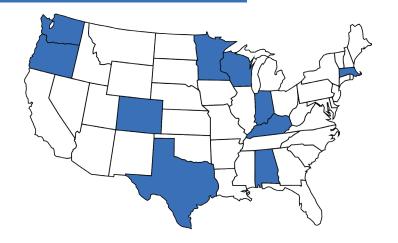


to Date



**Boston University** School of Social Work Center for Innovation in Social Work & Health The federal Maternal and Child Health Bureau has funded this Collaborative Improvement and Innovation Network (CollN) to test and spread promising care delivery strategies and innovative payment models for children with medical complexity (CMC). The goals of the CMC CollN are to improve the quality of life for CMC, the wellbeing of their families, and the cost-effectiveness of their care through development and implementation of innovative care and payment models. The CMC CollN is in Year 3 (through July 2020) of 4 total years (project ending in July 2021).

## Who We Are



**205+** individuals involved in the CMC CollN

**153+** team members across 10 state teams

**23** National Advisory Committee members

**15** individuals across 5 partner organizations

**6** MCHB partners (leadership and project officer)

8 Boston University evaluation team members

#### Key stakeholder groups on each state team, including:

- Title V MCH/CSHCN staff
- Family leaders
- Family-led organization representative(s)
- Youth and young adults with medical complexity
- Primary care medical home representative(s)
- Children's hospital representative(s)
- Medicaid and CHIP liaison(s)
- Private insurance and managed care liaison(s)
- State departments of health or human services representative(s)
- CMC practice site representative(s)

### What We Do

#### State team project focus areas

- Care coordination
- Supporting rural care via telemedicine and virtual care teams
- Transitions from youth to adult care, and from hospital to home
- Family/patient engagement
  - Family leaders as required members of QI team
  - Shared decision-making at the clinical level through shared plan of care (SPoC)
- Innovative partnerships
- Testing of innovative payment models

### **Target populations**

The state team projects focus on children with significant, chronic health problems that affect multiple organ systems, resulting in functional limitations, high health care need or utilization, and often the need for or use of medical technology. Other characteristics include specific durable medical equipment needs, age, transition to adult health care services, children living in rural areas, and candidates for specific types of procedures and diagnoses. **1,674+** CMC have been enrolled in interventions across the 10 state teams.



## How We Do It



#### **Family Engagement**

- Family partnership is at the center of the CMC CollN
- 33+ family representatives across 10 state teams
- 4 family leaders on the National Advisory Committee
- Family Voices National is a key collaborative partner
- Family representation on the measurement development work group
- Family Engagement spotlight in each <u>newsletter</u> to highlight activities and best practices
- Family Experience Survey Finalized
  - Utilized for outcome data collection by all state teams
  - 581 families surveyed across 10 state teams
- Family Focus Groups
  - **37** Family Focus Group Work Group members, with at least 2 family leaders from each of the 10 state teams, developed family-led qualitative focus group questions
  - 73 families participated in first round
- Family Engagement in Systems Assessment Tool (FESAT) baseline completed



#### **Technical Assistance to State Teams**

- Coaching Calls: 190 hours total across 10 state teams (130 hours this year)
- **Webinars: 17** state team learning webinars to date (**5** this year)
- Learning Sessions: 2 in-person learning sessions to date
- Consultation Visits: 10 on-site consultation visits, 1 for each state team
- **Expert Consultation: 36** one-on-one expert consultations to date (**16** this year)
- QI Tools: 9 QI tools shared to date with state teams by collaborative partner Population Health Improvement Partners
- Office Hours: 16 monthly open office hours held (10 months this year)
- **Resource Library:** Online literature and resource library for state teams with **370+** academic papers, policy briefs, and other resources to date (**305+** added this year)



# **Team Innovations & Cross-sharing**

- 9 instances to date of connecting state teams through shared areas of interest (4 this year)
- 150+ shared project-related files by state teams for state teams
- Peer cross-sharing during learning webinars and in-person meetings
- Google Groups on care coordination, shared plan of care, and family engagement
- Role-based affinity groups for state team leadership, Title V staff, and care coordinators
- Topic-specific calls, like EPIC user group



# Guidance and Consultation from the National Advisory Committee (NAC)

- Nationally recognized and experienced family leaders, clinicians, researchers, and other stakeholders
- **7** quarterly NAC meetings to date (**3** virtual meetings and **1** in-person meeting per year)
- NAC one-on-one consultations at state team on-site consultation visits and during NAC quarterly meetings



# **State Team Accomplishments**

All state teams finalized and started their first QI project and began—and some even finished—enrolling their cohort receiving the intervention.

**Alabama** Team Alabama, in conjunction with families and staff at the University of South Alabama Pediatric Complex Care Clinic (USC PCCC) and Children's Rehabilitation Service, developed a SPoC, which has received positive feedback from families. Through the CoIIN project, a CRS Care Coordinator has been providing care coordination services at the USC PCCC, which have had a positive impact in the quality of life for CMC and their families.

**Colorado** Team Colorado continues to rely upon the Coordination Plus Advisory Team and recently finalized their family engagement strategy to create a vision statement for family participation within the Special Care Clinic. They have had multiple successes in adapting the electronic medical record to facilitate co-management, including the co-managed identifier, piloting the role clarification table, standardizing communication to community partners, and clarifying follow-up appointment timeline with families.

**Indiana** Team Indiana built a state pediatric complex care coordination resource team at the school of medicine, built a care coordination team in two primary care practices—urban and rural—and enrolled 135 patients.

**Kentucky** Team Kentucky examined how to improve family engagement and family satisfaction based on survey data. Additionally, they finalized and distributed marketing material, including family and provider brochures and letters in Spanish and English. They also received additional referrals for virtual care team conferences (VCTC), which include a nurse, the VCTC coordinator, parent, and the family engagement leader.

**Massachusetts** Team Massachusetts has worked closely with their family advisory board and consultants to develop and implement the ENGAGE program for families of children with complex medical needs undergoing hip surgeries. So far, six patients have been enrolled in ENGAGE and are at various stages of the program. The major interventions are case coordination, the Get To Know Me form, and the SPoC.

**Minnesota** Team Minnesota conducted a full-day Care Coordination Seminar in June 2019, with three national speakers and 150 primary care, specialty care, public health and school clinicians and parents. They also garnered cohesion/gelling of their QI team, emphasized recognition of parent advisor expertise, and initiated several PDSA cycles focused on building infrastructure to support a rapidly growing complex care clinic.

**Oregon** Team Oregon created the youth-to-adult care transition workbook with their multidisciplinary implementation team of clinical partners, Title V, and family representatives. Additionally, they successfully collected baseline clinical staff survey data and shared the aggregated results with clinical partners and implementation team members, and used the data to inform revisions to their QI project.

**Texas** Team Texas developed and tested an electronic SPoC (with currently over 100 patients and 35 parents using the mobile version). They also signed a per member per month (PMPM) agreement with a managed care organization (MCO) for delegation of service coordination. They implemented the first phase of integrated service delivery with four sub-specialty service lines.

**Washington** Team Washington successfully implemented their Birth to One program, assuring activation of all medical and service referrals for newly-discharged CMC infants. At their one-year milestone, they graduated 7 of 85 currently enrolled families who are now able to navigate the health care system with minimal support, who are connected to a medical home, a nutrition home, and early intervention services. They have also engaged collaborators across agency silos to identify barriers and address system improvements in assuring activation of ESIT (early intervention) referrals and nutrition continuity.

**Wisconsin** Team Wisconsin tested, implemented, and improved new workflows to improve the percentage of Complex Care Program patients receiving services through Wisconsin's Children's Long-Term Support waiver. They developed tools including "goal cards" to facilitate discussions with families about their goals for their child to address this part of the SPoC.

# **Products/Outputs**

- Maintained a public-facing website for project and technical assistance materials
  - Number of pageviews: 2,186
  - Number of unique visitors: **1,622**
- 8 presentations to date by Boston University, partners, and state teams
  - **6** by BU and partners
  - 2 by state teams
  - **Upcoming: 1** presentation at the Association of Maternal and Child Health Programs' 2020 annual conference (Fall 2020) by BU and state teams
- Measurement Activities
  - Implemented Network-level Quality Improvement Measures Surveys with families across 10 state teams and completed baseline data collection by November 2019
    - Translated surveys into Spanish
    - 9 out of 10 state teams have added supplemental questions
  - Quality Improvement Data Aggregator (QIDA) for ongoing project monitoring through run charts
- Quality Improvement Tools
  - 9 OI tools shared to date
  - Tip sheets for recruitment with team-generated content
  - Tips for Recruitment
  - Tips for Selling Your Project to Partners
  - Measurement guides
  - State team toolkit for data collection and entry

# **Looking Ahead: Pivoting in the Wake of COVID-19**

- COVID-19 ECHO (<u>Extension for Community Healthcare Outcomes</u>) for CMC with collaborative partner, the American Academy of Pediatrics
  - To include one CMC CollN cohort and one external cohort
- One-hour pop-up support webinar series
- Vetted resource library of COVID-19 CMC resources available to the public on the CMC CollN webpage
- Monthly newsletter highlight on COVID-19 response for CMC
- Reconfiguring state team monthly project update to capture COVID-19 learnings and innovations
- Formation of telehealth work group to implement telehealth measures in family survey and beyond
- Care Coordination Academy (with Dr. Rich Antonelli and the National Center for Care Coordination Technical Assistance), with focus on COVID-19

# **Thank You to Our Partners**











