

HIV Health Care Access Working Group

And

Ryan White Working Group

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Dr. Koh:

On behalf of the undersigned members of the HIV Health Care Access Working Group and the Ryan White Working Group of the Federal AIDS Policy Partnership, we are writing to provide recommendations on the agency implementation plans for the National HIV/AIDS Strategy (NHAS) currently under development. The comments below focus on increasing access to care and improving health outcomes for people living with HIV and AIDS. Our recommendations recognize that successful implementation of the NHAS is inextricably tied to successful implementation of health care reform. To meet the access to care goals of the NHAS and to ensure that these goals are integrated into the broader goals of health care reform, the agency NHAS implementation plans should: (1) encourage accountability and communication between agencies; (2) facilitate a seamless transition and integration of HIV/AIDS services and programs into health care reform expansions and other public and private health care systems; and (3) ensure that there is access to care in the years leading up to some of the larger reforms – most notably the Medicaid expansion – that do not go into effect until 2014.

1. Greater Accountability and Communication between Agencies

Improve Accountability and Access to Information

The HIV Health Care Access Working Group is actively engaged in health reform implementation but remains concerned that there isn't a point person at the department that is tasked with ensuring the needs of people of HIV/AIDS are being considered in the numerous regulations and programs that are being established. For example, we were extremely disappointed that HIV disease was not established as a qualifying condition for eligibility in all the Pre-existing Condition Insurance Plans given studies showing that 100% of applicants with HIV are denied access to private insurance in the individual market. Opportunities include:

- Appointing a point person within HHS tasked with ensuring the care, treatment, and service needs of people living with HIV and AIDS are met through implementation of health care reform.

Encourage collaboration and information-sharing between CMS and HRSA

Because the vast majority of care being provided to people living with HIV and AIDS is through the Medicare and Medicaid programs, collaboration between HRSA and CMS is essential to any effective implementation plan. Information sharing between HRSA and CMS, wider dissemination of information about these programs to the public, as well as broader

engagement from multiple facets of these agencies will be important. Opportunities for CMS and HRSA include:

- Putting in place a heightened role for CMS to provide more information as to how individuals in Medicaid and Medicare are linked into care and the types of care they receive.
- Extending HRSA's role beyond the HIV/AIDS Bureau and include engagement from the Bureau of Primary Care, the Bureau of Maternal and Child Health and the Bureau of Health Professions. Given the significant increase in resources to Community Health Centers and the HIV workforce challenges, meaningful participation by these bureaus are essential to expanding access to quality care.
- Ensuring HRSA coordination with the HHS Office of Population Affairs to ensure better integration of HIV care with Title X provided services both preventive and on-going reproductive health care.
- Supporting Ryan White funded programs in the development of and utilization of health information technology/health information exchanges to increase quality improvements and achieve better health outcomes as well as facilitating public health disease reporting and monitoring of co-morbidities/epidemics.
- Working with CDC to ensure that prevention services are provided in clinical settings for both at-risk and HIV positive individuals.
- Ensuring appropriate oversight of federally funded programs that provide care to people living with HIV.
- Providing information to Congress on the implication of the Medicaid funding cap for Puerto Rico for people living with HIV.

2. Seamless Transition and Integration of HIV-related Services and Programs into Health Care Reform Expansions and Public and Private Health Care Systems

We ask the Administration to work in concert with HRSA to document and disseminate information about the complex needs of people with HIV and the critical role that the Ryan White Program will continue to play in the HIV care system. Ryan White will need to be reauthorized or extended in 2013, and the program will face increasing scrutiny in the coming years. The Strategy clearly states "the Ryan White HIV/AIDS Program and other Federal and State HIV-focused programs will continue to be necessary after the [health reform] law is implemented." Ryan White programs, services, and providers have provided critical wrap around and safety net services through two decades of the ever evolving HIV epidemic. The resulting wealth of experience and its ability to address rapidly evolving medical and service needs of people with HIV have proven invaluable in the U.S. response to AIDS. This important program will be critical during the transition into health care reform and beyond, as well as ensuring the complex needs of the aging HIV population who are facing multiple co-morbidities and complications are adequately addressed. For example, oral health remains one of the top unmet needs for uninsured and under-insured people living with HIV. Ryan White-funded oral health is a vital safety net service that was identified a core service in the reauthorization of 2006 and extension of 2009. Without Ryan White funding for oral health services, the vast majority of people living with HIV will no longer be able to access basic services such as elimination of pain and infection and restoration of function.

Guidance and support is needed from HHS, HRSA, and CMS to ensure that the Ryan White model of care – which is in many ways a blueprint for health care reform service models emphasizing holistic and comprehensive care – is integrated into health care reform.

Use Ryan White Programs as a Blueprint for Effective Care Models

In light of discretionary federal and state funding constraints, we urge HRSA and CMS to work together to identify opportunities to maximize the resources available to Ryan White-funded programs to sustain and expand these programs that have developed critical expertise in providing HIV care and support services over the last two decades. Specific opportunities include:

- Funding a pilot program to evaluate the coordinated, comprehensive care provided through the medical-home model by Ryan White funded-clinics and programs and to identify factors contributing to the success of the programs so that the model can be replicated for the expansion of HIV care and applied to the management of other chronic conditions.
- Providing technical assistance to Ryan White funded clinical programs to secure medical home certification and educating Ryan White funded clinical programs on states that offer enhanced payments for certification.
- Educating state Medicaid directors and their Medical directors on the benefits of health or medical home care for management of HIV and other chronic conditions and identifying HIV disease as a condition eligible for the new health home optional benefit in 2011.
- Ensuring HIV medical providers are eligible for the enhanced fee-for-service rates available under Medicaid for primary care services in 2013 and 2014.
- Developing a mechanism to provide prospective cost-based reimbursement under Medicaid to Ryan White-funded clinics that is similar to the reimbursement mechanism developed for Federally Qualified Health Centers (FQHCs) under Medicaid.
- Identifying opportunities where available through the CMS Balancing Initiative to support Medicaid eligibility expansions that allow individuals with HIV to delay illness and access health care before they develop AIDS (https://www.cms.gov/CommunityServices/15_Balancing.asp).
- Supporting collaborations between Ryan White-funded programs and FQHCs to build HIV capacity at FQHCs.
- Promoting the co-location of Ryan White services, especially Part D funded services, with Title X reproductive health and family planning services to ensure greater accessibility to both HIV care and reproductive health care for people living with HIV.
- Ensuring all state Medicaid programs are coordinating with ADAPs and other Ryan White programs to ensure payer of last resort requirements are met.
- Ensuring there are medical navigators, health care benefits counselors, comprehensive case managers available to assist Ryan White clients as they transition into new programs. Encourage states to fund Ryan White programs to serve as health system “navigators” for people living with HIV.

Provide Technical Assistance to Ryan White Grantees

Effective implementation of the coverage expansion provisions in the Affordable Care Act in 2014 will be critical to an overall expansion and strengthening of the HIV care system and to make significant progress in meeting all three of the President’s goals for the NHAS. We urge HRSA to incorporate a health care reform technical assistance plan for Ryan White grantees to

help them prepare for a seamless integration into the new health care financing environment in 2014. Specific technical assistance needs include:

- Learning to negotiate contracts with private plans.
- Developing the capacity to bill third-party payers.
- Developing administrative systems to respond to the increased administrative and utilization management requirements of third-party payers.
- Assisting grantees with the Federally Qualified Health Center application process.
- Educating grantees on the provision requiring insurers operating in the exchanges (beginning in 2014) to contract with essential community providers, including HRSA 340(b) programs.
- Evaluating the insurance plans available through the health insurance exchanges and their coverage and affordability for individuals living with HIV/AIDS. Additionally, information regarding wrapping-around these plans will be pivotal for many Ryan White grantees including ADAPs.
- Providing training modules that can be used with case managers across all Parts of Ryan White to assist clients in navigating the new health system.
- Assisting Ryan White clinical providers with utilization of health information technology/health information exchanges to increase quality improvements and achieve better health outcomes as well as facilitating public health disease reporting and monitoring of co-morbidities/epidemics. In addition clinical providers need technical assistance from HRSA and CMS to ensure that their electronic health records meet Meaningful Use criteria.
- Analyzing the impact of health reform on demand for HIV medications through AIDS Drug Assistance Programs (ADAP) that examines the implications of health reform within the current budget shortfalls and possible changing infrastructure needs. The evaluation should assess the impact of increased cost-sharing on access to medications as people with HIV transition to coverage under Medicaid or through the Exchange plans and the role ADAP could play in ensuring that low income people with HIV do not go without medications due to an inability to pay.

Increase the Number and Diversity of Available Providers of Clinical Care and Related Services for people Living with HIV

We must act aggressively to address HIV medical workforce shortages and ensure a diverse and qualified workforce is available throughout the country to improve access to care while also optimizing health outcomes. We urge:

- Increasing opportunities for clinicians interested in pursuing a career HIV medicine by supporting year-long HIV training programs for medical providers at Ryan White grantee sites. Ryan White grantee programs are models for delivering high quality, patient-centered medical home care.
- Targeting National Health Service Corps opportunities to HIV medical providers.
- Incentivizing nursing students to work in HIV care through loan repayment and forgiveness programs through which graduating students would commit to at least 3 years working in HIV care.
- Developing and offering clinical fellowships in HIV care for nurses at all levels of experience.

- Building on the successful infrastructure of the existing AIDS Education and Training (AETC) to increase the regional AETC programs that link the expertise of the Academic Medical Centers with the community providers (or providers at the medical home) to increase mentoring opportunities and longitudinal training opportunities for health care providers.
- Ensuring HIV medical workforce issues are addressed by the National Health Workforce Commission.
- Incorporating HIV training and resources into the Primary Care Extension Program
- Supporting increased opportunities for community-based clinical training at Ryan White-funded sites and FQHCs.
- Supporting increased opportunities for AETCs to undertake training and education to familiarize providers with the unique needs and experiences of gay, bisexual, and transgendered persons.

Identify New Funding Sources

While important opportunities for expanding access to care and developing a sustainable HIV care system will occur in 2014 through the coverage expansion, our progress will be impeded by insufficient HIV care and treatment capacity if new resources are not identified immediately to address the growing demand for HIV care and treatment. We urge HHS to work with HRSA and other agencies to identify new sources of funding through health reform for supporting the NHAS goals of identifying individuals with HIV earlier and improving linkage and retention in care. Opportunities include:

- Targeting Community Transformation Grants to programs that address HIV and STD prevention in communities with high HIV incidence and prevalence.
- Targeting Community-based Collaborative Care Network grants to support the development of integrated and coordinated networks of HIV clinical and social service providers.
- Monitoring access to HIV care and support services and health outcomes through the health disparities data and analysis that will be required of all federally supported programs.

Support Coordination and Co-location of Services

While the NHAS principally focuses on primary medical care, it is important not to lose sight of the critical importance of ancillary services in the lives of people living with HIV/AIDS. Ryan White provides their clients with a wide-range of support services that facilitate individuals in entering into care, staying in care, remaining adherent to their medications, and, most importantly, living healthy lives. Additionally, SAMHSA and HUD must be more fully engaged in coordinating services with HRSA and other agencies to ensure that a continuum of services continue to be providing to individuals living with HIV/AIDS. Substance abuse treatment, mental health services and housing are critical components of health care. Opportunities for HUD include:

- Recognizing housing assistance as a core health care activity for all targeted federal programs for the care of people living with HIV.
- Requiring individual housing need be assessed and reported by all grantees of targeted HIV funding and that data on housing needs be compiled nationally and funding be distributed in a manner that is based on real need in each community.

- Establishing a timeline for inventorying HUD-owned properties as well as HUD supported project-sponsors for suitability for co-location of HIV-related services.
- Basing federal planning on real housing need among people living with HIV/AIDS with an immediate goal of making 141,570 new units of housing available nationwide (see ONAP White House consultation on HIV/AIDS housing recommendations, Feb. 2010).
- Integrating the goals from *Opening Doors* with the NHAS.
- Developing, with all relevant federal departments and agencies, a uniform reporting tool to capture real “nonmedical supportive service” needs beyond housing.

Address Co-infection

While the strategy acknowledges the importance of supporting people living with HIV with co-occurring conditions, there are no implementation steps to address one of the leading causes of death of people living with HIV – viral hepatitis. HRSA must be more fully engaged in equipping Ryan White providers and FQHCs to address the care needs of the co-infected. Specifically the HHS Operational Plan should include specific actions for:

- Increasing the number of HIV-positive persons who know their hepatitis B and C status.
- Reducing liver disease mortality among those co-infected.
- Reducing the incidence of co-infection including specifically the reduction of incidence of hepatitis C transmission among HIV-positive persons who use injection drugs and gay and bisexual men.
- Reducing progression to cirrhosis and/or liver cancer among those co-infected.
- Increasing the proportion of those co-infected who are routinely screened for liver cancer.
- Increasing the proportion of people living with HIV who are vaccinated against hepatitis A and B.

Increase Access to Services for the Incarcerated and Those Transitioning Back to Communities

Comprehensive health care services are necessary in prisons and jails. In 2006, there were about 20,000 people with HIV in state and federal prisons. In addition, the rate of HIV among prisoners is five to seven times higher than that of the general population. In the United States, prisoners have a constitutional right to health care that meets community standards; however, in practice, medical care in a prison or jail depends on the local facility and, in general, prisoners do not receive health care that meets public health standards. The HHS Operational Plan should include specific actions to collaborate with the Department of Justice for:

- Reducing discrimination against people with HIV in prisons and jails.
- Ensuring all HIV positive prisoners have access to an experienced HIV provider and the treatments and lab tests necessary to monitor and treat HIV disease and any co-occurring conditions.
- Ensuring that each person transitioning back to the community has a complete health transition plan, including referrals to health care and medication assistance, if necessary.

Increase Access to Humane Health Care in Detention Facilities for People Living with HIV

There have been too many unnecessary deaths occurring for people with HIV and others while in Department of Homeland Security (DHS) detention. The HHS Operational Plan should include specific actions to collaborate with DHS for:

- Establishing policies for use in detention facilities requiring that all immigrants with HIV be treated with respect.
- Recommending to Congress that all Public Health Services guidelines which govern the Federal Prison system that normally apply to U.S. prisoners with chronic diseases are made mandatory for persons in DHS detention for alleged immigration violations.

3. Bridging the Gap to 2014

Prior to the major coverage expansions in 2014, there are other opportunities to expand access to care.

Support for 1115 Medicaid Waivers

The NHAS implementation plan calls on CMS to “promote and support the development and expedient review of Medicaid 1115 waivers to allow States to expand their Medicaid programs to cover pre-disabled people living with HIV” by the end of 2010. We urge CMS to work with states to successfully develop Section 1115 Waivers for people living with HIV. Specifically by:

- Appointing a senior advisor on HIV to the CMS Administrator and the Medicaid Director to assist in the waiver process as well as other NHAS implementation issues.
- Creating a new waiver initiative under Section 1115 to help states provide temporary Medicaid coverage through 2014 similar to the initiative that was created in response to Hurricane Katrina.
- Designing a waiver template that includes information states will need to submit successful applications, including meeting budget neutrality requirements.
- Expediting the application and review process.
- Sending a letter to state officials alerting states to the option of applying for a section 1115 waiver and promoting the waiver option on the CMS website.
- Organizing a conference call (or series of calls) to include state Medicaid Directors, HRSA representatives and AIDS Directors to discuss the waiver option and address questions.

Making the Temporary High Risk Pools Work for People with HIV and AIDS

To provide immediate access to care before 2014, the health care reform law allocates \$5 billion for the creation of temporary high risk pools in every state and the District of Columbia, allowing immediate access to coverage for people living with HIV who have been excluded from the private insurance market based on a pre-existing condition. The interim final rule on these pools – the deadline for public comment for which was September 28, 2010 – did not include a federal list of automatically qualifying pre-existing conditions (meaning that in order to demonstrate a pre-existing condition, an individual had to submit an insurance denial letter); however, most state pools have elected on their own to include HIV and AIDS as such automatically qualifying conditions. In addition, a significant hurdle to access to the coverage provided by these pools is cost. The Pre-existing Condition Insurance Plans present an immediate opportunity for developing and executing strategies to maintain and integrate HIV/AIDS models of care, services, and providers into health care reform expansions prior to the major expansions of 2014. Opportunities for HHS include:

- Putting in place a pre-qualifying condition list that includes HIV, AIDS, and chronic viral hepatitis.

- Issuing guidance, in conjunction with HRSA, regarding integration of Ryan White providers into high risk pool provider networks and explicitly allowing Ryan White Program funds to be used to wrap-around risk pool coverage to address unmet care and service needs and to allow use of ADAP funds to cover the premiums, copayments and deductibles of high risk pool insurance.

Adequately Funding Ryan White, including ADAP

To ensure access to care and treatment for people living with HIV, it is critical the Ryan White Programs continue to receive additional funding. There are formal and informal waiting lists around the country for access to care, treatment and support services. Despite an additional infusion of \$25 million for the AIDS Drug Assistance Programs (ADAP), almost 3,500 individuals are on waiting lists for receipt of ADAP services. Opportunities exist by:

- Requesting additional funding for the Ryan White Program, including ADAP, in the President's FY2012 budget request and future years.
- Including funding for the Ryan White Program, including ADAP, in supplemental funding requests to Congress.

We thank you for your leadership on implementation of the NHAS, and we welcome the opportunity to discuss these issues further with you. Please feel free to contact the HIV Health Care Access Working Group Co-chairs, Laura Hanen (lhane@nastad.org) or Robert Greenwald (rgreenwa@law.harvard.edu) and the Ryan White Working Group Co-chairs Ann Lefert (alefert@nastad.org) and Bill McColl (wmccoll@aidsaction.org).

Sincerely,

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 AIDS Foundation of Chicago, Chicago, CA
 The AIDS Institute, Washington, DC
 AIDS Legal Referral Panel, San Francisco, CA
 AIDS Project Los Angeles, Los Angeles, CA
 AIDS Project New Haven, New Haven, CT
 AIDS Treatment Activists Coalition, New York, NY
 AIDSNET, Bethlehem, PA
 Alaskan AIDS Assistance Association, Anchorage, AK
 Albany Damien Center, Albany, NY
 American Academy of HIV Medicine, Washington, DC
 American Social Health Association, Washington, DC
 Asian & Pacific Islander Wellness Center, San Francisco, CA
 Association of Nurses in AIDS Care, Akron, OH
 Association of Nutrition Services Agencies, Washington, DC
 Broward House, Fort Lauderdale, FL
 Care Resource, Miami, FL
 Cascade AIDS Project, Portland, OR
 Colorado AIDS Project, Denver, CO

Common Ground – the Westside HIV Community Center, Santa Monica, CA
Communities Advocating Emergency AIDS Relief Coalition, Washington, DC
Community Access National Network (CANN), Washington, DC
Community HIV/AIDS Mobilization Project (CHAMP), Brooklyn, NY
Community Servings, Boston, MA
Dab the AIDS Bear Project, Fort Lauderdale, FL
EAC, Inc., Hempstead, NY
Florida Keys HIV Community Planning Partnership, Key West, FL
Georgia AIDS Coalition, Atlanta, GA
Georgia HIV Advocacy Network, Atlanta, GA
Harlem United, New York, NY
HealthHIV, Washington, DC
HIV ACCESS, Alameda, CA
HIV Dental Alliance, Atlanta, GA
HIV Medicine Association, Arlington, VA
HIV/AIDS Programs and Services Citywide Project, Atlanta, GA
HIVictorious, Inc., Madison, WI
Housing Works, Washington, DC
Human Rights Campaign, Washington, DC
Hyacinth AIDS Foundation, New Brunswick, NJ
International AIDS Empowerment, El Paso, TX
L.A. Gay & Lesbian Center, Los Angeles, CA
Latino Commission on AIDS, New York, NY
Louisiana AIDS Advocacy Network (LAAN), Lafayette, LA
Lower East Side Harm Reduction Center, New York, NY
Mendocino County AIDS Volunteer Network (MCAVN), Ukiah, CA
Mendocino County AIDS/Viral Hepatitis Network (MCAVHN), Ukiah, CA
Michigan Positive Action Coalition (MI-POZ), Detroit, MI
Minnesota AIDS Project, Minneapolis, MN
Moveable Feast, Baltimore, MD
Nashville CARES, Nashville, TN
National AIDS Housing Coalition, Washington, DC
National Alliance of State and Territorial AIDS Directors, Washington, DC
National Association of People with AIDS, Silver Spring, MD
National Black Leadership Commission on AIDS, New York, NY
National Coalition for LGBT Health, Washington, DC
National Latino AIDS Action Network (NLAAN), Washington, DC
National Minority AIDS Council, Washington, DC
NC AIDS Education & Training Center, Durham, NC
North Carolina Harm Reduction Coalition, Durham and Winston Salem, NC
Okaloosa AIDS Support and Informational Services, Inc. (OASIS), Ft. Walton Beach, FL
Park West Health System, Inc., Baltimore, MD
Project Inform, San Francisco, CA
San Francisco AIDS Foundation, San Francisco, CA
Save the FoodBasket, Honolulu, HI
Servicios de la Raza, Denver, CO
Sexuality Information and Education Council of the U.S. (SIECUS), Washington, DC
Sisters Together and Reaching, Inc. (STAR), Baltimore, MD
Southern Colorado AIDS Project, Colorado Springs, CO
Treatment Access Expansion Project, Jamaica Plain, MA
Treatment Action Group, Washington, DC

Triad Health Project, Greensboro, NC
U.S. Positive Women's Network (PWN), New York, NY
Victory Programs, Inc., Boston, MA
VillageCare, New York, NY
Visiting Nurse Association of Central Jersey Community Health Center, Asbury Park, NJ
Women Organized to Respond to Life-threatening Disease (WORLD), New York, NY
Women Together For Change, St. Croix, U.S. Virgin Islands
Your Health Clinic, Sherman, TX
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