

## Recommendation for Operationalizing the Legislative Definition of Children with Medically Complex Conditions in the ACE Kids Act

### Background

The Advancing Care for Exceptional Kids Act (ACE Kids) was signed into law on April 18, 2019. The law creates a new state option to establish health homes tailored to “children with medically complex conditions.” The law includes six months of enhanced federal matching funds for health home services provided to eligible children enrolled in Medicaid.

The foundational goals of the law – to improve health care and manage costs for this population – will only be achieved with consistent data. Better national data that starts with a consistent and practical approach for participating states to operationalize the definition of eligible children is a primary goal of our recommendation and intent of the legislation. With data that is consistently reported, collected and aggregated, policymakers and providers can identify improvements in care and costs and ensure accountability for the care these children and families rely on. Without a consistent approach to operationalizing the national definition in the law and the resulting national data, we will make no material headway in improvements in health care and efforts to manage costs more effectively for this population of children. This is the main tenant of the ACE Kids Act.

The Children’s Hospital Association convened a group of experts who have substantial 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. This group met over three months to assess existing tools that could be used nationally to identify children with medically complex conditions who meet the statutory definition and whose care would be eligible for the associated enhanced federal matching funds. The group strived to balance the needs for a practical solution and data consistency with the need for a flexible approach that is workable for states and meets the intent of the law for better national data.

### Recommendation

We recommend the following approach to operationalize the definition of children with medically complex conditions in ACE Kids:

- Use claims data with a modified Chronic Complex Conditions (CCCs) classification system to identify children with three or more CCCs or who are technology dependent. CCCs is a public/open-source classification system that can identify from claims data a set of childhood complex, chronic health conditions that are strongly associated with mortality, morbidity, functional limitations, and high health care utilization.<sup>1</sup> To support use for identifying children with medically complex conditions, the existing CCC classification system should be modified by adding a mental health CCC defined by the Child and Adolescent Mental Health Disorders Classification System (CAMHD-CS).<sup>2</sup>
  - The CCC classification system, if modified as proposed by including mental health conditions as an additional CCC, would identify approximately 1.4% of children enrolled in Medicaid nationwide as meeting the definition in ACE Kids.
- Provide a process to include children who fit the ACE Kids definition but are not identifiable with claims data, such as some neonates, children with rare conditions or children moving into the state. This

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<sup>1</sup> Chris Feudtner et al., “Pediatric complex chronic conditions classification system version 2: updated for ICD-10 and complex medical technology dependence and transplantation,” *BMC Pediatrics* 14:199 (2014), <https://doi.org/10.1186/1471-2431-14-199>.

<sup>2</sup> Bonnie T. Zima et al., “Classification System for International Classification of Diseases, Ninth Revision, Clinical Modification and Tenth Revision Pediatric Mental Health Disorders,” *JAMA Pediatrics*, published online (March 23, 2020), <https://doi.org/10.1001/jamapediatrics.2020.0037>.

process would allow for families, providers and/or the state to identify children who clearly meet the ACE Kids definition, but were not initially identified, to submit a petition to the Secretary for their enrollment to benefit from health home services.

The main advantages of this recommendation, as explained further below include:

- Advances a clear, consistent definition across states that aligns with the statutory definition and intent of the law
- Uses publicly available classification system that has scheduled annual updates for new ICD-10 codes
- Provides a practical and feasible process for states and federal government to implement while not precluding states or providers from using other methodologies currently used to identify children with medically complex conditions

We anticipate this approach will require review and improvements as we learn more about this population of children and how well the recommended classification method identifies children with medically complex conditions included in ACE Kids.

## Analysis

### I. Discussion of the Recommendation:

#### A. *The approach aligns with definition and intent of the law*

Congress included a national definition of children with medically complex conditions in ACE Kids. Congressional intent of ACE Kids was that the definition would enable better national data collection related to this population of children, to support improving health care and reducing unnecessary costs. Below is how our recommended approach to operationalizing the definition maps to the main components of the statutory language and supports this legislative intent.

**Chart 1: Alignment with Statutory Definition**

Statutory Language	Our Recommended Approach
"is eligible for medical assistance under the State plan (or under a waiver of such plan); and"	CCCs and CAMHD-CS can be run on Medicaid claims to identify children included in ACE Kids
"has at least— (I) one or more chronic conditions that cumulatively affect three or more organ systems and severely reduces cognitive or physical functioning (such as the ability to eat, drink, or breathe independently) and that also requires the use of medication, durable medical equipment, therapy, surgery, or other treatments;"	Three or more CCC types (including potentially technology dependence) with inclusion of mental health diagnosis aligns with definition
"or (II) one life-limiting illness or rare pediatric disease (as defined in section 529(a)(3) of the Federal Food, Drug, and Cosmetic Act (21 U.S.C. 360ff(a)(3)))."	CCCs identify approximately 75-80% of rare diseases

The list of chronic conditions in section (i)(2) of the ACE Kids definition refers back to the definition of a child with medically complex conditions and is not meant to be a comprehensive list of conditions that would be included in the definition. This was confirmed throughout the legislative process. Therefore, our recommendation includes children with multiple complex conditions generally and not exclusively those noted in this section.

The statutory definition gives the Secretary some discretion but does not support each state using its own definition. A consistent approach across states allows for accountability for the federal enhanced Medicaid

matching funds to ensure the additional federal funds are targeted appropriately to the children included in the legislation. Within these statutory parameters, the group identified the approach that would be the easiest of the available options for states to implement.

In conversations with the law’s champions and the Congressional Budget Office (CBO) on the final version of the law, there was agreement that the final definition would include approximately 1% of children on Medicaid. The CBO estimate did not include the children who would be included because they have “one life-limiting or rare disease” as defined above due to there being no way to quickly estimate this group of children. Using the group recommendation outlined above, which includes most of the children who would be eligible based on having a rare disease, approximately 1.4% of children enrolled in Medicaid nationwide would be identified.

**B. The approach uses data available for public use**

We considered the three most commonly used classification systems for identifying children with medically complex conditions – CCCs, Pediatric Medical Complexity Algorithm (PMCA) and the 3M-developed Clinical Risk Groups (CRGs). Since the CRGs are a proprietary system and are not open source, the group eliminated it from further consideration. The other two options, PMCA and CCCs are both open-source and have their strengths and limitations. No tool does a perfect job of identifying children who meet the definition above. However, the group found through the comparison in Chart 1 that the CCCs mapped best to the statutory definition and would be the easiest for states to use to identify the ACE Kids-eligible population. This approach, as would any approach, is based on correct diagnosis of the children and this is foundational to the successful implementation of this definition and ACE Kids overall.

**Chart 2: Using PMCA and CCC to identify the cohort of children defined by ACE Kids Act language**

Criteria	PMCA	CCC
Chronic condition affecting 3 or more organ systems	Yes	Yes
Severely reduce cognitive or physical function	Yes	Yes
Requires use of medications, DME, surgery or other treatment	Yes	Yes
Identifies life limiting illness	Yes	Yes
Identifies rare pediatric disease	Potentially	75-80%
Identifies technology dependency	No	Yes
Can be modified to include scenarios to increase or decrease size of included population	Yes	Yes
Amount of data required	Best with 2-3 years of data	Single encounter or historical
Identifies neonates with complexity	Yes	Yes
Identifies “non-complex” chronic conditions	Yes	No
Identifies mental health conditions	Yes	Can be adapted to include MH conditions for ACE Kids definition

**C. Other approach issues discussed were as follows:**

**1) Supplemental Security Income (SSI)**

The group also discussed the use of SSI eligibility to identify eligible children for ACE Kids. While children receiving SSI benefits frequently have one or more chronic conditions, the presence of marked and severe functional limitations expected to last at least 12 months or result in death, rather than multiple affected body systems (as included in ACE Kids) or the need for intensive health home services, is used to define SSI eligibility. As such SSI does not align with the ACE Kids definition. In addition, children become eligible for Medicaid via multiple pathways; children with chronic conditions or disabilities do not always use the SSI pathway, as some are eligible based on their family's income. To focus on identifying children for whom the ACE Kids Act is targeted, we do not recommend the use of SSI for ACE Kids eligibility.

**2) Mental Health**

The group acknowledged that 41.5% of children with medically complex conditions have mental health conditions compared to 17.6% for other children.<sup>3</sup> Mental illness is a disorder of the central nervous system, tends to be chronic, and its presence is associated with increased utilization of physical health services. The work group wanted to ensure that children with a mental health diagnosis and who meet the definition of children in the statute would be included as eligible. To implement this, a mental health classification system is proposed to be added to the CCCs so that if a child had a mental health condition and 2 other CCCs they would be identified.

**3) Application process**

To use the modified CCCs, states would run the CCC and the CAMHD-CS classification systems on their Medicaid claims data to identify eligible children. Since this process will not identify all eligible children, we recommend relying on states and providers to implement an application process to additionally identify and include children who do not have sufficient claims data. Some examples include neonates with insufficient claims, children with rare diseases that the CCCs do not identify, children who recently moved into the state, or children who were previously privately insured. The statutory definition could be converted to a provider check list modeled from Chart 2 to verify the child has been screened appropriately to meet the definition. No classification system for identifying children is perfect and the process should be monitored to identify gaps or issues that need to be addressed in the future.

**D. The approach allows state flexibility and ease of use**

A major focus of the group was the desire to balance the need to reflect the legislative definition and the intent of having a consistency across states on the children included in ACE Kids with state flexibility and ease of use to best support ACE Kids implementation. We do not believe the law supports each state using their own way of defining and identifying children with complex medical conditions. A primary reason the group decided to recommend the modified CCCs is because it is available on a wide range of software platforms and is efficient to run on Medicaid claims data. For example, the group ran the modified CCCs on nine states' Medicaid claims data, and it took approximately two hours. We recognize implementing this in a state with Medicaid managed care may require additional steps and coordination between the state and the health plans, but this would be required no matter what method is used to operationalize the definition of children with medically complex conditions.

Some states already use different systems to identify children with special health care needs, including CCC, PMCA, SSI and CRGs. Use of the modified CCCs to identify ACE Kids-eligible children does not preclude states or providers from using other methods (e.g., PMCA, CRGs, homegrown systems) for other purposes. States could

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<sup>3</sup> Jessica E. Becker, Jonathan Rodean, and Jay G. Berry, "Mental Health Disorders in Medicaid-enrolled Children with Complex Chronic Physical Health Conditions," *Journal of the American Academy of Child & Adolescent Psychiatry* 58, no. 10, supplement (October 2019): 197-198, <https://doi.org/10.1016/j.jaac.2019.08.173>.

use the CCC classification system to identify children with medically complex conditions who are eligible for enhanced federal matching funds provided in the ACE Kids Act. The group found through the comparison in Chart 2 that the modified CCC approach is the least time- and resource-intensive publicly available tool for this use at this time. The group, including experts on the CCCs, agree that it could be easily run on Medicaid claims data for the purposes of ACE Kids and that states or providers could continue to use whatever definitions or tools they choose for other purposes. We do not expect that this would be unduly burdensome for a state to implement on top of other systems they are using.

**Chart 3: Technical and Other Factors – Comparisons of PMCA and CCC**

Criteria	PMCA	CCC
Software system requirements to run	SAS	SAS, Stata, or R
Would require modification from production state	Yes	Yes
Schedule to update ICD-10 codes annually	No	Yes
Approximate run time (9 states) – in hours	20	2
Predictive of mortality	Potentially	Yes
Predictive of future costs	Yes	Yes
National experience	Yes	Yes
State Medicaid offices’ experience	Yes	Unknown

We conducted an informal national scan to identify the classification systems states and providers are currently using to identify a population that would include children with medically complex conditions. From the publicly available information, it appears that only a few states use PMCA or CRGs. Both CCCs and PMCA are reported by our expert group to be used for care management and clinician-led research. There are a number of states using some type of clinical definition of complexity which relies heavily on provider input and feedback.

To be able to identify the children who are eligible for enhanced matching funds, we believe it is important to have a consistent method to identify the group of children across states and the use of CCCs would be the most appropriate classification system to use. Regardless of the methodology selected, any system based on claims will require a process to identify the small number of additional children who may be eligible based on the legislative definition, but who are not identified otherwise.

If the implementation of T-MSIS results in robust, timely and consistent state Medicaid data, CMS could explore running the CCCs on T-MSIS data at the federal level and then sending eligible enrollees to the states. The states could validate and use this list of enrollees to report data and quality measures on. This would result in a consistent approach and would reduce the burdens significantly for states. It is unclear to us, whether T-MSIS could support this currently or in the future.

**E. Continuous improvement and refinement**

As we have noted, no one approach is perfect. We ask that as this or any approach is implemented, the Centers for Medicare & Medicaid Services continuously gathers feedback from the states, providers and families on how it works and how it can be improved in the future. We would be happy to partner with you on this work.

## ACE KIDS DEFINITION WORKGROUP

**David Bergman, M.D.**, Professor Emeritus Pediatrics, Stanford University School of Medicine, and former Medical Director, Lucile Packard Children's Hospital Complex Primary Care Clinic. Dr. Bergman has dedicated his career to the care of children with complex medical conditions, is a recognized leader in quality improvement and measurement and served as Medical Director for the Coordinating All Resource Effectively (CARE) Award funded by CMMI which demonstrated the principles of the ACE Kids Act.

**Jay Berry, M.D.**, Assistant Professor of Pediatrics, Boston Children's Hospital and Harvard Medical School. Dr. Berry is a nationally known pediatrician and hospitalist specializing in the care of children with medical complexity. He is a National Institutes of Health and foundation-funded researcher with expertise in examining the care delivery, clinical outcomes, and health resource utilization of this important population of children.

**Chris Feudtner, M.D., Ph.D., M.P.H.**, Professor of Pediatrics, Medical Ethics and Health Policy, and the Director of Research for the Justin Michael Ingerman Center for Palliative Care, Children's Hospital of Philadelphia and University of Pennsylvania Perelman School of Medicine. Dr. Feudtner is the developer of the complex chronic conditions (CCC) classification system. As a pediatrician, epidemiologist, historian and ethicist, Dr. Feudtner focuses on improving the lives of children with complex chronic conditions and their families. His research is funded by the Agency for Healthcare Quality and Research, the National Institutes of Health, the National Library of Medicine, and private foundations.

**James Perrin, M.D.**, Professor of Pediatrics, Harvard Medical School, and former director of the Division of General Pediatrics at the MassGeneral Hospital for Children. Dr. Perrin previously served as president of the American Academy of Pediatrics, and chaired its' Committee on Children with Disabilities, and other prominent national committees and councils, such as the Evidence Working Group reporting to the Maternal and Child Health Bureau for the Secretary's Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children. He is the founding editor of *Academic Pediatrics* of the Academic Pediatric Association and recipient of the Robert Wood Johnson Foundation Investigator Award in Health Policy Research. Dr. Perrin's research has included childhood chronic illness and disabilities and organization of services for the care of children and adolescents with chronic health conditions.

**Edward Schor, M.D.**, former Senior Vice President for Programs and Partnerships, Lucile Packard Foundation for Children's Health. Dr. Schor is an experienced clinical leader in pediatric practice, academic pediatrics, health services research and public health with academic appointments at several major universities and serving on several pediatric journal editorial boards. His previous leadership included the Commonwealth Fund directing the State Health Policy and Practices and the Child Development and Preventive Care programs.

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**Christopher Stille, M.D., M.P.H./M.S.P.H.**, Section Head, General Academic Pediatrics, Professor of Pediatrics, University of Colorado School of Medicine, Children's Hospital Colorado. Dr. Stille is a general pediatrician who specializes in the care of children and youth with special health care needs (CYSHCN) providing leadership and expertise to national organizations on this topic. His pediatric health services research and quality improvement is funded by the U.S. Maternal and Child Health Bureau, Robert Wood Johnson Foundation, and others focusing on improving systems of care for CYSHCN in the Medical Home. Dr. Stille was the site project director participating in the Coordinating All Resource Effectively (CARE) for Children with Medical Complexity (CMC) Award funded by CMMI. His site is currently participating in the Collaborative Improvement and Innovation Network (CoIIN) to Advance Care for CMC supported by the Health Resources and Services Administration of HHS.