse Prevention, SAMHSA	<b>OCR</b>	Office of Civil Rights, HHS
<b>CSAT</b>	Center for Substance Abuse Treatment, SAMHSA	<b>OHAIDP</b>	Office of HIV/AIDS and Infectious Disease Policy, OASH
<b>EMR</b>	Electronic Medical Record	<b>OMB</b>	Office of Management and Budget, The White House
<b>FDA</b>	Food and Drug Administration	<b>ONAP</b>	Office of National AIDS Policy, The White House
<b>FQHC</b>	Federally Qualified Health Center	<b>ONC</b>	Office of the National Coordinator for Health Information Technology, HHS
<b>FY</b>	Fiscal Year (October 1 – September 30)	<b>OWH</b>	Office on Women's Health, OASH
<b>HAB</b>	HIV/AIDS Bureau, HRSA	<b>PACHA</b>	Presidential Advisory Council on HIV/AIDS
<b>HBV</b>	Hepatitis B Virus	<b>PLWH</b>	Person/People Living with HIV
<b>HCV</b>	Hepatitis C Virus	<b>PLWHA</b>	Person/People Living with HIV/AIDS
<b>HHS</b>	U.S. Department of Health and Human Services	<b>PrEP</b>	Pre-Exposure Prophylaxis
<b>HIE</b>	Health Information Exchange	<b>SAMHSA</b>	Substance Abuse and Mental Health Services Administration
<b>HIV</b>	Human Immunodeficiency Virus	<b>SMAIF</b>	Secretary's Minority AIDS Initiative Fund
<b>HPTN</b>	HIV Prevention Trials Network	<b>SPNS</b>	Special Projects of National Significance, Ryan White HIV/AIDS Program, HRSA/HAB
<b>HRSA</b>	Health Resources and Services Administration	<b>STI</b>	Sexually transmitted infection(s)
<b>HUD</b>	Department of Housing and Urban Development		



# Vision of the National HIV/AIDS Strategy

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*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.*

