Realizing the promise of ACE Kids

July 2022

CHILDREN'S HOSPITAL ASSOCIATION

Over the past 18 months, Children's Hospital Association (CHA) has actively engaged with children's hospitals that are interested in pursuing ACE Kids implementation in their states. The following are key strategic and operational considerations for ACE Kids implementation that have emerged from their experiences. We hope this provides useful insights for any children's hospital interested in strengthening care for children with medically complex conditions (CMC).

KEY CONSIDERATIONS

Beginning Oct. 1, 2022, states can opt in to the federal ACE Kids program to support better care coordination for CMC who rely on Medicaid. Through ACE Kids, states, children's hospitals and community providers can expand access to patient-centered, pediatric-focused coordinated care models across multiple providers and services that are specifically tailored to these children and ease access to out-of-state care.

- **Implement a care model.** The model should include capacity to deliver comprehensive medical and health home services that go beyond traditional CMC care, delivered outside the hospital across a wide geography.

  TIP: Networks of care should extend the health home to a broader geographic area and include different provider types; partnerships with community and school-based providers, other hospitals and health systems; and a mechanism for providing transition services into adulthood. The network will need to rely heavily on technology integration and data beyond the health system to promote shared metrics and support payment models and the tracking of outcomes.

  TIP: Consider including in your care model your state's specific mental health benefits and payment mechanisms.

- **Build out robust data sets and analytic skills.** Analytic capability will be needed to accurately identify target populations, understand and predict costs, and develop and track interventions and quality metrics.

  TIP: You may be able to work with your state Medicaid agency and health plans to access claims data to educate the state regarding the characteristics of their CMC population, identify care gaps in existing systems, and develop appropriate payment models.

- **Develop a preferred approach to alternative payment models (APMs) for the CMC population.** In adopting ACE Kids, your state may either require or encourage APM-based payments.

  TIP: Be aware of the full spectrum of APMs in your state and carefully assess your organization's readiness to participate in them. These payment models may range from fees paid for quality or case management services to upside and downside risk-sharing arrangements.

  TIP: Build appropriate capacity, as needed, to confidently participate in risk or non-risk bearing payment arrangements.

- **Develop a state advocacy strategy.** The strategy should address gaps in care for CMC.

  TIP: To demonstrate the need for ACE Kids, children's hospitals should document the significant gaps that exist in the care of CMC, even in states that have other programs focusing on this area.

OVERVIEW OF THE ACE KIDS ACT

In 2018, the Advancing Care for Exceptional (ACE) Kids Act (P.L. 116-16) was signed into law to improve care for CMC who are enrolled in Medicaid by expanding access to patient-centered, pediatric-focused coordinated care models specifically tailored for these children across multiple providers and services, and by easing access to out-of-state care. The law creates a new state Medicaid option—building on current law—to provide coordinated care through health homes for CMC, beginning on Oct. 1, 2022. Participation in an ACE Kids medical home is voluntary for children and their families, providers and states.

KEY PROVISIONS

- **STATE FINANCING** – States that opt to create ACE Kids health homes will receive a higher Medicaid federal matching rate (15% above regular matching rate for the state, not to exceed 90%) for six months for health home services. The bill also provides a total of $5 million for state planning grants.
- **ELIGIBLE CHILDREN** – To be eligible to participate in an ACE Kids health home, a child must have at least one chronic condition—cumulatively affecting three or more organ systems and severely reducing cognitive or physical functioning—and also require medication, durable medical equipment, therapy, surgery or other treatments. Children with one life-limiting illness or rare pediatric disease—as defined in the Food, Drug, and Cosmetic Act—are also eligible.
- **QUALIFYING AS AN ACE KIDS HEALTH HOME** – To qualify as a health home, providers and health teams must be able to coordinate prompt care of CMC, develop an individualized comprehensive pediatric family-centered care plan, coordinate access to subspecialized care, and coordinate appropriate care with out-of-state providers.
- **REQUIREMENTS FOR STATES** – States that choose to opt in to ACE Kids must submit a state plan amendment (SPA) to HHS that reflects the statutory requirements as well as upcoming guidance from CMS.
  - Children's hospitals may need to work with both their Medicaid agency and their legislature on implementation as some states will require legislative action to opt in to ACE Kids.
  - Beginning Oct. 1, 2022, states may apply to HHS for planning grants to develop their SPA. There is a total of $5 million in planning grants available to states. States awarded planning grants must contribute their state match rate for each year that the grant is awarded.
- **STATE REPORTING REQUIREMENTS** – States that opt in to ACE Kids must report to CMS on:
  - The number of CMC who are enrolled in a health home and the nature, number and prevalence of chronic conditions, illnesses, disabilities and rare conditions that the children have.
  - The type of delivery systems and payment models used.
  - The number and characteristics of providers and health professionals designated as ACE Kids health homes.
  - Quality measures developed specifically for services provided to this population of children.
  - The extent to which the children receive health care services from out-of-state providers.

NOTES

The Secretary of the Department of Health and Human Services (HHS) is tasked with operationalizing the specific definition of eligibility, but has not yet done so. In June 2020, a children's hospitals' expert group sent recommendations to the Centers for Medicare & Medicaid Services (CMS) on developing a consistent method for operationalizing the ACE Kids definition of CMC, both for eligibility and funding, as well as to enable better national data.

The HHS Secretary must establish the specific standards for qualification as a health home. The timing of the release of that guidance is unknown.

The insights from the Center for Medicare and Medicaid Innovation's (CMMI) CARE Award may be helpful to children's hospitals as they consider how to structure their CMC health home model. See Appendix C.

The HHS Secretary is required to issue further guidance on quality measures. A children's hospitals expert group sent recommendations to CMS in November 2020. CMS guidance is pending.

CMS released guidance in November 2021 on best practices for out-of-state care based on input it received on an earlier request for information (RFI). CHA and several children's hospitals provided comments to CMS in response to the RFI. Within 90 days of the approval of its SPA, the state must submit a report to HHS on how the state is implementing this guidance and make that report publicly available.

REALIZING THE PROMISE OF ACE KIDS—IMPLEMENTATION CHALLENGES AND STRATEGIES

In 2021, CHA held a series of interviews with a subset of children's hospitals to learn about their states' policy environments and likelihood of opting in to ACE Kids, and their institutional readiness and interest in participating in ACE Kids. Based on those conversations, CHA convened a Learning Group of seven children's hospitals that indicated interest in shared learnings about potential ACE Kids implementation. See appendices for lists of participating hospitals.

These discussions revealed a great deal of variability in state and hospital regulatory and legislative environments and clinical and operational readiness. Despite this variability, a set of common themes emerged related to implementation challenges and strategic opportunities. Those themes are centered on issues related to state-focused advocacy, the care model, data and analytics capabilities, and the development of APMs.

1. STATE ADVOCACY

Challenges: When it comes to children's health, state governments are prioritizing and implementing a range of state initiatives to address CMC.

- Some states are not specifically including plans for ACE Kids, which creates advocacy and implementation challenges.
- Some children's hospitals have found that the presence of competing or alternative initiatives at the state level has made it more challenging to demonstrate the need for ACE Kids and are specifically highlighting the significant gaps that still exist in the care of CMC under alternative models.

Strategic opportunities: Develop a state advocacy strategy that fits with the state's priorities, demonstrates the significant gaps that still exist in the care of CMC even in states that have other programs focusing on this area, and makes the case for using ACE Kids to close those gaps.

2. CARE MODEL

Challenges: Existing hospital-based CMC programs are common, but often lack community, state, regional or multi-state partnerships. They also lack the necessary infrastructure to provide comprehensive CMC health home services statewide, across different areas of the state or across state lines. ACE Kids will also require children's hospitals to expand beyond traditional care models. In particular, care models will need to:

- Include partnerships with a broad set of provider types and community,

Examples of state initiatives that hold promise for ACE Kids implementation

In Colorado, Children's Hospital of Colorado and other pediatric organizations' advocacy efforts resulted in the legislature including language in hospital provider fee legislation to require the state to move forward with implementation upon passage of the ACE Kids Act.

In Texas, the legislature mandated in 2021 that the state Medicaid agency implement a pilot program "substantially similar" to ACE Kids by 2024. The legislature acted in response to advocacy by parent and family organizations, and with the support of the Children's Hospital Association of Texas, which cited gaps in care for CMC under the state's Star Kids managed Medicaid program.

In Washington, the Health Care Authority (HCA) is prioritizing implementation of its existing health home program under the ACA Section 2703 health homes for individuals with chronic conditions, rather than ACE Kids specifically. The HCA is interested in ACE Kids but is awaiting the CMS guidance on patient population and the release of state grant funding before agreeing to move forward. The three pediatric hospitals in the state have come together to make a plan, and have done a crosswalk between the ACE Kids model and the Washington Health Home model to identify gaps for CMC under the Section 2703 approach.

In Mississippi, state Medicaid officials are supporting a pilot program under which one of the statewide Medicaid managed care organizations (MCOs) is paying supplemental fees to Children's of Mississippi for enhanced care coordination for a population of high-cost CMC. While the state has not made a decision regarding participation in ACE Kids, the hospital believes the state support for the pilot program for CMC and its findings may help create some momentum for participation in ACE Kids.

In Massachusetts, the state's renewal of its federal Medicaid Section 1115 waiver includes a new targeted case management benefit for CMC and payments for non-medical services addressing social determinants of health for children and families. The state's focus on CMC in the waiver renewal came about as a result of active participation by the Massachusetts AAP, Boston Children's Hospital and other child health providers and advocates in planning discussions with the state. Though Massachusetts is not focused specifically on ACE Kids implementation, this "kids-focused" waiver may create an opportunity to advance ACE Kids.

school-based and government partners to deliver comprehensive medical and social needs care to children and families with medical complexity. Children's hospitals also may want to explore multi-state partnerships to facilitate care across state lines.

Strategic opportunities: Children's hospitals bring significant expertise with the populations targeted by ACE Kids, including some that have expanded the clinical case management delivery model beyond the hospital to a broader geographic area. ACE Kids will also require children's hospitals to expand beyond traditional care models. In particular, care models will need to:

- Include partnerships with a broad set of provider types and community, school-based and government partners to deliver comprehensive medical and social needs care to children and families with medical complexity.
- Be geographically distributed and include other hospitals and health systems and a mechanism for providing transition services into adulthood.
- Adopt an approach to technology integration and data beyond the health system, including digital and telehealth strategies, which will support payment models and tracking of outcomes, and promote shared metrics.
- Address the gap in mental health services for this population.

Examples of clinical care models for CMC among children's hospitals

Primary Children's Hospital (PCH), in collaboration with the University of Utah Department of Pediatrics, continues to refine and expand the hospital-based Comprehensive Care Program for over 2,500 CMC, including those with technology dependencies and complex disabilities. Additionally, PCH offers the Connector Program, which delivers episodes of intense home-cased care coordination for a sub-group of children with high medical and psychosocial complexity, and a strong and mature program of Pediatric Palliative Care across the continuum.

Children's Hospital of Colorado and Seattle Children's have clinically integrated networks and are building infrastructure to support regionally distributed primary and specialty care presence and health home services.

Children's of Mississippi has expanded its existing hospital-based chronic care program using case management funds paid by one of the state's MCOs, to include more palliative care and accommodate a statewide population. The hospital is currently in negotiations with a second Medicaid MCO.

Boston Children's is working with its affiliated primary care providers (PCPs) on a regional basis to move the care for CMC into the ambulatory setting. The hospital is providing consultative support and education, as well as patient navigators/care coordinators, to PCP practices in alignment with its Medicaid ACO, which covers 125,000 children statewide.

Nemours Children's Health in Delaware has developed a tiered system to provide care management through a combination of a hospital-based clinic, enhanced primary care model, and an NCQA-accredited program providing care management for CMC. They have employed risk stratification strategies and use data to drive decision-making. They are actively exploring partnerships in neighboring states to participate in the care of CMC.

Cook Children's Health Care System in Fort Worth, Texas is piloting different models for CMC care in both its hospital and primary care settings. In 2023, they are planning the expansion of their multi-specialty programming and will also open a complex care clinic to serve as a medical home for CMC.

3. DATA AND ANALYTICS CAPABILITY

Challenges: Many pediatric health systems do not have the data or analytic capability needed to improve care and support the types of financial arrangements that may accompany ACE Kids participation.

- Without high-quality data and analytic capacity, hospitals contemplating ACE Kids implementation may be challenged in their efforts to:
  - Educate states regarding the characteristics of their CMC population and identify care gaps.
  - Identify target populations and design care models.
  - Set realistic expectations for improvements in cost, outcomes or financial risk associated with ACE Kids services.

- Develop cost and actuarial models, plan payment models and negotiate rates with payers using timely and accurate claims data.
- Select metrics and payment parameters for pay-for-performance financial arrangements, based on outcomes data.
- Assess impact of individual and population-based initiatives.

- As care systems develop more sophisticated approaches, including predictive models, comprehensive datasets that can link these elements become increasingly important.
  - There may be problems with reliability and timeliness of data that crosses sites of care, particularly for those hospitals that depend on Medicaid payers or state Medicaid agencies for data.
  - There may be a lack of reliable data when negotiating contracts with payers, particularly Medicaid MCOs, some of which do not have sufficient experience in pediatric utilization patterns or metrics.

Strategic opportunities: Build out robust data sets and analytic skills, possibly in collaboration with the state Medicaid agency and plans, to accurately identify target populations, understand and predict costs, and develop and track interventions and quality metrics. Some children's hospitals have experience working with state Medicaid agencies, statewide all-payer claims databases and health plans to access claims data. They have leveraged this information to inform conversations around defining populations, gaps in care, appropriate payment for medical services, and to evaluate business model proposals.

Examples of clinical, financial, and population-based analytics in support of potential ACE Kids implementation at select children's hospitals

Boston Children's has invested significant resources into the development of data analytic capabilities to support its participation in the state's Medicaid accountable care demonstration program and related advocacy work. Claims data has been used to identify CMC who are high utilizers of services. Analyses of their demographic, clinical, and spend characteristics have been used to identify target populations and evaluate potential opportunities for more appropriate, equitable, and higher quality care. For example, comorbid behavioral health conditions have been identified as a significant contributor to both medical complexity and the cost of care and have been a focus of its ACO. Claims and outcomes data have also been used to inform the development of financial models and examine health, utilization, and financial outcomes. A related benefit is a deeper dive on health disparities across patient populations, still a work in progress.

Children's of Mississippi (CMH) used a risk-based methodology, mutually agreed upon by CMH and the Medicaid MCO. Among its population of managed children, they showed improvement in length of stay, emergency department use, admissions, satisfaction, and total cost of care. The analysis resulted in a decision by Mississippi Medicaid and the MCO to complete a value-based care agreement under which CMH will provide care management services for a per member/per month (PM/PM) fee for a population of CMC.

Primary Children's tracks outcomes of the hospital-based Comprehensive Care Program for CMC. This program has resulted in significant reductions in hospital costs associated with decreased hospital lengths of stay and high levels of parental satisfaction.

The finance and clinical teams at **Mary Bridge Children's Hospital and Health Network** have undertaken a detailed analysis of costs and revenues associated with the care of Medicaid CMC within their facilities who may be candidates for an ACE Kids program in Washington state. They have used these data to inform estimates regarding potential alternative payment models.

Among **CHA hospitals participating in the federal Center for Medicare and Medicaid Innovation's (CMMI) CARE Award**, detailed cost analysis revealed the key role that pharmaceutical costs play in the care of CMC. The analysis highlighted how difficult it is for providers to reduce trajectory of cost increases when such a significant proportion of the spend is not in their control.

4. ALTERNATIVE PAYMENT MODELS

Challenges: Although APMs are not required for payment under the ACE Kids Act, most of the organizations contemplating participation in this program are anticipating that their respective states will either require or encourage APMs. These payment models may range from fees paid for quality or case management services to upside and downside risk-sharing arrangements.

- Few children's hospitals have a sufficiently mature managed care financial infrastructure to confidently deliver CMC services under different APMs, especially those involving financial risk.

Strategic opportunities: Expand the hospital's managed care infrastructure in order to confidently participate in APMs, including those that may involve risk arrangements, including:

- Enhancements of data and analytic capabilities that allow for the identification and stratification of high-risk, high-cost patients, as well as care and case management services that improve cost and quality.
- Network development and management, contracting, and IT integration to enhance quality improvement, coordination, and cost controls.

The experience of select children's hospitals with APMs

Children's of Mississippi (CMH) will be implementing an APM with one of the largest Medicaid MCOs in Mississippi to provide care management services for a selected group of high-cost Medicaid CMC. The payment arrangement involves initial PM/PM payments for care management services delivered through an expanded hospital-based CMC program and shared savings based on CMH achieving certain pediatric quality metrics. The savings are based on a total cost of care model. CMH and the MCO may consider a downside risk in future years. Over time, the payment model is intended to evolve to an upside/downside shared risk payment model that incorporates elements of total costs of care (including mental health, pharmacy, and post-acute care), and performance against a defined set of pediatric quality metrics.

A response from the **Children's Hospital Association of Texas** (CHAT) to a recent state RFI noted that a children's hospital-led model and/or a model led by an MCO affiliated with a children's hospital would be the optimal payment structure if the state moved to an ACO model for children enrolled in its Medicaid managed care program. That model could evolve to include more risk-sharing as the product matures. CHAT emphasized that flexibility in how and when more risk is taken on will be important because each ACO may mature differently.

Boston Children's Hospital (BCH) provides care to approximately 125,000 empaneled Massachusetts Medicaid patients (including CMC) through a statewide ACO in partnership with one of the 17 Medicaid managed care plans in the state. Under this arrangement, BCH is at risk for total costs of care for its covered population. Monthly PM/PM payments reflect risk-adjusted capitation and include risk corridors. BCH also serves as the major pediatric specialty provider for complex patients enrolled in others' ACOs. It has been challenging to come to an agreement with the state and the plans on the definition of CMC and to align that definition with an appropriate payment structure that reflects costs as well as possible savings.

In addition to these examples, about a dozen children's hospitals that participated in the CMMI Care Award experimented with APMs and tracked specific outcomes measures.

NEXT STEPS

Children's hospitals will face a number of challenges as they work within their own walls and with their states, plans, and community providers and partners to implement the ACE Kids Act. If they focus on these key strategic areas and utilize the CARE Award learnings, children's hospitals will be more likely to realize the promise of ACE Kids and improve care for CMC and their families.

- State-focused advocacy—Develop a robust state advocacy strategy to encourage state adoption of the ACE Kids approach that incorporates a thorough understanding of competing state priorities and other initiatives targeting CMC.
- Clinical care model—Children's hospitals bring significant expertise to the care of this population and must work to enhance and apply those capabilities to a medical home model on a statewide or regional basis that works under APMs.
- Data and analytics—Robust data and analytics capabilities are critical to successful and effective ACE Kids implementation. Data is needed to define the target population, understand its utilization and health care costs, and track quality metrics and outcomes.
- Participation in APMs—Children's hospitals considering ACE Kids should be able to build the necessary capabilities and infrastructure to participate in APMs associated with the care of the CMC who would be served by an ACE Kids health home.

LOOKING AHEAD TO FULFILLING THE PROMISE OF ACE KIDS

CHA plans a multi-pronged, focused effort to support children's hospitals' work to implement ACE Kids in their state. This effort will include ongoing advocacy with CMS on its implementation guidance to ensure it is consistent with congressional intent, support of collaborative learning and implementation across children's hospitals, the development and dissemination of informational materials and promising practices, and other focused activities to ensure that ACE Kids fulfills its promise of improving care for CMC and their families.

APPENDIX A

CHA Environmental / Readiness Assessment and Learning Group Approach

ENVIRONMENTAL AND READINESS ASSESSMENT

Between June and September 2021, CHA staff held a series of interviews with children's hospitals around the country in an effort to understand the local forces impacting these organizations' response to ACE Kids implementation. The interviews targeted children's hospitals for conversation about hospital/state readiness, including those which had previously reached out to CHA and/or were identified through a CHA Accountable Health Learning Collaborative survey in April 2020. The interviews included a focus on:

- State legislative and health care dynamics influencing the likelihood of implementing ACE Kids.
- Organizational preparedness to deliver a statewide medical home model contemplated by ACE Kids legislation.
- Interest and organizational capabilities to participate in alternate business models that could accompany a statewide ACE Kids implementation.

CHA ACE KIDS LEARNING GROUP

In follow-up to the national landscape and readiness assessment, between September and November 2021, CHA sponsored a seven-hospital collaborative learning group of children's hospitals that indicated they were interested in learnings regarding potential ACE Kids implementation.

The learning group focused on four aspects of ACE KIDS implementation:

- Delivery model to provide medical home care for complex patients across a wide geography.
- Capabilities and payment arrangements to support alternative payment models.
- Analytic capabilities to confidently participate in risk arrangements and manage populations.
- Advocacy to support statewide adoption of ACE Kids legislation.

APPENDIX B

CHA member hospitals participating in national environmental and readiness evaluation and learning groups

CHA MEMBER HOSPITALS PARTICIPATING IN NATIONAL ENVIRONMENTAL AND READINESS EVALUATION

Ann & Robert H. Lurie Children's Hospital of Chicago
Boston Children's Hospital
Children's Hospital Colorado
Children's Hospital of Philadelphia
Children's Mercy Kansas City
Children's National Hospital
Children's Health Dallas
Children's of Mississippi
Cook Children's Medical Center
Lucile Packard Children's Hospital
Mary Bridge Children's Hospital and Health Network
Nemours Children's Health, Delaware
Nemours Children's Hospital, Florida
Primary Children's Hospital
Seattle Children's
St. Joseph's Children's Hospital
Wolfson Children's Hospital

HOSPITALS PARTICIPATING IN LEARNING GROUP

Boston Children's Hospital
Children's Hospital Colorado
Children's of Mississippi
Mary Bridge Children's Hospital and Health Network
Seattle Children's
St. Joseph's Children's Hospital
Wolfson Children's Hospital

APPENDIX C

IMPROVING CMC CARE MODELS—LEARNINGS FROM THE CARE AWARD

The CARE Award was a landmark national study aimed at improving quality and reducing the cost of care for CMC enrolled in Medicaid. Funded by CMMI, the CARE Award was designed to test the concept of a new care delivery system supported by new payment models specific to CMC. Ten children's hospitals partnered with CHA, eight state Medicaid programs and MCOs, 42 primary care practice sites, and more than 8,000 children and their families. The following resources provide important insights gained through the CARE Award into the care of CMC.

- CARE Award Overview.
- Estimating Costs to Manage Care for Children with Complex Medical Conditions.
- Reducing the Health Care Spend for Children with Complex Medical Conditions.
- Payment Model Guidance for Caring for Children with Complex Medical Conditions.

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