

**The Future
of Care for
Children
with
Medical
Complexity**

**Cafe #2: Humanism in Clinical Care to
Meet Whole Child/Family Needs**

May 29, 2024

Discussants:

Dennis Kuo, MD, MHS, FAAP

Bethlyn Houlihan, MSW, MPH

Meg Comeau, MHA



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**This virtual café series is generously
funded by**



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About the Future of Care for CMC

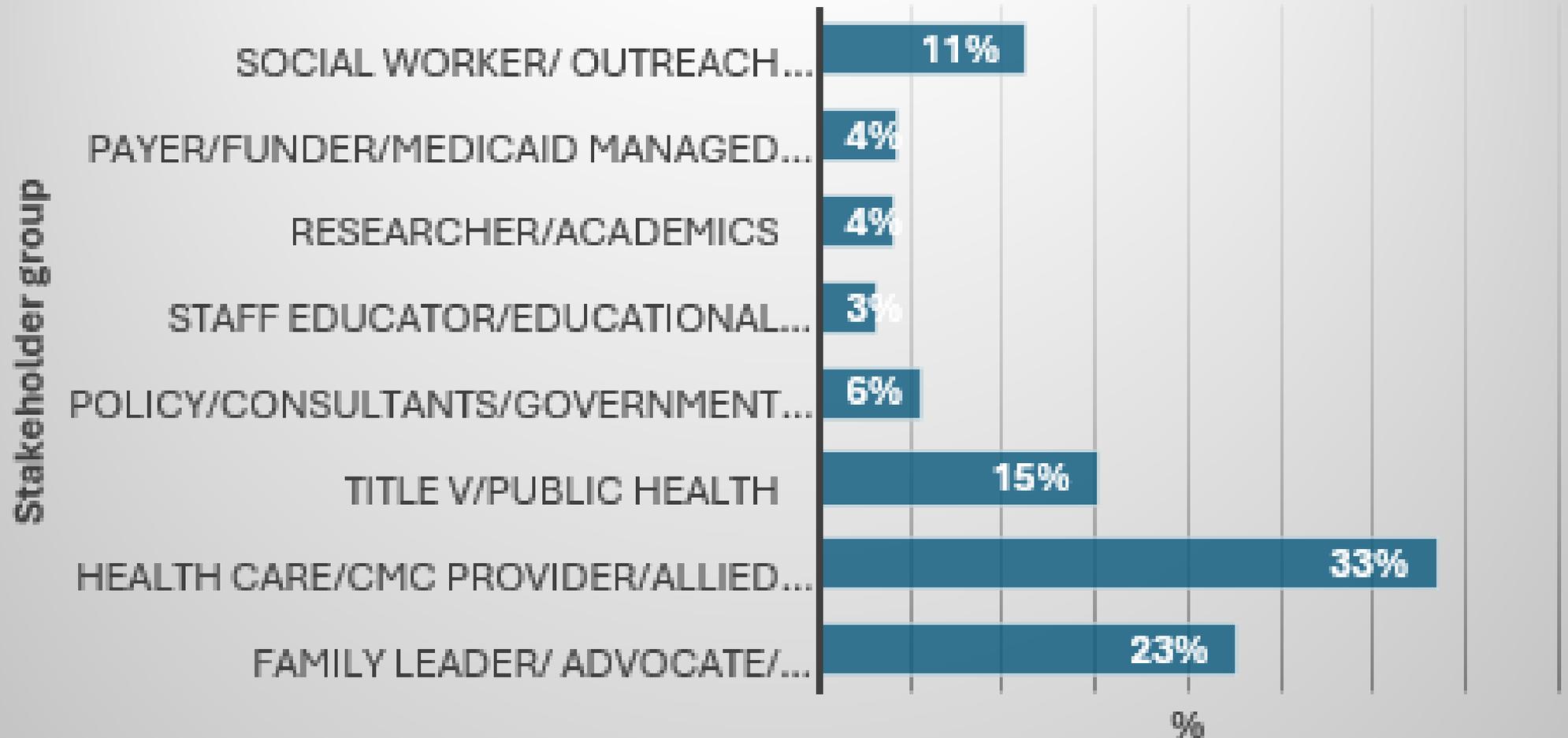
Virtual Cafe Series

- Aim: To foster interdisciplinary dialogue among participants interested in meaningful systems improvements for CMC
- 60 min sessions: 20 min intro/presentation/Q&A + 25 min facilitated breakout discussion + 10 min share out
- Family partners co-lead every session
- Discussion questions and analysis created by an interdisciplinary faculty



Who We Are

Cafe 2 Registrants (N=348)



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Discussion Format

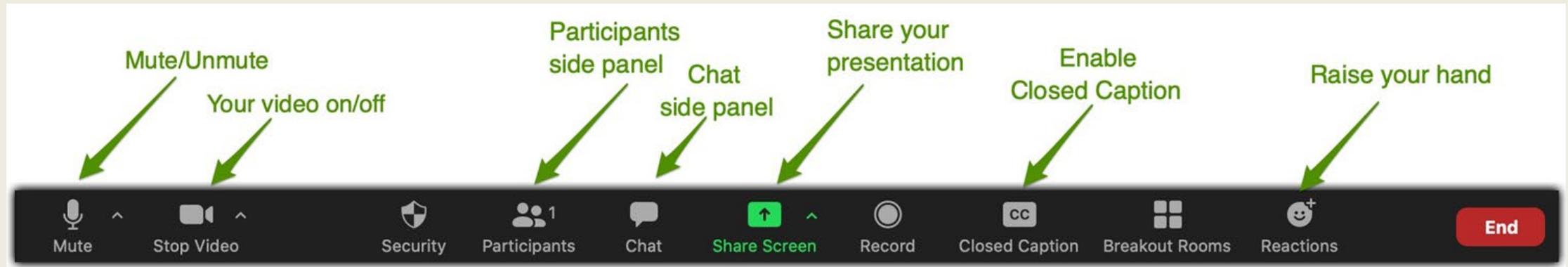
To participate in the discussion,
please **RAISE YOUR HAND** via Zoom
or
WRITE IN THE CHAT BOX

Both are equally valuable ways to participate!

This meeting is being recorded and the
chat transcript will be saved & analyzed
with support from AI



Zoom Platform Please Use Your Camera & Mute Your Line



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SUPPLEMENT ARTICLE | JANUARY 01 2024

The Collaborative Improvement and Innovation Network for Children With Medical Complexity **FREE**

Meg Comeau, MHA ; Anna Maria Padlan, MPH; Bethlyn Houlihan, MSW, MPH; Cara Coleman, JD, MPH; Christopher Louis, PhD, MHA; Treeby Brown, MA; Marie Mann, MD, MPH, FAAP

SUPPLEMENT ARTICLE | JANUARY 01 2024

What Families of Children With Medical Complexity Say They Need: Humanism in Care Delivery Change **FREE**

Bethlyn Vergo Houlihan, MPH, MSW ; Cara Coleman, JD, MPH; Dennis Z. Kuo, MD, MHS; Benjamin Plant, MPH; Meg Comeau, MHA

Address correspondence to Bethlyn Houlihan, Center for Innovation in Social Work and Health, Boston University School of Social Work, Crosstown Center, 3rd Floor, 801 Massachusetts Avenue, Boston, MA 02118. E-mail: bvergo@bu.edu

Pediatrics (2024) 153 (Supplement 1): e2023063424F.

<https://doi.org/10.1542/peds.2023-063424F> **Article history** 

SUPPLEMENT ARTICLE | JANUARY 01 2024

Measuring What Matters to Children With Medical Complexity and Their Families **FREE**

Greg Randolph, MD, MPH ; Cara Coleman, JD, MPH; Carolyn Allshouse; Benjamin Plant, MPH; Dennis Z. Kuo, MD, MHS

Address correspondence to Greg Randolph, MD, MPH, Gillings School of Global Public Health, Public Health Leadership, CB#7400, University of North Carolina at Chapel Hill, Chapel Hill, NC 27599-7400. E-mail: randolph@unc.edu



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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

CMC CoIN Family Focus Group Process

Existing QoL/WB measures too medically-focused & biased per family leaders

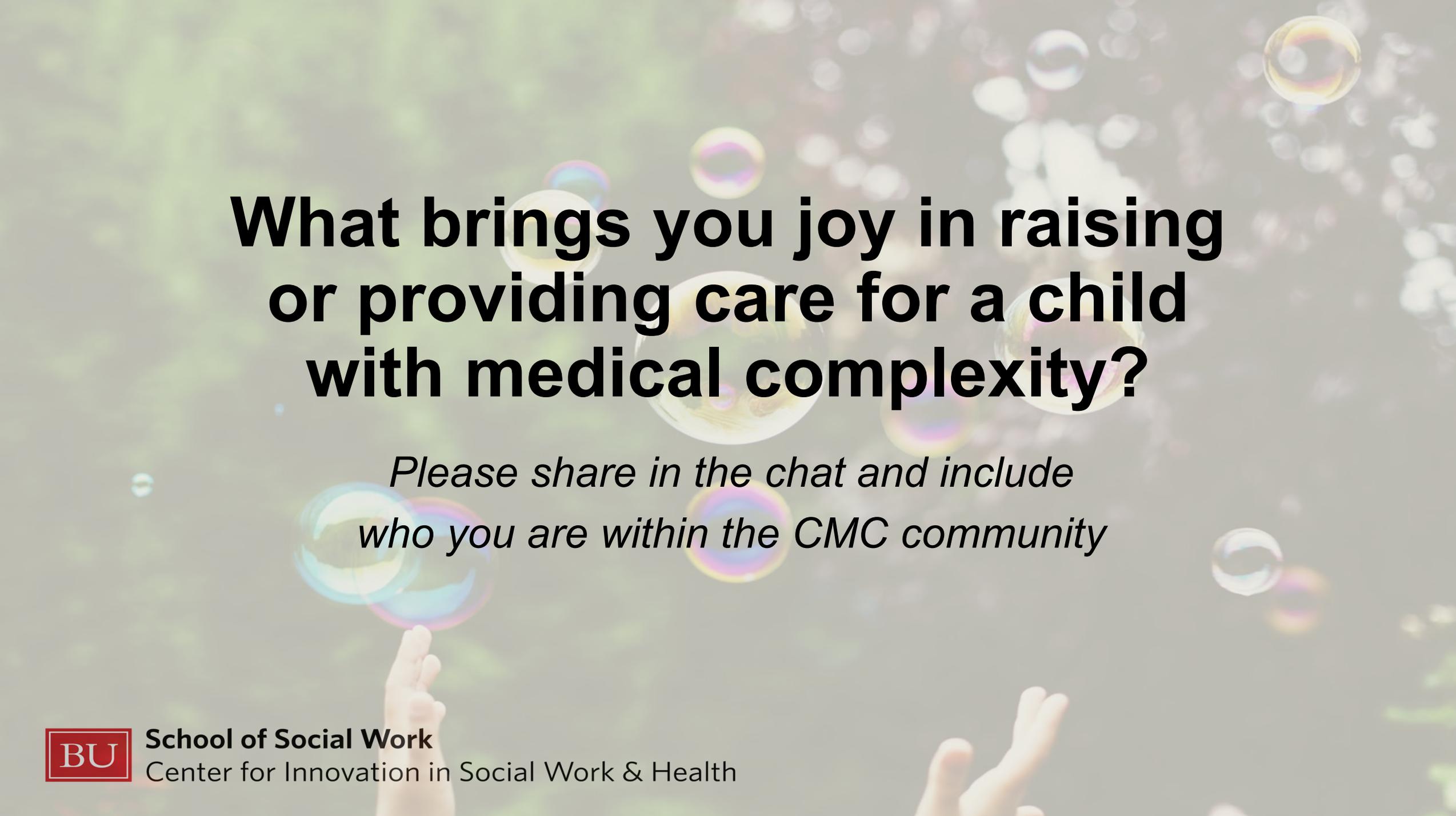
Workgroup: family leaders, led by Cara Coleman (FV) and Meg Comeau, create focus group guide

Asked about child QoL, family WB, how care teams could support

Implemented 27 family-led focus groups across 10 states (N=127)

Inductive thematic analysis of transcripts





What brings you joy in raising or providing care for a child with medical complexity?

*Please share in the chat and include
who you are within the CMC community*



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Why Humanism in Care Delivery Change?



“Sometimes when I was asked about my daughter’s quality-of-life or issues that she was having from her disorder, I was responded with...And it’s hard to talk about...‘Well, you do know that there’s no cure, right? There’s nothing we can do.’”

“Why do you keep saying I’m so strong and then I feel like if I show my weakness and everyone’s like - whoa, you know, like pity. I don’t want you to have pity.”



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What is Humanism?

- Any system or mode of thought or action in which human experiences, values, and dignity predominate.
- Every person throughout the health system—caregiver and patient alike—is first and foremost a human being.
- **Humanistic health professionals care *about* their patients as much as they *care for* them. They understand that compassion can be a powerful catalyst for healing.**

Sources:

<https://pubmed.ncbi.nlm.nih.gov/31135401/>

<https://explorehealthcareers.org/health-career-resources/humanism-health-care/>

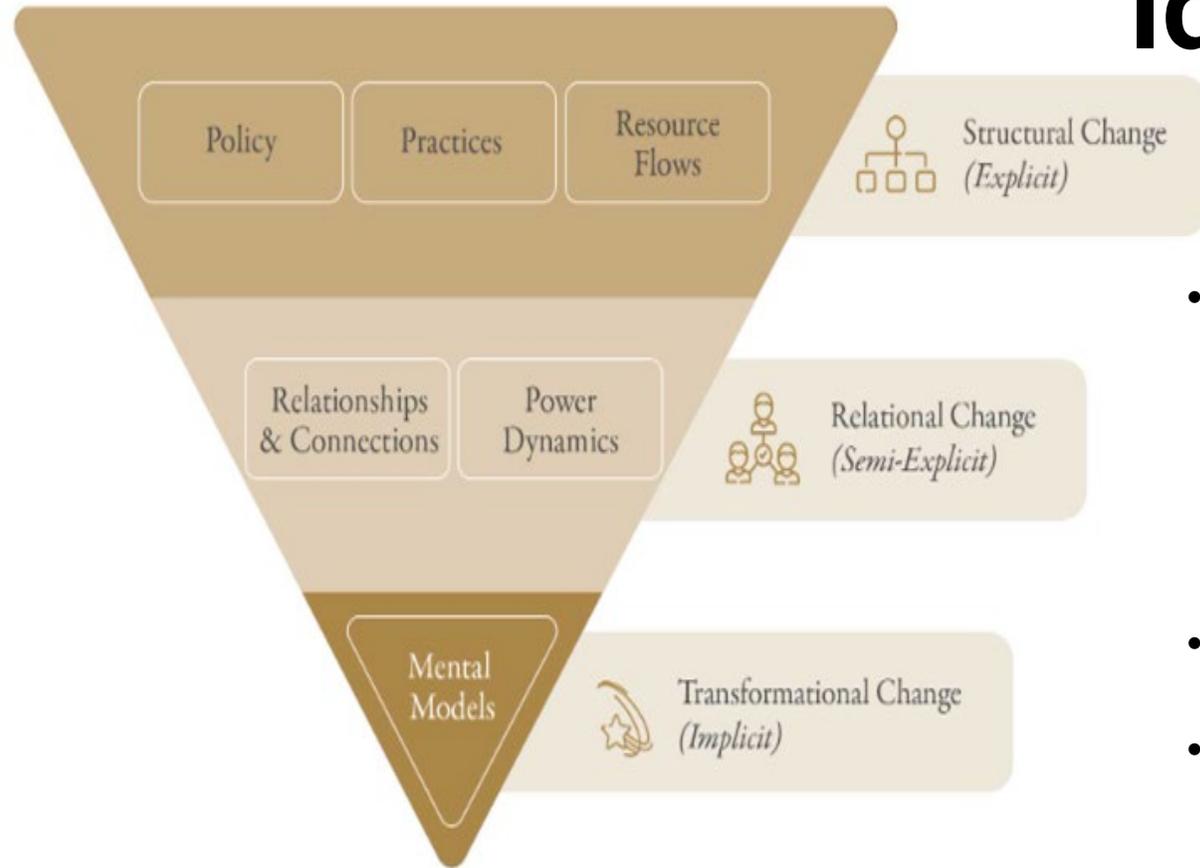


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How Can Humanism Drive Ideas for Care Changes?



- Brings breadth of human experiences families of CMC say drive quality care: **joy, compassion, human dignity, shared humanity, creativity**
- Tied directly to outcomes
- Systems of care are made up of humans
- Medical model → social model of care

What it Looks Like to CMC & Families

- ❑ **Creativity for whole child:** “...ask a question like ... “Is he able to get in his gait trainer for baseball or are you having a hard time?” ...to understand what we are trying to get their bodies to do. “...Maybe we can adjust medication.”
- ❑ **Relationship and trust:** “Where a physician has asked me how I’m doing...I’m so surprised ...I just start crying... you would think that my child’s provider would care more about how parents are doing...to just know that I’m that vital in my child’s life.”
- ❑ **Partnership and communication:** “He called me beforehand...there was a conversation... he was trying to understand exactly what was important to us.”
- ❑ **Undervalued power of family-to-family support:** “Just hearing from other parents ... to be able to talk to about the lows, too, to feel not so alone in it.”





We Do Not Need to Reinvent the Wheel

- FIRST: Families as partners in clinical care and systems change incl collaboration w family-led orgs → PRIORITIES
- Interpersonal skills AND structural elements that support humanism
 - See Humanism paper tables, and online **supplemental information 6** for expanded tables
 - Teachable
 - Many are PFCC best practices
 - Provider wellness is not optional!
- Elevated by families: Palliative care (separate from hospice)
- Other examples: Trauma-informed care, narrative medicine, human-centered design, shared decision-making

TABLE 4

Cultivating Partnership and Communication: Structural Elements for Humanizing Systems in Practice with Families of CMC

Structural Element in Practice	Illustrative Quotations
Little connections	Little connections can be huge. Doctors say hi when they see you and act like family. Or send a message...just checking in.
Consistent follow through	Follow through is... the caring side of care...shows parents that doctors are there and invested in [the child's] care.
Thorough follow up	That's where I feel like we get the support... I get very lengthy phone calls at home that don't make me feel like they're just trying to throw the test results at me. They want to talk about it.
Dedicated team navigator and advocate	A complex care coordinator has been hugely immensely helpful. I didn't even know some of the things that she could help me with until I asked ... She works with ... the pediatrician and care coordinator as well, to coordinate all these different aspects and it's not just healthcare.
Cross-clinic team-based collaboration	[To support well-being] I think care coordination and multiple providers working together well to serve my child, because he does see eleven specialty doctors, at least, and it's very hard to coordinate everyone and get everybody on the same page.

Translating to Practice: Thoughts

The importance of values and principles in systems of care

The roles of training (MCH), experience (community), and mentorship

The power of stories



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Things I've heard...

- *We'll make it up as we go along*
- *Statistics don't mean anything*
- *I have to figure this out myself*
- *I have to fight for everything*
- *I'm waiting for things I'm supposed to have*
- *I'm not respected*





Humanism in Practice: Examples

- 6-month-old twins, one with significant delays
- 18-month-old with feeding tube – child wasn't growing
- 2.5-year-old with a trach, hospitalized, one trained caregiver
- 4-year-old, foster care, global delay + feeding tube, agitation and trouble sleeping
- 10-year-old, moved from out of state, history of developmental delay and multiple “behavior” medications



Questions?
Comments?



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Facilitated Breakout Discussion – Grab your coffee!

- Aim: To consider together actionable strategies, resources, and leverage points for change
- “Our Whole Life is a Quality Improvement Project”
- Collective **wisdom** and collective **impact**:
It’s going to take ALL of us; we ALL matter
- Keep larger aspirational vision in mind AND make changes where we can now
- Multiple modes to capture breadth of perspectives – spoken AND chat
- ConverSketch: Karina Branson will bring the discussions alive visually afterwards



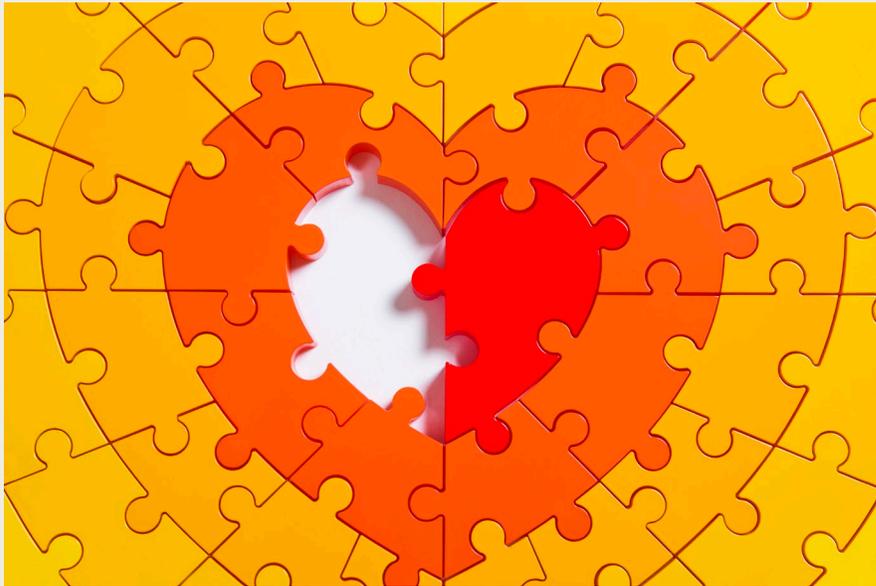
Going into Breakouts

- Randomly pre-assigned
- 4 breakouts w/ 2 co-facilitators each (one family partner)
- 25 minutes for discussion
- Automatically close
- Family Partner Co-Facilitators share out one highlight
- Participants chat key takeaways

breakouts will be recorded to be synthesized, packaged, and shared out (supported by AI)



Questions to Explore Together



What does humanism in care mean to you?

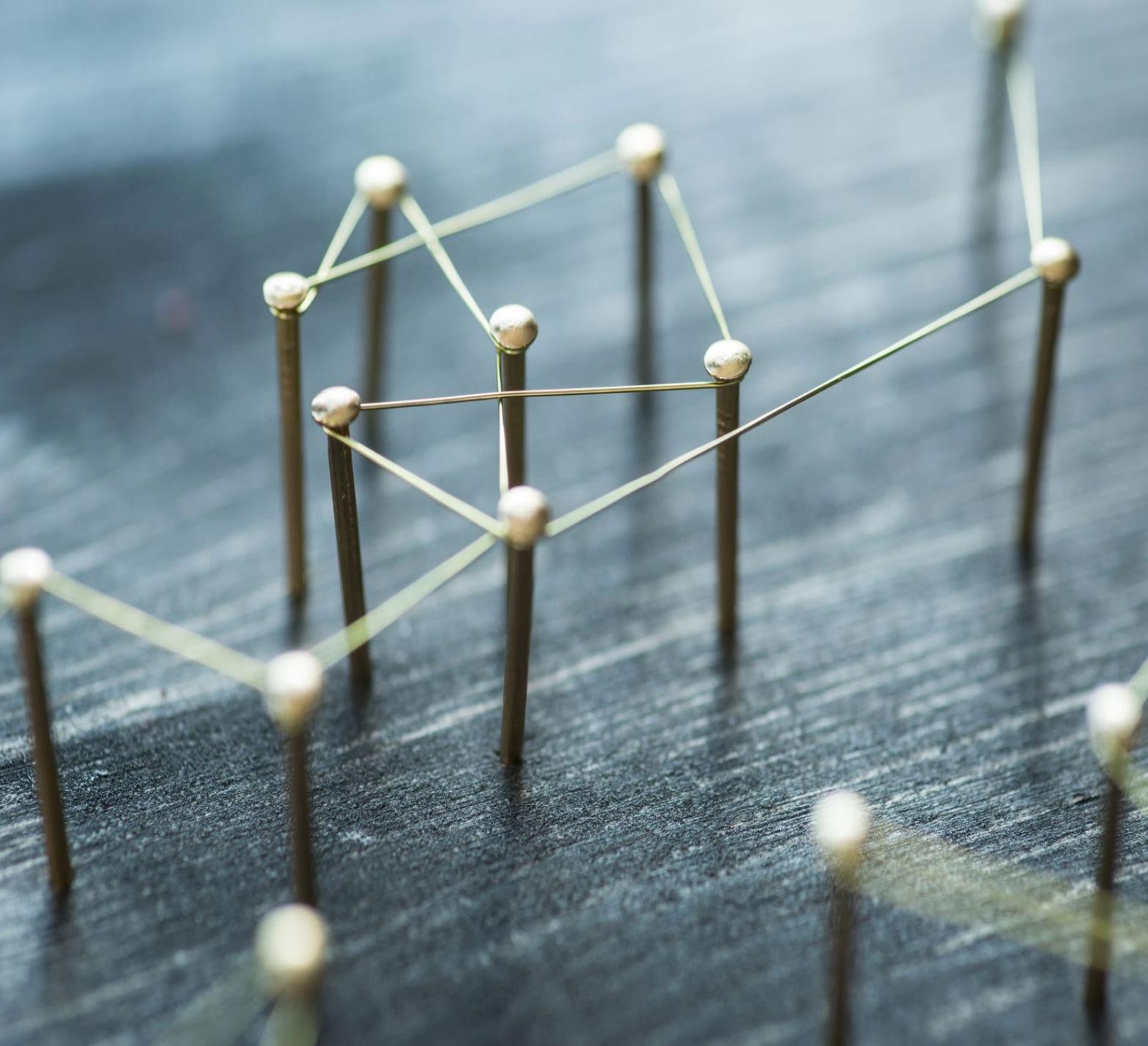
What techniques, strategies, and tools can we draw upon to operationalize humanism in care?

What changes need to happen to better integrate elements of humanism into care?



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Group Share Out

- Family Partner Co-Facilitators share one highlight out loud
- Participants share one takeaway in the chat

Future Café Topics

- Policy Opportunities – July
- Research: Family-Driven Approach to Understand Family Well-Being & its Facilitators - August
- Health Equity and Anti-Ableism - October
- Sustainability and Strategic Partnerships - December



Next Virtual Café: *Policy Opportunities*

Wed, July 24, 3-4p ET

Discussants:

Aimee Ossman

Children's Hospital Association

Lisa Kirsch, MPAff

Dell Medical School



[Register here](#) to attend the third café



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Evaluation Survey

Link in the chat box:

https://bostonu.qualtrics.com/jfe/form/SV_2tQ6xiKSHe14LMq



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Contact Us!

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