

I AM ESSENTIAL

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79 LEADING PATIENT GROUPS SEND LETTER TO HHS SECRETARY ON PROPOSED MEDICAID RULE

The AIDS Institute, Epilepsy Foundation, Lupus Foundation, National Alliance on Mental Illness, Parkinson's Action Network, and others urge Secretary Sebelius to ensure Medicaid beneficiaries have access to needed care and medications

Washington, DC, February 21, 2013—As part of the “I Am Essential” coalition, seventy-nine patient groups delivered a joint [letter \(http://bit.ly/YdthXI\)](http://bit.ly/YdthXI) to Secretary Kathleen Sebelius today in response to a proposed Centers for Medicare and Medicaid Services (CMS) rule that would allow states flexibility in the Medicaid coverage they offer for newly eligible beneficiaries and the fees Medicaid patients can be charged. The letter comes on the final day of the thirty-day comment period the Department of Health and Human Services has offered before it finalizes the Essential Health Benefit (EHB) and other requirements states must offer newly eligible Medicaid beneficiaries.

In its January 22 issuance, CMS proposed a rule that would give states flexibility in providing newly eligible Medicaid beneficiaries coverage, as long as the individuals received benefits that included the ten categories of EHBs that are required in private-market plans. The proposed rule would also allow new cost-sharing guidelines for Medicaid that would give states the ability to impose higher drug co-payments and doctors' fees on both newly eligible and existing beneficiaries.

“CMS has proposed higher cost-sharing for beneficiaries who by definition are low income and cannot afford it,” said Carl Schmid, Deputy Executive Director of the AIDS Institute. “These costs can quickly add up and deter individuals from seeking and adhering to care and treatment. This is especially worrisome when thinking about patients with complex and life-threatening medical conditions.”

On top of excessive cost-sharing, the groups voice strong opposition to the quantity limits on prescription drugs that the proposed rule allows states to impose. “Some states currently limit Medicaid beneficiaries to only 2 to 4 brand name drugs per month, thus denying them lifesaving treatments, and in the end, costing the health care system more. We certainly do not want to see this practice repeated for the expanded Medicaid population,” added Schmid.

In the letter, the seventy-nine patient groups state their concern to Secretary Sebelius that the proposed guidelines for covering the expanded Medicaid population would perpetuate an uneven system of coverage and the patient cost-sharing would jeopardize access to care.

Essential Health Benefits for Expanded Medicaid (Alternative Benefit Plans)

The patient groups request in their letter that HHS make the following alterations to the proposed rule on EHBs for the expanded Medicaid population:

- **Scope of Benefits.** Clarification is necessary on what is being proposed in the rule’s recommendation regarding prescription drugs limits. While the rule proposes that the Alternative Benefit Plan has to meet the benefits in one of the state EHB plans for the private market, the rule separately appears to replace the alternative benefit plan’s EHB drug benefit category with that described in Section 1927 of the Social Security Act, which allows restrictive quantity limits.
- **Adequate Public Comment Period.** The final rule should include a provision that a sixty-day comment period is necessary if a state changes its Alternative Benefits Plan.
- **Coverage of Preventive Services.** Preventive services in Alternative Benefit Plans should be offered without cost-sharing. Cost-sharing is prohibited by plans in the marketplaces, whose enrollees typically have higher income levels and can better afford to make contributions.
- **Definition of Medically Frail.** There should be clarification on the enrollment and selection process for “medically frail” beneficiaries to ensure these beneficiaries will not be forced into a plan that provides fewer benefits.

Patient Cost-sharing

The patient groups request in their letter that HHS make the following alterations to the proposed rule on cost-sharing:

- **Cap on Spending.** The final rule should include a modification to the proposed five percent cap on total out-of-pocket health spending. The five percent cap does not protect low-income and vulnerable beneficiaries. Instead, a nominal dollar limit on total monthly co-payments should be put in place.
- **Co-pays for Non-preferred Drugs.** The \$8 co-pay that CMS is proposing to allow states to charge for each non-preferred drug should not be considered “nominal.” It represents a doubling of the maximum co-pay for preferred drugs.
- **The Use of Cost-effectiveness Standards.** A cost-effectiveness standard should not be defined in Medicaid in a way that compromises access to needed care. The use of a cost-effectiveness standard as the basis for identifying preferred drugs in state Medicaid programs threatens access to needed treatment and would result in broad, one-size-fits-all policies that do not reflect important differences in individual beneficiary needs and circumstances.
- **Physician Determination.** Providers should receive guidance that Medicaid provide preferred cost-sharing on non-preferred drugs “if the prescribing physician determines that the preferred drug for treatment of the same condition either would not be as effective for the individual or would have adverse effects for the individual.”

Signatories of the letter include: The AIDS Institute, Asthma & Allergy Foundation of America, Coalition for Pulmonary Fibrosis, Crohn’s & Colitis Foundation of America, Epilepsy Foundation, Lupus Foundation, National Alliance on Mental Illness, National Hemophilia Foundation, National Minority Quality Forum, National Organization of Rare Disorders, National Viral Hepatitis Roundtable, and Parkinson’s Action Network

For a full text of the [letter](http://bit.ly/YdthXI) go to <http://bit.ly/YdthXI>

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