



# Impact of ACE Kids

## Past, Present and Future

CHA Webinar Presentation  
September 27, 2023

*Champions for Children's Health*

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## Speakers



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# Learning Objectives



## Where we were?

Learn how the field and our work has evolved through ACE Kids and broader efforts focused on CMC.



## Where we are?

Share examples of statewide initiatives informed by ACE Kids developed to address specific needs of CMC and spotlight two efforts underway in FL and TX.



## Where we are going?

Key capabilities needed for children's hospitals contemplating participation in ACE Kids or other state-based initiatives targeting CMC.

# At the Beginning of the Journey



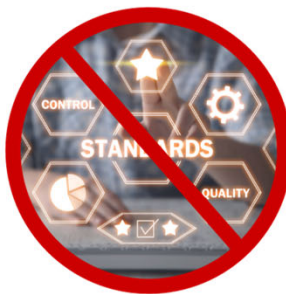
No understanding of kids with medical complexities by federal policymakers and many different definitions across the country



No to little support for care models to improve care for children with medical complexity



No national data to support policy improvements



No national quality measure sets

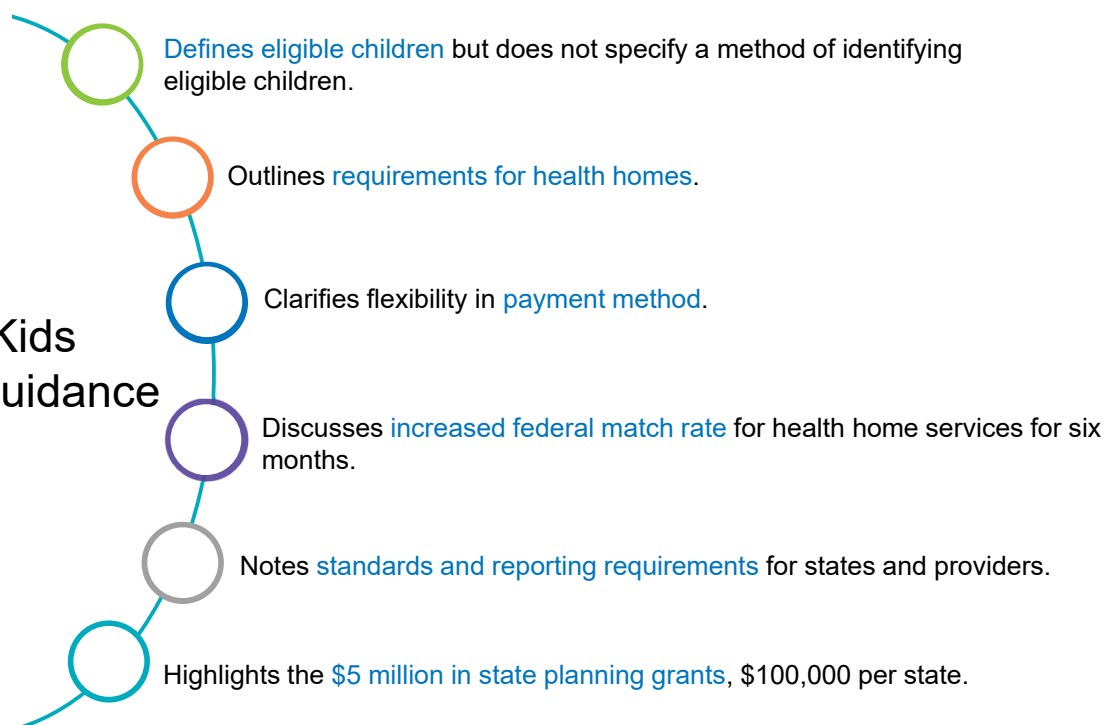
# Advancing Care for Exceptional (ACE) Kids Act

- Creates **health homes state option** tailored to children with medical complexity.
- Provides **state incentives** to participate: enhanced federal matching funds 15% above state's current match, not to exceed 90% for two quarters for health home services.
- Requires **data and quality measure reporting** for states and health homes.
- Allows **new payment models** that better align payment with best outcomes.
- Includes **national definition** for children with medically complex conditions.

**Effective October 1, 2022**

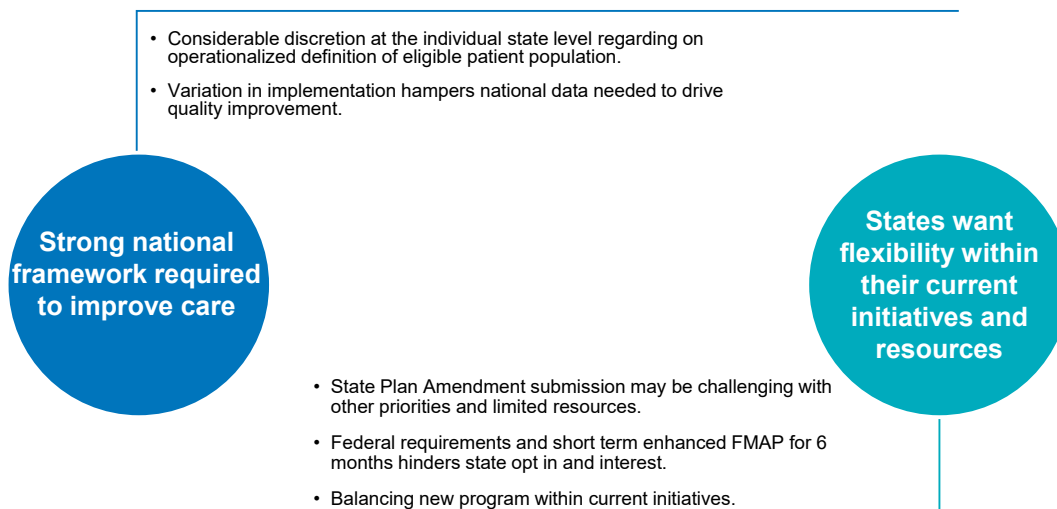
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## ACE Kids Federal Guidance



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## Changes and Transitions



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## Evolving Landscape to Improve Care for CMC

- [Educated policymakers](#) on this population of children and their needs
- Focused 6-year effort to [enact ACE Kids](#)
- [Led CARE award to](#) inform ACE Kids and broader implementation
- Convened two panels to [provide expert guidance](#) to inform CMS' guidance
- Worked with HHS and CMS leadership to [advocate for strongest guidance possible](#)
- Led children's hospital collaborative to [share learnings with interested hospitals](#)
- Ongoing engagement to [advise and support state level efforts](#)
- Created [white papers, presentations and convened with expert groups](#) on the law and capabilities needed to improve care
- Advocating for federal legislation to [streamline Medicaid out of state provider enrollment](#) to improve care for kids with special health care needs

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## ACE Kids Legislation: Implementation Update

We're seeing some progress in adoption of ACE Kids legislation and pilots.

Currently represent a relatively small proportion of overall CMC initiatives nationally

- Early adoption of legislation in **Colorado** in advance of ACE Kids approval
- Recent adoption in **Florida**
- Preliminary exploration in **Washington and Utah**
- Pilot project in **Texas** to develop a program “substantially similar” to ACE Kids
- Pilot in **Missouri** provides \$1.5M for a pilot to reduce hospital and ED use and improve quality of life for CMC using a team-based model

Let us know if you are exploring in your state.

## Increase in State Specific Initiatives Targeting CMC

- In advance of ACE Kids implementation, many states and Medicaid programs have prioritized initiatives to address CMC
- CMC initiatives informed by experience with the CARE Award, other CMMI projects, and MCHB funded projects (e.g. COiIN)
- Key drivers
  - Advocacy
  - Cost Control
  - 1115 waivers and State Plan Amendments
  - Legacy ACA programs

- **At least 19 states** have adopted *care coordination programs* for CMC
- **Several states** have developed *payment models* for CMC care coordination paid to MCOs or providers; many other in local markets

## Case Studies

### Advocacy in CO, FL & TX to Implement ACE Kids or Similar Models

**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 Florida**, St. Joseph's Children's Hospital / BayCare have advocated successfully for adoption of ACE Kids in the Florida Medicaid program (ACHA)

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## Case Study

### Cost Control in MS drives PM/PM Payment Model for Case Management

#### In Mississippi

- State Medicaid officials are supporting a pilot program under which **Medicaid managed care organizations (MCOs) are paying supplemental fees** to Children's of Mississippi for enhanced care coordination for a population of high-cost CMC. Arrangements include upside and downside risk
- 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.

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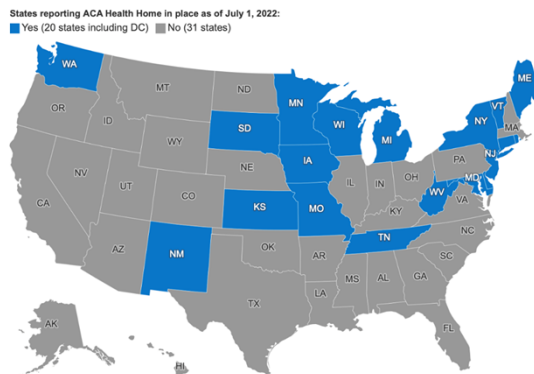
# Case Study

## Washington State Prioritizing ACA Legacy Program Supporting Health Homes

### In Washington State

Health Care Authority (HCA) is prioritizing implementation of its health home program under the ACA Section 2703 health homes for individuals with chronic conditions, including children

- Eligibility based on PRISM score
- Administered primarily through MCOs
- Services include initial assessments and ongoing care management



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# Case Study

## Medicaid Waiver in MA Includes Services Targeting CMC

### In Massachusetts

- Commonwealth's renewal of its federal Medicaid Section 1115 waiver includes a new targeted case management benefit for Mass Health members <21 Years old with medically complex care needs (CARES program)
- Includes PM/PM payment for non-medical services including care planning and coordination
- Monitoring of CARES services through family experience surveys and "health information exchange capabilities" with providers inside and outside their practice area

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## State Specific CMC Initiatives May Create Challenges for ACE Kids Implementation

- State specific CMC initiatives may create challenges in demonstrating ongoing existing gaps/needs addressed by ACE Kids
- Lack of standardization of eligibility requirements, payment models and data makes national evaluation of care models, costs and outcomes very difficult
- Local initiatives - especially if they include adults - may compete for resources at State Medicaid offices, leaving little bandwidth and funding for ACE Kids implementation

## Capabilities Required for ACE Kids or State Specific CMC Programs are Similar

CHA assessment identified 4 key capabilities needed to participate in programs targeting CMC

- **State-focused advocacy**—Develop a robust state advocacy strategy to encourage adoption of CMC programs including ACE Kids that incorporate a thorough understanding of competing state priorities and other initiatives targeting CMC.
- **Clinical care model**—Children's hospitals should work to enhance and apply capabilities to a medical home model on a statewide or regional basis that works under Alternative Payment Models (APMs).
- **Data and analytics**—Robust data and analytics capabilities are critical. 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 or other initiatives should be able to build the necessary capabilities and infrastructure to participate in APMs



# ACE Kids Advocacy Update

## Implementing the ACE Kids Act in Florida

*Keri Eisenbeis  
Chief-of-Staff  
BayCare Health System*



ACE Kids advocate Jaden walking the halls in Washington, D.C.



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# Overview: St. Joseph's Children's Hospital Chronic Complex Clinic



Congresswoman Kathy Castor, D-Tampa; Clinic patient, Caroline West, with her mother, Tish West

- Founded in 2001
- First medical home of its kind in Florida
- Patient population: between 650-700
- Partially funded by local philanthropy and a state appropriation



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# ACE Kids Advocacy Strategy

- Advocating all year long.
- Humanize our advocacy.
- Engagement by hospital leaders, patient advocates, and parent advocates.
- We tapped into this engagement for inclusion of proviso language in the Florida 2023-24 budget directing our state Medicaid agency to submit a State Plan Amendment to opt into ACE Kids.



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## Florida State Plan Amendment



State Rep. Tom Leek, R-Ormond Beach, meeting with Clinic patient Luke Calcines during the 2023 State Legislative Session. Rep. Leek chairs the House Appropriations Committee.

### ACE Kids Act of 2019 provides:

15% increase in federal matching dollars

Funding for planning grant

States develop method to track outcomes, improve care coordination across state lines, share data with CMS

“The Agency for Health Care Administration shall develop a plan to participate in the Advancing Care for Exceptional Kids (Public Law No. 116-16)...”

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# Next Steps



- Present SPA draft to State of Florida and urge them leverage CMS technical assistance or apply for planning grant.
- Advocate for proviso and funding in Florida's 2024-25 Budget during the 2024 State Legislative Session (January –March 2024).
- Questions?

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## Impact of ACE Kids on Care for Children with Medical Complexity: Past, Present and Future

**Roxane Mulenex, MBA**  
Vice President, Enterprise Care Management

**Christa Combs, BSN, RN, CCM**  
Senior Director, Enterprise Care Management

**September 27, 2023**

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- 110 years dedicated to making life better for the children of North Texas and beyond
- Two full-service hospitals licensed for 562 beds in Dallas and Plano
- Over 50 Pediatric Specialty and Sub-Specialty Programs
- Ranked in all 10 pediatric specialties by U.S. News & World Report for the sixth year in a row
- Complex Care Medical Services clinic that serves as the primary care medical home for medically fragile children
- Expansive Virtual Health Capabilities
  - Virtual Visits
  - Remote Patient Monitoring
  - TeleSpecialty Services
  - Bedside Telemedicine Programs
  - School Telehealth



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## ACE Kids Impact in Texas

- Senate Bill (S.B.) 1648 passed in 2021 and required Texas Health & Human Services to develop and implement a ***pilot program substantially similar to*** the program described in the federal ***Advancing Care for Exceptional (ACE) Kids Act of 2019***.
- The Comprehensive Health Homes for Integrated Care (CHIC) Kids Pilot was developed for STAR Kids Medicaid managed care plans and providers to model the effectiveness of enhanced care coordination provided through health homes designed specifically to support children with medically complex conditions and their families.
- The pilot was initially planned for 13 months but was extended to 33 months, from December 1, 2022 through September 1, 2025.
- The overall goals of the CHIC Kids Pilot are to:
  - Improve care coordination for children with medically complex conditions
  - Improve access to care, health outcomes, and member satisfaction; and
  - Reduce administrative burden for MCOs and providers



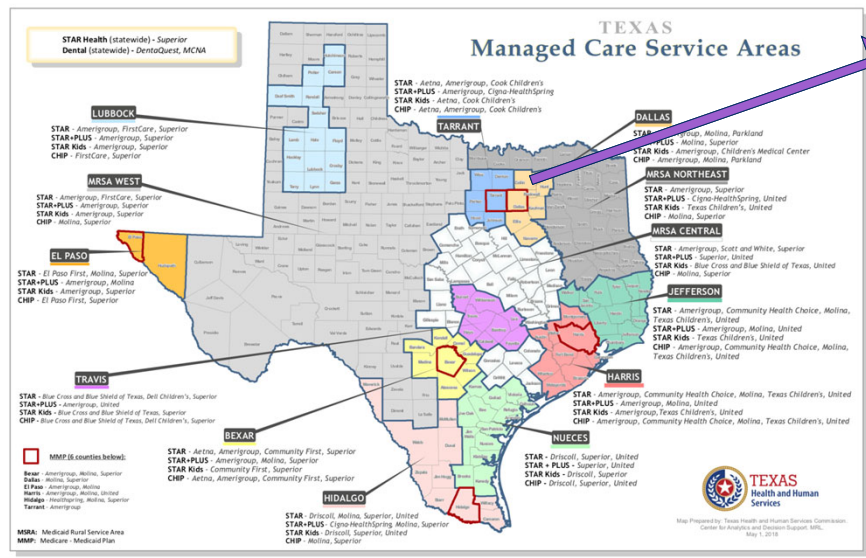
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## Texas Managed Care Service Delivery Area Map



### Dallas SDA

- Seven County Area
- Two STAR Kids Medicaid Managed Care Plans
  - Amerigroup
  - Aetna
- 22,500 STAR Kids Members
- 170,000 STAR Kids Members Statewide

## Children's Health CHIC Pilot Overview

- Proposed an expansion of the existing Complex Care Medical Services clinic program to Children's Health Medical Group primary care pediatricians caring for STAR Kids patients meeting the medically complex criteria
- Expanded telehealth offering for pilot participants already established with Complex Care Medical Services
- Developed a Medical Home Extension model to provide complex care consultative services and care coordination support for community providers
- Contracted with both STAR Kids MCOs in the Dallas Service Delivery Area
  - PMPM arrangement for care coordination services
  - Implementation expense reimbursement
  - Pay-for-Quality bonuses



## Children's Health CHIC Pilot Services

- Patient family outreach every 30 days while enrolled in the CHIC pilot program and more frequently based on needs
- Consolidation and better coordination of appointments in an effort to reduce frequent travel and remove unneeded burden for the family
- Provide extensive education for the patient family regarding medications, diagnoses, treatments, and self-management
- Collaborate with MCO Service Coordinators, home-health and supply companies, and community resources to meet the members' needs
- Follow the member when hospitalized and obtaining outpatient services at Children's Health to ensure consistency in care and information



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## Impact of ACE Kids – Case Example 1

### Patient Overview

16 year old male With Duchenne's muscular dystrophy (non ambulatory since age 4), speech disorder, dysphagia, g-tube dependence, restrictive lung disease, ventilator BiPap dependence, and cardiomyopathy. Sacral wound due to ill fitting wheelchair. No lift in the home.

#### Issues Identified

- High Social Needs - Caregiver managing their own complex medical history
- Social Determinants of Health - Food insecurity, loss of utilities, no transportation
- Frequent No Shows to specialty appointments
- Private Duty Nursing hours not staffed
- Not receiving therapies as ordered
- Not attending school due to transportation barriers
- Not tolerating sitting in a wheelchair

#### Initial Impact

- Established regular contact with Caregiver
- Became primary point of contact for the patient and family
- Advocated to local ambulance company to provide non-emergent medical transportation
- Connected private duty nursing and therapy providers to deliver ordered services and hours
- Addressed social determinant of health needs and provided resources
- Consulted School Services



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## Impact of ACE Kids – Case Example 2

### Patient Overview

15 year old male born at 23 weeks gestation. He has epilepsy, chronic lung disease, is g-tube dependent and developmentally delayed. He has a ventricular shunt that has required multiple revisions due to development of abdominal pseudocyst. He now has a V-Pleural shunt.

#### Issues Identified

- Managed by 10 specialists
- Private Duty Nursing 56 hours/week
- Receiving physical, speech, and occupational therapy multiple times per week
- Homebound
- Social Determinants of Health: Strong social network, financial insecurities

#### Initial Impact

- Patient was enrolled in a pilot using Remote Patient Technology
- Video capability with remote exam option
- 6 month comprehensive visit was completed remotely
- Less time away from work and school
- Mitigate transportation challenges
- Device can be used for enhanced telephone triage



## Lessons Learned

- Limitations in identifying patients meeting criteria for participation in the pilot
- Challenges in expanding the program to patients not already established in a complex care clinic
- Growing pains of deploying a different care model with new staff members in the primary care setting
- Slow ramp-up
- Too small of a population for participating providers to demonstrate a measureable impact to quality indicators (but too early to tell)
- Differences in provider care models may make it challenging to understand global impact
- Expansion of pilot from 13 months to 33 months allows for expanded participation and more insight into impact of the CHIC Kids pilot



# Impact of ACE Kids on Improving Care for CMC

Care for CMC is better than it was in 2013 when we first started.

Although many CMC still do not have a medical home, ACE Kids has helped drive evolving landscape of care for CMC kids locally and nationally by:

- Increasing awareness of challenges and solutions
- Providing expert guidance on definitions, care, quality metrics, payment models
- Sharing information and learnings among providers, policy makers, etc.

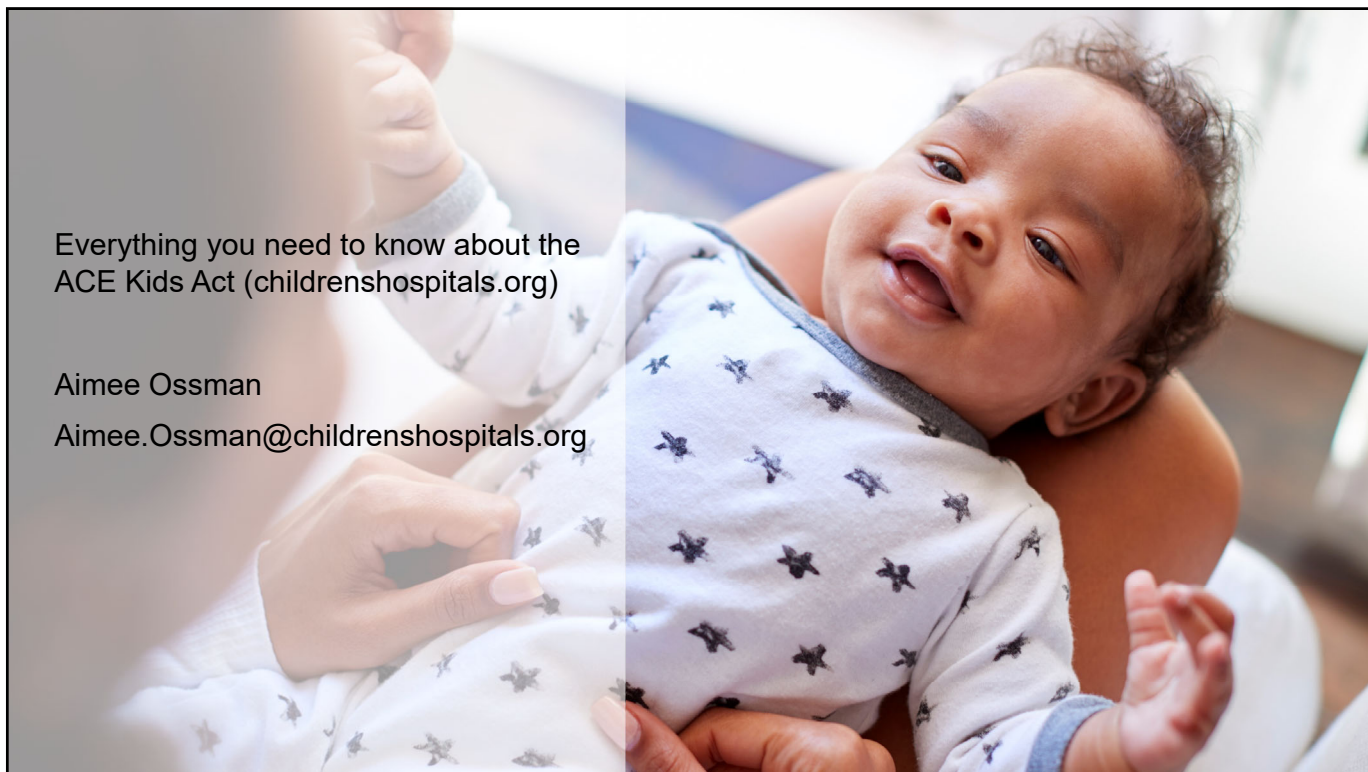
Measures of success might include:

- # of states opting-in to ACE Kids or state specific CMC initiatives
- # of CMC with adequate medical coverage and effective medical home
- quality and cost outcomes, including quality of life
- reduction of health disparities for CMC populations

## Summary

- Slow uptake of ACE Kids through legislative/policy action at state level.
- The ACE Kids Act legislative process contributed to improvements in care.
- State CMC initiatives driven by local advocacy, Medicaid waivers, ACA legacy programs, and imperatives for cost control have the potential to improve care but may not support goals for a standard national approach.
- CHA member hospitals contemplating participation in either ACE Kids or state initiatives need to enhance capabilities in advocacy, care model development, data and analytics, participation in alternative payment models.





Everything you need to know about the  
ACE Kids Act ([childrenshospitals.org](https://childrenshospitals.org))

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