

Congress of the United States
Washington, DC 20515

July 13, 2022

The Honorable Xavier Becerra
Secretary
Department of Health and Human Services
200 Independence Avenue SW
Washington, D.C. 20201

The Honorable Chiquita Brooks-LaSure
Administrator
Centers for Medicare & Medicaid Services
200 Independence Avenue SW
Washington, D.C. 20201

RE: ACE Kids Act Implementation

Dear Secretary Becerra and Administrator Brooks-LaSure:

As bipartisan Congressional champions for the Advancing Care for Exceptional Kids Act (ACE Kids, Public Law 116-16), we are excited to realize the promise of this law for children with medically complex conditions and their families. Since the law takes effect in just a few months on October 1, 2022, we urge you to release guidance for states, consistent with Congressional intent, that includes a national definition to identify children with medically complex conditions eligible for ACE Kids. Without this, we risk losing the opportunity to gather the national data required to better care for these children, improve their health outcomes, and reduce unnecessary costs.

We believe uniform national data on this population of children is needed to achieve the goals of this law, which is why we included a national definition of children with medically complex conditions in ACE Kids. Our intent was that this definition would be applied uniformly and consistently across states to achieve a better understanding of this group of children. With data that is consistently reported, collected, and aggregated, providers can better identify improvements in outcomes and costs and ensure accountability for the care these children and families rely on. We understand that you are actively working on guidance to states, and we hope to see a national definition reflected in the guidance to ensure consistency in identifying children eligible for ACE Kids.

We strongly encourage the Centers for Medicare and Medicaid Services (CMS) to consider the attached "Recommendation for Operationalizing the Legislative Definition of Children with

Medically Complex conditions in the ACE Kids Act.” This recommendation was developed by a group of experts who have extensive experience providing health care to children with medically complex conditions, implementing quality standards to improve care and support for these children and their families, and conducting research that has informed the field and supported the development of ACE Kids. We believe this group’s work successfully balances the need for a practical solution and uniform, consistent data with the need for a flexible approach that is workable for states and meets the intent of this law for reliable national data to better care for children with medical complexities.

We know you share our goal of improving health outcomes for children with medical complexities and appreciate your continued engagement on this important legislation. We urge you to adopt timely guidance that supports the Congressional intent of the law by including a consistent, national definition of children who qualify for ACE Kids. If you have any questions, please feel free to reach out to us or our staff.

Sincerely,



Kathy Castor
Member of Congress



Gus M. Bilirakis
Member of Congress