

CHARTING THE COURSE TO BETTER CARE FOR CHILDREN WITH MEDICAL COMPLEXITY: **The CMC CoIIN: Capturing the Journey**

*Has your team ever struggled to capture the essence of a project in a compelling way?
This article offers a powerful, captivating visual tool.*

What is the CMC CoIIN?

Children with medical complexity (CMC), a subgroup of children and youth with special health care needs (CYSHCN), have been characterized as having substantial family-identified needs, chronic and severe conditions, functional limitations, and high health care use (Cohen et al., 2011)¹. In 2017, a learning collaborative - the Collaborative Improvement and Innovation Network to Advance Care for Children with Medical Complexity (CMC CoIIN) - was created to test and disseminate promising care delivery strategies and innovative payment models to improve quality of life for CMC and the well-being of their families.

In this four-year project funded by the Maternal and Child Health Bureau under the Health Resources and Services Administration (HRSA), multi-disciplinary teams from across the country consisting of family leaders, pediatric primary and specialty care clinicians, leaders of integrated health care delivery systems and/or freestanding children's hospitals, state Title V CYSHCN program staff, and Medicaid leaders work together to test strategies and build evidence for optimizing high quality, cost-effective, family-centered care for CMC.

What is a Journey Map?

In Year three (2020) of the CMC CoIIN project, each state team developed a journey map. As a quality improvement (QI) project, maps provide a way to effectively visualize opportunities for improvement in each team's journey towards shared objectives. These maps are individualized but share core components including lessons learned, resources needed, challenges faced, progress made, and the people and organizations involved.

A graphic artist, often specializing in mapping illustration, works with a team to graphically represent team discussion and reflections to develop a journey map.² Karina Branson, founder of [ConverSketch](#), created the featured "journey maps".

¹ Cohen, E., Kuo, D., Agrawal, R., Bhagat, S., Simon, T. and Srivastava, R. (2011). Children With Medical Complexity: An Emerging Population for Clinical and Research Initiatives. *Pediatrics*. 2011 Mar; 127(3): 529–538. doi: 10.1542/peds.2010-09101

² Computer software is also available to create journey maps.



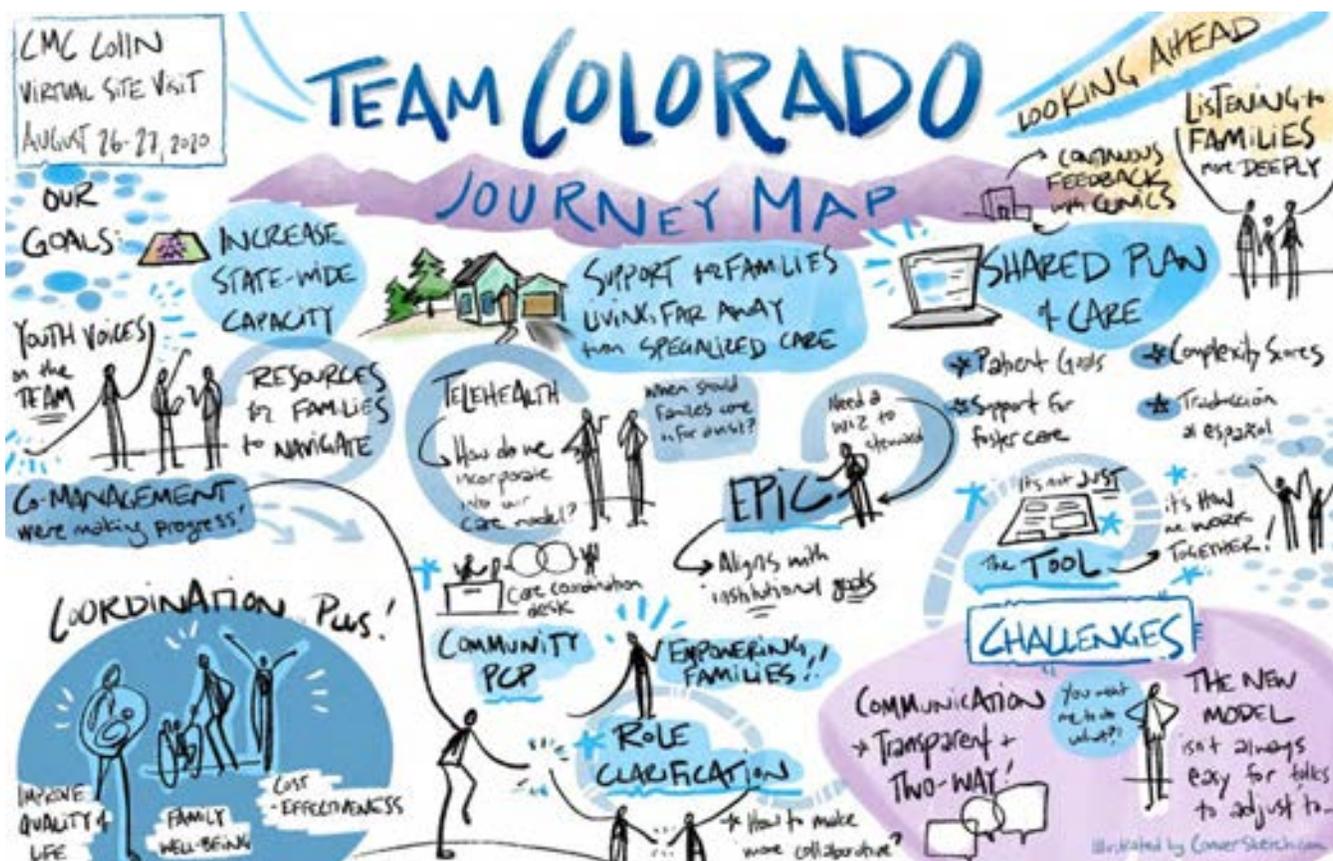
How Can a Journey Map Help Tell a Story?

The CMC CoIN state teams used their maps to **gain qualitative insights** into the evolution of their project journey: where they have been, where they are going and what they need to ultimately achieve their goals.

Every state has a **unique map that captures the essence of their CoIN projects**. States describe their maps as “clarifying, focused and enlightening;” “adaptable, comprehensive, and [reflective of] COVID stressors;” “family-centered, learning-[focused] and relationship-[driven];” and “a useful historical record of the steps we have taken together.” A common theme of many team journey maps is the importance of engaging and partnering with families.

Teams have **integrated their journey maps into the broader work** of their programs and sponsoring organizations. One state remarked that its map “identifies the areas on which we need to focus more, [including] policy support and meaningful family partnerships.” Another state indicated that “for the past year, our primary

focus has been to better support families and increase clinic staff to provide better coordinated care. We used metrics from the QI measures survey to guide this work and help justify the need for more staff."



CMC COLIN
VIRTUAL SITE VISIT
OCTOBER 1, 2020

TEAM INDIANA

LESSONS LEARNED and NEXT YEAR

2020 ACCOMPLISHMENTS

OUR JOURNEY MAP



CMC COLIN
VIRTUAL SITE VISIT
JUNE 16, 2020

TEAM TEXAS' JOURNEY

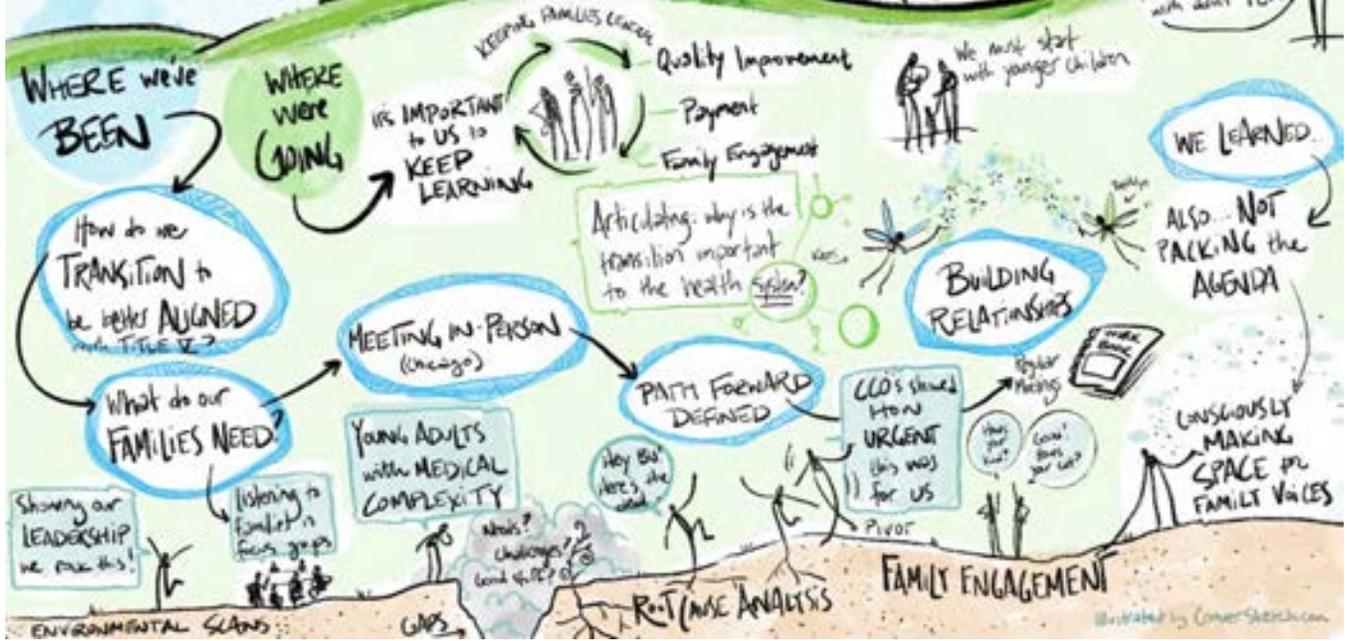
This team has made this complex work so CLEAR to others
MOVING FORWARD
Leaving a SOLID FOUNDATION for a BIGGER PILOT



CMC Lollin
VIRTUAL SITE VISIT
JULY 25, 2020

TEAM OREGON

OUR JOURNEY MAP



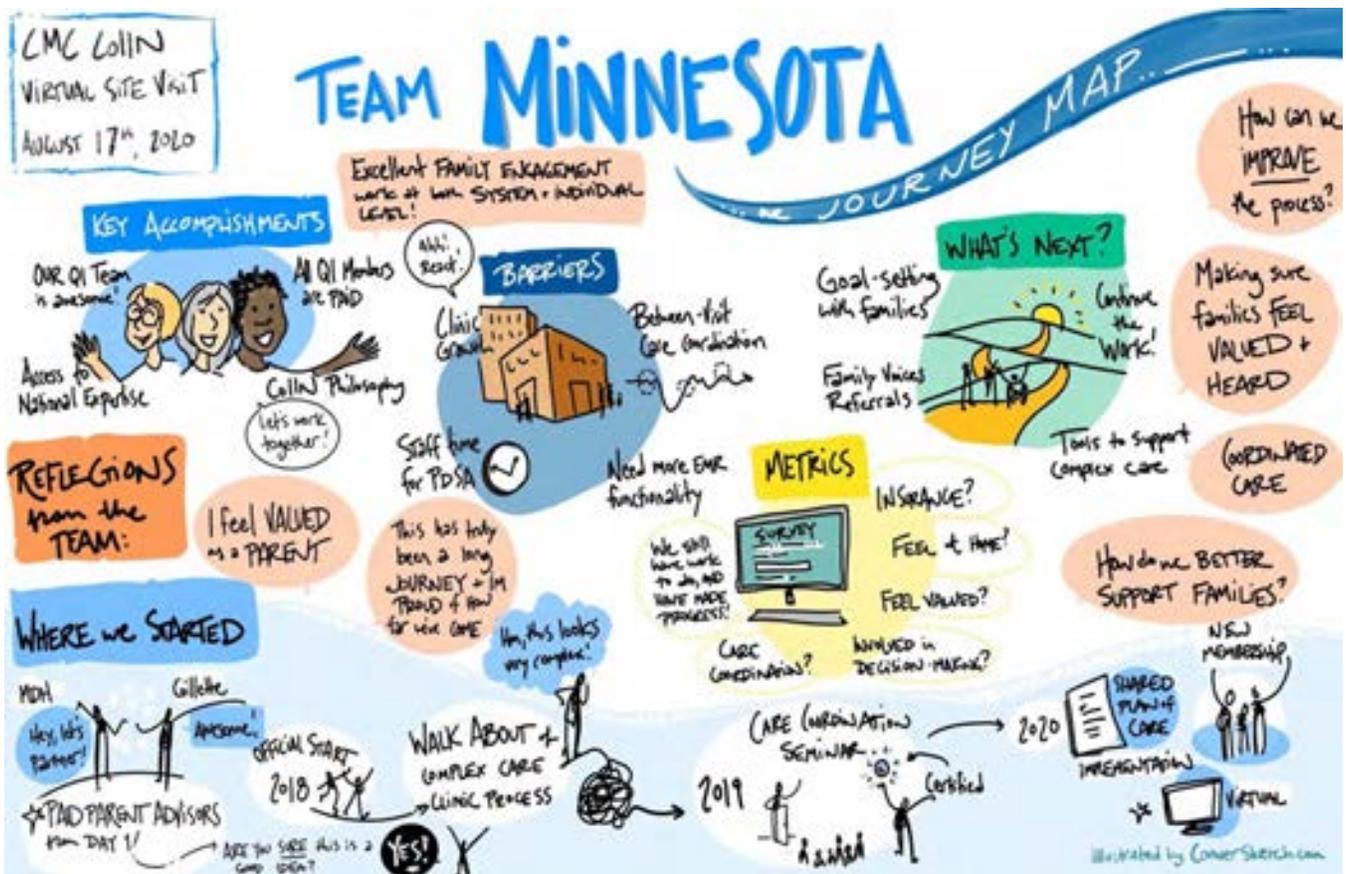
CMC Lollin
VIRTUAL SITE VISIT
SEPTEMBER 8, 2020

TEAM MASSACHUSETTS



Journey maps are also **useful tools for communicating a team’s work to a wider audience**. This is especially helpful for those who are visual learners and can better understand, or conceptualize, the information through this type of representation. States shared how they used their maps as communications tools:

- “We used these images to communicate our goals and progress and the importance of family engagement to leadership and other departments.”
- “We have shared [our map] on a Cabinet level, staff level and with our families via social media.”
- “It is a great way to start the conversations and add a visual overview to any presentation or conversation around our work.”



Journey maps are a creative, engaging, and valuable way to share work with teams, organizations, and families. As one team member stated, “It is a wonderful visual representation of our experience in the CMC CoIIN and has been shared with upper management and the full team.... we realized the benefit of hanging the journey map in the clinics to show families how we have and are continuing to work to improve the way we serve them.”

Full-size journey maps can be viewed [here](#). For more information on the CMC CoIIN journey maps, please contact Bethlyn Vergo Houlihan, at bvergo@bu.edu.

CMC COLLIN
VIRTUAL SITE VISIT
AUGUST 6-7, 2020

TEAM WISCONSIN

OUR JOURNEY MAP



WHERE WE'VE BEEN

What LEVEL Focus on?



PARTNERS:

YOUR ROLE:

- AFDT** - Informal representation
- CAW** - Clinical partner + leadership
- FAMILY PARTNERS** - Providing day-to-day realities + families
- FAMILY VOICES** - Bringing collective voice + families to the table
- BASED + CHAIRMAN SPONSOR** - Building a more collaborative relationship to support families
- TITLE V** - Supporting participation, Quality improvement in working
- REGULATORY CONCERNS** - Smooth journey for care
- WMTA II** - SPOC and home care pipeline
- YOUTH HEALTH TRANSITIONAL INITIATIVE** - System level work, Training + technical support for Transition work

How DOES CMC COLLIN RELATE to YOUR OTHER WORK?

- Learning + applying to other projects
- Learning's collaborative!
- Learning work on an already doing
- SYSTEMS PROSPERITY in CARE** - Better advocate!
- Representing many unique children
- More great communicators
- Standing next + voice
- Dealing Together Guide
- SPOC + Goals are all aligned!
- Improving kids quality of life
- We work with the SPOC families
- SPOC quality improvement
- Challenges + benefits of coordinated care + how we support other families with different needs

WHAT are You EXCITED ABOUT?

- Collaborative care for these children!
- Collaboration for INTACT STATE-WIDE?
- Advocating for DIVERSE ACCESS + EQUITY + LOVE
- This is a STRONG and EFFECTIVE COLLABORATION!
- Learning + growing + improving our representation
- Continuing to develop a working partnership!
- Cross-department collaboration
- Expanding use of Goal Cards
- Welcoming families + sharing resources
- Contributing to learn + work together
- Sharing what we've learned + developed with other providers

Illustrated by CoverSketch.com

CMC COLLIN
VIRTUAL SITE VISIT
JULY 16-17, 2020

Team Alabama

JOURNEY MAPPING

YEAR 4: WHAT'S AHEAD



FAMILY ENGAGEMENT!



ACCOMPLISHMENTS

LESSONS LEARNED

Building a Plan to CMC making change happen!



How can we ALL WORK TOGETHER + SUPPORT CHILDREN + FAMILIES?

Listening to kids + families!

Practice Site Coordinator

Meeting in-person

PARTNERS in CARE SUMMIT

Learning from Coaches

Listening with families

DEVELOPING + SHARED PLAN + CARE

How to make sure families bring to every appointment?

METRICS

CYCLE 1: pilot + survey

CYCLE 2: Roles more clearly defined

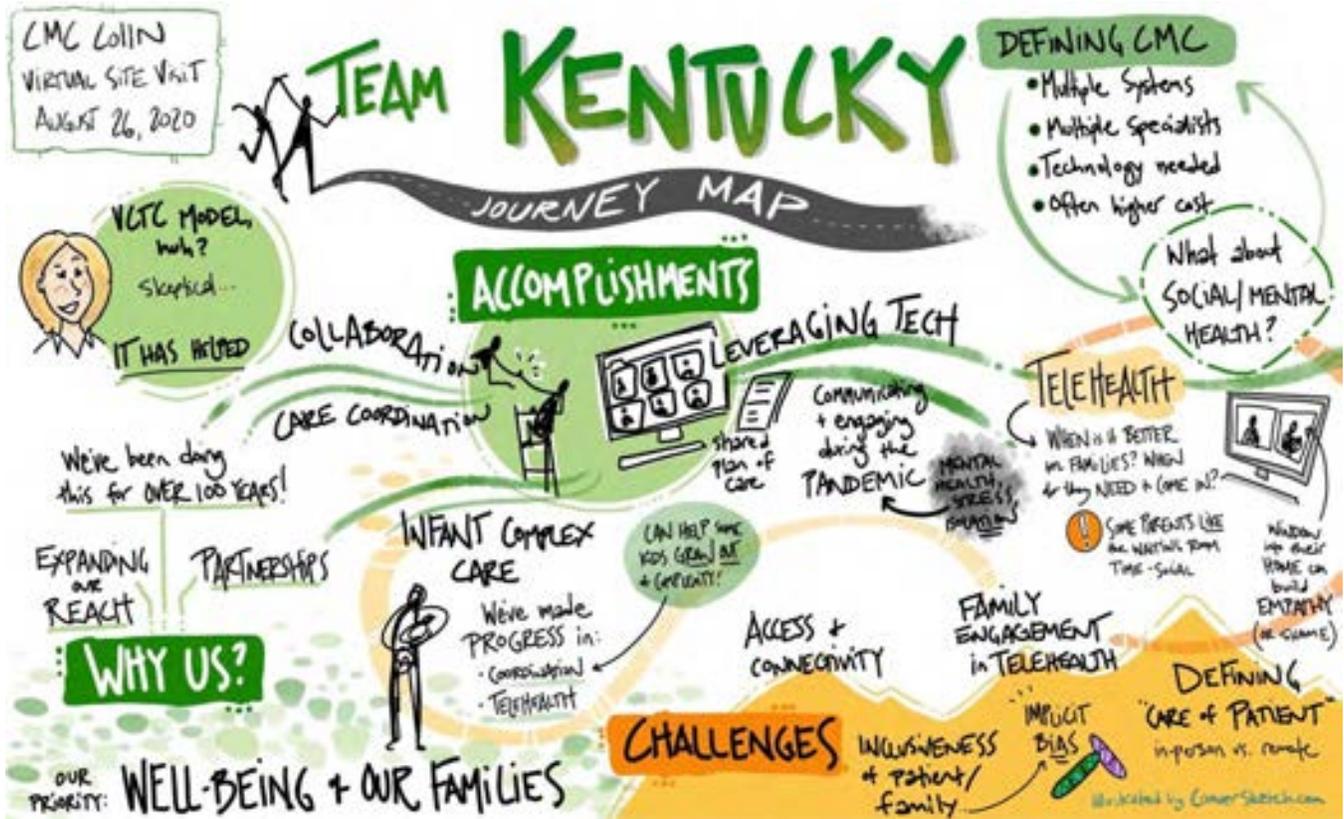
CYCLE 3: Under way: 3 CRIS in 2020

working on ASKING FAMILIES

WORKING WITH FAMILIES + EXPERTISE

CARE COORDINATION

Illustrated by CoverSketch.com



Disclaimer

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