

# Caring for children with medical complexity through transformative family partnership

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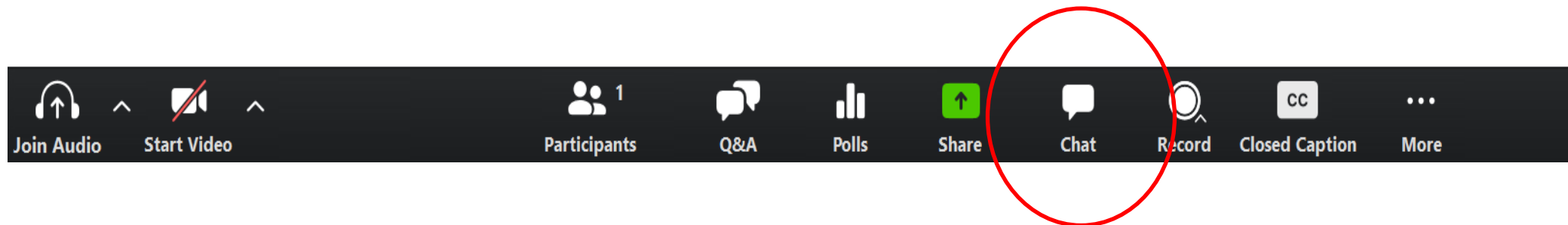
# Agenda

- 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



# Caring for children with medical complexity through transformative family partnership



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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

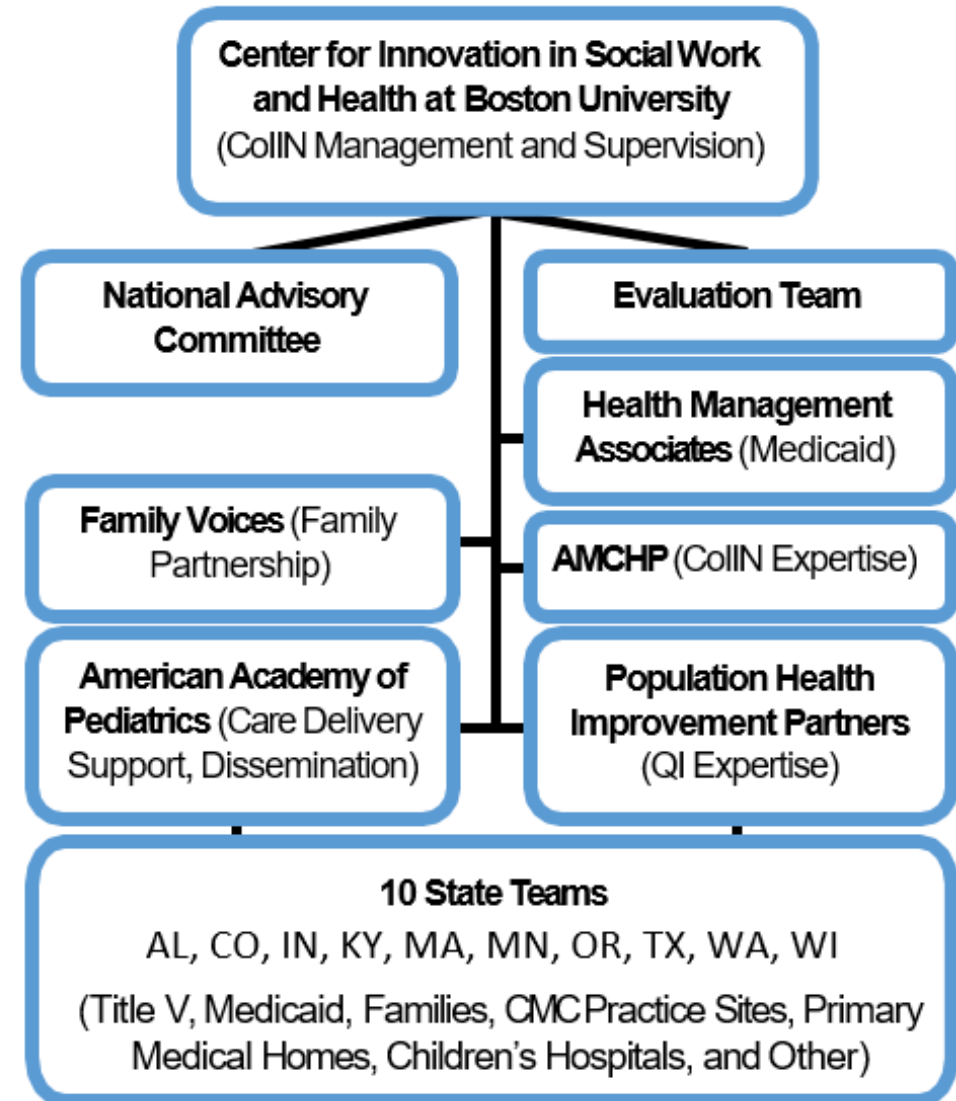
**BOSTON  
UNIVERSITY**

## 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

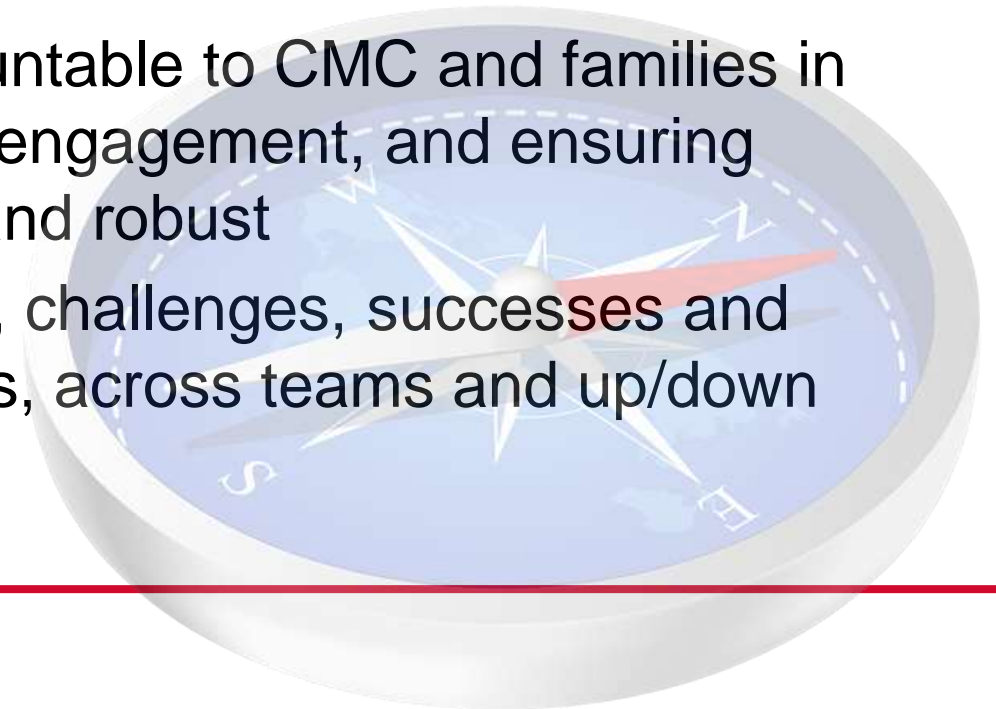


# CMC CoIN Project Structure



# 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

## Leadership

- ~Family Voices National as partner
- ~National Advisory Committee & Subcommittee
- ~PI = CMC parent
- ~ Focal point for learning

## Network

- ~Affinity group/mentoring
- ~Workgroups
- ~Family-reported outcomes
- ~Family focus groups (2x)

## State Team

- ~Core group member on each state team
- ~Additional roles: advisory members, interviewers
- ~FV® FESAT consensus-driven action plan

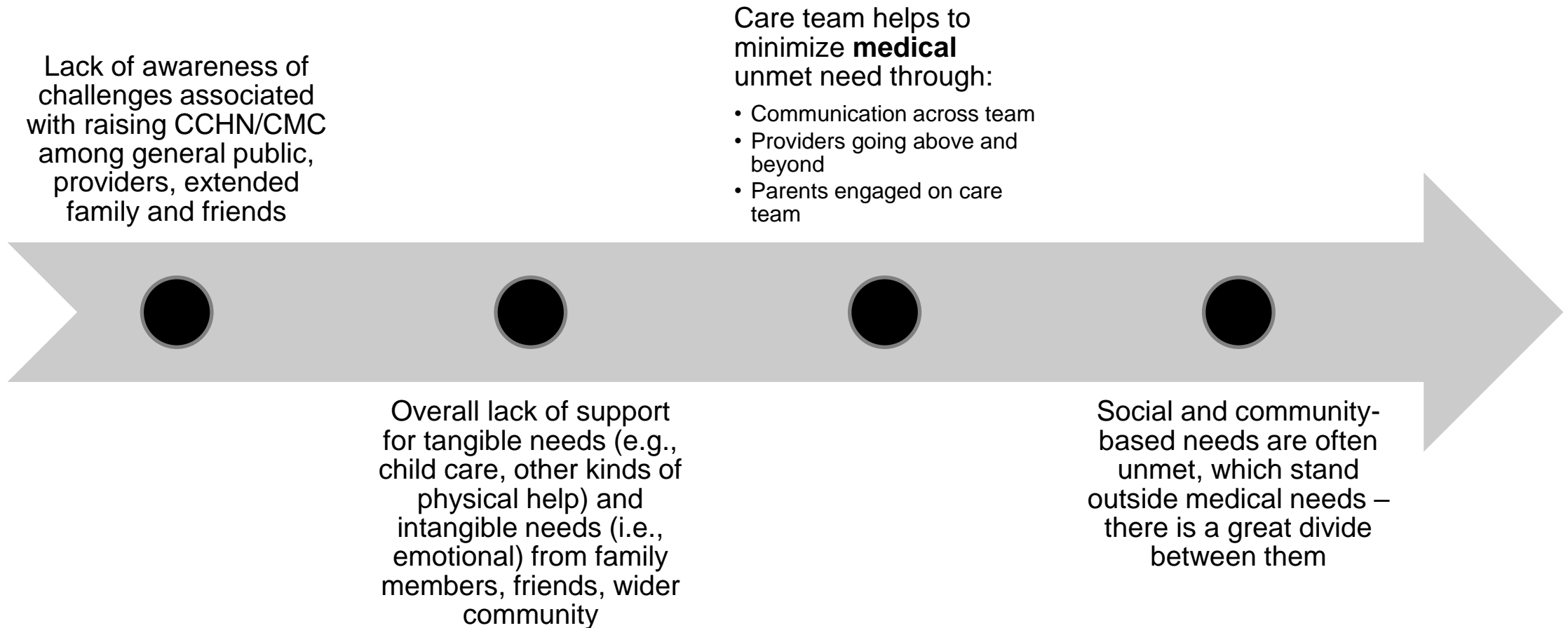


## Measuring child quality of life, family well- and unmet need

- 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?

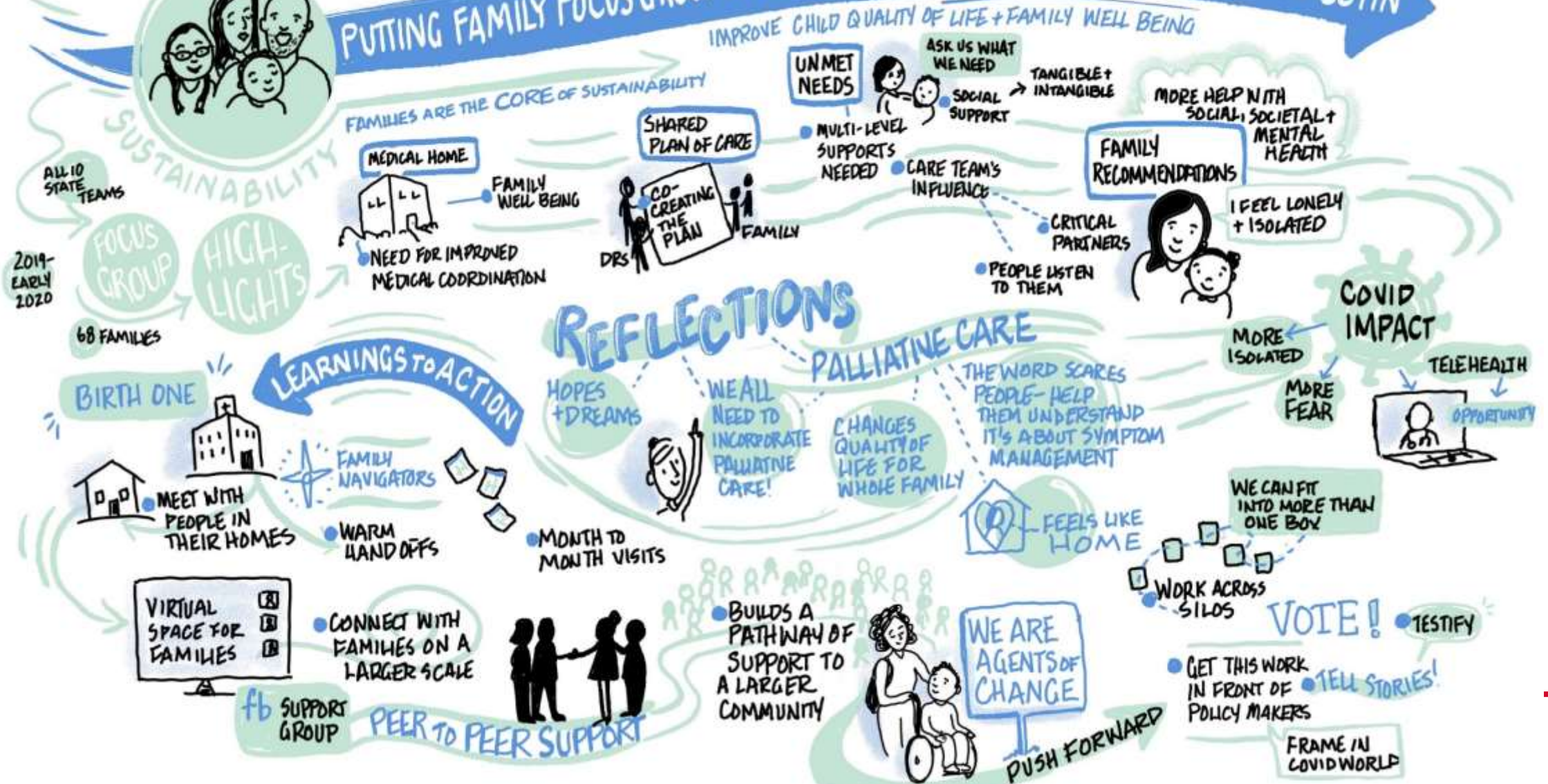


What strategies did families identify for improving child QoL, family well-being and reducing unmet need?

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



# PUTTING FAMILY FOCUS GROUP RESULTS INTO ACTION WITHIN AND BEYOND the COIN



# 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

COVID-19  
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 BABIES' 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

3X MORE BLACK KIDS LIVE IN POVERTY

AND IT'S MUCH WORSE FOR DISABLED CHILDREN



LACKING:  
• FOOD  
• EDUCATION  
• SAFETY

EQUITY HELPS THE ECONOMY

BREAK DOWN BARRIERS + GIVE EVERYONE A FAIR CHANCE!

# Making Partnerships Real Through ENGAGE

Judith Palfrey, MD  
Sarah K. Perkins, MAPS



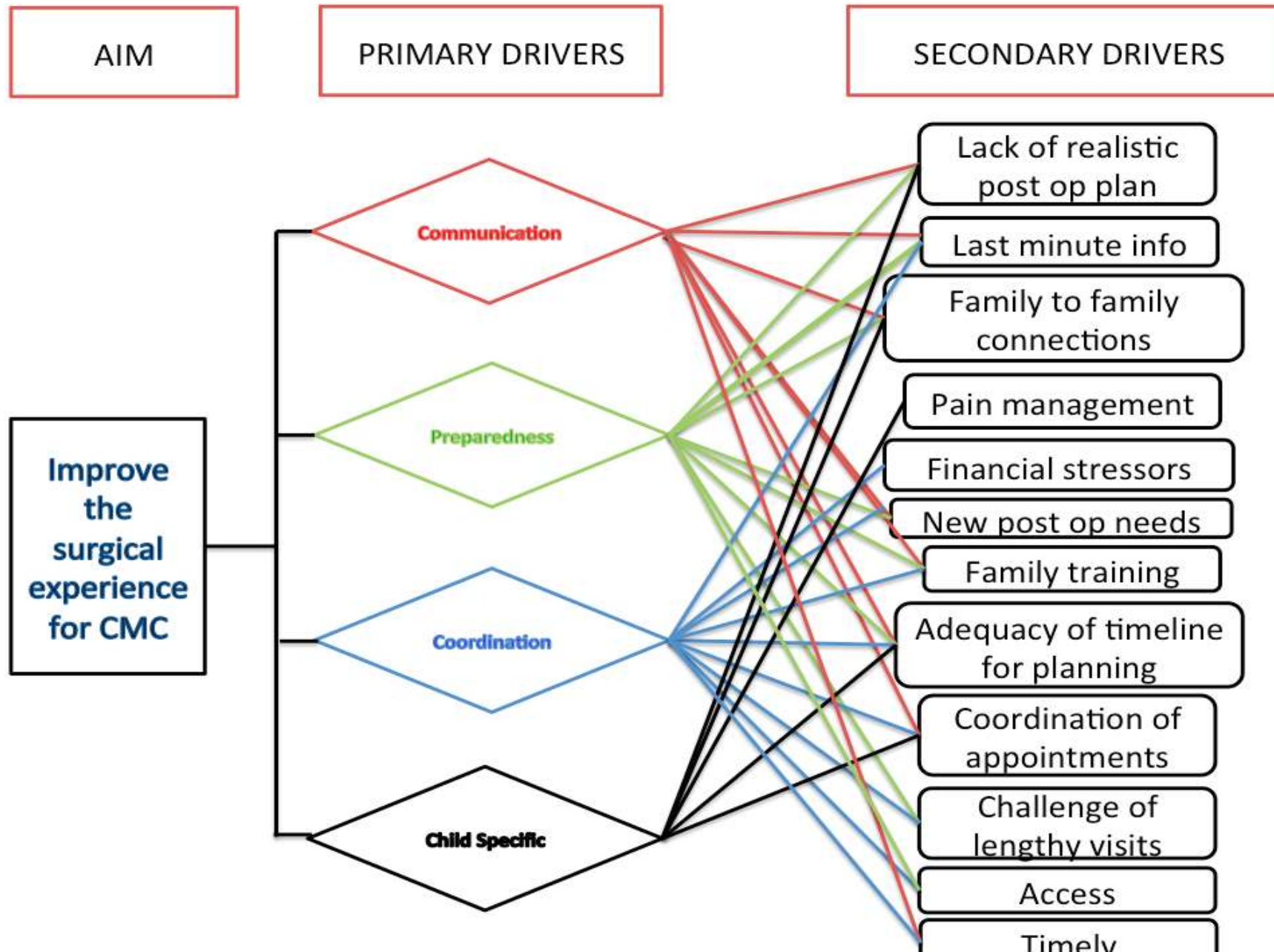
# Goal

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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

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- CMC CollN 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

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- 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.



# Caring for Children with Medical Complexity Through Transformative Family Partnership

The Texas CollN Experience



# Building Relationships

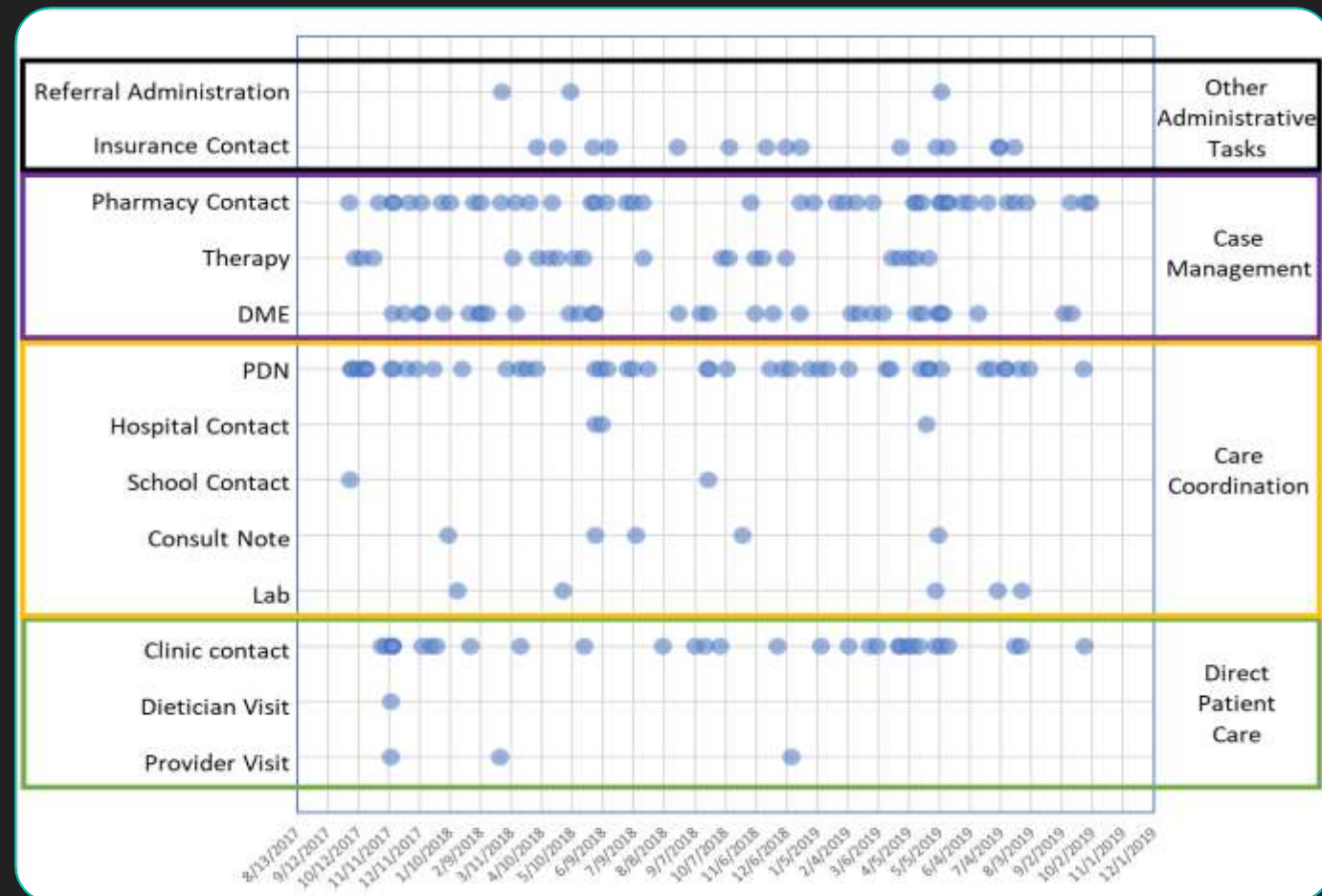
- The Texas CollN: Radical Change to the Medicaid Managed Care Delivery System
- Unique, Texas-sized collaboration of key stakeholders
- Growing Trust and Comfort
- About Me App: Leveraging technology to bridge the power hierarchy

# Level the Playing Field

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

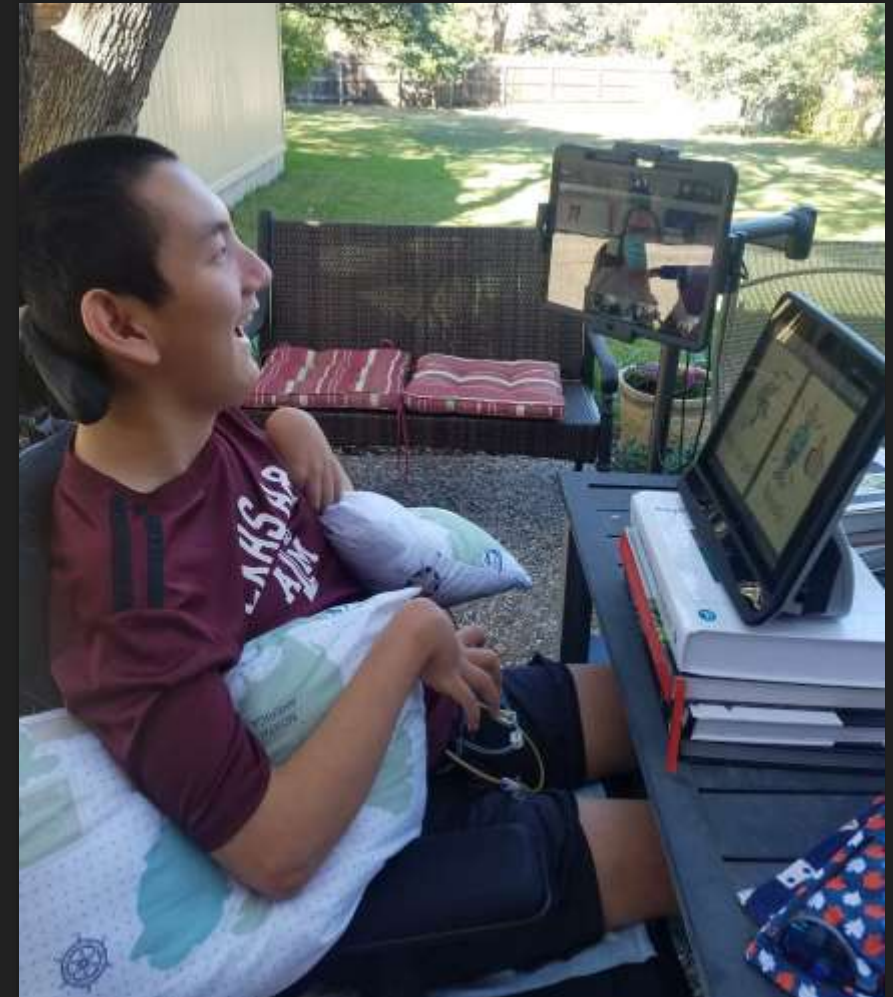
# Partnership Through Shared Learning

- 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



- National Center for Complex Health and Social Needs: [nationalcenter@camdenhealth.org](mailto:nationalcenter@camdenhealth.org)
- Dr. Maureen Benschoter, Family Leader, Dell Children's Medical Center Comprehensive Care Clinic, Austin, TX: [maureen.benschoter@gmail.com](mailto:maureen.benschoter@gmail.com)
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- Sarah Perkins, Family Liaison, Boston Children's Hospital: [sarahkperkins@yahoo.com](mailto:sarahkperkins@yahoo.com)

# Upcoming National Center webinars



April 29, 2:00 – 3:00 ET

Improving care transitions for older adults

Register at [www.nationalcomplex.care/events](http://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*

[www.nationalcomplex.care](http://www.nationalcomplex.care)

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