

ACE Kids Act Implementation

NACBH Conference
July 19, 2019



Agenda

- Background on CHA
- Review the key highlights of the final bill
- Discuss timeline for implementation
- What you can do to prepare to participate
- Discussions/questions

You ACED it!

BIPARTISAN ACE KIDS ACT ENACTED



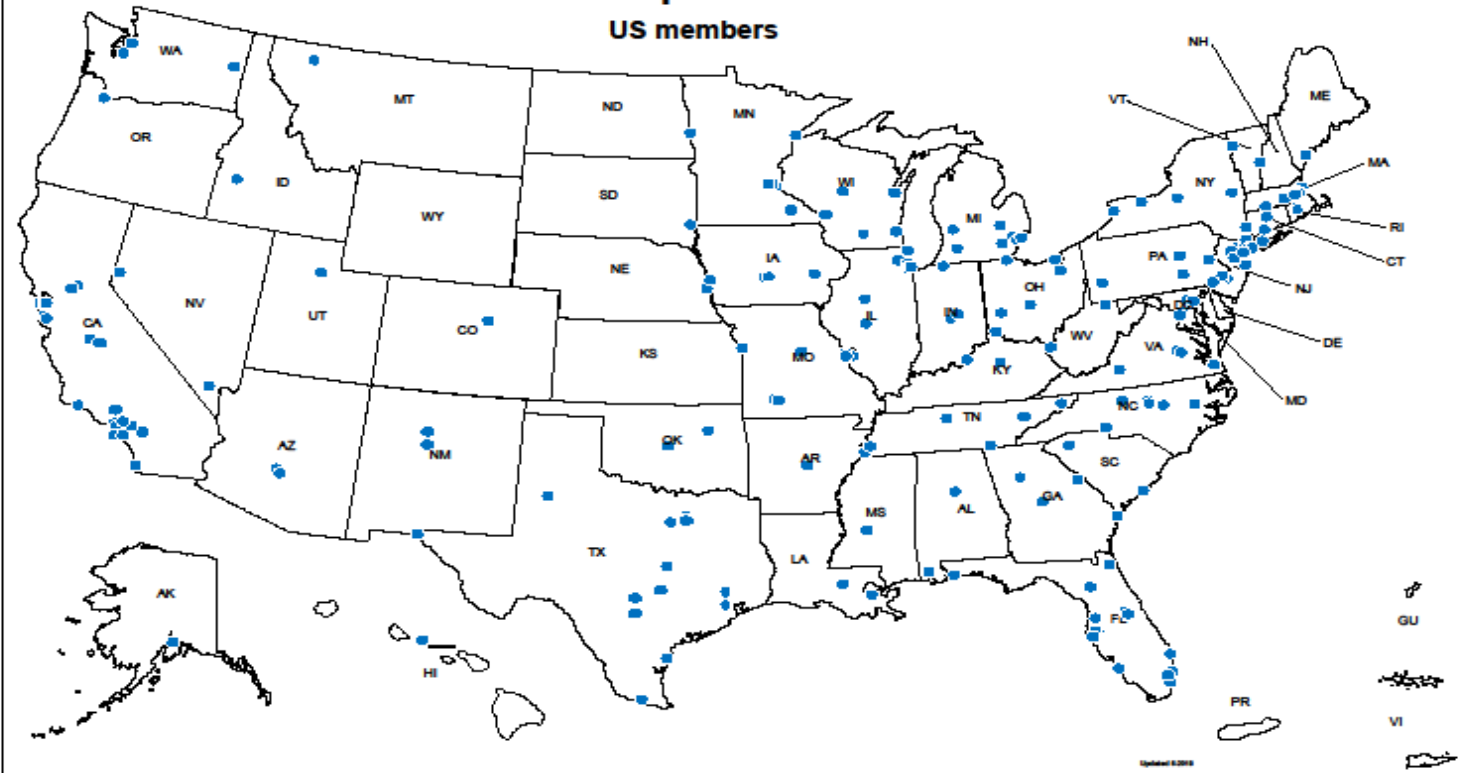
Stronger Together: Our Collective Mission



We advance children's health through the quality, cost and delivery of care with our children's hospitals.

Children's Hospital Association

US members



Currently, Children with Medical Complexity

- Small % of children on Medicaid, large % of the 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



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



A brief retrospective

113th Congress

March 2013 – budget resolution language

December 2013 – Bipartisan Budget Senate Finance amendment to support care for children with medical complexity

June 2014 – ACE Kids Act first introduced in House; HR 4930

114th Congress

January 2015 – Bipartisan, Bicameral ACE Kids Act of 2015 introduced; HR 546, S 298

July 2016 – First House E&C Health Subcommittee hearing on ACE Kids Act

115th Congress

Bipartisan ACE Kids Act of 2017 Introduced; S 428 (February 2017), HR 3325 (July 2017)

September 2018 – House E&C Committee advances ACE Kids Act

October 2018 – CBO score for ACE Kids released

December 2018 – ACE Kids Act passes House (400-11); included in HR 7217

116th Congress

February 2019 – Bipartisan ACE Kids Act of 2019; HR 1226, S 317

March 2019 – ACE Kids Act included in HR 1839 package

March / April 2019 – ACE Kids Act passes Congress; included in HR 1839

ACE Kids Act enacted
PL No: 116-16

Pulling together; champions; persistence

- President Trump signed April 18
- Champions:
 - Sens. Grassley, R-Iowa, and Bennet, D-Colo.;
 - Reps. Castor, D-Fla., Bilirakis, R-Fla., Eshoo, D-Calif., and Herrera Beutler, R-Wash.
- Persistent advocacy key to success



Supporting Organizations



American Physical Therapy Association..



American Board of Pediatrics



AMERICAN COLLEGE OF SURGEONS
Inspiring Quality: Highest Standards, Better Outcomes



American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™



Pediatric Congenital Heart Association



FAMILY VOICES®
... keeping families at the center of children's health care



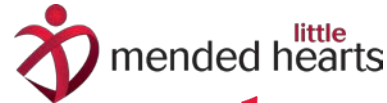
American Heart Association



AMERICAN ACADEMY OF CHILD & ADOLESCENT PSYCHIATRY
WWW.AACAP.ORG



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AMERICAN PSYCHOLOGICAL ASSOCIATION



aapcsw
American Association for Psychoanalysis in Clinical Social Work



NACBH

national association for children's behavioral health

Main provisions

- **Creates health homes** tailored to children with medical complexity; voluntary for states, families and providers
- **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; also provides planning grants, \$74 million FY 2019-2029
- **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

Creates tailored health homes

- Creates health homes tailored to children with medical complexity; voluntary for states, families and providers
- Health homes need to coordinate prompt care, develop family-centered care plans, work in culturally appropriate manner with child and family and coordinate access to specialized and out of state care
- Health homes must be able to coordinate full array of care needed (includes physical and behavioral health)

Provides incentives for states to opt in

- Provides enhanced federal matching funds 15% above state's current match not to exceed 90% for two quarters
- Enhanced matching funds only for health home services:
 - Comprehensive care management
 - Care coordination and health promotion
 - Comprehensive transitional care
 - Patient and family support
 - Referrals to community and social support services; and
 - Use of health information technology to link services, as feasible
- Provides state planning grants not to exceed \$5 million total

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**

Behavioral Health Coordination

- Often children with complex medical conditions do have behavioral health issues and health homes could help better coordinate/integrate care across physical and behavioral health
- Requires states to consult and coordinate with Secretary of HHS in addressing issues regarding the prevention and treatment of mental illness and substance abuse among children with medically complex conditions receiving health home services
- Services provided are the same services provided to children on Medicaid today
- Mental health providers and organizations would be key health home partners

Key Milestones

2019

- Check in with HHS/CMS on operational process

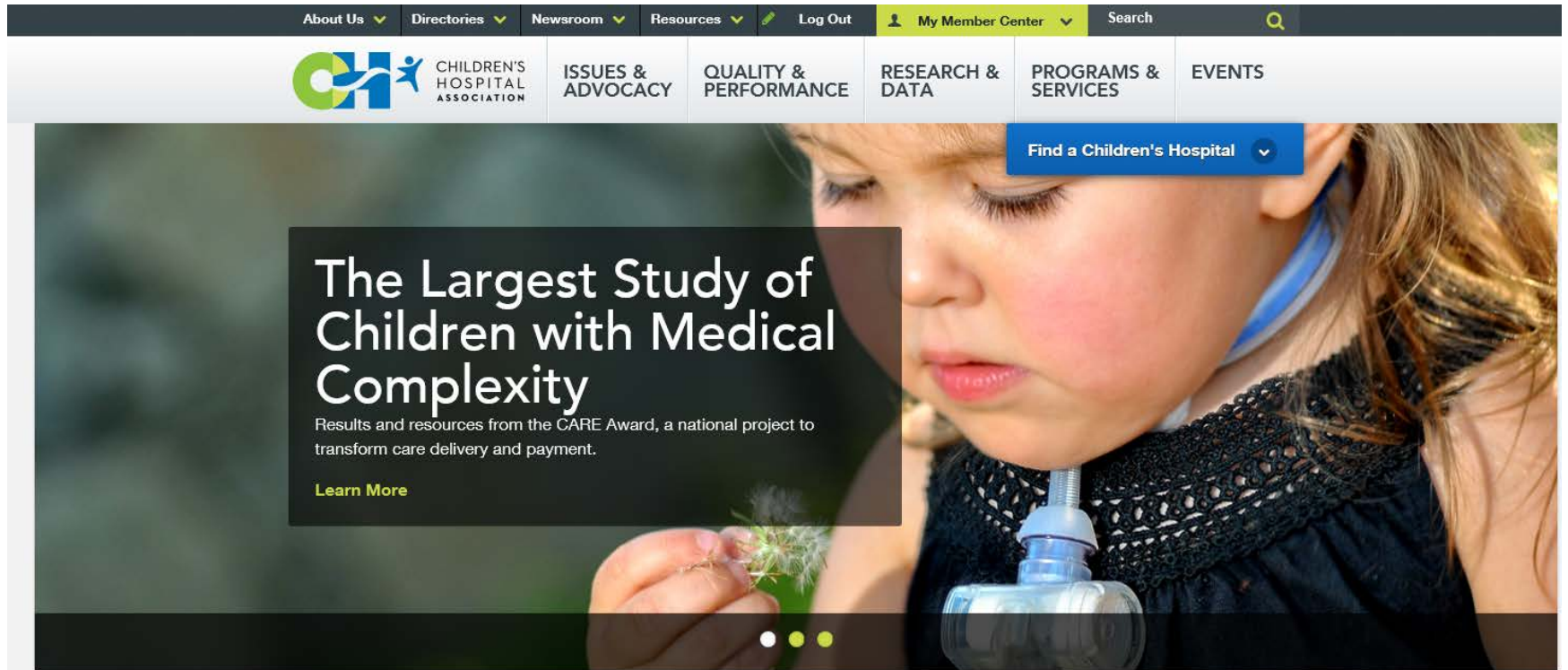
2020-2021

- Guidance on definitions, data collection, standards, best practices for out of state care and state plan amendment process;
- Opt-in states incorporation into MCO contracts FY2022; complete contractual and network preparatory work

2022

- Beginning on Oct. 1, 2022 states can opt in and begin to receive planning grants

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CHILDREN'S HOSPITAL ASSOCIATION ISSUES & ADVOCACY QUALITY & PERFORMANCE RESEARCH & DATA PROGRAMS & SERVICES EVENTS

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The Largest Study of Children with Medical Complexity

Results and resources from the CARE Award, a national project to transform care delivery and payment.

[Learn More](#)

What you can do

- Wrap up thanking members of Congress; keep the message going on importance of Medicaid
- Connect with children's hospital(s) and other potential partners in your state
- Highlight ACE Kids with your state Medicaid program
- Stay tuned for updates, particularly on bill progress through CMS
- Let us know what questions you have and stay in touch as implementation progresses in your states



CHILDREN'S
HOSPITAL
ASSOCIATION

Aimee Ossman
Vice President, Policy Analysis and Implementation
aimee.ossman@childrenshospitals.org

Children's Hospital Association
600 13th St., NW | Suite 500 | Washington, DC 20005 | 202-753-5500
16011 College Blvd. | Suite 250 | Lenexa, KS 66219 | 913-262-1436
www.childrenshospitals.org