

EFFECTIVE FAMILY PARTNERSHIP TOOLS TO DRIVE GLOBAL and LOCAL IMPROVEMENTS

Bethlyn Houlihan, Project Director, BU
 Meg Comeau, Principal Investigator, BU
 Cara Coleman, Director of Public Policy and Advocacy, Family Voices
 Mary Jo Paladino, Project Coordinator, Family Voices

LEARNINGS from the CHILDREN with MEDICAL COMPLEXITY (CMC) COIIN

PROBLEM

EVIDENCE BASED PRACTICES SHOW FAMILY ENGAGEMENT IS ESSENTIAL

- EQUITY
- INCLUSION
- VALUE OF LIVED EXPERIENCE

AND DIFFICULT TO DO.

OF course we know what families need!
 WE DON'T ALWAYS KNOW WHAT WE DON'T KNOW...
 UNLESS YOU ASK!

WHAT REALLY MATTERS to the PEOPLE WE SERVE?

SYSTEMIC BARRIERS

- POLICY
- MONEY
- SILOS
- CULTURE

OVERHAUL REQUIRED!

I DON'T KNOW HOW...

CMC COIIN SPECIAL SAUCE

FAMILY ENGAGEMENT IS REQUIRED:
 NON-NEGOTIABLE!

FLEXIBILITY TO MAKE IT HAPPEN IN YOUR PLACE & SYSTEM

WE ARE GIVING TEAMS SUPPORT

MULTIDISCIPLINARY TEAM

- MONEY
- TECHNICAL ASSISTANCE
- COACHING

CMC COIIN CORE VALUES

ACCOUNTABILITY • EQUITY • TRANSPARENCY

LEARNING RELATIONSHIP BUILDING

CAN BE A POSITIVE THING!

ACTION PLAN
 → IDENTIFY CHANGE
 → ASSESS IF IT WORKED
 → MOVE FORWARD

FLATTENED HEIRARCHY

Hi Len!
 Hi Janelle, how's your family?

FAMILY LEADER AFFINITY GROUP

→ LEARNING IN
 → SAFE & SUPPORTIVE SPACE

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

- TRANSPARENCY
 - REAL SHARED PLANS OF CARE
- COMMITMENT
 - ALL EXPERIENCES ARE VALUED!
 - HERE'S WHAT REALLY MATTERS TO US
 - 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

FAMILY-DRIVEN PROCESS FROM THE START!
 → DRIVE PRIORITIES, ACTIONS, AND PUSHED FOR CHANGE!

MEASURING HOSPITALIZATIONS DOESN'T GET US THERE

WE CARE ABOUT...

QUALITY OF LIFE!

FAMILY WELL-BEING!

References:
 CMC ColiIn website: <https://ciswh.org/project/colin-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
 FESAT information and requests at: <https://familyvoices.org/familyengagementtoolkit/>