



December 22, 2011

Secretary Kathleen Sebelius  
U.S. Department of Health & Human Services  
200 Independence Avenue, SW  
Washington, DC 20201

Dear Secretary Sebelius:

On behalf of the HIV Health and Human Services Planning Council of New York (Planning Council), I write concerning the essential health benefits package of the Affordable Care Act for People Living with HIV/AIDS (PLWHA). The Planning Council is comprised of health care and service providers, advocates, and consumers and is charged with setting priorities for and allocating approximately \$121 million in HRSA funding for treatment and care for PLWHA in the five boroughs of New York City and in Westchester, Rockland, and Putnam counties.

Planning Council members want to commend you for addressing some very challenging issues as you revamp the dysfunctional US health care system. Currently, an excessive number of PLWH cannot take advantage of the extraordinary care and treatment options that exist: only approximately half of PLWH have consistent entrée to treatment for their infections, and less than one-fifth have undetectable viral loads. The Affordable Care Act provides an unparalleled chance to build a health care structure that benefits PLWH and promotes the objectives of the National HIV/AIDS Strategy of diminishing the number of new cases, fostering entrée to treatment, enhancing health, and decreasing HIV-linked inequalities.

The Planning Council recommends that the following components are integrated into the essential health benefits package:

- For ambulatory patient care, no caps on medical services or appointments. Easy entrée to a skilled HIV medical provider coupled with limited co-pays fosters involvement in and adherence to treatment and prevents disease advancement.
- No monthly or yearly caps on prescription drugs, restrictions on co-pays, specific safeguards for some groups of drugs, such as antiretrovirals, and firm constraints on inequitable cost-sharing.

- PLWHAs should be allowed to join chronic illness control programs, in the same way as the Center for Medicare and Medicaid Services permitted in the November 2010 letter to directors of state Medicaid programs concerning the Medicaid Health Home Program.
- Case management should involve care coordination and steering, compliance with treatment and care, and counseling.
- The ability to gain entrée to the care that successfully helps with psychological illness and drug use problems is vital in order to prevent inpatient stays and enable PLWHAs to continue in treatment and care in order to remain in good condition.
- Interim case management for people with multiple risk factors assists with accessing and remaining in treatment.
- No rationing of coverage for laboratories to follow the course of a patient's disease, and lab tests at each 3- to 6-month interval to check the patient's reaction to the HIV medications and to examine the progress of co-occurring illnesses as a consequence of treatment or of the advancement of the disease.
- Prohibition of bias by guaranteeing that utilization management is used to improve the standards of care, not to hinder entrée to medically vital treatment. Prolonged care, for a year (for example), should be permitted when suggested by a provider of HIV medical care.
- Facilitate stability of care, with instruction and coordination via patient navigators.
- Incorporate safeguards regarding expense-sharing for patients with chronic illnesses, including HIV, who need routine entrée to medical providers, medications, lab services, and additional health services.

Planning Council members are convinced that incorporating these features into the essential health benefits package will help all of us to build a stronger health care system that will engage and retain patients in care and, ultimately, reduce community viral load and improve the health of the community as a whole. The views expressed in this letter do not necessarily reflect the positions of the Mayor or the Commissioner of Health of the City of New York.

Thank you very much for your time and attention.



Dorella Walters, MPA  
Community Co-Chair

cc: Hon. Michael Bloomberg  
Thomas Farley, MD, MPH  
Jan Carl Park