Children with Complex Medical Conditions

- Small % of children on Medicaid account for the largest % of costs
- 50% of care in children’s hospitals
- Often cross state lines for care
- No national data on care or costs
- Moving into managed care over time
- Require tailored, intensive organized system of care
- Payment does not align with best outcomes
Lucia's Story

A care map by Lucia's parents illustrates the complexity of integrating her health care needs into everyday life.

Lucia's parents mapped out a care web to illustrate the many moving pieces and challenges they face in integrating coordination of her health care into everyday life. Lucia is the only person in the U.S. diagnosed with early onset myopathy with areflexia, respiratory distress and dysphagia (EMARDD).

- Red dot = must go wherever Lucia goes

Diagram of care map with categories such as Diagnosis, Pharmaceuticals, Insurance Coverage, Well-Being, and Home Environment.

BayCare St. Joseph's Children's Hospital
Anything worthwhile doesn’t come easy

*Healthier children, better care, smarter spending*

What are the challenges today in serving children with complex medical conditions?

Photo: Joy Cannis, Children’s Healthcare of Atlanta, Atlanta, Georgia
CARE Award

- **10** Children's Hospitals
- **8,000** Complex Children and Families
- **$380M** Total Annual Care Costs
- **8** State Medicaid Agencies
- **42** Primary Care Practices
- **8** Inpatient Days
- **-32%**
- **-26%** ED Visits
- **-2.6%** Spending Pre/Post
- **-4.6%** Spending Observed to Expected
- **5** Payment Models

Visit childrenshospitals.org/care
ACE Kids Act Passes April 18, 2019

- Creates health homes 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

States can opt in beginning October 1, 2022
<table>
<thead>
<tr>
<th>Year</th>
<th>Milestones</th>
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<tr>
<td>2019</td>
<td>• Check in with HHS/CMS on operational process</td>
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<td>• CMS RFI on out of state care</td>
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<td>2020-2021</td>
<td>• Guidance on definitions, data collection, standards, best practices for out-of-state care and state plan amendment process</td>
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<td>• Opt-in states incorporation into MCO contracts FY 2022; complete contractual and network preparatory work</td>
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<td>2022</td>
<td>• Beginning on Oct. 1, 2022, states can opt in and begin to receive planning grants</td>
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What we are hearing

• Important for broader state and federal Medicaid strategy/initiatives
• National consistency on data, definition, model, quality metrics etc.
• Opportunity to improve care across state lines
• More support for care coordination
• Raising the visibility of this population of kids, the challenges they face and the ways to improve their care
• Leverage the conversation about ACE Kids to make the case for better payment for these kids
• Opportunity to change the conversation with state policymakers
• Demonstrates how to manage costs in specialty environment
• Opportunity for new payment models that support those managing the care
• Possibility of better behavioral health data
Emerging Vision for Children’s Hospitals

• Raise the visibility of children with medically complex conditions covered by Medicaid prioritizing their unique needs effective models of care locally, within states, and regionally (multi-state)

• Sustainably improve care and family experience and reduce costs for this population of children over time

• Access national data to measure and improve health status, quality, and cost of care

• Transform care delivery within Medicaid, demonstrating children’s hospitals as critical partners for future Medicaid/CHIP policy efforts affecting pediatric populations
CHA’s Preliminary Near-Term Goals Leading to 2022 Implementation

1. Partner with CMS to advance federal policy
2. Partner with stakeholder groups to support policy and state implementation
3. Partner with children’s hospitals to support state adoption and practice implementation
Goal 1 - Partner with CMS to Advance Federal Policy

Task #1 - influence the guidance provided by CMS
- Advocate for early guidance
- Maintain good communication; keep children’s hospitals informed

Immediate interest
- National definition of the population of children covered by the ACE Kids Act and ensuring there is national consistency on operationalizing that definition.
- Identification of data and quality measures and process, health home standards and best practices on out-of-state care.
- Provide information to members on existing Health Home guidance to inform implementation efforts at the state level.
Legislative definition of an ACE Kid

• A child with medically complex conditions is a child under 21 who is eligible for Medicaid and has at least:
  – One or more chronic conditions that affects three or more body systems and severely reduces cognitive or physical functioning (such as the ability to eat, drink or breathe independently) and which also requires the use of medication, durable medical equipment, therapy, surgery or other treatments; OR
  – One life-limiting illness or rare pediatric disease (as defined in the Federal Food, Drug, and Cosmetic Act), such as a form of cancer.
  – The Secretary has the option to establish higher levels as to the number or severity of chronic, life threatening illnesses, disabilities, rare diseases or mental health conditions for purposes of determining eligibility for receipt of health home services under this section.

• Guidance needed from CMS on how to operationalize
Goal 2 - Partner with Stakeholder Groups to Support Policy and State Implementation
Goal 3 - Partner with Children’s Hospitals to Support State Adoption and Practice Implementation

State/regional implementation model development

Policy + Practice and Payment = Successful Implementation

Children’s hospital delivery system implementation
Work-to-date highlights

- *Children’s Hospitals Today* summer article
- ACE Kids Act webinars (May recordings available on CHA website)
- Dedicated electronic communication
  - ACEKids@groups.childrenshospitals.org Discussion group
  - ACEKids@childrenshospitals.org Email CHA’s team
- State associations, national organizations, and CMC expert groups connections
- CMS leadership meeting and touch-base process

Input from...
- CHA Public Policy Committee and Child Health Committee
- Accountable Health Learning Collaborative
- GR Subcommittee
- GR Professionals
- Annual Leadership Conference

In progress
- Draft talking points for children’s hospitals to use with state policymakers (in progress)
- Inventory of existing CMS guidance on health homes relevant to ACE Kids Act (in progress)
We look forward to working together to improve care for children with complex conditions

You ACED it!

BIPARTISAN ACE KIDS ACT ENACTED