



Children with Medical Complexity and School Re-opening Amidst COVID-19

CYSHCNet Steering Committee Meeting

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CMC CoIIN: timeline and goals

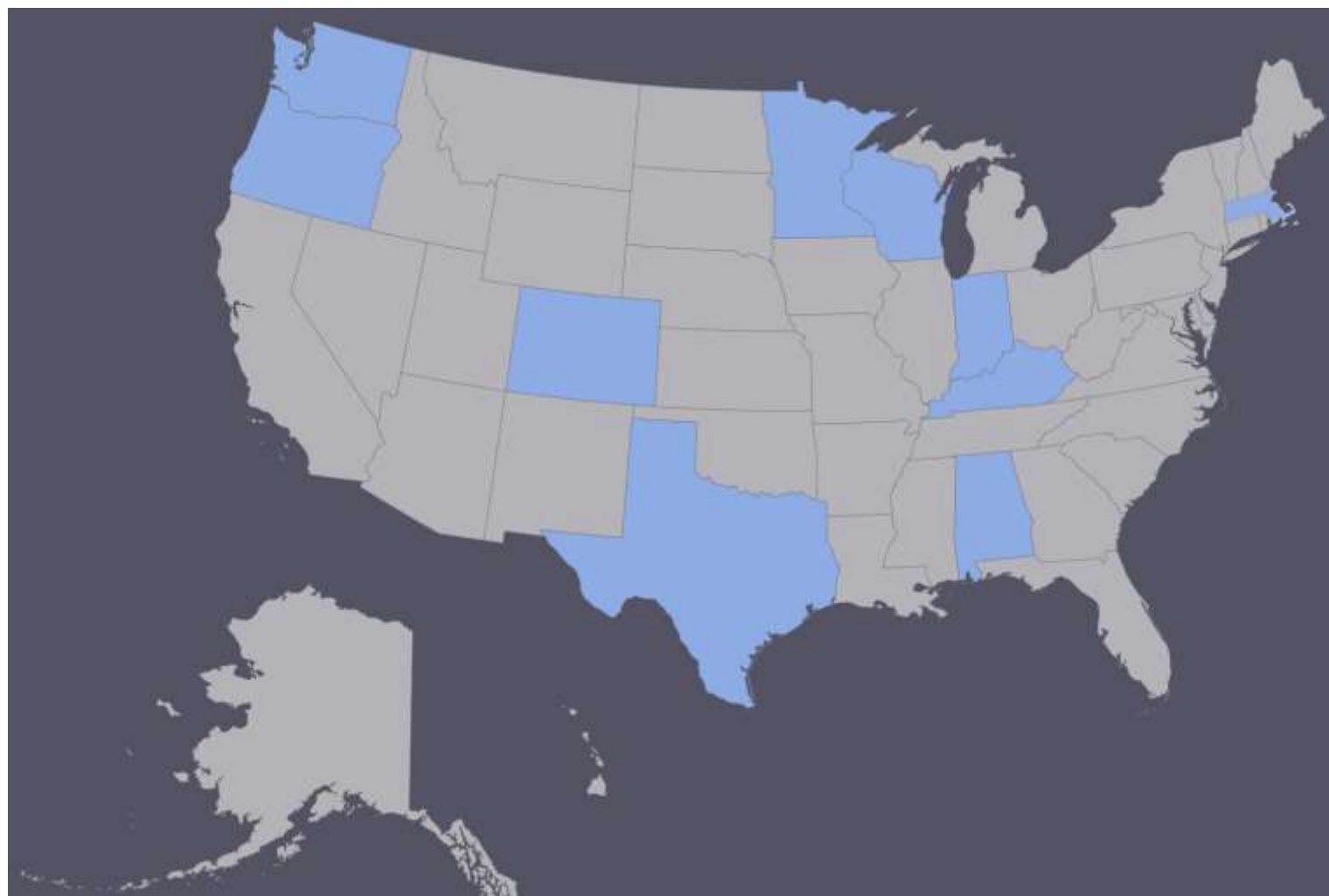
- Four-year cooperative agreement with MCHB
 - Launched in August 2017 – ending July 2021
- Improve
 - Quality of life for children with medical complexity
 - Well-being of their families
 - Cost-effectiveness of their care



CMC CoIN objectives

- Increase by 50%
 - Cohort-enrolled CMC who have a single locus of care in a medical home and a shared plan of care
 - Families of cohort-enrolled CMC who report family engagement on the individual clinical level
- Increase by 25%
 - Families of cohort-enrolled CMC who report previously unmet needs being met
- 25% of state teams will have piloted an innovative payment model





Ten State Teams

- Alabama
- Colorado
- Indiana
- Kentucky
- Massachusetts
- Minnesota
- Oregon
- Texas
- Washington
- Wisconsin



Select technical assistance and training supports

- Individual state team QI coaches
- Annual two-day state team learning session
- Quarterly webinars
- Monthly e-newsletter
- Annual individual state team consultation visits
- Annual family focus groups
- Family Engagement in Systems Assessment Tool (FESAT)
- Consultation with National Advisory Committee members (by request)
- Care Coordination Academy
- **COVID-19 & CMC ECHO**



Project ECHO

(Extension for Community Healthcare Outcomes)

- A tele-mentoring medical education program designed to create communities of learners by bringing together health care providers and experts using didactic and case-based presentations
 - “All Teach, All Learn”
 - Encourages knowledge exchange
 - Utilizes technology
 - Promotes case-based learning



COVID-19 & CMC ECHO

- Launched May, 2020 in partnership with the AAP
- Developed in response to need for CMC-specific information during the pandemic
- Two topics per month, alternating between cohorts
- Two cohorts
 - CMC CoIIN state teams (interdisciplinary – closed to CMC CoIIN affiliates)
 - General CMC community (primarily physicians; mostly primary care – open to anyone)
- Meets every Wednesday at 11 AM ET
- 12 session topics to date



COVID-19 & CMC ECHO faculty

- Rishi Agrawal, MD, MPH, FAAP
- Jeffrey Brosco, MD, PhD, FAAP
- Cara Coleman, MPH, JD
- Meg Fisher, MD, FAAP
- Dennis Kuo, MD, MHS, FAAP
- Jennifer Lail, MD, FAAP
- Marie Mann, MD, MPH, FAAP
- Judy Palfrey, MD, FAAP
- James Perrin, MD, FAAP
- Rylin Rodgers
- Chris Stille, MD, MPH, FAAP
- Carol Weitzman, MD, FAAP



COVID-19 & CMC ECHO session topics and presenters

Date	Topic	Presenter(s)
May 20, May 27	What we know about transmission and disease presentation in CMC – what do we need to know?	Meg Fisher & Dennis Kuo
June 3, June 10	Home care supports part 1: Home nursing & personal care attendants	Jennifer Lail
June 17, June 24	Home care supports part 2: Access to other services and supports (DME, medications, medical foods, social supports, etc.)	Cara Coleman
July 1, July 8	Back to school considerations part 1: Return to school decision making	Nathaniel Beers and Stephanie Porter
July 15, July 22	Telehealth part 1: Best practice strategies for providing care via telehealth	Chris Stille (15), David Fox (22)
Aug 5, Aug 12	Back to school considerations part 2	Nathaniel Beers

Date	Topic	Presenter(s)
Aug 19, Aug 26	Telehealth part 2: reimbursement strategies/coding	Linda Walsh, AAP
Sept 2, Sept 9	Supporting the mental health needs of CMC/siblings/parents	Kourtney Santucci and Kristina Malik – CO Children's
Sept 16, Sept 23	Burnout and secondary trauma: clinicians	Heather Forkey
Oct 7, Oct 14	Impact of COVID-19 on immunization rates, including influenza, for CMC	Meg Fisher
Oct 21, Oct 28	Testing considerations for children with medical complexity	Meg Fisher
Nov 4	Social Determinants of Health issues and inequities	David Ming and Neal deJong
Nov 18	Family-centered virtual care coordination	Rich Antonelli
Dec 2, Dec 9	AAP guidance on family presence in hospitals	TBD
Dec 16	Emergency planning for CMC, families and providers	Renee Turchi



”Big picture” categories of concern/need

- National/state/local policies/mandates
- Child’s health status
- Child’s capacity to adhere to infection control guidelines
- School policies/resources
- Mental health needs
- Distance learning
- Inclusion/SPED/legal considerations
- Family needs/preferences



Questions from school re-opening sessions

- High degree of uncertainty among families, pediatricians and educators
 - What is known about transmission among children in general and vulnerability of CMC specifically?
 - Who is involved in making decisions on the federal, state and school district level – what are their priorities?
 - Clinical guidance and shared decision-making – who to trust?
 - What are the decision points needed to determine whether an individual child can return to school safely? What weight do you place on each?
 - Funding for adaptations – will schools have the resources they need to follow clinical guidance?



Highlights from school re-opening sessions – select decision points

- **Considerations re: going back to in-person learning**
 - Parents' need to work
 - Remote learning didn't work for many CMC
 - IEP/504 plan compliance
 - Loss of therapies, social opportunities, other services/supports provided in school
 - Academic, therapeutic and developmental stagnation/regression
 - Mental health stressors on everyone
- **Considerations re: not returning to in-person learning**
 - Transmission rates in local area
 - Child's baseline health status, especially pulmonary and immune systems
 - Child's need for aerosolized procedures
 - Low availability of PPE, ability of child to wear a mask, adhere to social distancing and handwashing
 - Poor ventilation in classroom/school building – crowding
 - Risk tolerance and past medical trauma



Some early learnings

- Many children and families have high levels of physical and emotional stress related to poor experiences with remote learning, the strong desire to return to in-person learning for many compelling reasons, and fear about the safety of doing so
- Decisions are often being made on an ad hoc, individualized basis due to conflicting guidance from national, federal, state and local authorities
- Practical strategies such as desensitizing CMC to mask-wearing need to be more widely spread
- Greater attention to improving remote learning for CMC and access for all children is required
- Algorithms with standardized decision points can help pediatricians advise and families make decisions about returning to in-person learning
- **Shared decision-making between schools, pediatricians and families is key**



Select resources

- July 1 & 8, 2020: School re-entry for CMC
 - Nathaniel Beers and Stephanie Porter, didactic presenters. Link to recording, slides and other resources: <https://cmccoiin.box.com/s/9hj2cs1ucklile1gfoyfibjgcb3k8gzp>
- August 5, 2020: Supporting Education of CMC in the Era of COVID-19
 - Nathaniel Beers, didactic presenter; Stephanie Porter, discussant. Link to recording, slides and other resources:
 - <https://cmccoiin.app.box.com/folder/119798725565?s=8uqv8jrckt6qjfpgalcsh1emejifodyr>
- 8/19/20 AAP COVID-19 Planning Considerations: Guidance for School Reentry <https://services.aap.org/en/pages/2019-novel-coronavirus-covid-19-infections/clinical-guidance/covid-19-planning-considerations-return-to-in-person-education-in-schools/>
- The COVID-19 and CMC ECHO is scheduled to run through the remainder of the year and into the first quarter of 2021. **To sign up to get notice of future sessions, email Amy Shah at ashah@aap.org.** (And tell your friends!)



Questions/Discussion

