

# EFFECTIVE FAMILY PARTNERSHIP TOOLS TO DRIVE GLOBAL and LOCAL IMPROVEMENTS:

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## LEARNINGS from the CHILDREN with MEDICAL COMPLEXITY (CMC) COIN

### PROBLEM

EVIDENCE BASED PRACTICES SHOW FAMILY ENGAGEMENT IS **ESSENTIAL**

AND **DIFFICULT** TO DO.

OF course we know what families need!

WE DON'T ALWAYS KNOW WHAT WE DON'T KNOW... UNLESS YOU ASK!

- EQUITY
- INCLUSION
- VALUE OF LIVED EXPERIENCE

WHAT REALLY MATTERS to the PEOPLE WE SERVE?

SYSTEMIC BARRIERS

OVERHAUL REQUIRED!

I DON'T KNOW HOW...

POLICY MONEY SILOS CULTURE

### CMC COIN SPECIAL SAUCE

FAMILY ENGAGEMENT is REQUIRED: **NON-NEGOTIABLE!**

FLEXIBILITY TO MAKE IT HAPPEN IN YOUR PLACE & SYSTEM

WE ARE GIVING TEAMS SUPPORT

MONEY TECHNICAL ASSISTANCE COACHING

MULTIDISCIPLINARY TEAM

### CMC COIN CORE VALUES

ACCOUNTABILITY • EQUITY • TRANSPARENCY

- LEARNING RELATIONSHIP BUILDING
- ACTION PLAN
  - IDENTIFY CHANGE
  - ASSESS IF IT WORKED
  - MOVE FORWARD
- FLATTENED HEIRARCHY
  - Hi Len!
  - Hi Janelle, how's your family?
- FAMILY LEADER AFFINITY GROUP
  - LEANING IN
  - SAFE & SUPPORTIVE SPACE

### FAMILY ENGAGEMENT IN SYSTEMS ASSESSMENT TOOL (FESAT) FOUR DOMAINS:

- TRANSPARENCY
  - REAL SHARED PLANS OF CARE
  - HERE'S WHAT REALLY MATTERS TO US
- COMMITMENT
  - ALL EXPERIENCES ARE VALUED!
  - PRIOR EXPERIENCE
  - NOT ASSUMING THEY HAD TO BE CONNECTED TO A FAMILY ORG.
- REPRESENTATION
  - MENTORSHIP FOR THE WHOLE TEAM INCLUDING PROFESSIONALS
  - ROBUST FAMILY MENTORING + SUPPORT
- IMPACT
  - CONSENSUS-BUILDING EXERCISE
  - SHARING ACROSS TEAMS

### FAMILY FOCUS GROUPS

SYSTEM-LEVEL TOOLS - FESAT + FAMILY FOCUS GROUPS

INDIVIDUAL LEVEL

FAMILY-DRIVEN PROCESS FROM THE START!

MEASURING HOSPITALIZATIONS DOESN'T GET US THERE

WE CARE ABOUT...

QUALITY OF LIFE!

FAMILY WELL-BEING!

References:  
CMC COIN website: <https://ciswh.org/project/coin-cmc>  
Hoover, C., Paladino, M.J., Dworetzky, B., and Wells, N. (2018). Issue Brief: A Framework for Assessing Family Engagement in Systems Change. Family Voices and Lucille Packard Foundation for Children's Health. [https://familyvoices.org/wp-content/uploads/2018/10/FamilyVoices\\_LPFC\\_H\\_assessing\\_family\\_engagement\\_April2018.pdf](https://familyvoices.org/wp-content/uploads/2018/10/FamilyVoices_LPFC_H_assessing_family_engagement_April2018.pdf)  
FESAT information and requests at: <https://familyvoices.org/familyengagementtoolkit/>