



April 17, 2020

The Honorable Charles Grassley
135 Hart Senate Office Building
United States Senate
Washington, DC 20510

The Honorable Patricia Murray
154 Russell Senate Office Building
United States Senate
Washington, DC 20510

The Honorable Sherrod Brown
503 Hart Senate Office Building
United States Senate
Washington, DC 20510

The Honorable Elizabeth Warren
309 Hart Senate Office Building
United States Senate
Washington, DC 20510

The Honorable Tammy Baldwin
709 Hart Senate Office Building
United States Senate
Washington, DC 20510

The Honorable Lisa Murkowski
522 Hart Senate Office Building
United States Senate
Washington, DC 20510

The Honorable Michael Bennet
261 Russell Senate Office Building
United States Senate
Washington, DC 20510

The Honorable Edward Markey
255 Dirksen Senate Office Building
United States Senate
Washington, DC 20002

RE: Accelerating Kids' Access to Care Act

Dear Senators Grassley, Brown, Baldwin, Bennet, Murray, Warren, Murkowski and Markey:

We are writing to express our appreciation for your efforts to improve access to specialized care for Medicaid beneficiaries. Our member advocacy organizations are eager to support policy refinements that ease the burden of accessing the care they need, and would ask that your legislation, the Accelerating Kids' Access to Care Act, address the need to alleviate access issues for *adults* as well as children with rare disorders, including rare cancers, requiring treatment from out-of-state specialists through Medicaid.

Haystack Project is a 501(c)(3) non-profit organization enabling rare and ultra-rare disease patient advocacy organizations to coordinate and focus efforts that highlight and address systemic reimbursement obstacles to patient access. The Rare Cancer Policy Coalition (RCPC) is a Haystack Project initiative that brings together rare cancer patient organizations to focus specifically on reimbursement, access and value issues across the rare cancer community.

Working within the Haystack Project enables RCPC participants and rare and ultra-rare patient advocates to leverage synergies and common goals to optimize advocacy in disease states where unmet need is high and treatment inadequacies can be catastrophic.

Access to out-of-state providers is an important issue for rare and particularly ultra-rare patients relying on Medicaid to access the limited care options available to the rare disease community. Haystack Project and RCPC have identified this issue as critical to our community. Many, but not all of the diseases represented by our advocacy organizations are genetic and impact children. Some patients, however, do not receive a diagnosis until adulthood due to a long diagnostic journey, late symptom onset, or both.

Although the Centers for Medicare & Medicaid Services has implemented regulations directing that state Medicaid programs pay for ALL care provided by out-of-state providers in circumstances of emergency or inability to receive the needed care in-state, access burdens like that addressed in your legislation are rampant. Our patients know first-hand that these burdens can be an insurmountable obstacle to appropriate care for children and adults alike, but especially for rare cancer patients who experience vastly divergent outcomes if unable to access specialized care, ideally through one of the NIH-designated Cancer Centers.

Although Haystack Project fully supports the legislation's goal of facilitating care access for children, we are concerned that limiting the benefits of its pragmatic provider enrollment approach would create divergent levels of access to out-of-state Medicaid providers based upon a patient age distinction that does not currently exist. This would be an unprecedented creation of two-tiered care, splitting the rare community with respect to Medicaid benefits that are already in place for children and adults alike. We believe that the legislation can be read to create a simplified, uniform path for out-of-state provider enrollment that, once satisfied, would result in the out-of-state provider's eligibility to treat all patients meeting the out-of-state care requirements under the CMS regulations. Haystack Project participating groups would welcome such a clarification.

Haystack and RCPC urge that you avoid giving state Medicaid programs implicit permission to apply your sensible, pragmatic provider enrollment requirements to out-of-state care for children while maintaining needlessly burdensome enrollment requirements that impede adults with rare diseases and rare cancers from accessing their currently-covered benefits. Adopting a single, simple, uniform approach to out-of-state provider enrollment is likely within CMS' rulemaking authority and accomplishing it through legislative means should not have a significant impact on the scoring of your bill.

We would welcome an opportunity to share specific examples and patient stories that highlight both our support for the pragmatic solution your legislation offers, and the concerns our patient groups have with creating an artificially two-tiered system of access to out-of-state provider services currently covered through Medicaid.

Respectfully,



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