I AM (STILL) ESSENTIAL Sign On Letter to Secretary Burwell

July x, 2014

The Honorable Sylvia Mathews Burwell
Secretary of Health and Human Services
200 Independence Avenue SW
Washington, D.C. 20201

Dear Madame Secretary:

We, the undersigned patient and community organizations representing millions of patients and their families, have been and continue to be committed to the successful implementation of the Affordable Care Act (ACA). Many people, who have been denied access to health insurance in the past because of denials and exclusions for pre-existing conditions, as well as unaffordable premiums, can now gain meaningful access to quality and affordable care. We are encouraged by high enrollment numbers in the new Health Insurance Marketplace, and by early data showing low-income people who were previously uninsured are taking advantage of premium and cost-sharing assistance.

At the same time, we are increasingly aware of evidence that new enrollees, especially those with chronic health conditions, are still facing barriers to care. As implementation continues, assuring that all enrollees in Qualified Health Plans (QHPs) are able to realize the benefits of health insurance must be a top priority.

We urge you to take action now in order to improve benefit designs and guarantee that there is plan transparency for enrollees. We believe the suggested actions, outlined below, are critical steps to assure that all enrollees have access to the medications, providers, and services they need to improve and maintain their quality of life as intended by the ACA.

Based on reports of enrollee experiences during the first year of Marketplace implementation, we have identified a number of concerns. These include discriminatory benefit designs that limit access, such as restrictive formularies and inadequate provider networks; high cost-sharing; and a lack of plan transparency that may deprive consumers of information that is essential to making informed enrollment choices.

Limited Benefits: Due to the manner in which Essential Health Benefits (EHBs) are defined for plan years 2014 and 2015, select plans do not include all the medications that enrollees may be prescribed to address their health care needs. Plans are further restricting access to care by imposing utilization management policies, such as prior authorization, step therapy and quantity limits. Tying plan formulary requirements to the number of drugs in each class in the state benchmark has resulted in some plans not covering critical medications, including combination therapies. Additionally, there is no requirement for plans to cover new medications and plans can remove medications during the plan year as long as the plan continues to meet the state's benchmark requirements. Narrow provider networks and a lack of access to specialists are also negatively impacting access to quality care for enrollees. These design elements appear to affect certain patient populations disproportionately – many of the same populations that were subject to pre-existing condition restrictions prior to ACA implementation.

High Cost-Sharing: Despite enrollee out-of-pocket limits that are included in the ACA and reduced cost-sharing for people with very low income levels, some plans are placing extremely high co-insurance on lifesaving medications, and putting all or most medications in a given class, including generics, on the
highest cost tier. This creates an undue burden on enrollees who rely on these medications. Unlike employer-sponsored plans, where enrollees usually experience reasonable co-pays, enrollees in the Marketplace are being subject to plans that impose 30%, 40% and even 50% co-insurance per prescription. Such high co-insurance is shocking enrollees and will lead to reduced medication adherence and medical complications as people are unable to afford to begin or stay on medications. Some plans are also imposing high deductibles for prescription medications and high cost-sharing for accessing specialists.

We believe these practices are highly discriminatory against patients with chronic health conditions and may, in fact, violate the ACA non-discrimination provisions.

Transparency and Uniformity: Individuals must have access to easy-to-understand, detailed information about plan benefits, formularies, provider networks, and the costs of medications and services. Unfortunately, individuals cannot access this information easily through an interactive web tool such as a plan finder or benefit calculator that matches an individual’s prescriptions and provider needs with appropriate plans (such as the one utilized by the Medicare Part D program). Most troubling is the practice of requiring co-insurance without information for an individual to understand what their actual cost-sharing will be. Transparent, easy-to-navigate grievances and appeals processes are needed, along with special enrollment procedures when patients lose access to a medication due to formulary changes during a plan year.

These issues need attention if the ACA is to deliver on its promises for people with chronic health conditions. Actions should include enforcing the ACA non-discrimination provisions, prohibiting restrictive formularies and inadequate provider networks; addressing high cost-sharing, including inappropriate use of coinsurance; and improving plan transparency so that consumers can make informed decisions. We look forward to working with you as efforts are made to revise the EHB standards for future plan years, implement a strong oversight system, and continually improve meaningful access to medications and providers.

Thank you very much.

Sincerely,

The AIDS Institute
American Autoimmune Related Diseases Association
Easter Seals
Epilepsy Foundation
Lupus Foundation of America
National Alliance on Mental Illness