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As the Epilepsy Foundation maintains focus on preserving patient access to potentially life-saving medications, we were alarmed at a recent proposal in the White House budget that would allow states to alter their Medicaid drug plans to exclude certain medications.

While we were relieved that the Massachusetts Medicaid waiver application seeking to exclude certain drugs from its formulary was not approved, at a time when Centers for Medicare and Medicaid Services is contemplating giving states additional flexibility to restrict patient access, we know to expect similar ideas to be newly proposed as Medicaid waivers or as part of state-based demonstrations.

In a concerning development, New York State’s Drug Utilization Review Board has begun using a cost effectiveness threshold to assess the value of some treatments. It is yet another example of patients caught in the crossfire of policies seeking to control costs at the expense of physician-driven, patient-centered care.

In effect, if the state can’t get the price it wants (on top of federally mandated rebates), the state can overrule the judgment of prescribing doctors in favor of cheaper alternatives without consideration of the individual needs and circumstances of the patient. Furthermore, the process through which this new policy was implemented has lacked transparency. The implications of such a program are unclear, and it is uncertain what patient protections would be put in place to prevent discrimination if a medication exceeded the cost determined to be “worth it.”
New York’s decision to use cost effectiveness thresholds in its Medicaid program will certainly be viewed with great skepticism by people with disabilities such as epilepsy. Patients and people with disabilities have been fighting the implementation of such policies for years. In fact, Congress recognized the risk of using quality-adjusted-life-years — the basis for most cost effectiveness analyses — by prohibiting its use in Medicare policy.

As far back as 1992, the secretary of the U.S. Department of Health and Human Services publicly recognized the discriminatory impact of cost-per-QALY measures for people with disabilities when used to determine access to care in Medicaid. The re-emergence of these ideas represents a dangerous shift in Medicaid policy that has strong potential to undermine patient access to treatments.

Epilepsy treatment decisions are tailored to the individual’s seizures, his or her lifestyle and his or her ability to tolerate side effects. Patients work with their treating physician to determine their best treatment plan by weighing their needs related to driving, employment and family life.

When it comes to epilepsy medications, individuals often react quite differently to available treatments. That’s why patients need meaningful access to the full range of treatments available — and the specialists who know how to prescribe them. This is quality physician-directed care that must be provided for patient-centered care. Recently published research shows that most cost effectiveness analyses do not account for these important differences among patients.

Patients just want the treatment that works for them. Let’s call on states to demonstrate the impact of empowering patients and providers with information before we start taking away treatment options.

Restrictive formularies at the expense of access to physician-directed care would only harm Medicaid’s most-vulnerable beneficiaries and lead to medical complications that will cost states more in the long run.

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