

# HIV Health Care Access Working Group

December 1, 2011

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

RE: Comprehensive Essential Health Benefits for People with HIV/AIDS

Dear Secretary Sebelius:

On behalf of the HIV Health Care Access Working Group thank you for your commitment to obtaining broad stakeholder input on the Essential Health Benefits (EHB) package that will set the coverage standard for health plans operating in the state-based exchanges and the benefits available to the Medicaid expansion population beginning in 2014. We are writing to you again on this issue because we are concerned by many of the recommendations offered by the Institute of Medicine (IOM) in its report *Essential Health Benefits: Balancing Coverage and Cost* and their potential implications for people with chronic conditions, including HIV/AIDS. (For our initial comments to you on this issue, please see attached letter.)

Of the estimated 50 percent of people with HIV in regular care today -- fewer than 20% have private insurance coverage and nearly 50% rely on the Medicaid program for lifesaving care and treatment. Under the current health care system, health coverage is left out of reach for a majority of people with HIV because of practices that allow insurers significant flexibility in denying coverage and designing benefits packages that discriminate against individuals with higher cost conditions, such as HIV/AIDS. Setting a high national standard with the EHB package is critical to end these practices and to ensure meaningful access to health care coverage for people with HIV/AIDS through the Affordable Care Act (ACA).

Tying the EHB package to the benchmark benefits package for small employer coverage as recommended by the IOM will not reflect "typical employer coverage" and will set a low bar for populations that are gaining access to health coverage through the exchanges and Medicaid. Many of these individuals will be gaining access to health coverage and services for the first time and will need comprehensive and affordable coverage to meet their medical needs and stay healthy and productive. Restrictive service limits or complex service approval processes will severely limit the value of the new health coverage to people with HIV and others with chronic conditions. A national standard in this regard is critical to reducing health-care disparities – including for people with HIV/AIDS.

An EHB package that covers the services necessary for people with HIV to stay healthy will result in better health outcomes and lower health care expenditures. Comprehensive HIV care is vital to the health of people with HIV and important to public health as effective treatment significantly reduces the risk of transmitting HIV infection to others. In balancing affordability and comprehensive coverage, it is important to consider people with HIV and others with chronic conditions who rely on robust underlying coverage to afford the range of services that they need to stay healthy, prevent disease progression and stay out of the hospital. As people with HIV get sicker, their health costs increase. Average annual costs for people with HIV average \$19,912 per year but range from \$16,614 per year for healthier individuals

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to \$40,678 per year for individuals with more advanced disease.<sup>1</sup>

A robust EHB package that defines patient protections and ensures meaningful access to medically necessary health care services for people with HIV/AIDS and others with chronic conditions will be a key factor in determining the success of the ACA . With this in mind, we support the principles developed by Community Catalyst and others and urge you to:

- Maintain a transparent and consumer driving process that clearly delineates the role for consumers in defining, evaluating and revising the EHB package through the annual review process.
- Ensure the ACA provides meaningful health coverage through the exchanges and the Medicaid expansion that does not leave consumers underinsured and at risk for going without medically necessary care or incurring substantial debt. This is critical to not undermine the meaningful health care reform intended by the ACA.
- Set a high national benefits design standard and ensure individuals are not subject to discriminatory cost sharing, harmful service limits or other cost-controlling measures that limit, impede or delay access to medically necessary care and treatment. Do not leave important benefits and cost sharing issues to be defined by insurers.

We would appreciate the opportunity to discuss this important issue with you or your staff as soon as possible. Please note that we made this request in our initial letter. Please contact the HIV Health Care Access Working Group co-chairs, Robert Greenwald with the Treatment Access Expansion Project ([rgreenwa@law.harvard.edu](mailto:rgreenwa@law.harvard.edu)) or Andrea Weddle with the HIV Medicine Association ([aweddle@idsociety.org](mailto: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 United | American Academy of HIV Medicine | Broward House | Community Access National Network | Communities Advocating Emergency AIDS Relief (CAEAR) Coalition | Gay Men's Health Crisis | Georgia AIDS Network | Harlem United | Health and Disability Advocates | HIV Medicine Association | HIVictorious, Inc. | HIV Prevention Justice Alliance | 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

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<sup>1</sup> Gebo KA, Fleishman JA, Conviser R, et al. Contemporary costs of HIV healthcare in the HAART era. AIDS. 2010;24(17):2705-15.