

Caring for children with medical complexity through transformative family partnership

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Agenda

- Introduction – Rebecca Sax, National Center
- Housekeeping – Rebecca Sax
- Presentation:
 - Maureen Benschoter, MD, CMC CoIIN Dell Children’s Medical Center Comprehensive Care Clinic, Austin, TX
 - Rahel Berhane, MD, CMC CoIIN Dell Children’s Medical Center Comprehensive Care Clinic, Austin, TX
 - Meg Comeau, Boston University CMC CoIIN
 - Bethlyn Houlihan, Boston University CMC CoIIN
 - Judy Palfrey, CMC COIIN Project, Boston Children’s Hospital
 - Sarah Perkins, CMC CoIIN Project, Boston Children’s Hospital
- Q&A
- Wrap-up & next steps – Rebecca Sax

Housekeeping



- This event is being recorded. The recording and slides will be emailed to you after the webinar
- Please keep yourself on mute (by phone or on the Zoom platform)
- All questions and resources should be submitted through the chat feature



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Collaborative Improvement and Innovation Network to Advance Care for Children with Medical Complexity (CMC CoIN)

Four-year quality improvement project funded by the federal Maternal and Child Health Bureau



10 state teams across the country



Shared goals:

- Improve the quality of life for children with medical complexity
- Improve the well-being of their families
- Improve the cost effectiveness of their health care

Boston University School of Social Work
Center for Innovation in Social Work & Health

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number #UJ6MC32737: *Health Care Delivery System Innovations for Children with Medical Complexity* (\$2,700,000 annually). This information or content and conclusions are those of the authors and should not be construed as the official position or policy of, nor should any endorsement be inferred, by HRSA, HHS or the U.S. government. Anna Maria Padlan, HRSA/MCHB Project Officer

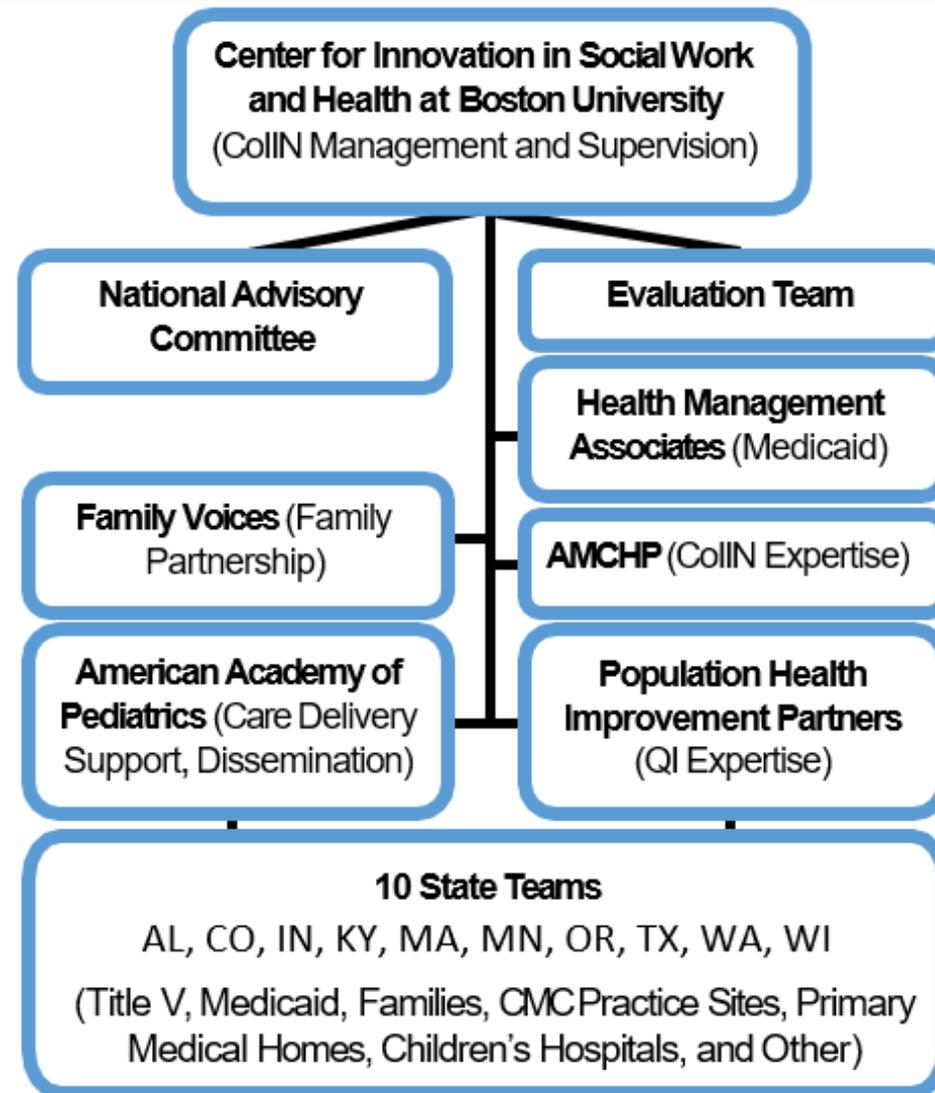


Who do we mean when we say *children with medical complexity*?

- Children and youth between ages 1-21 with:
 - Multiple, significant chronic health problems that affect multiple organ systems;
 - Resulting in:
 - a) functional limitations and b) high health care **need** or utilization; and,
 - Often the need for or use of medical technology
- Examples: kids with tracheotomies on ventilators living at home, children dependent on tube feeding, children with severe neuromuscular impairment

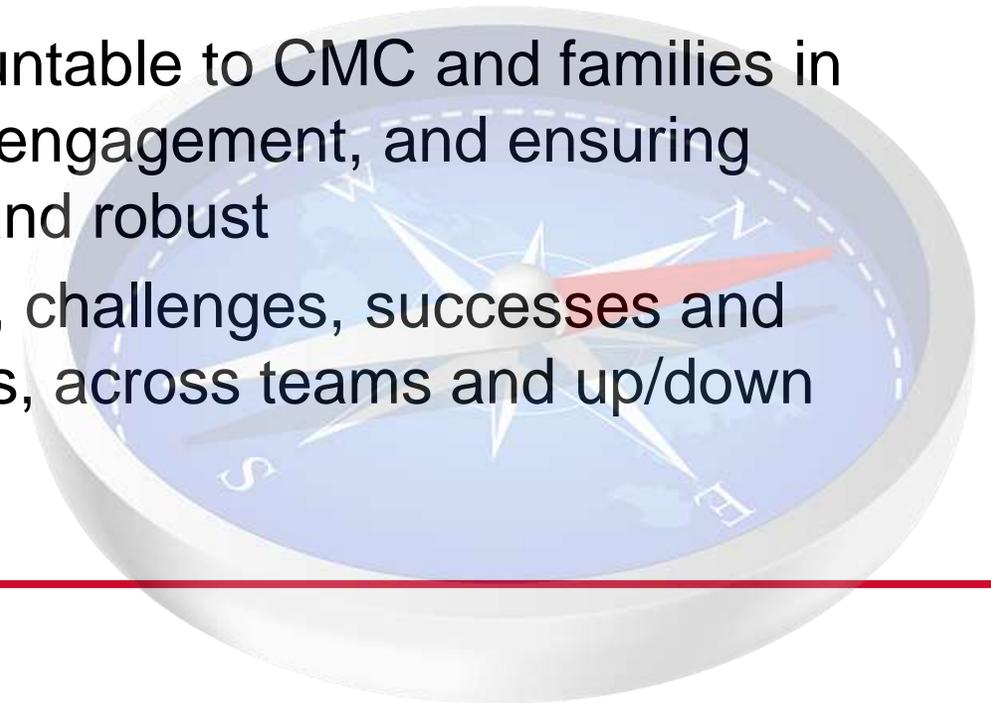


CMC CoIN Project Structure

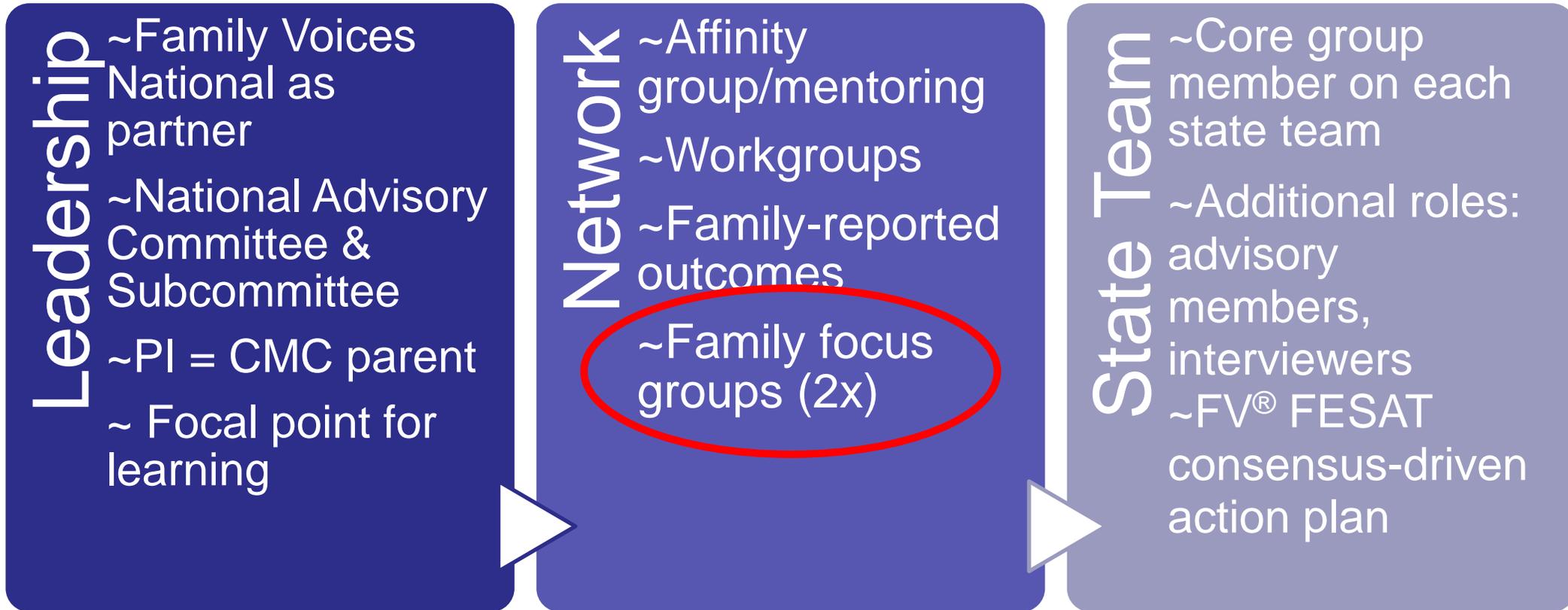


CMC CoIIN Guiding Principles of Family Engagement

- **Equity:** all family voices are equal, regardless of role, child's diagnosis, status as a paid family leader or a volunteer. Family voices are equal to those of clinicians/other team members
- **Accountability:** project leadership is accountable to CMC and families in providing opportunities for authentic family engagement, and ensuring that state teams' activities are meaningful and robust
- **Transparency:** information about activities, challenges, successes and learning is shared across roles within teams, across teams and up/down the hierarchy of project management



Structures to Ensure Power Sharing w/ Family Partners



Measuring child quality of life, family well- and unmet need

- Designed a written survey to capture families' experiences
- Family leaders told us that wasn't going to be enough
 - We needed to hear the stories behind the data, to get a full picture of what life is like for CMC and their families
 - Organized a workgroup composed primarily of family leaders, led by a parent, which created a focus group guide with qualitative questions
 - Conducted focus groups in each state, transcribed, cleaned, coded and analyzed the data



What did we learn about unmet need from focus groups?

Lack of awareness of challenges associated with raising CCHN/CMC among general public, providers, extended family and friends

Care team helps to minimize **medical** unmet need through:

- Communication across team
- Providers going above and beyond
- Parents engaged on care team

Overall lack of support for tangible needs (e.g., child care, other kinds of physical help) and intangible needs (i.e., emotional) from family members, friends, wider community

Social and community-based needs are often unmet, which stand outside medical needs – there is a great divide between them



What strategies did families identify for improving child QoL, family well-being and reducing unmet need?

What did project leadership and the state teams do about them?



PUTTING FAMILY FOCUS GROUP RESULTS INTO ACTION WITHIN AND BEYOND the COIIN



PARTNERSHIP
COLLABORATION
TEAMWORK
FAMILY ENGAGEMENT

IMPROVE CHILD QUALITY OF LIFE + FAMILY WELL BEING

FAMILIES ARE THE CORE OF SUSTAINABILITY

UNMET NEEDS

ASK US WHAT WE NEED
SOCIAL SUPPORT
TANGIBLE + INTANGIBLE

MORE HELP WITH SOCIAL, SOCIETAL + MENTAL HEALTH

FAMILY RECOMMENDATIONS

I FEEL LONELY + ISOLATED

MEDICAL HOME

FAMILY WELL BEING

SHARED PLAN OF CARE

CO-CREATING THE PLAN

FAMILY

MULTI-LEVEL SUPPORTS NEEDED

CARE TEAM'S INFLUENCE

CRITICAL PARTNERS

PEOPLE LISTEN TO THEM

NEED FOR IMPROVED MEDICAL COORDINATION

REFLECTIONS

PALLIATIVE CARE

HOPES + DREAMS

WE ALL NEED TO INCORPORATE PALLIATIVE CARE!

CHANGES QUALITY OF LIFE FOR WHOLE FAMILY

THE WORD SCARES PEOPLE - HELP THEM UNDERSTAND IT'S ABOUT SYMPTOM MANAGEMENT

FEELS LIKE HOME

COVID IMPACT

MORE ISOLATED

MORE FEAR

TELEHEALTH



WE CAN FIT INTO MORE THAN ONE BOX

WORK ACROSS SILOS

VOTE!

TESTIFY

GET THIS WORK IN FRONT OF POLICY MAKERS

TELL STORIES!

FRAME IN COVID WORLD

WE ARE AGENTS OF CHANGE

PUSH FORWARD

BUILDS A PATHWAY OF SUPPORT TO A LARGER COMMUNITY



LEARNINGS TO ACTION

BIRTH ONE



MEET WITH PEOPLE IN THEIR HOMES

FAMILY NAVIGATORS

WARM HAND OFFS

MONTH TO MONTH VISITS

VIRTUAL SPACE FOR FAMILIES

CONNECT WITH FAMILIES ON A LARGER SCALE



fb SUPPORT GROUP

PEER TO PEER SUPPORT

SUSTAINABILITY

ALL 10 STATE TEAMS

2019-EARLY 2020

FOCUS GROUP

HIGHLIGHTS

68 FAMILIES

Multi-Level Systems Transformation to Meet Needs of Families

- Individual clinical level – adapted to different cultures/backgrounds → Best practices/lessons learned (family-centered approaches!)
- Systems design, implementation, evaluation → CMC CoIN → Family partners; philosophical/operational models, tools, resources, assessments
- Systems – payer level → Metrics! Current/needed

If the family isn't healthy, the child can't be healthy



HEALTH EQUITY

VIRTUAL LEARNING SESSION - OCT. 27 2020

UNMET NEED - IMPACT OF 3 OVERLAPPING CRISIS ON CMC AND THEIR FAMILIES

PANDEMIC RACISM
RECESSION

ABLEISM/RACISM/CLASSISM

OUR ROLE
UNMET NEED IN THE COLLIN

COVID IS AMPLIFYING NEED

COVID SURVEY RESULTS AVAILABLE

THERE IS A DISCONNECT BETWEEN FOCUS GROUPS + SURVEYS

FAMILIES DON'T KNOW WHAT THEY DON'T KNOW

WE'RE CHANGING THE QUESTION RE: UNMET NEED

MOVE BEYOND THE STANDARD CHECKLIST

IMPROVE THE SYSTEM

LOOKED AT 20 FAMILIES IN INDIANA...

WE ASKED:

WHAT DO YOU NEED?

WIDE ARRAY IN ALL DOMAINS OF LIFE

MEDICAL/SOCIAL MODEL

DETAILED ASSESSMENT

IDENTIFIED 7.3 MORE NEEDS PER FAMILY: 67 ISSUES

ASKING MUCH MORE DETAIL IN MANY CATEGORIES...

- PARENT NEEDS
- COMMUNITY
- SOCIAL WORK CONSULTS
- CULTURAL/SOCIETAL
- NURSING NEEDS

SCREENING QUESTIONS

NOW THAT YOU ASK, WE DO NEED A CAR SEAT

WHERE ARE YOU AT?
WHAT DO YOU DREAM OF?

CHILDREN'S HEALTH

SOCIAL DETERMINANTS

CONDITIONS
ACCESS



HEALTH EQUITY
EVERYONE HAS A FAIR + JUST OPPORTUNITY TO BE HEALTHY

STRUCTURAL RACISM
NEGATIVE HEALTH OUTCOMES

THE RICH KEEP GETTING RICHER + POOR POORER

BLACK BABIE'S MORTALITY RATE IS LOWER WHEN CARED FOR BY BLACK DRs

DISABLED PEOPLE ARE EXPECTED TO HAVE A POOR QUALITY OF LIFE

WE TEACH CHILDREN TO BE ABLEIST

DON'T STARE!



BULLYING!

ENCOURAGE! CURIOSITY!

ASK AND LISTEN



CHILDREN WHO ARE COMPLEX HAVE MORE UNMET NEEDS

FAMILY CENTERED CARE

WE CAN END POVERTY!

HIRE HEALTHCARE WORKERS WHO LIVE THERE

WORK WITH COMMUNITIES

CONFRONT OUR RACIST BRAINS

GET KIDS FUNDAMENTAL THINGS

43% OF CHILDREN ARE LIVING WITHOUT THEIR BASIC NEEDS MET

MY NEIGHBORHOOD ISN'T SAFE

EQUITY HELPS THE ECONOMY

3X MORE BLACK KIDS LIVE IN POVERTY

AND IT'S MUCH WORSE FOR DISABLED CHILDREN

LACKING: FOOD, EDUCATION, SAFETY

BREAK DOWN BARRIERS + GIVE EVERYONE A FAIR CHANCE!

Making
Partnerships
Real Through
ENGAGE

Judith Palfrey, MD
Sarah K. Perkins, MAPS

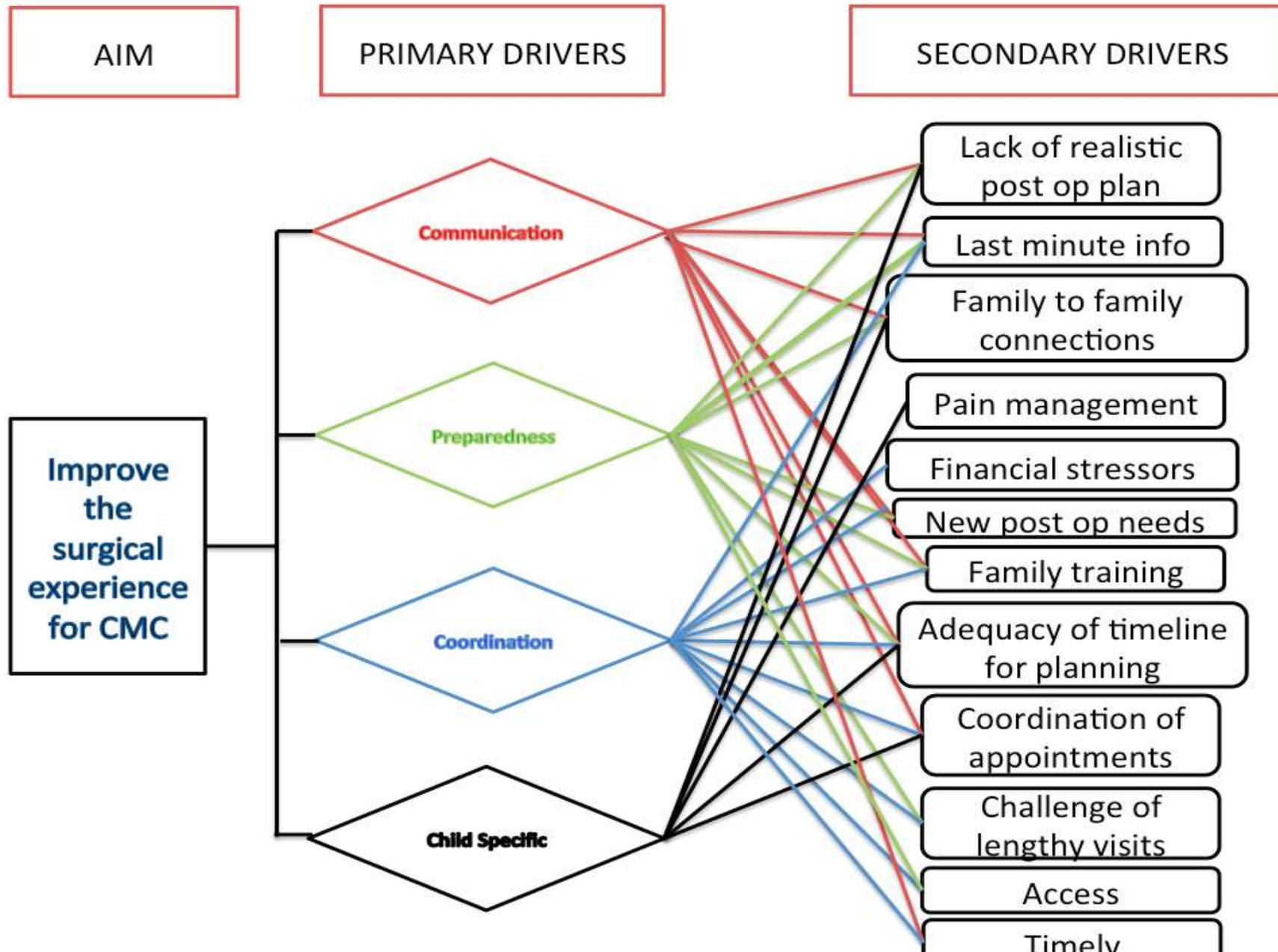


Goal

Children with Medical Complexity (CMC) often need to undergo major procedures such as hip and spine surgery.

The **ENGAGE** project's goal is to improve surgical preparation and coordination for children with medical complexity (CMC) by empowering families to take an increasingly active role in their child's healthcare.

Community participatory research



Interventions

ENGAGE Interventions

- Get to Know Me
- Individualized Numeric Rating Scale for Pain
- Shared Surgical Care Plan



Seeds Were Planted

- CMC CollIN requires collection of survey data, yearly family focus groups, and regular completion of Family Engagement in Systems Tool (FESAT).
- Each of these measurement tools yielded complementary information.
- Are we asking the best questions to address the possible sticking points that prevent partnership?

What Grew & Growing

- The family focus groups highlighted the need for community and desire to collaborate in clinical aspects.
- We can't just invite families to the table and expect them to stay. They need support to meaningfully participate (ex. paid positions, schedule considerations).
- Give family members opportunities to use the skills that they have, in addition to being a family member.



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The Texas CollN Experience



Building Relationships

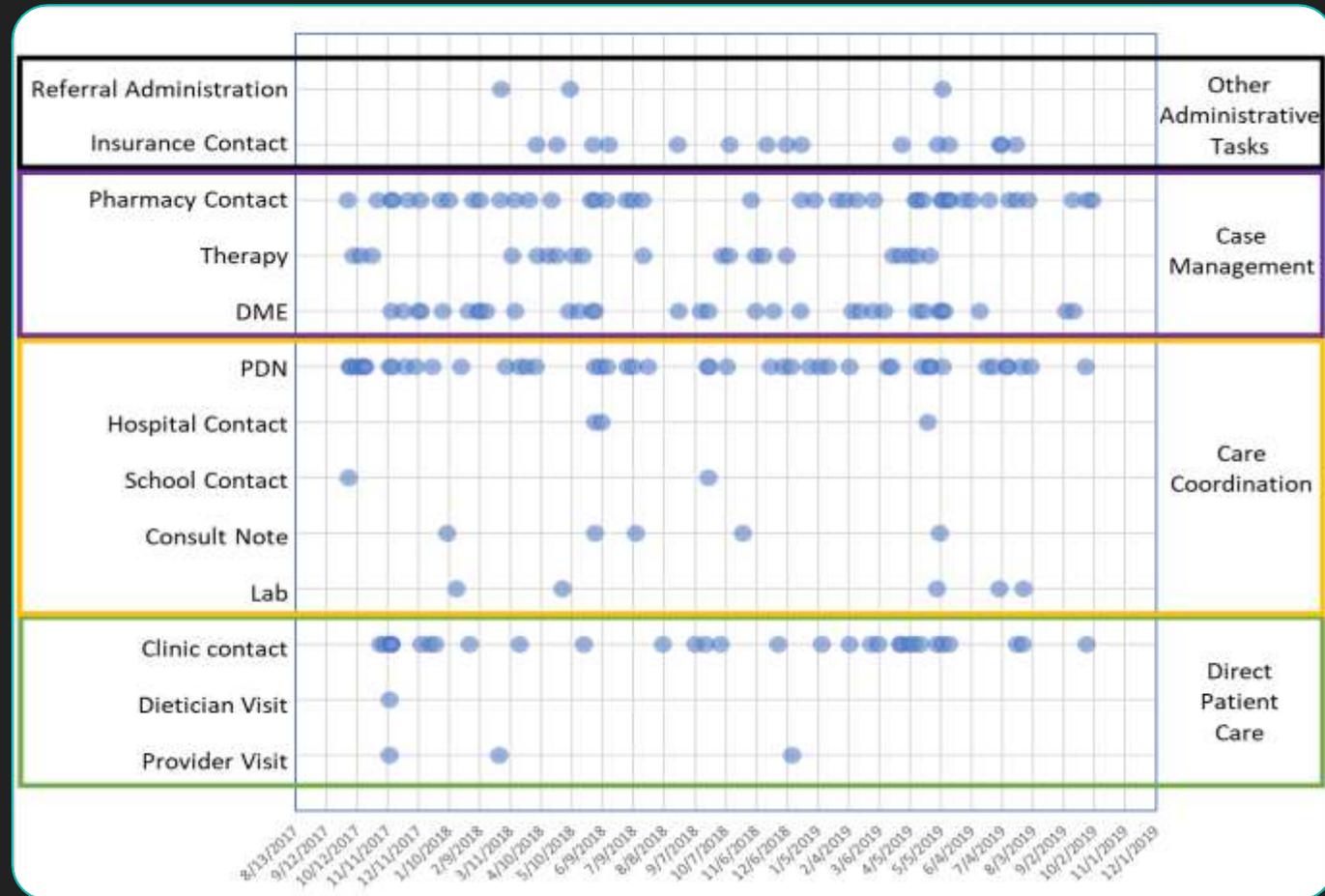
- The Texas CollN: Radical Change to the Medicaid Managed Care Delivery System
- Unique, Texas-sized collaboration of key stakeholders
- Growing Trust and Comfort
- About Me App: Leveraging technology to bridge the power hierarchy

Level the Playing Field

- Essential training
- Watch the acronyms!
- More than one place at the table
- Transparency on clinic operations, finances and workflow

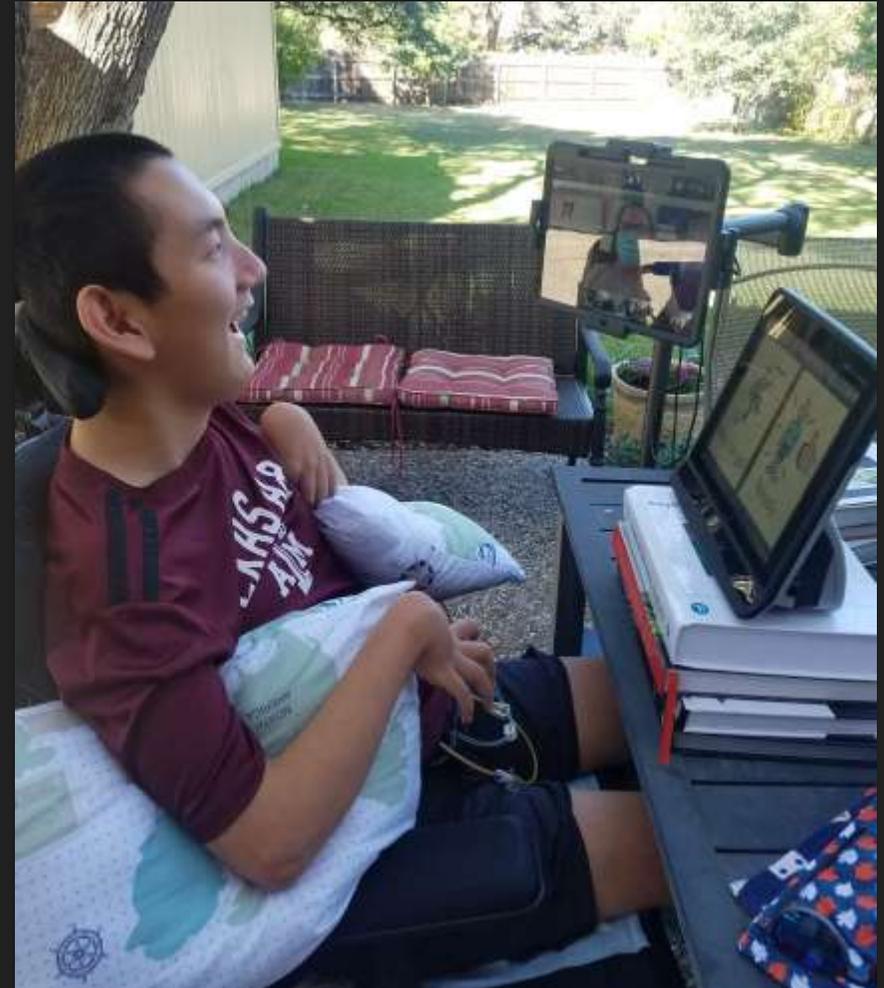
Partnership Through Shared Learning

- Getting into the details
- Mutual “Aha!” moments



Outcomes That Matter: Caregiver Stress and Isolation

- Families: caregiver stress, isolation and loneliness highlighted by the pandemic and a natural disaster
- The Whole Child: Our transformative model engages parents as equal partners in envisioning what is possible for their child
- Our children, living their best lives





Questions?

Submit your questions through the chat feature

For more information



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Upcoming National Center webinars



April 29, 2:00 – 3:00 ET

Improving care transitions for older adults

Register at www.nationalcomplex.care/events



We want your feedback!

*An evaluation survey will be sent
out after this webinar*

Thank you!

National Center for Complex Health and Social Needs
An initiative of the Camden Coalition of Healthcare Providers

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