

# I AM (Still) ESSENTIAL

November 12, 2014

Shaun Donovan, Director  
Office of Management and Budget  
725 17th Street NW  
Washington, DC 20503

Marilyn Tavenner, Administrator  
Centers for Medicare and Medicaid Services  
U.S. Department of Health and Human Services  
7500 Security Boulevard  
Baltimore, MD 21244

Re: Notice of Benefit and Payment Parameters Proposed Rule

Dear Mr. Donovan and Ms. Tavenner:

We are writing to reiterate earlier comments submitted to HHS Secretary Burwell this past summer on behalf of the patient community on some barriers to access patients have experienced in the Marketplace qualified health plans based on the first year of enrollment. As you prepare to issue a proposed rule on the Notice of Benefit and Payment Parameters for calendar year 2016 (RIN: 0938-AS19), we ask that you consider the comments the **I AM (Still) ESSENTIAL** coalition of patients groups included in our [letter](#) to Secretary Burwell signed by 333 patient organizations. The main areas of concern addressed in the letter include limited benefits (particularly as it relates to prescription medications and provider networks), high cost-sharing, and lack of transparency and uniformity.

As we begin year two, we look forward to a successful enrollment and re-enrollment period and pledge to commit our resources to ensure its success. We are in the beginning stage of reviewing the 2015 plans and based on some early plan reviews, we have discovered that the problems we identified persist. While we do not know all the subjects that will be addressed in the Proposed Rule, we hope that the concerns that we have identified in our letter will be addressed in this rule or other rules and guidance in the near future.

We remain strongly committed to implementation of the ACA and hope the issues we have identified will be resolved so the ACA will be able to deliver on its promises to people with chronic health conditions.

Thank you very much.

Sincerely,

Carl Schmid  
Deputy Executive Director  
The AIDS Institute

Andrew Sperling  
Director of Federal Legislative Advocacy  
National Alliance Mental Illness

Angela Ostrom  
Chief Operating Officer  
Epilepsy Foundation

Attachment

# I AM (Still) ESSENTIAL

July 28, 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,

A Support Alliance  
ACCSES  
ActionAIDS  
Addario Lung Cancer Foundation  
The Advocacy Center  
Advocates for Responsible Care  
AIDS Action Baltimore  
AIDS Action Coalition  
AIDS Action Committee of Massachusetts  
AIDS Alabama  
AIDS Alliance for Women, Infants, Children,  
Youth & Families  
AIDS Assist  
AIDS Foundation of Chicago

The AIDS Institute  
AIDS Legal Referral Panel  
AIDS Network of WNY  
AIDS Research Consortium of Atlanta  
AIDS Task Force of the Upper Ohio Valley  
AIDS United  
Aimed Alliance  
Alabama Council of CMHB  
Alabama Council of Community Mental Health  
Boards  
Alliance of AIDS Services - Carolina  
ALPHA Pittsburgh, Inc.  
Alzheimer's & Dementia Resource Center  
American Association on Health and Disability

American Autoimmune Related Diseases Association  
 American GI Forum of California Veterans Outreach Program  
 American GI Forum Women of California  
 The American Kidney Fund  
 American Liver Foundation Rocky Mountain Division  
 American Lung Association  
 American Society for Metabolic and Bariatric Surgery  
 The Arc of the United States  
 Arthritis Association of Louisiana  
 Association of Community Cancer Centers  
 Asthma and Allergy Foundation of America, New England Chapter  
 Aunt Rita's Foundation  
 Autoimmune Advocacy Alliance  
 BDD Consulting  
 Behavioral Health & Wellness (TM)  
 Big Bend Cares Inc.  
 Birmingham Health Care  
 Bladder Cancer Advocacy Network  
 Bleeding Disorders Alliance Illinois  
 Blue Ribbon Advocacy Alliance  
 Brain Injury Alliance of Connecticut  
 Breathe California  
 California Asian Pacific Chamber of Commerce  
 California Hepatitis C Task Force  
 California Senior Advocates League  
 Callen-Lorde Community Health Center  
 Cancer Support Community  
 Caring Ambassadors Program  
 Cascade AIDS Project  
 Center for Lawful Access and Abuse Deterrence  
 Central Florida Behavioral Health Network  
 Chicago House and Social Service Agency  
 City of Hartford Commission on HIV/AIDS  
 Coalition of Texans with Disabilities  
 Colon Cancer Alliance  
 Colorado AIDS Project  
 Combined Health Agencies  
 Community Access National Network (CANN)  
 Community AIDS Resource and Education Services (CARES)  
 Community Health Action Network  
 Community Health Center of Central Missouri  
 Community Health Charities of Florida  
 Community Health Charities of Iowa  
 Community Health Charities of Kentucky  
 Community Health Charities of Nebraska

Community Health Charities of Oklahoma  
 Community Health Charities of the National Capital Area  
 Community Health Charities of Wisconsin  
 Community Volunteers Association  
 Commwell Health  
 Concilio Latino de Salud, Inc.  
 Cutaneous Lymphoma Foundation  
 Cystic Fibrosis Foundation  
 Delaware Academy of Medicine  
 Delaware Ecumenical Council on Children and Families  
 Delaware HIV Consortium  
 Delaware Public Health Association  
 Depression and Bipolar Support Alliance  
 Dialysis Patient Citizens  
 Disability Policy Consortium  
 Easter Seals  
 Easter Seals Central Texas  
 Easter Seals Colorado  
 Easter Seals Massachusetts  
 Elder Advocacy of Florida  
 Embracing Latina Leadership Alliances (ELLAS)  
 Epilepsy Association of Central FL  
 Epilepsy Association of Oklahoma  
 Epilepsy Foundation  
 Epilepsy Foundation Central & South Texas  
 Epilepsy Foundation Heart of Wisconsin  
 Epilepsy Foundation Louisiana  
 Epilepsy Foundation Northwest  
 Epilepsy Foundation of Alabama  
 Epilepsy Foundation of Arizona  
 Epilepsy Foundation of the Chesapeake Region  
 Epilepsy Foundation of Colorado  
 Epilepsy Foundation of Connecticut  
 Epilepsy Foundation of East Tennessee  
 Epilepsy Foundation of Florida  
 Epilepsy Foundation of Greater Chicago  
 Epilepsy Foundation of Greater Cincinnati and Columbus  
 Epilepsy Foundation of Greater Los Angeles  
 Epilepsy Foundation of Greater Southern Illinois  
 Epilepsy Foundation of Indiana  
 Epilepsy Foundation of Kentuckiana  
 Epilepsy Foundation of Long Island  
 Epilepsy Foundation of Metropolitan New York  
 Epilepsy Foundation of Michigan  
 Epilepsy Foundation of Minnesota  
 Epilepsy Foundation of Mississippi  
 Epilepsy Foundation of Missouri and Kansas

Epilepsy Foundation of New England  
 Epilepsy Foundation of New Jersey  
 Epilepsy Foundation of North Central Illinois,  
     Iowa, Nebraska  
 Epilepsy Foundation of Northeastern New York  
 Epilepsy Foundation of Northern California  
 Epilepsy Foundation of San Diego County  
 Epilepsy Foundation of Texas-Houston/Dallas-  
     Fort Worth/West Texas  
 Epilepsy Foundation of Vermont  
 Epilepsy Foundation of Virginia  
 Epilepsy-Pralid Inc.  
 Equality Maryland  
 EveryLife Foundation For Rare Diseases  
 FAIR Foundation  
 Familia Unida Living with MS  
 Family Health Center of Boone County  
 Fight AIDS for LIFE Foundation  
 Fight Colorectal Cancer  
 Filipino American Service Group Inc. (FASGI)  
 Firehouse Family Ministries  
 Florida CHAIN  
 Florida Hemophilia Association  
 Florida State Hispanic Chamber of Commerce  
 FMS Pharmacy  
 Frannie Peabody Center  
 Friends For Life  
 GBS/CIDP Foundation International  
 Global Colon Cancer Association  
 Global Healthy Living Foundation  
 GMHC (Gay Men's Health Crisis)  
 Good Samaritan United Methodist Church  
 Granny Connection  
 GT23 Foundation  
 H.E.A.L.S. of the South  
 Hawaii Island HIV/AIDS Foundation  
 HEAL International  
 Health People: Community Preventive Health  
     Institute  
 HealthHIV  
 Healthy African American Families  
 Heartland Alliance for Human Needs & Human  
     Rights  
 Hemophilia Alliance of Maine, Inc.  
 Hemophilia Association of the Capital Area  
 Hemophilia Foundation of Greater Florida  
 Hep C Connection  
 Hepatitis Foundation International  
 HIV a Southern Epidemic!  
 HIV ACCESS  
 HIV and the Aging

HIV Dental Alliance  
 HIV Medicine Association  
 HIV Prevention Justice Alliance  
 HIV/AIDS Law Project  
 HomeCare For The Carolinas  
 Human Rights Campaign  
 Huntington's Disease Society of America  
     (HDSA)  
 Illinois African American Coalition for  
     Prevention  
 Immune Deficiency Foundation  
 Interfaith Community Health Center  
 International Foundation for Autoimmune  
     Arthritis  
 International Institute For Human  
     Empowerment, Inc.  
 International Myeloma Foundation  
 International Pemphigus & Pemphigoid  
     Foundation  
 The Jewish Federations of North America  
 Jonah's Just Begun-Foundation to Cure  
     Sanfilippo Inc.  
 Joshua Tree Feeding Program, Inc.  
 Kansas Association of Osteopathic Medicine  
 Keeping It Real Neighborhood Institute, Inc.  
 Lambda Legal  
 Latina Breast Cancer Agency  
 The Leukemia & Lymphoma Society  
 The Leukemia & Lymphoma Society,  
     Connecticut Westchester Hudson Valley  
     Chapter  
 The Leukemia & Lymphoma Society,  
     Mississippi/Louisiana Chapter  
 Loaves & Fishes Community Services  
 Lone Star Chapter of National Hemophilia  
     Foundation  
 Los Angeles County HIV Drug & Alcohol Task  
     Force  
 Los Angeles LGBT Center  
 Louisiana A.I.D.S. Advocacy Network  
 Lupus Alliance of Long Island/Queens, Inc.  
 Lupus Alliance of Upstate New York  
 Lupus and Allied Diseases Association, Inc.  
 Lupus Foundation of America  
 Lupus Foundation of America, Florida Chapter  
 Lupus Foundation of America, Georgia Chapter  
 Lupus Foundation of America, Indiana Chapter  
 Lupus Foundation of America, Texas Gulf Coast  
     Chapter  
 Lupus Foundation of Florida  
 Lupus Foundation of Genesee Valley NY, Inc.

Lupus Foundation of Southern California  
 Lupus Research Institute  
 Lupus Society of Illinois  
 Lutheran Services in America  
 The Marfan Foundation  
 Maryland Women's Coalition for Health Care Reform  
 Massachusetts Association for Mental Health  
 MedChi, The Maryland State Medical Society  
 Medical AIDS Outreach of Alabama  
 The Medical Oncology Association of Southern California, Inc.  
 Medical Society of Northern Virginia  
 Medical University of South Carolina/Lowcountry AIDS Services C.A.B.  
 Men's Health Network  
 Mental Health & Addiction Advocacy Coalition  
 Mental Health Action  
 Mental Health America  
 Mental Health America of Colorado  
 Mental Health Association of Minnesota  
 Mental Health Systems  
 Minnesota State Grange  
 Missouri Family Health Council, Inc.  
 Missouri Health Advocacy Alliance  
 MLD Foundation  
 Mother & Child Health Coalition  
 Nashville CARES  
 National Alliance of State & Territorial AIDS Directors  
 National Alliance on Mental Illness  
 National Alliance on Mental Illness Alabama  
 National Alliance on Mental Illness Colorado  
 National Alliance on Mental Illness Florida  
 National Alliance on Mental Illness Illinois  
 National Alliance on Mental Illness Maryland  
 National Alliance on Mental Illness Minnesota  
 National Alliance on Mental Illness North Carolina  
 National Alliance on Mental Illness South Carolina  
 National Alliance on Mental Illness South Dakota  
 National Alliance on Mental Illness Tennessee  
 National Alliance on Mental Illness Washington  
 National Alliance on Mental Illness Wyoming  
 National Association of Hepatitis Task Forces  
 National Association of Hispanic Nurses  
 National Association of Hispanic Nurses El Paso Chapter  
 National Association of Social Workers  
 National Coalition for LGBT Health  
 National Community Pharmacists Association (NCPA)  
 National Council for Behavioral Health  
 National Council of Negro Women Inc. View Park  
 National Fibromyalgia & Chronic Pain Association  
 National Gay and Lesbian Task Force  
 National Grange  
 National Hemophilia Foundation  
 National Kidney Foundation  
 National Kidney Foundation of Florida  
 National Minority Quality Forum  
 National MS Society, Alabama-Mississippi Chapter  
 National Osteoporosis Foundation  
 National Patient Advocate Foundation  
 National Psoriasis Foundation  
 National Stroke Association  
 National Viral Hepatitis Roundtable  
 Neurofibromatosis, Inc. Mid-Atlantic  
 Neuropathy Action Foundation  
 New England Hemophilia Association  
 New Jersey Association of Mental Health and Addiction Agencies, Inc.  
 New Jersey Mayors Committee on Life Sciences  
 New Orleans Council on Aging  
 The Noonan Syndrome Foundation  
 Obesity Action Coalition  
 The Obesity Society  
 Ohio Council of Behavioral Health & Family Services Providers  
 OK AIDS Care Fund  
 Open Door Clinic  
 Ovarian Cancer Coalition of Greater California  
 Ovarian Cancer National Alliance  
 OWL - The Voice of Women 40+  
 Parkinson's Action Network  
 The Parkinson's Association  
 Partnership Project  
 Pediatric AIDS Chicago Prevention Initiative  
 Philadelphia Center  
 Plaza Community Services  
 Positive Effect Outreach Ministry  
 Positive Life Series  
 Power of Pain Foundation  
 Prevent Blindness  
 Prevent Blindness, Iowa Affiliate  
 Prevent Blindness, Ohio Affiliate  
 Prevent Blindness, Texas Affiliate

Prevent Cancer Foundation  
Private Advocate for PLWH  
Program for Wellness Restoration  
Pulmonary Hypertension Association  
PWA Coalition Colorado  
RAIN  
RAIN Oklahoma  
Renal Support Network  
Resource Center  
RetireSafe  
Rush to Live  
S.L.E. Lupus Foundation  
Scleroderma Foundation  
Sickle Cell Disease Association of Florida  
Sickle Cell Foundation Incorporated  
Sjogren's Syndrome Foundation  
Society for Public Health Education  
Society for Women's Health Research  
Solidarity Project Advocacy Network  
Southwest CARE Center  
Southwest Center for HIV/AIDS  
St. Louis Effort for AIDS  
START at Westminster  
Suicide Awareness Voices of Education  
Sunburst Projects  
Tech Council of Maryland  
Tennessee Association of People With AIDS  
Texas Bleeding Disorders Coalition  
Texas Central Hemophilia Association  
Transformation Birmingham  
Tuberous Sclerosis Alliance  
Umass Memorial  
United Cerebral Palsy  
United Spinal Association  
Veterans Health Council of Vietnam Veterans of  
America  
Vietnamese Social Services of Minnesota  
Virginia Hemophilia Foundation  
The Wall Las Memorias Project  
Windows of Hope  
Women Against Prostate Cancer  
Wyoming Epilepsy Association



