Collaborative Improvement and Innovation Network Improves Pediatric Family-Centered Engagement

Rhonda Cady, RN, PhD, Clinical Scientist
Tricia Brisbine, MA, Family Advisor
Gillette Children's Specialty Healthcare

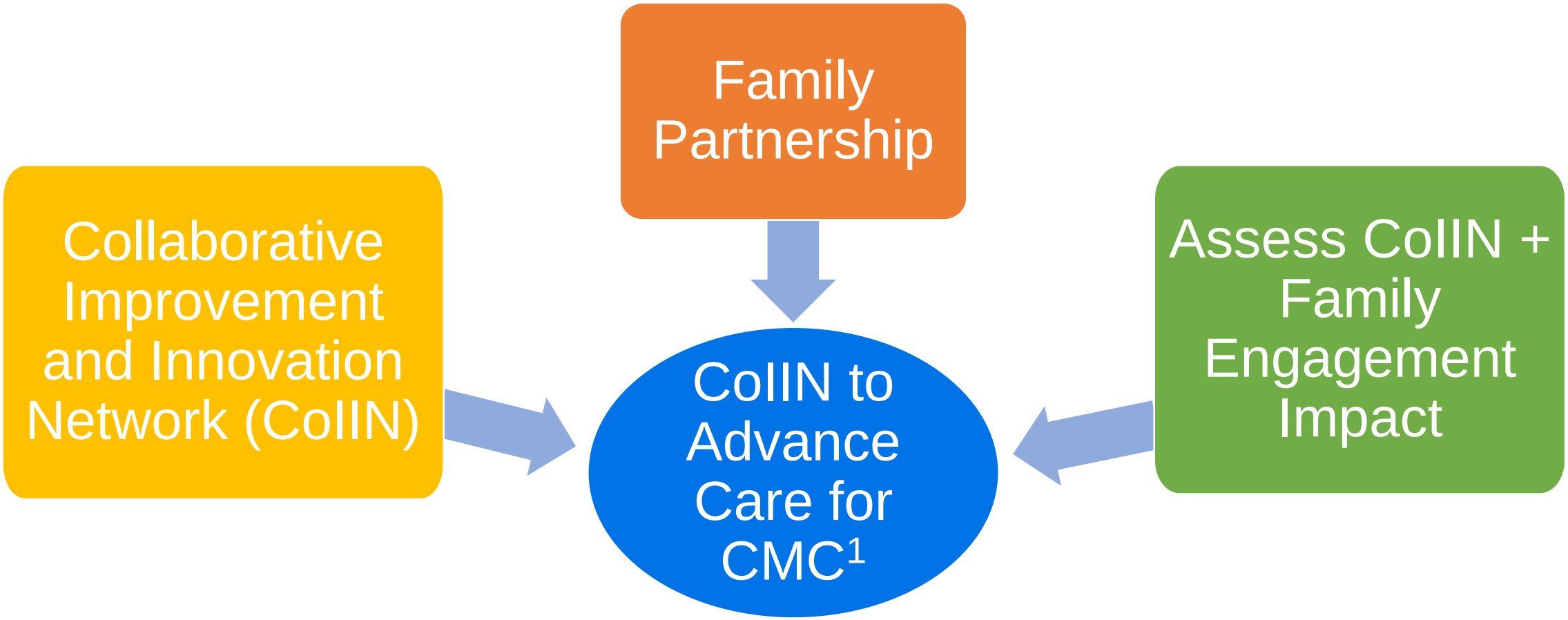
This project is supported by HRSA of the U.S. Department of Health and Human Services (HHS) under grant number UJ6MC32737, Health Care Delivery System Innovations for Children with Medical Complexity, $2,700,000 (annually). This information or content and conclusions are those of the authors and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

This project is supported in part by the generous donors of Gillette Children's Specialty Healthcare.

LEARNING OBJECTIVES

Examine	Examine CoIIN (Collaborative Improvement and Innovation Network) methodology
Differentiate	Differentiate between patient- and family-centered care and patient- and family-centered engagement
Discuss	Discuss impact of family advisors in designing, implementing and evaluating care delivery innovations within a CoIIN
Apply	Apply lessons learned to current organizational initiatives

PROJECT OVERVIEW



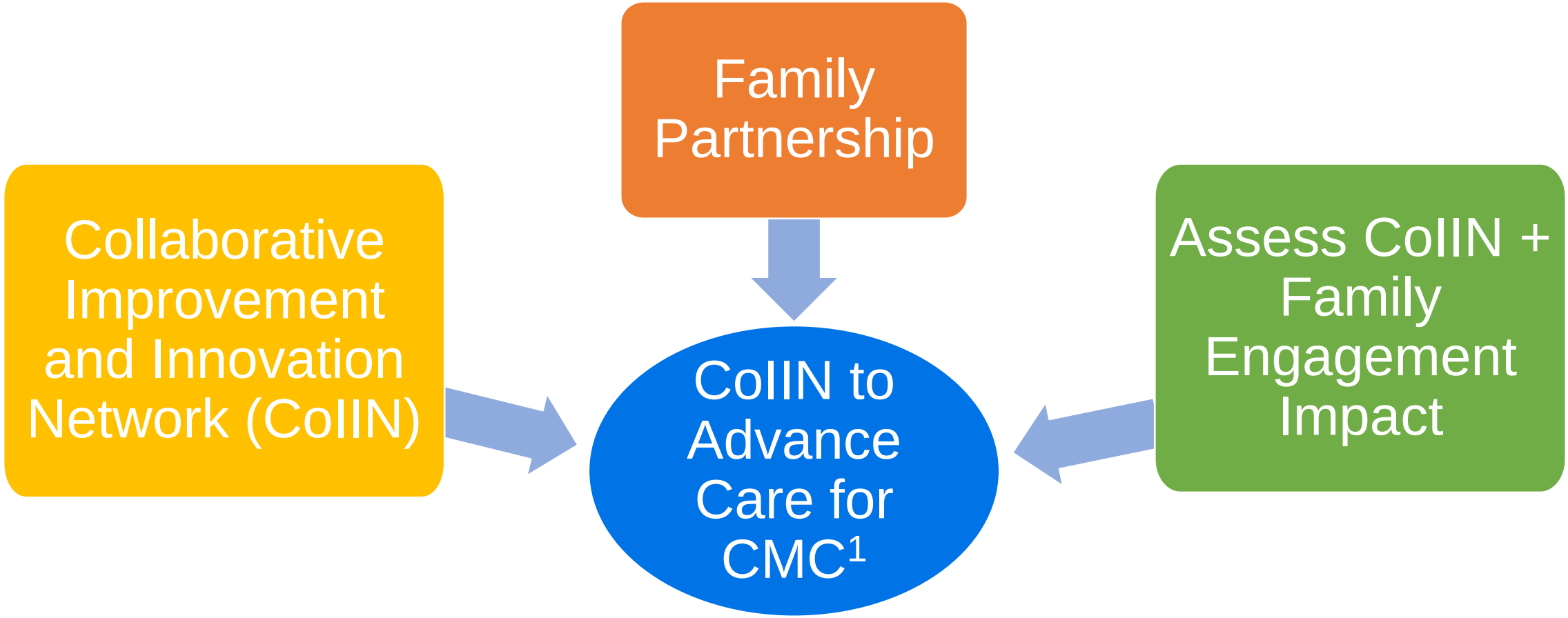
CMC CoIIN OBJECTIVES & POPULATION

Objectives

- Improve Quality of Life for Medically Complex Children
- Increase Well-Being of their Families

Children with Medical Complexity (CMC)[2]

- Multiple complex chronic conditions (Cerebral Palsy, Muscular Dystrophies, Epilepsy, Spina Bifida, Congenital Anomolies)
- Severe functional limitations
- Technology dependence (tracheostomy, feeding tube, ventricular-peritoneal (VP) shunt)
- < 1% of US children but ~ 40% pediatric health resource utilization


Family Partnership
Collaborative Improvement and Innovation Network (CoIIN)
Assess CoIIN + Family Engagement Impact
CoIIN to Advance Care for CMC[1]

WHAT IS A COLLABORATIVE IMPROVEMENT AND INNOVATION NETWORK (CoIIN)?[6,7]

- Platform & Methodology
- Virtual, Collaborative Teams
- Common Aim
- Quality Improvement Methods
- Spread & Scale Innovation

CMC CoINN COLLABORATORS

Center for Innovation in Social Work and Health at Boston University

National Advisory Committee

Family Voices (Family Partnership)

American Academy of Pediatrics (Care Delivery Support, Dissemination)

Health Management Associates (Medicaid Expertise)

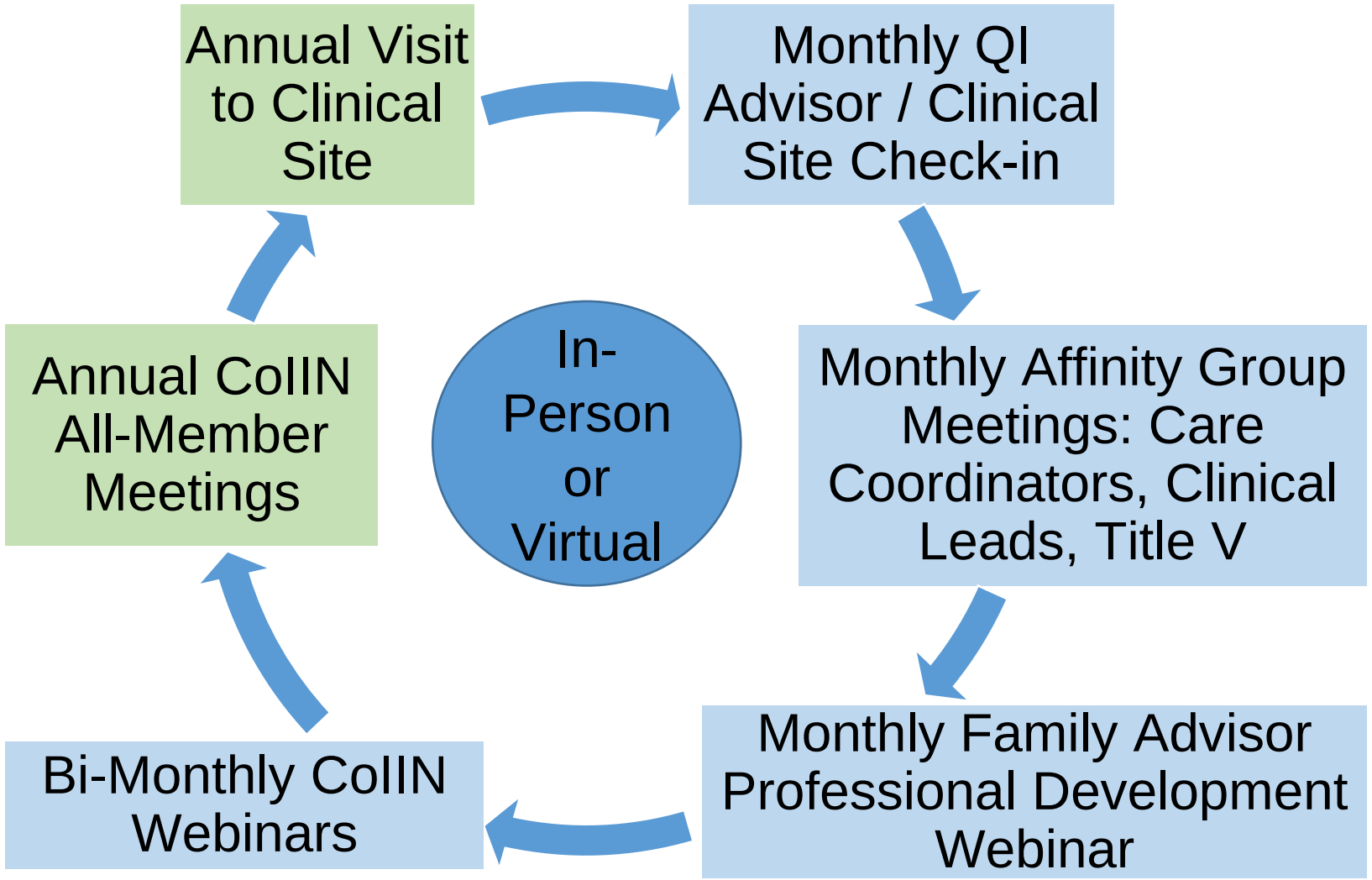
Association of Maternal Child Health Programs (CoIIN Expertise)

Population Health Improvement Partners (QI Expertise)

10 State Clinical Site Complex Care Teams:
AL, CO, IN, KY, MA, MN, OR, TX, WA, WI

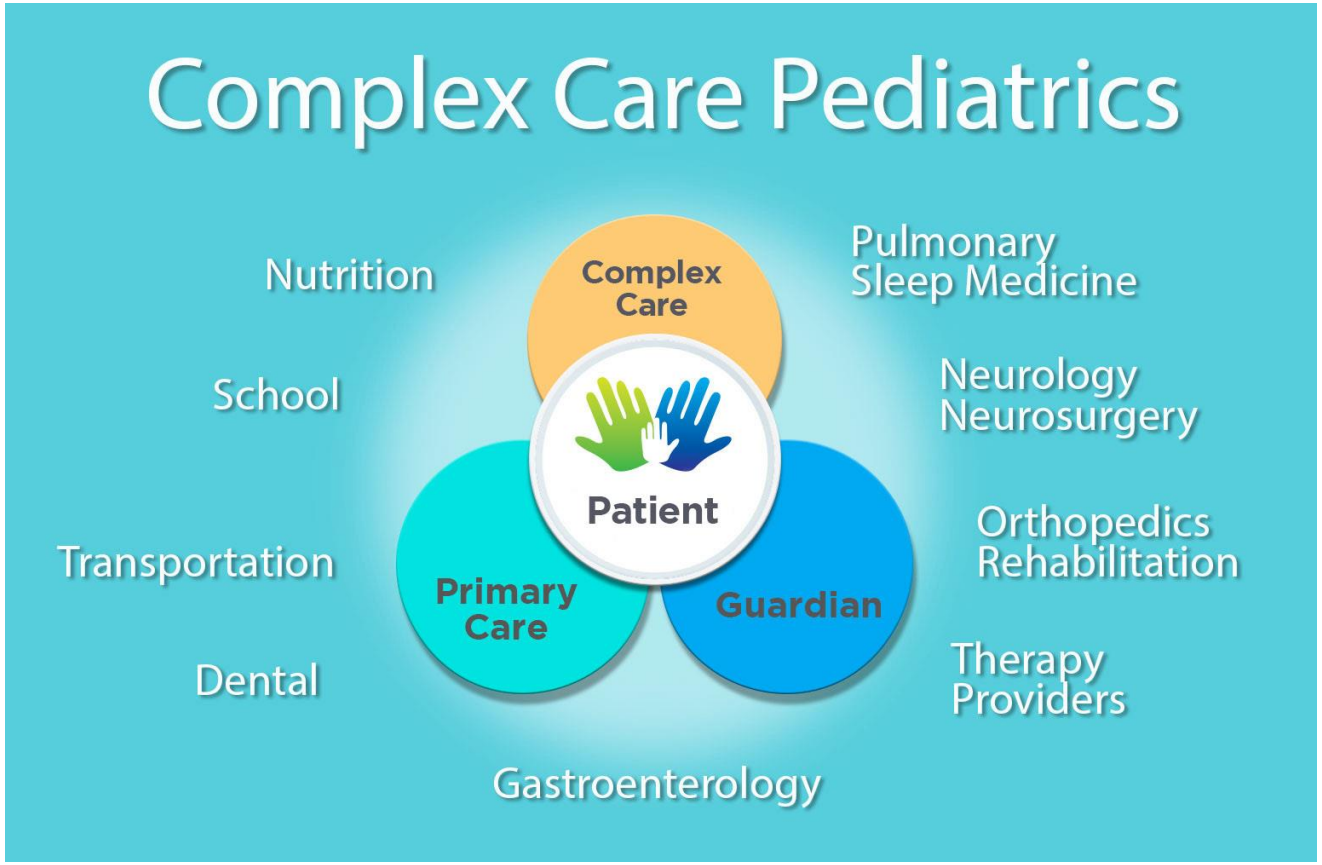
Project timeline: 8/1/2017—7/31/2022
Enrollment: 150-300/site ➔ **1500-3000** CMC and their Families

WHAT MADE THIS A CoIIN?



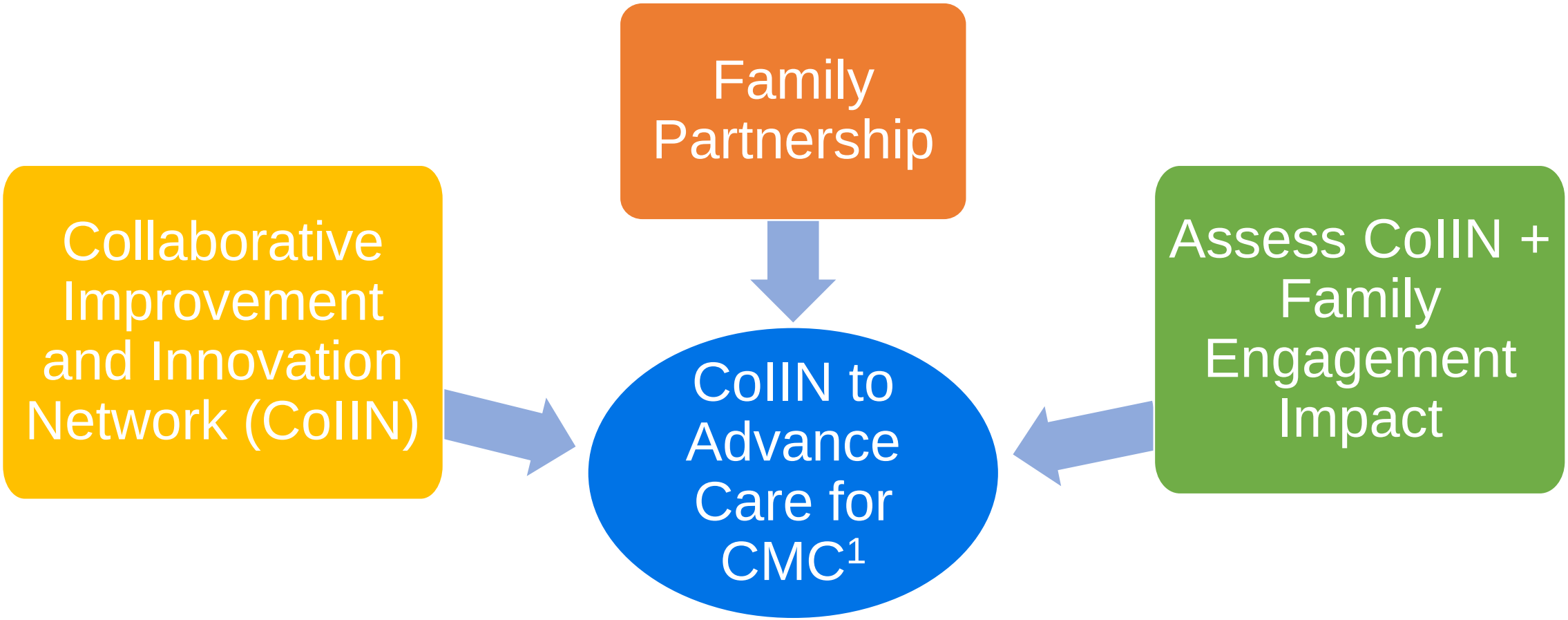
CMC CoIIN ‘TEAM MN’ SETTING

Gillette Children’s Specialty Healthcare Complex Care Program[3-5]



TEAM MN CoIIN IMPLEMENTATION

- Ground rules for equal inclusion and voice of all members
- Team members trained on process improvement[8] and evidence-based care coordination processes[9]
- All team members paid, including family advisors


Family Partnership
Collaborative Improvement and Innovation Network (CoIIN)
CoIIN to Advance Care for CMC[1]
Assess CoIIN + Family Engagement Impact

CoIIN FAMILY PARTNERSHIP & ENGAGEMENT PRINCIPLES

Why

- Family advisors provide expertise and experience to knowledge translation team
- **Evidence-based practice ➔ improved patient and family outcomes**[10-11]

Who

- Parents/Caregivers of children with medical complexity enrolled in clinical site complex care program

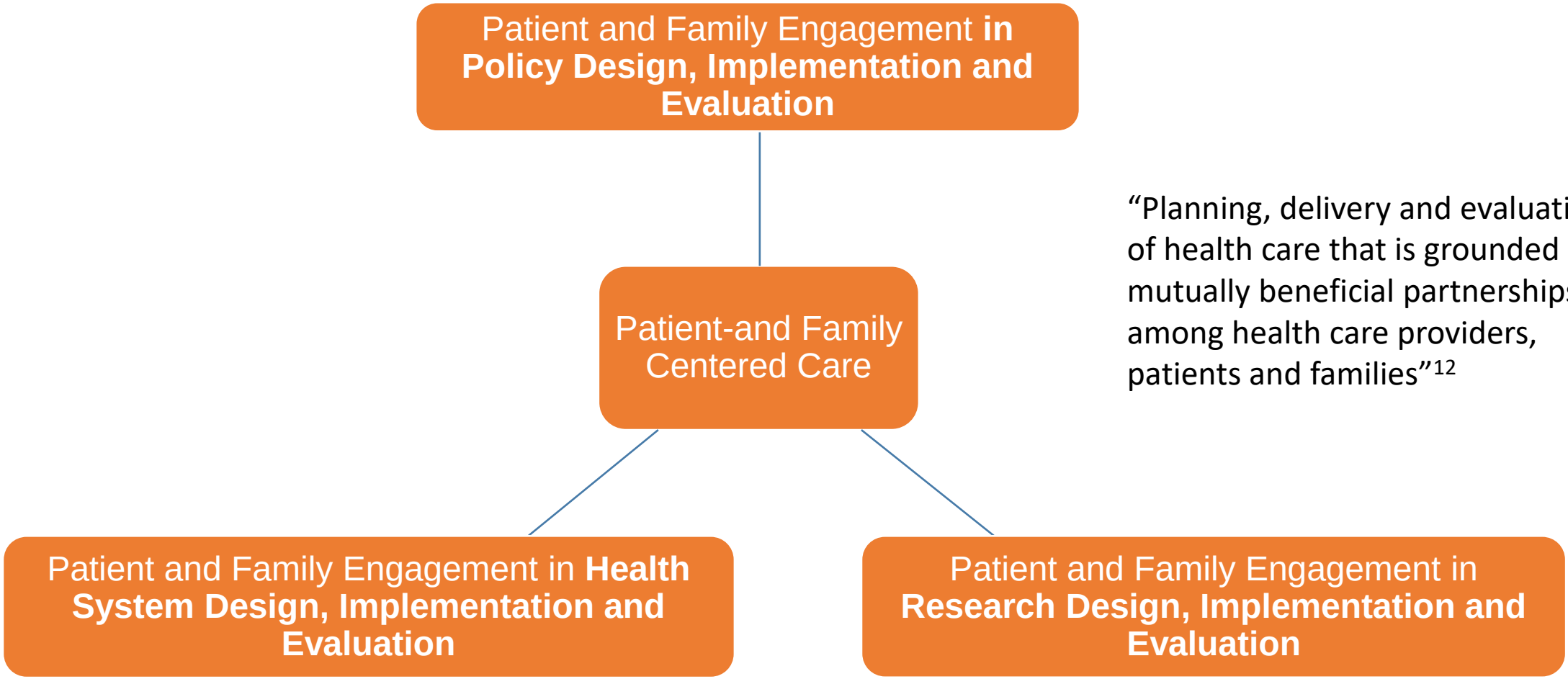
What

- **Identify** and **implement** evidence-based care coordination processes
- **Evaluate** process uptake and **parent perception of care integration**

How

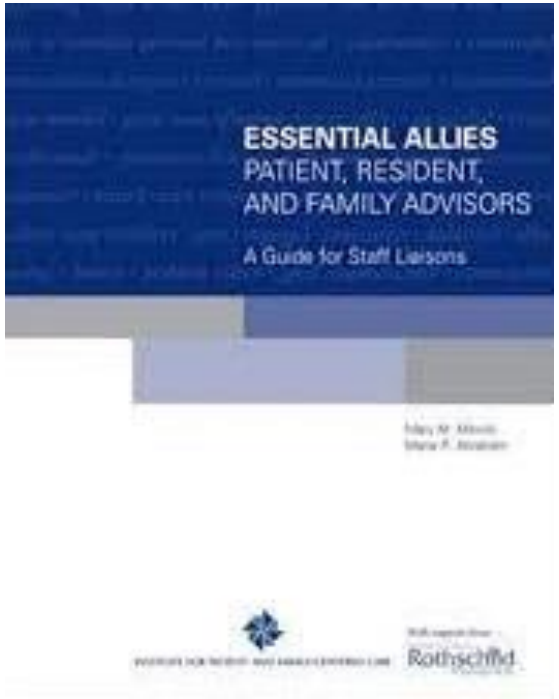
- **Partner** with **Family-Led Organization** (Family Voices, Parent to Parent USA) for **parent leadership training** and **on-going professional development** and mentorship

FOUNDATION = PATIENT- AND FAMILY-CENTERED CARE



"Planning, delivery and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients and families"[12]

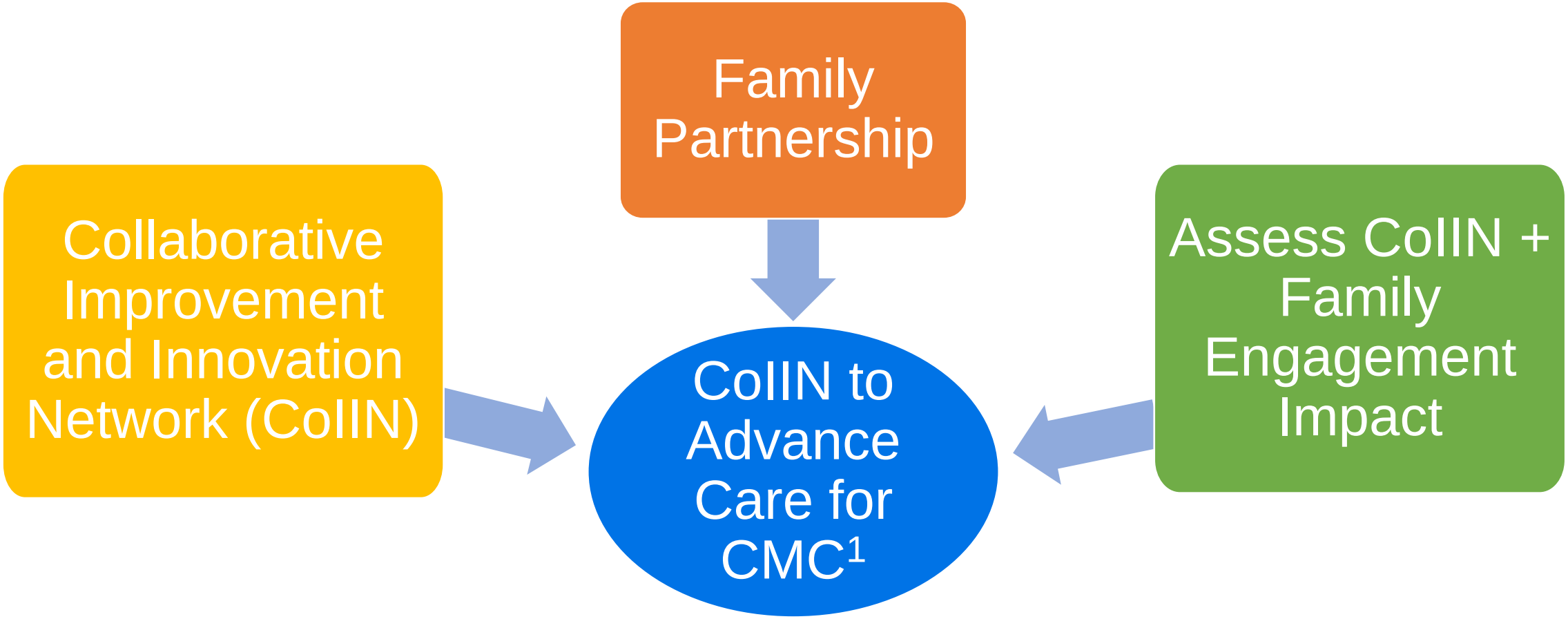
IMPLICATIONS FOR POLICY AND PRACTICE



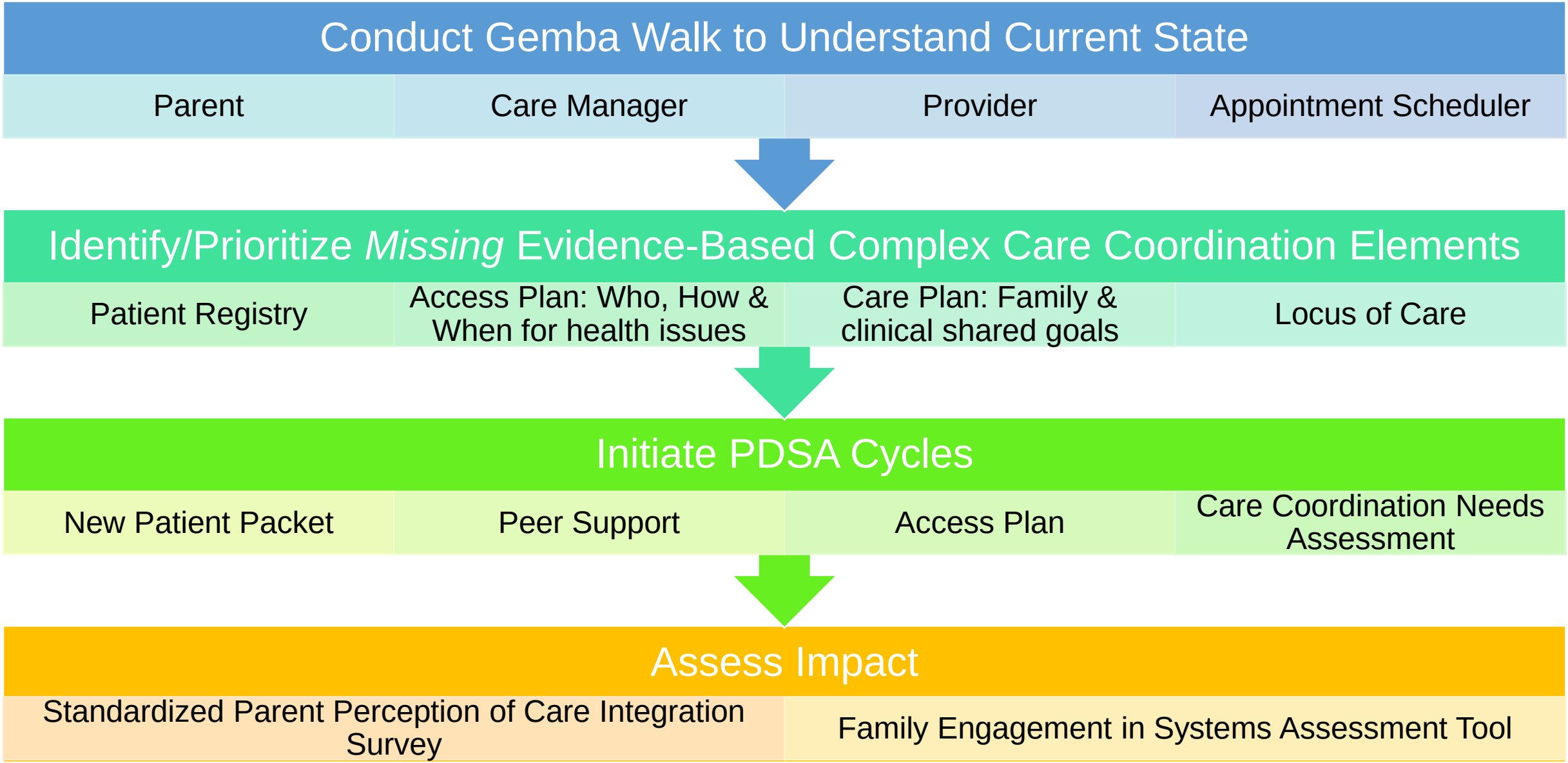
- Building *Essential Allies*[13] is a structured approach that requires support, resources and work
- Institute for Patient-and Family Centered Care resources provide expert guidance

WHAT WE LEARNED

Organizational leadership support for equal and paid family advisors	Parent/caregiver readiness to serve and training as a family advisor	Clinical staff readiness to serve and training on working with family advisors
Ground rules for equitable participation established/enforced	Conflicts will happen; address immediately, openly and equitably	Conduct assessment of engagement and build action plans to address deficiencies


Family Partnership
Collaborative Improvement and Innovation Network (CoIIN)
Assess CoIIN + Family Engagement Impact
CoIIN to Advance Care for CMC[1]

CoIIN Methodology + Family Partnership



Family Engagement in Systems Assessment Tool (FESAT)[4]

FAMILY VOICES®
www.familyvoices.org

Commitment

- Promote engagement as a core value
- Establish engagement at all levels, in all systems of care

Representation

- Reflect diversity of the community (race, ethnicity, language, income, education level and geography)
- Partner with family-led and community-based organizations

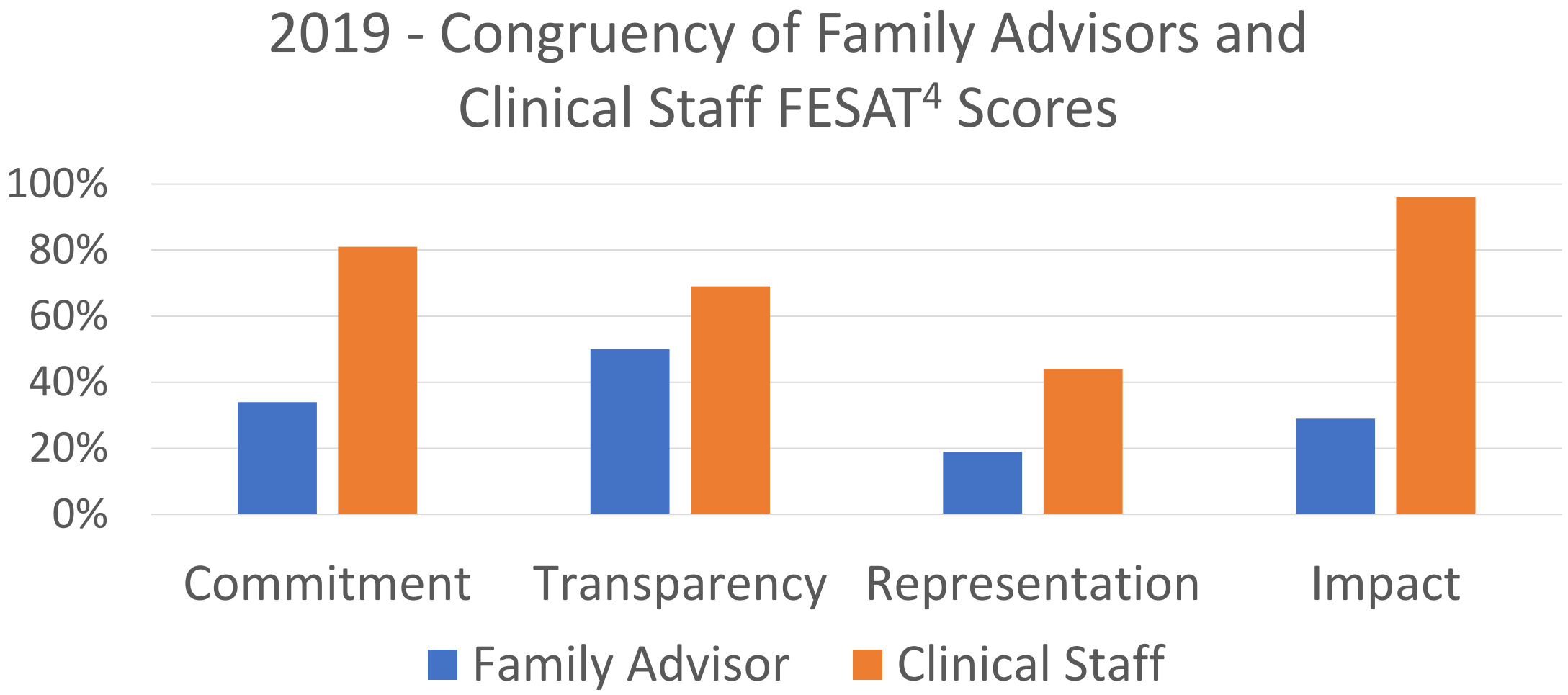
Transparency

- Provide access to relevant knowledge
- Practice partnership in all parts of the process

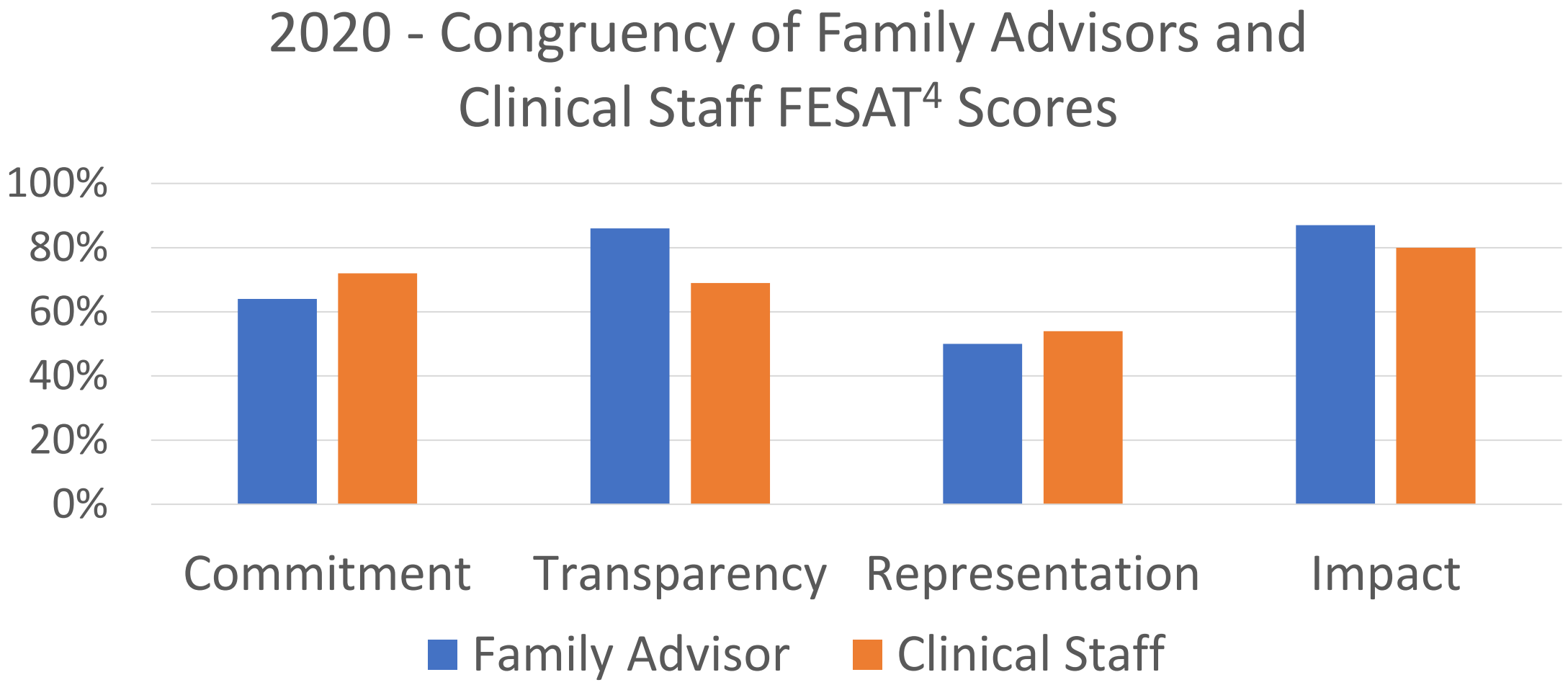
Impact

- Identify what has changed and what the organization or system of care is doing differently because families were involved

TEAM MN INITIAL FAMILY ENGAGEMENT ASSESSMENT



TEAM MN SECOND FAMILY ENGAGEMENT ASSESSMENT



QUESTIONS?

Rhonda Cady: RhondaGCady@GilletteChildrens.com

Tricia Brisbine: TKBrisbine@gmail.com

Bibliography

1. Boston University School of Social Work. CoIIN to Advance Care for CMC - Center for Innovation in Social Work & Health. https://ciswh.org/project/coiin-cmc/. Published 2021. Updated 2021. Accessed 7/27/21.
2. Cohen E, Kuo DZ, Agrawal R, et al. Children with medical complexity: an emerging population for clinical and research initiatives. Pediatrics. 2011;127(3):529-538.
3. Gillette Children's Specialty Healthcare. Complex Care | Gillette Children's Specialty Healthcare. https://www.gillettechildrens.org/conditions-care/complex-care. Published 2022. Accessed 1/4, 2022.
4. Cady R, Bushaw A, Davis H, Mills J, Thomasson D. Care coordination for children with medical complexity. The Nurse practitioner. 2020;45(6):11-17.
5. Cohen E, Berry JG, Sanders L, Schor EL, Wise PH. Status Complexicus? The Emergence of Pediatric Complex Care. Pediatrics. 2018;141(Supplement 3):S211.
6. Gloor PA. Swarm creativity : competitive advantage through collaborative innovation networks Oxford ; New York Oxford University Press. Published 2006.
7. Hirai AH, Sappenfield WM, Ghandour RM, Donahue S, Lee V, Lu MC. The Collaborative Improvement and Innovation Network (CoIIN) to Reduce Infant Mortality: An Outcome Evaluation From the US South, 2011 to 2014. American Journal of Public Health. 2018;108(6):815-821.
8. Institute for Healthcare Improvement: How to Improve. Institute for Healthcare Improvement. http://www.ihi.org/resources/Pages/HowtoImprove/default.aspx. Published 2022. Accessed 01/04, 20228.
9. Children's Hospital Association. Partnering With Patient Families to Better Care for Children With Medical Complexity. https://www.childrenshospitals.org/Newsroom/Childrens-Hospitals-Today/Articles/2019/01/Partnering-with-Patient-Families-for-Better-Care-for-Children-with-Medical-Complexity. Published 2019. Accessed 7/28, 2021.
10. Cooley C, Allshouse C, Taylor J, Bergman D, Dull S. Invoking the Power of Family Partnerships to Improve Outcomes for Children with Medical Complexity. Kansas City, MO: Children's Hospital Association;2018.
11. Children's Hospital Association. CARE Award. https://www.childrenshospitals.org/Care. Published 2021. Accessed 7/28, 2021.
12. Institute for Patient and Family Centered Care. What is PFCC? http://www.ipfcc.org/about/pfcc.html. Accessed 1/4, 2022.
13. Minniti ME, Abraham MR. *Essential Allies - Patient, Resident and Family Advisors.* Bethesda, MD: Institute for Patient- and Family-Centered Care; 2013.