

ACE Kids Act Quality Measures Recommendation

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 foundational goals of the law are to improve health care and manage costs for the ACE Kids population. As such, the law includes requirements for states to report quality measures tailored to ACE Kids-eligible children. Building on the need for national data to achieve the foundational goals, a recommendation of how best to identify children eligible for ACE Kids was developed by an expert group convened by the Children’s Hospital Association (CHA) and offered to CMS in June. CHA subsequently convened another group of experts to recommend this national quality measures set tailored to the same population of children under the same goals.

The group of experts recommending quality measures 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. The expert group brought together perspectives of pediatricians, families, health plans and states. Two of the clinicians also worked on the first recommendation to define ACE Kids-eligible children. This group met over three months to review and discuss existing national measures best tailored to children with medically complex conditions, and which measures could demonstrate how ACE Kids health homes deliver and improve care for this population when used together. In their recommendation, the group strived to balance the need for a limited set of national metrics to assess quality of care across health home settings with a practical solution workable for states.

Recommendation

We recommend that the following measure set is reported by states to CMS on the ACE Kids population:

Table 1: ACE Kids Quality Measures Set Recommendation

Domain	What is being Measured?	Metric Source	NQF Reference
Effectiveness of Care	Childhood Immunization Status	Children’s Health Care Quality for Medicaid and CHIP (CIS-CH) – <i>CORE SET</i>	NQF # 0038
Effectiveness of Care	Immunizations for Adolescents	Children’s Health Care Quality for Medicaid and CHIP (IMA-CH) – <i>CORE SET</i>	NQF# 1407
Effectiveness of Care	Influenza Immunization	Preventative Care and Screening: Influenza Immunization (CMS 147v9)	NQF# 0041
Effectiveness of Care	Mental and Developmental Health Screening	Screening required: Specific instrument at individual state discretion	N/A
Coordination and Integration of Care	Continuity of Primary Care	Continuity of Primary Care Quality Measure for Children with Medical Complexity	NQF # 3153
Coordination and Integration of Care	Family Experience with Coordination of Care	Family Experience with Coordination of Care (FECC) Survey, questions 1, 3, 5, 7, 8, 9, 15, 16 <ul style="list-style-type: none"> • Has care coordinator (CC) • CC helped w/ community services • CC asked re: concerns, health changes 	NQF # 2842 2843 2844

Domain	What is being Measured?	Metric Source	NQF Reference
		<ul style="list-style-type: none"> • CC assisted w specialist services • CC knowledgeable, supportive • Written visit summary appropriate • Medical interpreter access • Shared care plan 	2845 2846 2847 2849 2850
Child and Family Experience	Consumer Assessment of Healthcare Providers and Systems	CAHPS 5.0H Child Version including Medicaid and Child Chronic Conditions Supplement (CPC-CH) – <i>CORE SET</i>	N/A
Access to Needed Medical Care Across All Settings	Access to Dental Services	Children’s Health Care Quality for Medicaid and CHIP (PDENT-CH) – <i>CORE SET</i>	N/A
Access to Needed Medical Care Across All Settings	Access to Specialty Services and Therapies	CAHPS 5.0H Child Version including Medicaid and Child Chronic Conditions Supplement (CPC-CH) Access questions– <i>CORE SET</i> <ul style="list-style-type: none"> • Getting care right away • Getting care child needed • Ease of getting special medical equipment or devices • Ease of getting special therapy (PT, OT, speech) • Ease of getting treatment or counseling • Child has a personal doctor • Ease getting a specialist when needed • Ease of getting prescription medicine through child’s health plan 	N/A
Access to Needed Medical Care Across All Settings	Children and Adolescent Access to Primary Care	HEDIS (CAP)	N/A
Access to Needed Medical Care Across All Settings	Well-child Visits in first 15 months of life; Well-child visits in 3 rd , 4 th , 5 th and 6 th years of life	Children’s Health Care Quality for Medicaid and CHIP – <i>CORE SET</i> W15-CH W34-CH	NQF # 1392 1516
Cost	Pediatric Readmissions	Center of Excellence for Pediatric Quality Measurement (CEPQM)	N/A
Cost	Emergency Department Visits	CMS Measures Inventory Tool (AMB-CH) – <i>CORE SET</i>	N/A

The main advantages of this recommendation are:

- Advances a clear, consistent set of measures across states that aligns with the intent of the law
- Uses several measures already included in the Medicaid and CHIP Child Core Set (which will be required beginning in FY 2024) that are applicable to this population and uses additional measures that are practical for use today
- Addresses the main domains of quality for this population of children, including child and family experience

- Allows states flexibility to add measures relevant to the specific needs while also providing critical national quality outcome information

Much like the Medicaid and CHIP Child Core Set, we expect this set of measures will require review and improvements as the quality measures for children with medically complex conditions evolve. This recommendation also describes a number of “aspirational” areas within quality that should be included over time.

Analysis

I. Discussion of Recommendation

A. The approach aligns with the law’s intent and requirements

The ACE Kids Act requires the health homes to report to the state quality measures from the Medicaid and CHIP Child Core Set that are applicable to children with medically complex conditions. The state is required to report this information to the Secretary of the U.S. Department of Health and Human Services. The law also requires states to report “quality measures developed specifically with respect to health care items and services provided to children with medically complex conditions.” With these requirements to report quality measure information to the Secretary, it is clear the law envisions a more tailored core set of national measures to be used for this population.

To inform this national measures set, the expert group’s goals were to identify measures from the Medicaid and CHIP Core Set that are applicable to children with medically complex conditions and identify additional measures that are tailored to this population of children. The expert group believes this set is an appropriate initial set of measures for ACE Kids that will provide important information on the quality of care provided to this population of children and opportunities for improvement. Due to the low numbers of children in this group, examining and analyzing the data at the national level is necessary to achieve the foundational goals to improve health care and manage costs. National data is the only way we can transform care for this population of children and their families.

B. Measure set recommendation requirements

The expert group outlined requirements to provide a framework for their measure recommendations:

- **Technically rigorous and evidence based:** The expert group examined the expected population of children and their range of health care conditions, population size and available data to ensure that the measures chosen were relevant to the population and credible, based on the small population size. The group did discuss the need to primarily rely on administrative data for measures, and that future work needed to reflect an outcome focus.
- **Reflect stakeholder interests:** The expert group did include representatives from provider, state, health plan and family perspectives.
- **Practical for states to implement:** The group understands the need to make the measures as practical as possible for state implementation. Having a former state Medicaid staff person in the group helped highlight which measures were more practical than others. One

reason to include Medicaid and CHIP Core Set measures was the acknowledgement that these measures are currently used by states.

- **Timely implementation:** The group focused on applicable measures that are available to implement today and highlighted gap areas for future work to continue to evolve the measures set.
- **Cross cutting:** Due to the small size of the population and the focus on health homes and care coordination in the law, the group focused on cross-cutting measures as most tied to the goals of ACE Kids and measures applicable to multiple types of conditions rather than measures specific to a single condition.
- **Advances health equity:** The group strongly recommends that with this initial set of measures equity is examined through the stratification of the sample by race and ethnicity to track disparities in care.

C. Domains and Quality Measures Recommended

Using this guiding framework, the group outlined the important domains of quality to focus on for the measures set. Within these domains, the group identified which Medicaid and CHIP Child Core Set measures are applicable to children with medically complex conditions, and additional measures tailored to this population that would be important. The experts organized measures into their most relevant domains recognizing many of the recommended measures add to our understanding of multiple quality domains. The group drew on previous work of a similar expert group in 2016 on an earlier version of the ACE Kids Act,¹ a recent CHA compilation of pediatric quality measures,² and reviewed existing measures for their applicability to this population and the law's main tenets.

- **Effectiveness of Care**

In this category, the measures recommended are childhood immunization status, immunizations for adolescents and influenza immunization. Timely and adequate immunizations for children with medically complex conditions is important and may demonstrate that a child has visited their provider (to receive these immunizations). The first two measures are also currently included in the Medicaid and CHIP Child Core Set. As Influenza can be very serious for children with complex medical conditions, the group added influenza immunization to the list. All three of these measures are endorsed by the National Quality Forum (NQF). This measure has also been field tested by several state Medicaid programs.

The experts also recommend states include mental health screening. The group highlighted that 41.5% of children with medically complex conditions have mental health conditions

¹ Children's Hospital Association, *Networks for Children with Medical Complexity: Measure Selection Report, Version 1* (January 2016).

² Children's Hospital Association, *Measure Selection Framework: The Principles, Conceptual Framework, and Processes of Pediatric Quality Measure Selection for Accountability Applications* (October 2015), <https://www.childrenshospitals.org/Quality-and-Performance/Measurement-and-Standards/Resources/Measure-Selection-Framework-for-Pediatric-Quality-Accountability-Measures>.

compared to 17.6% for other children.³ The states should choose their method/measure for mental health screening from available options.⁴ While there is not one clear national standard for screening, the group strongly recommends that mental/behavioral health needs should be assessed and addressed as part of the health home.

- **Coordination and Integration of Care**

The health homes ability to improve care coordination and integration of care is a goal of the law and an important domain to reflect in the quality measures set. The expert group looked at available measures of coordination of care and recommends the continuity of primary care for children with medical complexity measure. It measures children who are 1-17 years old with complex medical needs and who have had more than four primary care visits during the year. Since the measure captures children who had at least four acute or preventive care visits, it may not include under-utilizers. Even with this limitation, the group believes this measure combined with others in the set is a good indication of the continuity of primary care for this population of children.

Family experience with coordination of care is vital to the success of the ACE Kids and the health homes that will be put in place. To that end, the group recommends the inclusion of the NQF-endorsed measures in the Family Experience with Coordination of Care (FECC). Use of the FECC survey provides many advantages, including filling in a gap in current approaches by measuring the quality of care coordination, rather than just whether coordination was provided or not, and doing this in a family-centered way. We understand survey use by states and families can be challenging, but the FECC field testing showed that caregivers were willing to complete the survey. Also, the FECC measures are intended for aggregation and comparison at the state level.⁵

- **Child and Family Experience**

Assessing and addressing family experience is critical to improving care for children with medically complex conditions. The expert group recommends using CAHPS 5.0H child version including Medicaid and children with chronic conditions supplement for ACE Kids. This is the same measure that is used in the Medicaid and CHIP Child Core Set. Although the survey and the questions focused on children with chronic conditions is broader than the ACE Kids population, it's relevant to overall experience of care and specifically to health homes for children with medically complex conditions because it addresses care coordination, access and other factors important to their care. Children with complex medical conditions require a broad a variable spectrum of services and this survey captures

³ 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>.

⁴ Paul H. Lipkin et al., "Promoting Optimal Development: Identifying Infants and Young Children With Developmental Disorders Through Developmental Surveillance and Screening," data supplement, *Pediatrics* 145, no. 1 (January 2020): https://pediatrics.aappublications.org/content/pediatrics/suppl/2019/12/13/peds.2019-3449.DCSupplemental/PEDS_20193449SupplementaryData.pdf, and The REACH Institute, *Guidelines for Adolescent Depression in Primary Care (GLAD-PC) Toolkit*, Version 3 (2018), <https://www.thereachinstitute.org/images/pdfs/glad-pc-toolkit-2018.pdf>.

⁵ Agency for Healthcare Research and Quality, *Measures: Family Experiences with Care Coordination measure set (FECC)*, AHRQ Pub. No. 15-P002-EF (March 2015), https://www.ahrq.gov/sites/default/files/wysiwyg/policymakers/chipra/factsheets/chipra_15-p002-ef.pdf.

that experience. In addition, the FECC measures noted above contribute and inform this quality domain as well since the measures focus on the family perspective.

- **Access to medical care across settings**

Ensuring that children, including children with medically complex conditions, have access to the care they need when they need it is paramount to a quality health care system. In this area, the group recommends using the preventive dental services measure from the Medicaid and CHIP Child Core Set. Access to dental care is a challenge for all kids and particularly children with complex medical needs.

The group also recommends use of the access measures in CAHPS included above and the well-child visit measures in first 15 months of life and visits in 3rd, 4th, 5th and 6th years of life included in the core set and HEDIS access to primary care practitioners to more fully examine access to care. Although the group recognizes these measures have limitations for examining access, combined with other measures recommended they do provide meaningful information on access to care for this population of children.

- **Cost**

The improvement of care and management of costs for this population are important goals of the ACE Kids Act. The examination of the impact on costs for this population is critical to assessing the overall performance of the health homes and to inform delivery of care and payment models. To that end, the expert group recommends two cost measures to be included in the measures set – pediatric readmissions and emergency department visits (Medicaid and CHIP Child Core Set). The group believes these measures are best to use in the initial set for ACE Kids and recommends further exploration of measures of hospitalizations or other cost measures in future versions. The pediatric readmission measure can be used nationally by hospitals and states. The measure excludes readmissions for procedures that were likely to be planned in advance, as well as a case-mix adjusted, which is important for use with children with medically complex needs.

II. Future Work

As we noted above, the expert group focused on identifying recommended measures for an ACE Kids set that are ready to be used today. In our discussions, the group also highlighted aspirational measure needs as we look to evolve the measures set in the future:

- **Equity:** There is a growing body of evidence that children of color and/or living in poverty who have complex medical conditions face a disproportionate burden of chronic illness, and are more likely to have poor outcomes and a higher level of disability. Metrics that track access to care and disease outcomes by race and socioeconomic status are needed to better understand the impacts of health disparities. These measures will also be useful for tracking the outcomes of interventions designed to improve care for all children.
- **Mental health:** Mental health conditions among children with complex medical conditions are extremely common and are a significant predictor of long-term negative health outcomes and total health care expenditures. Effective screening and prompt referral for mental health conditions in this cohort of children is an important intervention to improve outcomes. Given the high prevalence of mental health conditions in this population, and limited access to

treatment in many areas, including metrics to evaluate mental health screening and access to care will be an increasingly important quality metric.

- **Functional outcomes and quality of life:** One of the most important goals in caring for children with complex medical conditions is to improve their quality of life and health outcomes. However, due in part to the difficulty in measuring these outcomes, there is less attention paid to functional outcomes and quality of life. Future versions of this quality of care measure set should include measures of functional outcomes for children with chronic conditions, as well as quality of life.
- **Family/patient experience:** Effective care coordination is critical for the population of children with medically complex conditions, resulting in increased family satisfaction and the potential for decreased utilization of expensive services. However, measurement of the patient and family experience, especially for children with chronic and complex conditions, is an evolving field and we encourage the inclusion of additional metrics focusing on this area as they become available in future revisions of this measures set.

We thank CMS for their focus on children’s measures through the core set—the source of many of the groups’ recommendations—and the investment in development of measures for children with complex conditions through the Pediatric Quality Measurement Program. Your agency, along with the Agency for Healthcare Research and Quality, has helped move the field forward in important ways. We hope this recommended quality measures set is helpful as you consider national measures for ACE Kids.

ACE KIDS QUALITY WORKGROUP

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Nathaniel Beers, MD, MPA, FAAP, is the President at The HSC Health Care System at Children’s National Hospital. The health care system includes a health plan, pediatric hospital, home health agency, rehabilitation centers and a nonprofit foundation serving children with complex medical needs and their families. He previously served as the Chief Operating Officer, Chief of Specialized Instruction, and Executive Director for Early Stages in the Office of Special Education in DC Public Schools. Nathaniel sees patients as a general and developmental-behavioral pediatrician at Children’s National Hospital, where he was the Medical Director of the Children’s Health Center at CNMC. Prior to joining DC Public Schools, he was the Deputy Director of Policy and Programs for the Community Health Administration of the DC Department of Health and the Title V Director for DC. He has served on the Mayor’s Advisory Committee on Child Welfare and the Children with Special Health Care Needs Advisory Board. Nathaniel is a graduate of George Washington School of Medicine and the Harvard University Kennedy School of Government. He completed his pediatric residency at Children’s National Hospital and the Anne Dyson Child Advocacy Fellowship at The Boston Children’s Hospital.

Andrea Benin, M.D., Andrea Benin, MD is Deputy Chief, Surveillance Branch, Division of Healthcare Quality Promotion, National Center for Emerging Zoonotic and Infectious Diseases. Dr. Benin is a pediatrician with background and training in informatics, public health, epidemiology, and infectious diseases. Dr. Benin is also an expert in quality and safety in healthcare and has particular expertise in developing, validating, and measuring metrics of quality of care. In her prior position (2012-2018), as Senior Vice-President, Quality and Patient-Safety for the Connecticut Children's Medical Center, Dr. Benin drove the agenda and activities to provide the safest, highest quality, zero-harm care for patients of the free-standing children's hospital. Previously (2006-2012), she was System Executive Director, Performance Management for the Yale New Haven Health System and Quality and Safety Officer, Yale-New Haven Children's Hospital in New Haven, Connecticut. In that role, she oversaw the quality and safety activities for the multiple-hospital Yale New Haven Health System as well as for the Children's Hospital.

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.

Meg Comeau, M.H.A is a senior project director at the Center for Innovation in Social Work & Health (CISWH). She is a nationally recognized expert on the impact of Medicaid and federal health care reform for children with special health care needs, medically complex conditions, and disabilities. She brings more than 15 years of health care delivery and financing experience to her role as principal investigator for the Collaborative Improvement and Innovation Network (CoIIN) to Advance Care for Children with Medical Complexity and as principal investigator of the Catalyst Center, a project focused on improving insurance coverage and financing of care for children and youth with special health care needs. Before joining CISWH in 2005, Meg was the coordinator of the Family Initiatives program at Boston Children's Hospital. In that position, she incorporated family input into hospital policy and programming related to family/professional communication, pediatric palliative care, and bereavement support.

Bob Duncan serves as President, Children's Community Health Plan and Executive Vice President at Children's Wisconsin. Mr. Duncan oversees the strategic contracting for Children's systems of care, population health and the development of value-based contracts. He also leads Children's Community Health Plan (CCHP) serving more than 130,000 low-income Wisconsin residents. Bob previously served as Director of the Governor's Office of Children's Care Coordination for the State of Tennessee. He also held a dual role as the Director for CoverKids, Tennessee's children's health insurance program that provides free, comprehensive health coverage for qualifying children 18 and younger. He received his Bachelor of Business Administration from the University of Memphis and his MBA from the University of Tennessee at Martin. He also completed the Johnson & Johnson/UCLA Health Care Executive Program at UCLA.

Angelo P. Giardino, MD, PhD, MPH, CMQ, is the Wilma T. Gibson Presidential Professor and Chair of the Department of Pediatrics at the University of Utah School of Medicine. He also serves as the Chief Medical Officer at Intermountain Primary Children's Hospital in Salt Lake City, UT. Prior to arriving in Utah, Dr. Giardino served as Senior Vice President/Chief Quality Office at Texas Children's Hospital and

was Professor of Pediatrics and Section Chief of Academic General Pediatrics at Baylor College of Medicine (BCM). He received his medical degree and doctorate in education from the University of Pennsylvania, completed his residency and fellowship training at The Children's Hospital of Philadelphia (CHOP), earned a Master's in Public Health from the University of Massachusetts, a Master's in Theology from Catholic Distance University (CDU), a Master's in Public Affairs from the University of Texas Rio Grande Valley, and is a Certified Physician Executive (CPE) within the American Association for Physician Leadership. He completed the Patient Safety Certificate Program from the Quality Colloquium, is certified in medical quality (CMQ) as designated by the American Board of Medical Quality and is a Distinguished Fellow of the American College of Medical Quality.

Rita Mangione-Smith, MD, MPH, (AAP Liaison) was appointed Vice President for Research and Health Care Innovation at Kaiser Permanente Washington and Executive Director of Kaiser Permanente Washington Health Research Institute (KPWHRI) in August 2019. She is also a Professor in the Department of Health System Science at Kaiser Permanente Bernard J. Tyson School of Medicine. Before joining Kaiser Permanente Washington, Dr. Mangione-Smith served as Professor and Chief of the Division of General Pediatrics and Hospital Medicine in the University of Washington Department of Pediatrics and as an Investigator in the Center for Child Health, Behavior, and Development at Seattle Children's Research Institute and Chief. As a Senior Investigator at KPWHRI, Dr. Mangione-Smith's research primarily focuses on assessing pediatric quality of care and then developing, evaluating, and implementing quality improvement interventions in areas such as transitions between sites of care and hospital-based care for respiratory illness and mental health. In 2018, AcademyHealth honored Dr. Mangione-Smith with its "Child Health Interest Group Lifetime Achievement Award," recognizing her significant and lasting contributions to child health services research. She also received the 2017 Academic Pediatric Association Research Award, the organization's highest award for research excellence and achievement.

Christopher Stille, M.D., M.P.H. is Section Head, General Academic Pediatrics, and Professor of Pediatrics at the University of Colorado School of Medicine and Children's Hospital Colorado, Aurora, 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. Dr. Stille was co-site project director in the Coordinating All Resources Effectively (CARE) for Children with Medical Complexity Award funded by CMMI. His site is currently participating in the Collaborative Improvement and Innovation Network (CoIIN) to Advance Care for Children with Medical Complexity (CMC) supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS).

Sara Toomey, M.D., M.P.H., M.Phil., M.Sc. is Chief Experience Officer and Director/PI of the Center of Excellence for Pediatric Quality Measurement (CEPQM) at Boston Children's Hospital (BCH). Dr. Toomey is an Associate Professor at Harvard Medical School (HMS) and in the Division of General Pediatrics at BCH. In her role as Director of CEPQM, she has been integral to the development of multiple nationally-recognized pediatric quality measures and has continued her health services research. Her research aims to measure the quality of pediatric care, demonstrate the association between quality measures and healthcare outcomes, and develop interventions to improve outcomes. In her role as Chief Experience Officer, she leads the experience efforts at BCH and oversees measurement and improvement activities working broadly on all aspects of experience including patient experience, staff engagement, and referring provider experience. She received her BA from Holy Cross College. As a

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