December 23, 2018

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

Dear Secretary Azar and Secretary Mnuchin:

The I Am Essential coalition of patient and community organizations, representing millions of patients and their families, appreciates the opportunity to submit comments on the new guidance for 1332 waivers. We have serious concerns that weakening the guardrails as proposed would have negative impacts on the health of individuals—in particular those living with chronic and serious conditions. We urge the Administration to withdraw this guidance to protect access to care for the people who need it the most.

I Am Essential unites diverse national and state patient and community organizations, each representing a unique mission, to ensure access to quality and affordable health care for the millions of individuals and families enrolled in Qualified Health Plans established under the Affordable Care Act (ACA). We believe in access to health care for all, regardless of one’s illness or disability, and strongly support the ACA’s non-discrimination and other patient protections. We also believe that beneficiaries need access to the Essential Health Benefits - including the full range of prescription drugs needed to treat chronic and serious health conditions - as guaranteed in statute.

The purpose of Section 1332 waivers is to allow states to innovate and pursue alternative coverage approaches in the individual and small group markets so long as the following guardrails intended to protect consumers are met:

- coverage and cost sharing protections against excessive out-of-pocket spending are at least as affordable as it would have been without the waiver;
- coverage remains as comprehensive as it would have been without the waiver;
- a comparable number of people are covered with the waiver as would have been without; and
- the waiver does not add to the federal deficit.
This is a worthy innovation opportunity that we support—so long as the statute’s guardrails remain strong. **Unfortunately, this new guidance eviscerates many of these guardrails, in turn dissipating guaranteed protections and rights for beneficiaries.**

**Access vs. availability**
Perhaps most fundamentally, the guidance seems to indicate that the Department will no longer look at whether people actually purchase and enroll in affordable and comprehensive coverage, but rather merely whether coverage that meets an unspecified standard for affordability and comprehensiveness is available. This flies in the face of statutory intent and even more worrisome for many of the populations our coalition members represent is that there will no longer be a distinct analysis of impact on vulnerable residents. Seemingly small changes in health care plans can have outsized impact on people with complex medical needs that may not be obvious without conducting a specific analysis from the perspective of these individuals. By only examining the aggregate impact of a policy change, there is no way to know whether that change will have unintended detrimental impact on people with serious health issues.

**Minimum essential coverage**
The coverage guardrail is further diminished by waivers no longer having to meet “minimum essential coverage” as defined by the ACA. For people with acute or chronic health conditions or disabilities, short-term limited-duration and association health plans simply aren’t sufficient. Because they are not subject to same rules as qualified health plans offered through the ACA, waivers encouraging the use of so-called “short-term” and association health plans undermine the ACA’s core protections for people with pre-existing and/or complex health conditions. Short-term limited-duration and association health plans enable carriers to cherry-pick enrollees by discriminating against people with pre-existing conditions, conduct post-enrollment health status reviews of people who receive diagnoses while covered, and design formularies that exclude or place barriers between patients and lifesaving prescription drugs.

For example, under a 1332 waiver as described by this guidance, plans may be able to place all drugs used to treat a condition on a specialty tier that requires very high patient cost-sharing, cover fewer than two drugs per class, or exclude coverage of drugs to treat certain conditions altogether. Without a review of enrollment or an analysis of the impact of such plans on people with specific health needs, it may appear on the surface that such a plan is meeting the needs of the general state population when it is instead shunting the risk of covering people living with certain health conditions to other issuers or onto public programs. People with serious and chronic health conditions need access to a comprehensive set of health benefits and services, including health care specialists and prescription medications and we do not want to see the rights ensured through the ACA weakened.
I Am Essential is extremely concerned with the direction this guidance. Weakening critically necessary guardrails in this manner undermines the core goals of the Affordable Care Act and curtails access to care for people with serious and chronic health conditions and disabilities who are in most need of affordable, comprehensive coverage. We ask that the Administration withdraw this guidance and restore the protections guaranteed under the Affordable Care Act for patients with complex health care needs.

Sincerely,

Carl Schmid
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The AIDS Institute

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Director, Legislative and Policy Advocacy
NAMI

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Epilepsy Foundation