

United States Senate
WASHINGTON, DC 20510

April 29, 2022

The Honorable Chiquita Brooks-LaSure
Administrator
Centers for Medicare & Medicaid Services
U.S. Department of Health and Human Services
200 Independence Avenue S.W.
Washington, D.C. 20201

Dear Administrator Brooks-LaSure,

We appreciate the Centers for Medicare & Medicaid Services (CMS) commitment to implementing the *Advancing Care for Exceptional (ACE) Kids Act*.¹ Our most vulnerable kids and their families deserve a health care system that coordinates care and produces healthier outcomes. Kids with complex medical conditions face myriad challenges including an uncoordinated and burdensome health care system. On average, these kids see five to six specialists and up to as many as 20 to 30 allied health professionals.² Parents are often overwhelmed at the scope of that care. Helping these families navigate the bureaucracy and cut red tape makes sense. This is why we passed the *ACE Kids Act* in 2019 that allows kids with medically complex conditions to choose to enroll in a health home, if a state Medicaid program permits. This law helps CMS and state Medicaid programs align rules and reimbursement to improve health outcomes, reduce unnecessary hospitalizations, and provide better care coordination.

CMS has less than six months to fully implement the *ACE Kids Act*, and we request an update on the implementation of this legislation. Beginning on October 1, 2022, kids with medically complex conditions will be able to enroll in a health home, if a state Medicaid program permits.³ In October 2021, following a request-for-information on implementation to stakeholders, your agency produced guidance to states and indicated further guidance is expected.⁴ We have a strong interest in ensuring this bipartisan law is implemented in a timely manner to improve the lives of kids and their families across the country. We request a briefing with you about the law's implementation or a written response to the following questions:

- What states are exploring a waiver or state plan amendment? If you cannot provide the specific states, please specify the number of states exploring a waiver or state plan amendment.

¹ Public Law (P.L.) 116-16. <https://www.congress.gov/116/plaws/publ16/PLAW-116publ16.pdf>.

² Berry, J., Agrawal, R., Cohen, E., Kuo, D. (2013). *The Landscape of Medical Care for Children with Medical Complexity*. Children's Hospital Association.

³ P.L. 116-16. <https://www.congress.gov/116/plaws/publ16/PLAW-116publ16.pdf>.

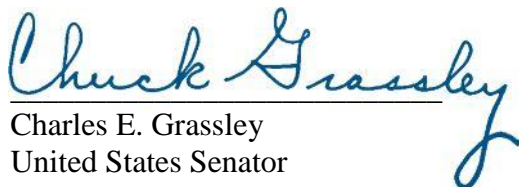
⁴ CMS – Center for Medicaid & CHIP Services, “Guidance on Coordinating Care Provided by Out-of-State Providers for Children with Medically Complex Conditions,” October 20, 2021. <https://www.medicare.gov/federal-policy-guidance/downloads/cib102021.pdf>.

- What technical assistance has CMS provided to states interested in a waiver or state plan amendment? If formal or informal technical assistance has not been provided, please specify what level of conversation CMS has had with states about a potential waiver or state plan amendment.
- How has CMS engaged stakeholders (e.g., state Medicaid directors, Family-to-Family Health Information Centers, kids with medically complex conditions and their families, providers, managed care plans, children’s health groups, family and beneficiary advocates, and other stakeholders with respect to coordinating the care for such kids provided by out-of-State providers) since the October 21, 2021 guidance was released to state Medicaid programs? If CMS has engaged stakeholders, please provide a list of those stakeholders and in what manner stakeholders have been engaged (e.g., conference, meeting, webinar).
- What is the status of the further guidance specified in the October 21, 2021, guidance? If further guidance is still expected, when will that guidance be released? If further guidance is not expected, why and how was that decision made?

While we are focused on the implementation of the *ACE Kids Act*, we continue to work in a bipartisan manner to improve upon the law. We have introduced the *Accelerating Kids’ Access to Care Act* to provide states the ability to streamline the screening and enrollment process for out-of-state pediatric care providers.⁵ This lets those providers enroll in another state’s Medicaid program while at the same time maintain safeguards and important program integrity processes. We acknowledge your fiscal year 2023 budget request includes funding to continue supporting and expanding the Medicare Provider Enrollment, Chain, and Ownership System (PECOS), which would collaborate with our legislative effort under Medicaid.⁶

We appreciate your attention to implementing the *ACE Kids Act* and the promise it will provide for kids and families across the country. With the hard work of CMS and state Medicaid programs across the country, we expect the *ACE Kids Act* will be ready for implementation by October 1, 2022.

Sincerely,


Charles E. Grassley
United States Senator


Michael F. Bennet
United States Senator

⁵ Accelerating Kids’ Access to Care Act, S.1544, 117th Congress (2021). <https://www.congress.gov/bill/117th-congress/senate-bill/1544>.

⁶ Department of Health & Human Services, CMS, “Justification of Estimates for Appropriations Committees,” Fiscal Year 2023. <https://www.cms.gov/files/document/fy2023-cms-congressional-justification-estimates-appropriations-committees.pdf>.