

Dear Mr. President:

We thank you for your leadership in advancing healthcare access in the United States. As you know, people living with HIV/AIDS are among the tens of millions of individuals in the nation who struggle to achieve the healthcare and stability they need to stay alive and to thrive. We look forward to the day when health reform provisions are actualized. While the reforms under consideration are likely to improve access to care for many people with HIV/AIDS, they will not fully address the needs of people with HIV/AIDS, which is why we applaud your Administration's efforts to develop and implement the first National HIV/AIDS Strategy and your ongoing support of the Ryan White Program. This document offers targeted recommendations and strategies designed to increase the number of HIV-positive people who gain access to and benefit from HIV care, treatment, and support services in the U.S. We ask that you integrate our recommendations into the National HIV/AIDS Strategy that your Administration develops and implements.

## **PROCESS**

A diverse group of 34 stakeholders with expertise in HIV-related service provision, policy, and planning met in December 2009 to develop these HIV care and treatment recommendations for the National HIV/AIDS Strategy. Subsequently, additional stakeholders gave input and agreed to endorse the recommendations in order to build a stronger federal response to the domestic HIV/AIDS epidemic. While the December 2009 community consultation on care and treatment was sponsored by the Coalition for a National AIDS Strategy, the emerging recommendations represent only the views of the undersigned endorsers.

## **VISION**

The U.S. will be the global leader in reducing the spread of HIV and in assisting people living with HIV to lead longer and more productive lives.

The U.S. will maximize scarce public resources by using strategies of documented effectiveness—including voluntary testing, linkage to care activities, and care services; medical and non-medical interventions, such as housing, case management, harm reduction, substance abuse treatment, and mental health services; anti-discrimination strategies; and workforce development—scaled to increase the number of HIV-positive people who gain access to, remain in, and benefit from HIV care services and who achieve a high quality of life.

Care efforts will target communities and populations disproportionately impacted by HIV such as all races/ethnicities of men who have sex with men, women of color, the homeless and unstably housed, people with mental illness, drug users, abandoned youth, female victims of partner violence, and those with a history of incarceration, among others.

The capacity of community-based and minority providers to deliver high-quality HIV medical, essential non-medical, and supportive services in culturally competent, linguistically appropriate settings will be enhanced.

People with HIV in the U.S. will be encouraged and supported in the workforce. We will make it easier for low-income workers to qualify for housing, healthcare, and other services; we will support small employers who hire people with HIV and other disabilities; and we will vigorously enforce anti-discrimination laws.

The public health, ambulatory care, and support service systems in the U.S. will be effective, proactive, and trusted.

The workforce will be supported, and careers in HIV care will be incentivized and encouraged.

Federal guidelines will inform service provision, availability, and accessibility across all relevant agencies, departments, and programs.

HIV infection will be de-stigmatized in the U.S. Elimination of the stigma of HIV infection will require concurrent commitments to reduce homophobia, transphobia, racism, homelessness, joblessness, and discrimination based on current or past drug use or a history of incarceration.

## **RATIONALE**

Thanks to medical advances, life expectancy and future options for people with HIV are more hopeful than ever. Improvements in anti-HIV treatments can render HIV infection into a chronic, manageable disease, but only for those who know their status, gain access to and remain in care, receive the psychosocial and supportive services they need to stabilize their lives, and address other life challenges associated with an HIV diagnosis.

Ensuring that people with HIV gain access to early, comprehensive, and affordable care serves relevant public interests: people with HIV who are stabilized medically and emotionally remain productive, contributing members of society; affordable, accessible care reduces unnecessary and high-cost healthcare and hospitalizations to treat end-of-life or advanced disease; and effective HIV care results in reduced viral load and positive behavior changes, which decrease the likelihood of transmitting HIV to others.

Despite these prospects, an estimated 500,000 people with HIV—half of all people infected in the U.S.—do not receive the HIV health care they need to improve their lives. Half of all people with HIV live on less than \$10,000 a year, and unemployment rates among people with HIV are ten times higher than the general population. In many parts of the country, HIV medical care, treatment, and key non-medical services are in limited supply. As a result, tens of thousands of people with HIV across the country do not have access to voluntary HIV testing, psychosocial support, case management, housing, transportation, healthcare, medication assistance, dental care, nutrition, harm reduction, drug treatment, and other services they desperately need.

## **VALUES**

Disparities based on race/ethnicity, age, sexual orientation, gender identity and expression, employment, history of drug and alcohol use, education, and economic class are eliminated.

HIV medical care and non-medical care services are widely available everywhere in the U.S.

The U.S. promotes a social-justice approach in meeting its urgent HIV care and treatment needs.

The U.S. harmonizes its approaches to domestic and international efforts against HIV/AIDS and sends a consistent message about optimal ways to combat the pandemic.

The National HIV/AIDS Strategy sets ambitious goals and takes deliberate and transparent steps with regular reporting and clear accountability to meet them.

The allocation of sufficient funds supports achievement of defined goals. Funding must be distributed based on sensible, rational, and transparent criteria.

Inter- and intra-agency integration sustains and incentivizes HIV specialty services and strives to develop more efficient and effective HIV care systems. Efforts toward greater integration are advanced at all levels (federal, state, local, and point of care) and between HIV care and prevention activities.

The National HIV/AIDS Strategy engages consumers, service providers, allied health professionals, community-based organizations, community health centers, public health officials, advocates, and other non-governmental stakeholders in achieving its goals.

## **AGENCIES**

To meet its care and treatment goals, the National HIV/AIDS Strategy must be implemented by several federal entities, including but not limited to:

Centers for Disease Control and Prevention  
Centers for Medicare and Medicaid Services  
Department of Defense  
Department of Education  
Department of Housing and Urban Development  
Department of Justice  
Department of Labor  
Department of Veterans Affairs  
Health Resources and Services Administration  
National Institutes of Health  
Office of Minority Health  
Office of National Drug Policy  
Office of Women's Health  
Substance Abuse and Mental Health Services Administration

## **DISCUSSION**

Urgent action is needed to respond to the growing healthcare crises affecting people living with HIV/AIDS in the U.S. Access to HIV medical care and critical non-medical services has been

severely compromised by underfunding. Consider:

- Unemployment and the prolonged economic downturn have forced individuals living with HIV to increasingly rely on publicly funded HIV services to maintain their access to HIV treatment and medical care. Meanwhile states are responding to the economic recession with service reductions that further jeopardize access to HIV care and prevention services.
- Across the country AIDS Drug Assistance Programs (ADAPs)—a lifeline for HIV-positive people who have no other means to obtain their lifesaving HIV medications—are facing funding shortfalls as state and local funds are reduced and federal resources fail to keep pace with the growing need. ADAP waiting lists are growing at an alarming rate, and many states are unable to provide needed medication assistance to their low-income, HIV-positive residents.
- With virtually stagnant Ryan White funding and inadequate Medicaid and Medicare reimbursement rates, HIV medical providers are finding it difficult to keep their doors open. Meanwhile the number of people needing HIV medical care increases daily.
- As the payer of last resort, Ryan White cannot keep up with the unmet need for HIV medical and non-medical services, which have been fueled by increases in the number of uninsured individuals and limits on Medicaid and Medicare coverage. Additionally, even if health care reform is implemented, current Ryan White funding levels will likely be insufficient to help low-income consumers meet premium and co-payment obligations that will remain significant for individuals struggling to meet the costs associated with the care and treatment of long-term chronic illness.
- With medical providers increasingly asked to provide more services with fewer resources, people living with HIV/AIDS are at serious risk of having no medical providers to manage their care.
- Essential services such as transportation, food, case management, dental care, mental health, substance abuse treatment services, and housing are in scarce supply. Moreover, low-income, under/uninsured people with HIV who need to consult specialists in dermatology, hematology, cardiology, oncology, gynecology/obstetrics, neurology, pediatrics, gerontology, or other medical sub-specialties struggle to obtain needed care; finding a specialty provider with HIV expertise is even more challenging. Without these and other services, low-income people with HIV are unlikely to achieve medical stability.
- The systems of care in many jurisdictions provide clients too few opportunities to realize true independence and stability. More must be done to help support able clients in preparing for and securing gainful employment without jeopardizing their health and other essential benefits.

Clearly swift action and additional resources are urgently needed and must not wait for a National HIV/AIDS Strategy to go into effect. Many of the urgent concerns identified above, such as ADAP shortfalls across the country, require an immediate, emergency response from the federal government. Failure to do so will only hinder efforts to achieve the Strategy's goals.

## **ACTION AGENDA**

The National HIV/AIDS Strategy must address the ongoing drivers of the epidemic, which include:

- **Stigma—both surrounding the disease and some of the populations at highest risk—which may keep individuals from ascertaining their serostatus or entering or continuing care.** Poverty, homelessness, racism, homophobia, misogyny, and other forms of prejudice, including discrimination against former or active drug users, compound HIV-related stigma, discrimination, and isolation experienced by most people living with HIV/AIDS.
- **Lack of access to the most up-to-date information on HIV treatment, research, care, and prevention in communities most disproportionately impacted.** The lack of uniform distribution of accurate, user friendly, culturally competent, and linguistically appropriate information to individuals in various formats undermines national prevention, research, care, and treatment access and utilization efforts.
- **Inadequate support for organizations serving racial and ethnic communities of color disproportionately impacted by the HIV epidemic.** The lack of sufficient culturally competent materials and providers limits the effectiveness of efforts to encourage testing, care, and treatment.
- **Unequal medical and non-medical service infrastructure in some areas heavily impacted by HIV disease. This lack of capacity** results in grossly uneven distribution of resources and access to services, particularly in communities of color and non-urban areas, including areas that are geographically isolated or otherwise poorly served with transportation options.

Only when these drivers are addressed we will achieve the goals of maximizing the number of people tested and in care and improving the quality of life for those affected by HIV/AIDS.

## **RECOMMENDATIONS**

Ideas generated to address these ongoing drivers and to achieve our goals are described below. For each of the following recommendations, the National HIV/AIDS Strategy must seek to reduce HIV-related health disparities experienced by racial/ethnic minorities, gay and bisexual men, drug users, those recently released from jails or prisons, women including those who are or may become pregnant, homeless or unstably housed individuals, immigrants and the undocumented, young people, older adults, and those with co-occurring conditions such as sexually transmitted infections (STIs), viral hepatitis, and mental illness. Geographic and income disparities must also be addressed. The following recommendations are separated into three categories: **testing, linkage to care, and provision of essential services.**

### **VOLUNTARY TESTING AS A PATHWAY TO HEALTH STABILITY FOR PEOPLE WITH HIV/AIDS.**

Efforts to fully expand voluntary HIV testing throughout the United States must be anchored in deliberate steps to link those diagnosed with HIV to readily available, accessible, affordable, and high-quality healthcare, housing, and essential services. Doing so will increase the number of people in care, maximize treatment potential, and minimize the impact of the disease. Ultimately

expanding HIV testing and ensuring reliable access to care will support HIV prevention efforts by increasing the number of HIV-positive people with a controlled viral load, which lowers their future risk of transmission, and by reducing the number of people who, unaware they are infected, unknowingly expose others to HIV. A national goal should be set to ensure that no less than 85 percent of all people estimated to be living with HIV know their status by 2013 and no less than 95 percent remain aware of their serostatus by 2017.

Steps to achieve these goals include:

1. Mandate an offer of **HIV, STI, and viral hepatitis testing as a standard of care** and support medical associations and the Ryan White AIDS Education and Training Centers (AETCs) to promote the standard and train clinicians on the importance of the early identification of people with HIV through routine testing and linkage to care. Create nationally recognized quality of medical care metrics for HIV/STI/hepatitis testing and publicly report these metric results.
2. Launch a **coordinated initiative** (funded by multiple federal agencies) to provide integrated HIV, viral hepatitis, and other STI services with **expanded testing and linkage to comprehensive medical and non-medical care and treatment services** in three dozen or more targeted communities of demonstrated need across the U.S.
  - The program must have leadership from a single federal official with authority to ensure there are common indicators, integrated approaches, and a singular vision to expanded testing, linkage, and care.
  - In all cases, the federal agencies investing in the initiative should **simplify and integrate grants** from multiple funding streams to both governments and community-based providers and **standardize implementation and reporting requirements**.
  - The initiative should utilize **risk/behavior profiles** and **mapping strategies** to identify priority communities for funding, infrastructure support, service-capacity development, testing expansion, and integrated linkage-to-care projects.
3. Provide sufficient federal resources to ensure **adequate reimbursement rates for HIV testing services** through public systems and require, as some states have done, private payers to match those rates.
4. Expand fixed-site, community-based, mobile, and healthcare-delivered voluntary HIV testing services with linkage to care.

## **LINKAGE TO CARE: EXPANSION OF CARE AND TREATMENT PROVISION IN KEEPING WITH ESTABLISHED TREATMENT GUIDELINES**

As voluntary testing is increased, a coinciding focus must ensure that people living with HIV are linked with medical care and essential non-medical care services immediately upon learning their status. Once a person with HIV becomes aware of his or her status and acknowledges the need for care, such care must be readily accessible in a variety of ways. If the full spectrum of care

and support services is not accessible, there is a great risk of people not adhering to treatment programs and leaving care.

To improve linkage to care, the federal government should:

5. Dedicate new resources to **ensuring timely linkage to medical care, appropriate treatment, and critical non-medical services** with the goal of setting initial medical and service appointments at the point of diagnosis and achieving the first medical appointment as soon as possible.
  - Initial services should include **peer navigation and bridge counseling** to ensure that the medical appointment, treatment assessment, and other essential services are accessed.
  - Enhanced linkage activities must also serve individuals who are **already aware of their HIV-positive status but are not currently in care**.
  - Ensure that the **continuum of care** from diagnosis to provision of medical care, treatment assessment, and essential non-medical care services is as smooth as possible through a variety of strategies including co-location of HIV testing and comprehensive medical and non-medical services, where possible.
6. Support the implementation of **consistent treatment guidelines** across federal departments, agencies, and programs, and provide adequate program and funding support to government and community-based providers to guarantee access to care and treatment in keeping with the federal standard of care for treating HIV disease.
7. Mandate that public and private **reimbursement rates reflect the true cost of care using methods such as prospective cost-based reimbursement** and taking into account the increased requirement for “cognitive services”—clinician time to counsel patients and determine the best course of care.
8. Commit to **workforce development**:
  - Develop a domestic **HIV Work Corps** for doctors, nurses, physician assistants, nurse practitioners, and other medical and non-medical service professionals with targeted loan forgiveness to incentivize HIV/infectious disease specialization and benefit protections for persons with HIV who work in peer outreach, testing, and care programs.
  - Develop medical school and AETC continuing education programs and opportunities for clinical training in HIV medicine to increase the pool of clinicians with the expertise necessary to effectively manage HIV care. Work with HIV medical providers and AETCs to develop targets for training providers to ensure the HIV workforce can meet the demands of HIV care.
  - Ensure that **medical school curricula include training to facilitate cultural competence** needed to effectively serve people living with HIV/AIDS.

9. Prioritize funding in healthcare reform legislation for **prevention, wellness, public health, health disparity, and clinical workforce development** for chronic infectious diseases including HIV, viral hepatitis, and STI initiatives.
10. Ensure that the **Ryan White CARE Act** is adequately funded. Even if health insurance reform is passed and implemented, Ryan White services will be needed to wrap around healthcare reform to ensure access to necessary medical and non-medical care, treatment, and support services.
  - **Ryan White funding must increase** immediately to match the growth and complexity of care and emerging issues of a population that is thankfully surviving longer with HIV than ever before.
  - The ADAP funding crisis in states across the country warrants an **emergency supplemental appropriation** to prevent destabilizing treatment interruptions for tens of thousands of people with HIV in the U.S., and to address the needs of thousands of individuals seeking ADAP services for the first time.
  - Create a national standard for **ADAP programs**, using the Department of Veteran Affairs pricing, that provides a comprehensive, consistent benefits package regardless of geography and ensure that services are completely portable, including across state lines.
  - Invest in ADAP so that **no person with HIV is ever on a waiting list to receive HIV medicines**.
  - Reevaluate the **Ryan White program's 75/25** coverage in 2014 to redefine and potentially expand services included within the 75 percent for core services.
11. Ensure that federal programs support the delivery of coordinated, comprehensive care through the patient-centered “health care home” service delivery model.
12. Leverage community-health centers and dental schools to increase the supply of dental care and medical sub-specialty services for under/uninsured people with HIV/AIDS.

**TESTING IS NOT ENOUGH: PEOPLE WITH HIV MUST BE LINKED TO APPROPRIATE AND ESSENTIAL SERVICES AND BE SUPPORTED TO SUSTAIN ENGAGEMENT IN CARE.**

The National HIV/AIDS Strategy must make clear to all stakeholders that HIV care goes far beyond medical/medication treatment, and sufficient funding must be provided to address ongoing HIV-related stigma and discrimination and ensure adequate support for a range of critical services such as harm reduction services, legal assistance, substance abuse and mental health treatment, housing, transportation, child care, food/nutritional services, and discharge and re-entry services for people leaving corrections settings.

The government must commit to providing essential care services for people who accept testing and are subsequently diagnosed with HIV. Current service restrictions, including inadequate access to housing, peer support, medication assistance, and other essential services, undermine testing and care expansion efforts. Without adequate care services available, public health risks

identifying people with HIV who have no means to achieve better health outcomes because of lack of available services to meet their needs.

13. Develop **strong national anti-discrimination and confidentiality laws** designed to protect people living with HIV/AIDS and ensure new anti-discrimination laws are adequately monitored and enforced. In particular, HIV transmission must be decriminalized, and antidiscrimination laws against race/ethnicity and sexual orientation must be strengthened. The federal government must regularly collect data from people with HIV who report stigma as a barrier to care access in order to take deliberate steps to decrease this indicator over time.

14. To **address persistent HIV misinformation** the federal government must:

- Expand comprehensive, culturally and linguistically competent, and age-appropriate **sexual health education initiatives** that include HIV/STI prevention.
- Dramatically expand **national social marketing campaigns** to encourage testing and increase awareness of the benefits of testing and care. The campaign, which could be supported by non-governmental stakeholders, should showcase key leaders accepting testing and present positive images of people living with HIV/AIDS.

15. Acknowledge that **adequate housing** is inextricably linked with successful care, and support the development of housing programs to address this critical area of need.

- Since the evidence for housing supports a **shift in paradigm**, federal officials should view housing as a core component of the HIV care and prevention continuum.
- Require HRSA, SAMSHA, NIH, and CDC to document the housing status of clients who receive funded services so as to provide these agencies with **better data** to plan for ongoing initiatives to address homelessness and unstable housing as a structural driver of the HIV/AIDS epidemic.
- The Housing Opportunities for People With AIDS (**HOPWA**) **program funding must be significantly increased** and new resources must be apportioned based on a living HIV/AIDS formula and consistent with the Ryan White funding formula.
- **Revise HUD's definition of "homelessness"** so that it does not exclude those being discharged from institutions including correctional facilities, long-term care, nursing homes, psychiatric facilities, etc.; eliminate exclusions from federally funded housing based on prior correctional or drug use history. Fund **harm reduction or low threshold models of public housing** to increase housing access to homeless people with HIV who may be active substance users and at high risk of loss to care.
- Permanent housing restrictions and multiple (and often cumbersome) homeless and unstably housed **definitions should be simplified** to achieve greater access and lower barriers to housing services.
- The federal regulation instituting a **24-month lifetime cap** on temporary housing assistance in the Ryan White program must be lifted permanently. Housing assistance is a proven, cost-effective structural intervention that has a direct, independent, and powerful impact on HIV incidence, outcomes, and disparities.

16. **Build capacity in rural and other geographically isolated settings** to increase HIV medical care and non-medical care service integration with all other health care services and ensure that by 2013, 50 or more new service delivery sites are in underserved communities. These sites should:
  - Lower clients' travel-times and increase care access and retention in their region of the state/territory or municipality.
  - Extend clinic hours to improve access for working people.
  - Ensure that the HIV medical and non-medical services are culturally competent and linguistically appropriate.
  - Encourage mentoring, traineeships, and task sharing to use existing resources better.
  - Increase the capacity of nurse practitioners, physician assistants, and other allied health professionals to support HIV ambulatory care provision.
  - Support individuals with HIV moving into careers in AIDS service organizations through adequate training and job placement and formalize the work of peers.
17. Maintaining full sensitivity toward confidentiality, transform and adequately fund **surveillance activities** to collect and utilize better data (particularly aggregate data) to inform patient management outcomes.
18. **Simplification should occur across** systems in order to facilitate entry into programs, grant funding, reporting, and evaluation.
  - Coordinated and common processes for application, collection of information, oversight, and reporting should be mandated.
  - Policies and procedures should be aligned for all programs, including the meaningful use of electronic records.
19. Support the development of comprehensive **patient information on accessible services**.
  - Recognize that **AIDS service organizations** are essential to achieving comprehensive care goals and support the integration of these organizations into the HIV care system.
  - Ensure that adequate focus is placed on **retention** in and **adherence** to care, so that by 2013, 75 percent of people with HIV are being maintained in care.

**ENDORSERS OF THESE RECOMMENDATIONS** (*list in development; endorsements as of February 17, 2010*)

#### ORGANIZATIONS

AIDS Foundation of Chicago, Chicago, IL  
AIDS Legal Council of Chicago, Chicago, IL  
BIENESTAR, Southern California  
HIV Medicine Association, Arlington, VA

Kaiser Permanente, Oakland, CA  
Test Positive Aware Network, Chicago, IL  
Treatment Access Expansion Project (TAEP), Washington, DC  
National Working Positive Coalition, New York, NY  
Project Inform, San Francisco, CA

INDIVIDUALS

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Thank you again, Mr. President, for this opportunity to help inform the National HIV/AIDS Strategy. We look forward to the great changes that the Strategy will bring and to the day when all people living with HIV will be able to access the care and services needed to achieve the high quality of life they/we deserve. If you have any questions or comments about our recommendations, please feel free to contact David Ernesto Munar at [dmunar@aidschicago.org](mailto:dmunar@aidschicago.org) or 312-334-0933.