



December 20, 2018

The Honorable Alex M. Azar II
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue SE
Washington, D.C. 20201

The Honorable Steven T. Mnuchin
Secretary
U.S. Department of the Treasury
1500 Pennsylvania Avenue NW
Washington, D.C. 20220

Re: State Relief and Empowerment Waivers (CMS 9936-NC)

Dear Secretary Azar and Secretary Mnuchin:

The Epilepsy Foundation (“Foundation”) appreciates the opportunity to comment on newly issued guidance for states applying for 1332 waivers. Because of the significant changes to guardrails vital to ensuring that people are enrolled in affordable, comprehensive coverage, the Foundation urges the Departments of Health and Human Services and Treasury to withdraw the guidance.

The Epilepsy Foundation is the leading national voluntary health organization that speaks on behalf of at least 3.4 million Americans with epilepsy and seizures. We foster the wellbeing of children and adults affected by seizures through research programs, educational activities, advocacy, and direct services. Epilepsy is the fourth most common neurological disorder and affects people of all ages. Epilepsy is a spectrum condition with a wide range of seizure types and control varying from person-to-person. As such, the treatment of epilepsy is highly individualized. For the majority of people living with epilepsy, anti-convulsants are the most common and cost-effective treatment for controlling and/or reducing seizures—so it is vital for people with epilepsy to have meaningful and timely access to physician-directed care.

Per the Affordable Care Act (ACA), Section 1332 waivers allow states to waive certain requirements of the ACA so long as four statutory guardrails are still met: coverage must be as affordable as it would be without the waiver; coverage must be as comprehensive as it would be without the waiver; a comparable number of people must be covered under the waiver as would be without it; and the waiver must not add to the federal deficit. These guardrails allow states to innovate and experiment while simultaneously ensuring that all people and particularly vulnerable populations with acute and chronic conditions and disabilities like epilepsy have affordable access to the care that they need.

The Foundation is concerned that the new 1332 guidance relaxes many of these guardrails—dissipating these all-important protections, contrary to the statute’s intent. For instance, when evaluating whether a waiver meets the affordability and comprehensiveness guardrails, the guidance states that it does not matter whether individuals actually enroll in affordable, comprehensive coverage. It changes the standard to simply be that affordable, comprehensive coverage be *made available* to them. This is contrary to statutory intent and is further complicated by the fact that the new guidance seems to allow states to satisfy the coverage guardrail by counting individuals enrolled in plans that do not comply with the ACA’s individual and small group market consumer protections such as short-term limited-duration (STLD) plans.

As expressed in the Foundation’s April 2018 comments on the proposed federal rule to expand access to short-term, limited duration (STLD) plans, while STLD plans may be sufficient for some, health status is dynamic and

people usually cannot predict when they will experience health challenges that require additional healthcare services and more comprehensive coverage. And STLD plans are never sufficient for people with epilepsy—as they can deny coverage to people with pre-existing conditions, offer bare bones benefits and can charge people more based on health status. The Foundation was dismayed that—despite much opposition—the proposed rule on STLD plans was finalized with few changes and now, is concerned that the 1332 guidance further encourages states to pursue these plans and even allows subsidies to be used towards them. Promoting sub-standard plans alongside plans with adequate protections will be confusing for consumers and particularly since STLD plans are cheaper, consumers will be steered towards them. This, in turn, will undermine the risk pool and drive up the cost of insurance for people with epilepsy and other pre-existing conditions.

Regarding affordability, 1332 guidance from 2015 stated that waiver applications would not be approved if they reduced the number of people with coverage that provides both an actuarial value (AV) equal to or greater than 60 percent and a maximum out-of-pocket limit compliant with the ACA. These protections against excessive cost sharing are notably absent in the new guidance. Instead, the guidance invites states to apply for waivers that would increase enrollment in STLD plans and other coverage options that typically do not provide 60 percent AV, do not have to include an out-of-pocket maximum and can even impose annual or lifetime limits on coverage.

Regarding comprehensiveness, the new guidance incorporates changes to states' essential health benefits (EHB) benchmark plans that the Administration finalized in the Notice of Benefit and Payment Parameters for 2019 and allow states to design EHB benchmark plans that provide less generous coverage for individuals. Additionally, the new guidance allows states to design a hypothetical benefit package specifically for the purposes of its waiver application that is not reflective of the state's actual benchmark plan, and then use this — potentially skimpier — benefit package as the baseline for determining whether waiver coverage is sufficiently comprehensive.

The guidance seeks to implement numerous significant policies that are not in line with statutory intent. Relaxing the guardrails, in particular, will have serious negative consequences for people with epilepsy and other pre-existing conditions. It's important to note that these proposed changes are happening amidst many other threats to healthcare for people with pre-existing conditions including the already mentioned expansion of short-term limited-duration plans, expansion of association health care plans, proposed weakening of Medicare's six protected classes and a lawsuit that threatens the entire Affordable Care Act. While the Foundation knows that consumer choice is important, this should not come at the detriment of people with pre-existing conditions who have fought long and hard to not be discriminated against in the healthcare system and need access to affordable, comprehensive coverage. The Foundation believes that changes of this magnitude should go through formal and full rulemaking process and asks that this guidance be withdrawn immediately. Please do not hesitate to contact Laura Weidner, Esq., Vice President of Government Relations and Advocacy at our national office at 301-918-3766 or lweidner@efa.org with any questions.

Sincerely,



Philip M. Gattone, M.Ed.
President & CEO
Epilepsy Foundation