

January 11, 2010

The Honorable Harry Reid Majority Leader United State Senate Washington D.C. 20510 The Honorable Nancy Pelosi Speaker United States House of Representatives Washington D.C. 20515

Dear Majority Leader Reid and Speaker Pelosi:

The Coalition to End the Two-Year Wait for Medicare is grateful for your leadership in securing passage of health reform legislation in both the House and Senate. Although neither the House nor Senate bill ends the two-year wait for Medicare for people with disabilities—the ultimate goal of our coalition—both bills provide new coverage options for the uninsured, including people with disabilities waiting for their Medicare coverage to begin. Insurers will no longer be able to deny coverage based on the existence of a pre-existing condition or disability and the expansion of Medicaid and new tax credits will help make coverage more affordable. It is out of concern over the affordability of these new coverage options that we write to you today.

The two-year waiting period for Medicare inflicts considerable hardship on people with disabilities. By the second year of their wait for Medicare coverage, people with disabilities are more likely to live in poverty, more likely to go without insurance and to find cost to be a barrier in accessing care and more likely to see their health decline as a result. The burden of the waiting period is greatest for those living in or near poverty: they are the least likely to have health coverage from their former employer or the employer of their spouse and the most likely to be unable to afford the medical care they need.

As you work to reconcile the House and Senate legislation, we urge you to make sure that people with disabilities in the waiting period have access to health insurance that provides affordable medical care. Two important characteristics of people with disabilities in the waiting period should inform your efforts:

- Two-thirds of people in the waiting period live below 200 percent of the federal poverty level;
- Over half of people in the waiting period are over 50 years old.

While both bills have a Medicaid expansion as an essential element in providing coverage to the uninsured, the House bill extends eligibility to people not eligible for Medicare with incomes up to 150 percent of the federal poverty level. The Senate bill's ceiling on eligibility is set at 133 percent of the federal poverty level. Expanding eligibility for Medicaid will provide people with disabilities living near the poverty level access to comprehensive health coverage with limited

cost sharing. Compared to providing coverage through an exchange, expanding Medicaid is both cost-effective and provides a level of benefits that helps eliminate cost as a barrier to care. We urge you to adopt the House bill's directive to set eligibility for Medicaid at 150 percent of the federal poverty level.

The House and Senate bills also differ considerably in the help they provide with premiums and cost-sharing for individuals with limited incomes but above the Medicaid eligibility threshold. For example, under the Senate bill, individuals at 200 percent of the federal poverty level pay a higher share of income in premiums for plans that pay a smaller percentage of health care costs (lower actuarial value) than under the House bill. As a result, people with disabilities and limited incomes could face a combination of high premiums and large deductibles that make cost, even under the new coverage options available through the exchange, a continuing barrier to care. The Senate bill does provide valuable protections worth maintaining in the final bill, including overall caps on out-of-pocket spending and more generous premium subsidies for individuals between 250 percent and 400 percent of the federal poverty level. However, it is essential that the final bill provide affordable coverage to people with disabilities on limited incomes. We urge you to adopt the actuarial values for exchange plans and the premium subsidies for people with limited incomes from the House bill.

Both the House and Senate bills cap the amount that the insurers can charge older adults for coverage, with the House bill setting age-rating at 2:1 and the Senate at 3:1. The cap on age rating will be a key determinant of the affordability of coverage for older adults with disabilities in the waiting period. We urge adoption of the 2:1 cap on age rating in the House bill.

The passage of health reform legislation by both the House and Senate represents a milestone in the decades-long effort to provide health coverage to all Americans. Both bills are the product of difficult political compromises and the reconciliation of the House and Senate bills will similarly require a combination of practicality and political resolve. As you lead these negotiations, we urge you to bear in mind the needs of a particularly vulnerable group of your constituents—people with disabilities in the two-year wait for Medicare—and ensure that the coverage they will receive under the final bill allows affordable access to the medical care they need.

Sincerely,

ACCSES
AIDS Action Baltimore, Inc.
AIDS Treatment Data Network
Alpha-1 Association
Alpha-1 Foundation
Alzheimer's Association
Alzheimer's Foundation of America
American Association for Geriatric Psychiatry
American Association of People with Disabilities (AAPD)
American Autoimmune Related Diseases Association
American Mental Health Counselors Association
American Music Therapy Association
American Network of Community Options and Resources (ANCOR)
American Psychosocial Oncology Society

Amputee Coalition of America

Amyloidosis Support Groups

APS Foundation of America

APSE

Arthritis Foundation

Association for Ambulatory Behavioral Healthcare

Association for Frontotemporal Dementias

Association of Programs for Rural Independent Living (APRIL)

Asthma and Allergy Foundation of America (AAFA)

Barrier Free Living, Inc.

Bazelon Center for Mental Health Law

Brain Injury Association of America

Breast Cancer Network of Strength

Brooklyn Center for Independence of the Disabled

Center for Disability Rights, Inc.

Center for Independence of the Disabled of New York

Center for Medicare Advocacy

Children's Tumor Foundation

Community Access National Network

Community Health Charities of America

COPD Foundation

Cystic Fibrosis Foundation

Disability Rights Education and Defense Fund

Disability Rights Wisconsin

Disabled In Action of Metropolitan New York

Dystonia Medical Research Foundation

Easter Seals

Eastern Maine AIDS Network (EMAN)

Ehlers Danlos National Foundation

Empire Justice Center

Epilepsy Foundation

Families USA

Friends of Jazz

Geriatric Mental Health Alliance of New York

Harlem Independent Living Center

Health Assistance Partnership

HIV Medicine Association

HIVictorious, Inc.

Incontinentia Pigmenti International Foundation

International Foundation for Alternative Research in AIDS (IFARA)

International Pemphigus and Pemphigoid Foundation

Kennedy's Disease Association

Long Term Care Community Coalition

Lupus Alliance of America, Inc

Lupus Foundation of America

Lupus Foundation of Mid and Northern New York, Inc.

Lymphoma Research Foundation

Medicare Rights Center

Mental Health America

Mississippi Coalition for Citizens with Disabilities

Myasthenia Gravis Foundation of America (MGFA)

National Academy of Elder Law Attorneys (NAELA)

National Alliance of State and Territorial AIDS Directors (NASTAD)

National Alliance on Mental Illness (NAMI)

National Association of Councils on Developmental Disabilities

National Association of County Behavioral Health and Developmental Disability Directors

National Association of State Head Injury Administrators

National Association of State Mental Health Program Directors (NASMHPD)

National Committee to Preserve Social Security and Medicare

National Council for Community Behavioral Healthcare

National Council on Independent Living (NCIL)

National Disability Rights Network

National Family Caregivers Association

National Health Council

National Multiple Sclerosis Society

National Organization for Rare Disorders

National Organization of Social Security Claimants' Representatives

National Patient Advocacy Foundation

National Patient Advocate Foundation

National Respite Coalition

National Senior Citizen Law Center

National Spinal Cord Injury Association

New Yorkers for Accessible Health Coverage

NISH

North American Brain Tumor Coalition

Not Dead Yet

Parkinson's Action Network

Platelet Disorder Support Association

Positive East Tennesseans

Project Inform

Regional Center for Independent Living

Shwachman Diamond Syndrome Foundation

Sjögren's Syndrome Foundation

Special Needs Alliance

The AIDS Institute

The Arc of the United States

The Campaign for Mental Health Reform

The Legal Aid Society

The Resource Center for Accessible Living, Inc.

Treatment Access Expansion Project (TAEP)

United Cerebral Palsy

United Spinal Association

Westchester Independent Living Center

Wiggle Your Toes Foundation