

HIV Health Care Access Working Group

January 17, 2012

The Honorable Kathleen Sebelius
Secretary
United States Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Re: Essential Health Benefits Bulletin

Dear Secretary Sebelius:

We are writing on behalf of the HIV Health Care Access Working Group – a coalition of over 100 national and community-based AIDS service organizations representing HIV medical providers, public health professionals, advocates and people living with HIV and AIDS who are all committed to ensuring access to critical HIV-related health care and support services. We urge you to ensure that the Essential Health Benefits (EHB) provisions created under the Affordable Care Act (ACA) are implemented in ways that protect against discrimination, establish a high national floor for coverage, and ensure adequate coverage for people living with HIV and AIDS and other vulnerable populations.

In 2014, thousands of people living with HIV and AIDS will have access to private insurance – many for the first time. But to be meaningful, insurance coverage must include the comprehensive services that people living with HIV and AIDS need to stay healthy. Services that play a vital role in effective management of HIV disease include comprehensive prescription drug coverage, preventive services such as routine HIV testing, routine access to medical providers and appropriate laboratory testing, chronic disease management services and mental health and substance abuse services. Such services are necessary to ensure that people living with HIV/AIDS are diagnosed early, stay in regular care and treatment and realize the lifesaving benefits of HIV treatment. Further, because we now know effective HIV treatment prevents HIV transmission, comprehensive care for people living with HIV and AIDS is important to our nation's public health.

People living with HIV and AIDS have largely been shut out of the private insurance market by rules that allowed plans to deny coverage to individuals with higher cost conditions, such as HIV/AIDS, or to place coverage out of reach for certain populations due to high premiums or cost sharing. Of the 13 percent of people with HIV with private coverage – many find themselves underinsured due to the limitations of the coverage. The ACA includes explicit protections to safeguard against discriminatory insurance practices, and we urge HHS to consider these protections as it develops more detailed regulations and guidance:

- In defining the EHB, the Secretary is directed to “not make coverage decisions, determine reimbursement rates, establish incentive programs, or design benefits in ways that discriminate against individuals because of their age, disability, or expected length of life.” (§1302(b)(4)(B)).
- The Secretary is also directed to “take into account the health care needs of diverse segments of the population, including women, children, [and] persons with disabilities.” (§1302(b)(4)(C)).

- The Secretary is also directed to “ensure that health benefits established as essential not be subject to denial to individuals against their wishes on the basis of the individuals’ age or expected length of life or of the individual’s present or predicted disability.” (§1302(b)(4)(D)).

Allowing state flexibility to choose benchmark plans that may not cover essential HIV/AIDS services does not meet the letter and spirit of the ACA’s anti-discrimination mandates, nor does it forward the goals of the ACA to provide a national standard of coverage. Even within the benchmark approach identified in the EHB Bulletin, there are ways to ensure that people living with HIV/AIDS and other vulnerable populations are protected from discrimination.

Specifically, we urge you to consider the following in refining the EHB guidance and subsequent regulations:

1. HHS should ensure that its EHB approach creates a higher national floor and does not penalize state residents for their state government’s inaction.

There is incredible variation in the scope of coverage and affordability within the range of plans HHS has indicated states will be allowed to choose from as their benchmark. For instance, small group insurance plans have historically been less comprehensive than most large group plans, state employee plans, or Federal Employee Health Benefit Program plans. The largest for-profit commercial HMO operating in a state may be similarly limited. We, therefore, urge HHS to eliminate the small group plan as a benchmark option and limit the HMO benchmark option to “non-profit” HMOs. If HHS retains the small group benchmark choice, we urge HHS to consider one of the other benchmark options as the fallback option for states that fail to choose a benchmark plan.

2. HHS should prohibit plans from substituting benefits across categories.

Because of the unique needs of people living with HIV and AIDS and other complex conditions, we are deeply concerned that allowing plans to substitute benefits will result in limits on or elimination of important services as a mechanism for discouraging certain populations from enrollment. A substitution policy is counter to Congressional intent of establishing a national floor for benefits that enrollees can count on regardless of where they live in the U.S. We urge HHS not to allow substitution across and within benefits categories.

3. The EHB must include protections and safeguards to ensure that people living with HIV and AIDS and other vulnerable populations have access to essential care and treatment.

The ACA envisioned an EHB that provides a national standard for insurance coverage. The ten mandatory categories of services as well as the explicit protections against discriminatory insurance practices were meant to guard against insurance underwriting practices that can be used to discourage enrollment by people living with HIV and AIDS and others chronic, expensive conditions, leaving them without access to medically necessary care and treatment. Within the benchmark approach discussed in the Bulletin, we urge HHS to issue guidance and specific regulations for services for which the scope of coverage is likely to vary considerably by plan and for which there is a likelihood of continued discriminatory insurance practices that discourage enrollment and limit access to essential care and treatment as detailed below:

- *Prescription Drugs*
Access to comprehensive and affordable prescription drugs is essential to HIV/AIDS care and treatment. Private insurers use drug formularies to discourage enrollment by certain populations, such as people living with HIV and AIDS, by not covering latest and most-effective

prescription drugs or placing them on higher cost-sharing tiers. The current guidance that would allow plans to cover one drug in each category or class covered by the benchmark would not support the current standard of care for people living with HIV and AIDS according to the federal HIV treatment guidelines (National Institutes of Health, Federal HIV-related Guidelines and Recommendations, available at, <http://www.aidsinfo.nih.gov/Guidelines/Default.aspx>). People living with HIV and AIDS rely on a minimum of three drugs from the antiretroviral drug class to effectively suppress the virus. Explicit protections, such as those provided under Medicare Part D, are needed within the guidance and subsequent regulations to ensure people with certain conditions, such as HIV infection, have access to all drugs to treat their condition. Unrestricted access to lifesaving medications without prior authorization requirements and other utilization controls is necessary to ensure access to the appropriate standard of care in the U.S. We also urge HHS to include protections for newer, more effective viral hepatitis medications, particularly given the rates of hepatitis co-infection among people with HIV infection. Currently, these medications remain out of reach for many people with viral hepatitis, including people living with HIV and AIDS and access barriers contribute to high mortality rates due to liver disease among people living with HIV and AIDS.

- *Ambulatory Patient Services*

Access to HIV experts, including those trained in infectious diseases, and a range of other specialists is critical to successfully treat HIV disease and other co-occurring conditions common among people living with HIV and AIDS. We urge HHS to ensure that medically necessary access to specialists is included in the EHB and that protections are in place to prevent insurance plans from making it unduly burdensome to access specialists, for instance through requiring higher co-payments for specialty care.

- *Preventive Services*

All plans subject to the EHB requirement should, at a minimum, cover all services with an A or B rating from the United States Preventive Services Task Force and the women's preventive services required under the ACA (including annual HIV screening and counseling, sexually-transmitted infection counseling, FDA-approved contraception and contraceptive counseling, and domestic violence screening and counseling). We urge you to specify routine HIV screening as a required preventive service in the EHB package. We were pleased to see the Secretary recognize the importance of routine HIV testing by including it in the women's preventive service package. This benefit should be extended for men as well. This standard must be available to all individuals in the U.S., and preventive services must uniformly be available across the insurance markets, including the expanded Medicaid coverage.

- *Rehabilitative and Habilitative Services*

HHS acknowledges that this is a service not regularly covered or uniformly defined by insurers so the service category has the potential to vary greatly in scope and definition depending on the plan. We urge HHS to better define services for which there is likely to be significant variation and interpretation left to states. For instance, case management plays an important role in helping people living with HIV access services to stay healthy and reduce the use of more intensive health care services, and we recommend defining case management as including care coordination and navigation, HIV/AIDS treatment and care adherence and counseling.

- *Mental Health and Substance Use Treatment*

We urge you to consider the recommendations offered by the Coalition for Whole Health that many of our organizations endorsed. Access to the range of services effective at treating mental illness and substance use disorders is critical to prevent inpatient hospitalizations and to

support people living with HIV and AIDS with maintaining the care and treatment that they need to stay healthy. Moreover, the EHB should be implemented in ways that promote the Mental Health Parity and Addiction Equity Act and limit the variation in scope of mental health and substance abuse services that could exist both among states and among insurance plans.

- *Chronic Disease Management*

We urge you to define the chronic disease management benefit in the guidance and subsequent regulations and ensure that people living with HIV and AIDS have access to chronic disease management programs. HIV has evolved into a chronic condition for individuals with access to care and treatment. With the support of the Ryan White Program, HIV providers and programs have developed effective chronic disease management programs to meet the complex needs of many people with HIV/AIDS. This model must be included as part of any EHB package.

- *Laboratory Services*

We urge HHS to specify coverage for laboratory monitoring according to the standard of care for HIV disease and other conditions. We also urge HHS to ensure that service limits for this and other services not be driven by price. Laboratory tests are recommended every three to six months to assess an individual's response to HIV therapies as well as the development of co-occurring conditions as a result of treatment or disease progression.

4. The guidance and future EHB regulations must include patient protections concerning benefit limitations, medical necessity determinations, and utilization management practices.

It is important to ensure meaningful access to medically necessary health care services, particularly for individuals with higher cost chronic conditions, such as HIV/AIDS. We urge HHS to issue regulations and guidance that prohibit insurance companies from limiting access to lifesaving care and treatment through dollar or visit limits on essential services, condition-specific restrictions, and unduly burdensome utilization management and prior authorization practices. Service limits penalize individuals with HIV infection and others with chronic conditions who rely on routine medical visits and laboratory monitoring to stay healthy and prevent disease progression. We understand that separate guidance will be issued specifically on cost sharing, and we urge HHS to ensure that people living with HIV and AIDS and other complex and high cost medical conditions have access to affordable care and treatment.

5. Implementation decisions regarding the EHB must be transparent and include opportunities for stakeholder engagement.

We strongly urge HHS to set forth strong public process requirements and standards for state EHB implementation. The Institute of Medicine report included recommendations for a robust public deliberation process, drawing from examples of notice and public hearing processes preceding major changes to state Medicaid programs. We urge HHS to include similar requirements for state processes, such as public notice and hearing opportunities as each state develops its benchmark plan. Requiring that states solicit input from a range of stakeholders and communities is necessary to ensure that the proposed benchmark plan takes into account the needs of diverse populations and to satisfy the requirements of the ACA for meaningful public involvement.

6. HHS should issue guidance encouraging states to utilize AIDS Drug Assistance Program and other Ryan White Program funds to pay for premiums and co-payments for private insurance purchased through exchanges.

Private insurance reforms coupled with the roll-out of state exchanges will allow thousands of people living with HIV and AIDS to access private insurance for the first time. However, even with federal subsidies and premium tax credits, cost will be a barrier for many low-income people living with HIV and AIDS. In states where state-based health reforms have increased access to insurance coverage (e.g., Massachusetts), the AIDS Drug Assistance Program (ADAP) has played a critical role in helping to defray some of the out-of-pocket costs of insurance through its coverage of beneficiary insurance premiums and cost-sharing obligations. Similarly, in many states ADAP has played a crucial role in helping people living with HIV and AIDS access insurance through Pre-Existing Condition Insurance Plans (PCIPs). We urge HHS to issue explicit guidance to states encouraging the use of ADAP and other Ryan White Program funds in this way and encourage states to enter into the necessary data-sharing agreements to enable to them to maximize resources and ensure access to care for low-income and vulnerable populations.

We understand that there will be future guidance and regulations on how the EHB will be implemented for newly eligible Medicaid beneficiaries. We urge HHS to consider the issues and concerns raised and ensure that people living with HIV and AIDS who will be newly eligible for Medicaid have access to comprehensive coverage.

Thank you for the opportunity to comment on the Bulletin. As we learn more about the plans proposed as benchmark options, we may follow up with additional recommendations before the deadline but wanted to offer these initial recommendations for your consideration as you finalize the initial guidance and begin developing subsequent regulations. Please contact the HIV Health Care Access Working Group co-chairs, Robert Greenwald with the Treatment Access Expansion Project (rgreenwa@law.harvard.edu) or Andrea Weddle with the HIV Medicine Association (aweddle@idsociety.org), with questions and to schedule a meeting.

Respectfully Submitted by the Steering Committee of the HIV Health Care Access Working Group,

AIDS Action Baltimore | AIDS Alliance for Children, Youth & Families | AIDS Foundation of Chicago | The AIDS Institute | AIDS Project Los Angeles | AIDS Treatment Data Network | AIDS United | American Academy of HIV Medicine | Broward House | Community Access National Network | Community HIV/AIDS Mobilization Project | Gay Men's Health Crisis | Harlem United | Health and Disability Advocates | HIV Medicine Association | HIVictorious, Inc. | Housing Works | Moveable Feast | National Alliance of State and Territorial AIDS Directors | National Association of People With AIDS | National Minority AIDS Council | The National Working Positive Coalition | Project Inform | San Francisco AIDS Foundation | South Carolina Campaign to End AIDS | Treatment Access Expansion Project | Treatment Action Group | VillageCare