

The Future of Care for Children with Medical Complexity

**Cafe #4: Family-Driven Approach to
Understand Family Well-Being and Its
Facilitators**

August 21, 2024

Discussants:

Nikki Montgomery, MA, MEd, GPAC

Katie Huth, MD, MMSc, FRCPC

Jay Berry, MD, MPH



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



Lucile Packard
Foundation

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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



DRUM ROLL PLEASE...



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The Future of Care for Children with Medical Complexity

Café 1: WHERE WE ARE NOW AND WHERE WE NEED TO GO Summary of Key Points from Interdisciplinary Discussion

- 1 IMPORTANCE OF AUTHENTIC FAMILY PARTNERSHIP AT ALL LEVELS**
 - Families of CMC possess essential expertise in the care of their child and in navigating multiple systems. Families' integration into care teams as valued colleagues meaningfully improves quality of life and well-being for CMC/families.
 - For tangible solutions that matter most, foster real partnership
- 4 EXPANDING ACCESS TO SERVICES & SUPPORT**
 - Address the shortage of skilled professionals and essential medical services (especially home and community-
- 5 LEVERAGING INNOVATIVE CARE MODELS & SHARED DATA**
 - Scale successful programs based on community needs, leveraging partnerships and proven models alongside

Key Highlights: WHERE WE ARE NOW & WHERE WE NEED TO GO

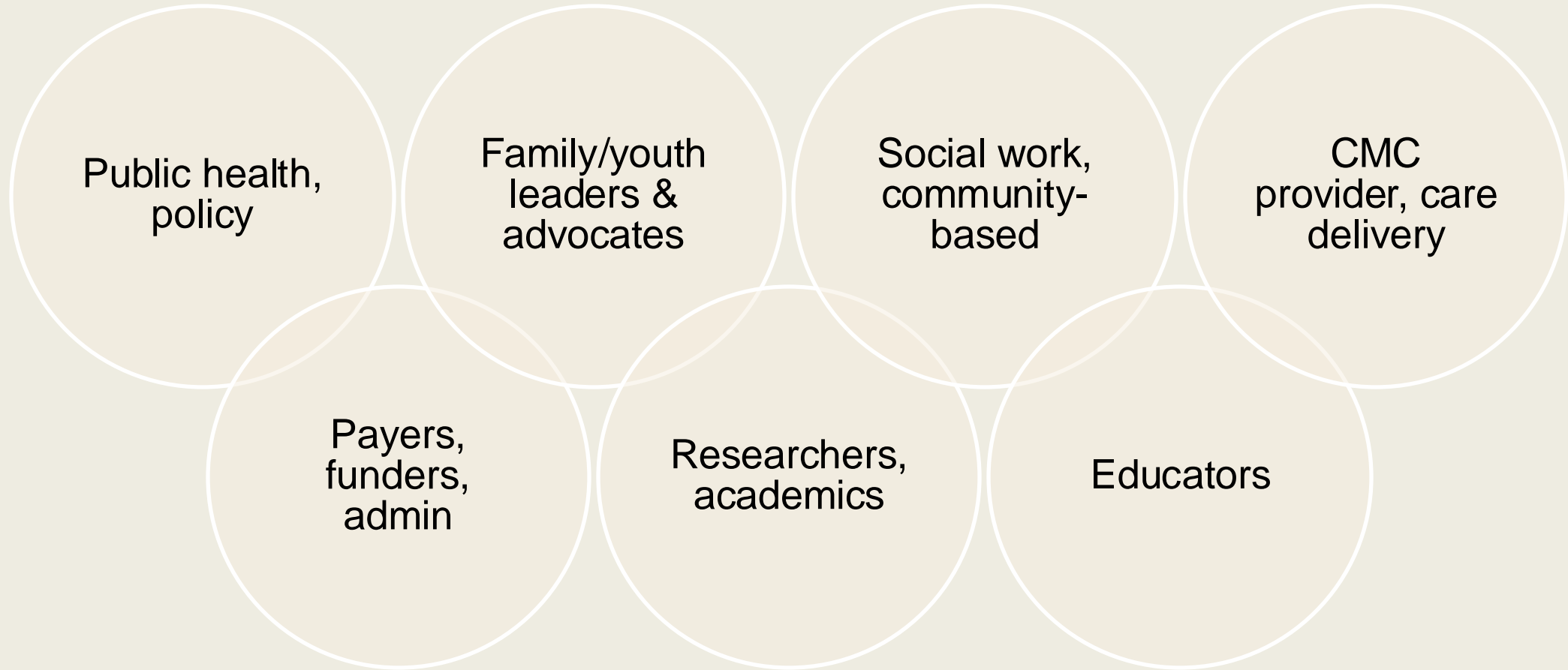
The Future of Care for Children With Medical Complexity Virtual Cafe Series
Family-Driven Priorities & Change Ideas from Cafe 1



March
27,
2024



Who We Are



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Discussion Format

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

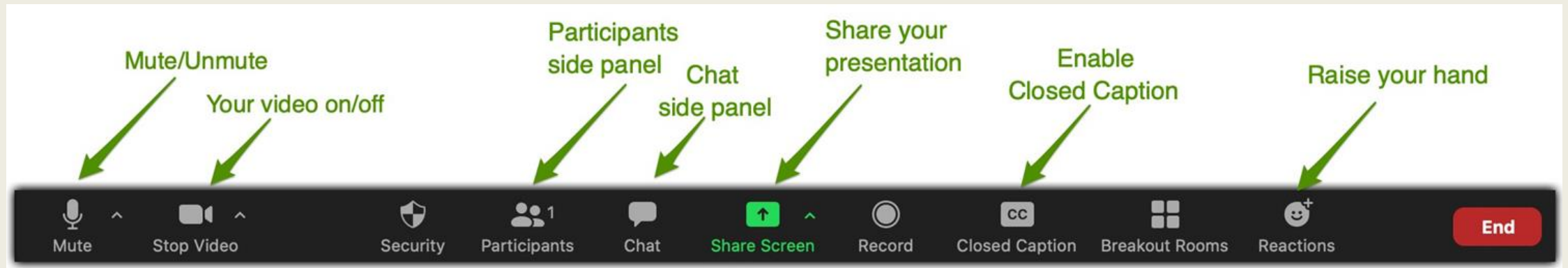
Both are equally valuable ways to participate!

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



What is **family well-being**?



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Where the world comes for answers



What is **family well-being**?

What facilitates family well-being for families with children with medical complexity?



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Where the world comes for answers

Family-driven approach

- Leadership team with lived experience to guide study aims, survey design, recruitment methods, interpretation, dissemination
- Family engagement groups to ensure clarity, accessibility, accuracy, and relevance of the study/tools for diverse families
- Iterative, multimodal crowdsourcing method –
every voice counts



Reaching families

Family Voices & Affiliates

Lucile Packard

CYSHCNet

CMC CoIN Teams

Association of University Centers on Disabilities

Complex Care Listserv

Association of Maternal & Child Health Programs

American Academy of Cerebral Palsy & Developmental Medicine

Social Media Groups



¿Está usted al cuidado de un niño, joven o un joven adulto con condiciones de salud complejas?



Utilice el enlace para completar la corta encuesta.

Queremos comprender mejor como es el día a día en la vida de su familia, y qué puede hacer el sistema de salud para mejorar el bienestar de su familia.

https://uwmadison.co1.qualtrics.com/jfe/form/SV_6MuOWRtNDcwyXjG



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DO YOU CARE FOR A CHILD, YOUTH OR YOUNG ADULT WITH COMPLEX HEALTH ISSUES?

We want to understand better what day-to-day life is like for your family, and things that the healthcare system can do for your family to improve family well-being.



SCAN THIS QR CODE TO PARTICIPATE:



>300 family caregivers from across the US

>300 family caregivers from across the US

...

800 ideas about what facilitates family well-being

>300 family caregivers from across the US

...

We have the
support of our
healthcare team

800 ideas about what facilitates family well-being



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Questions?
Comments?



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Breakout questions

1. **What are meaningful ways of assessing family well-being for families with children with medical complexity?**
2. **How should we educate/build awareness of facilitators of FWB for CMC?**

Clinicians, researchers, policymakers, families...



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



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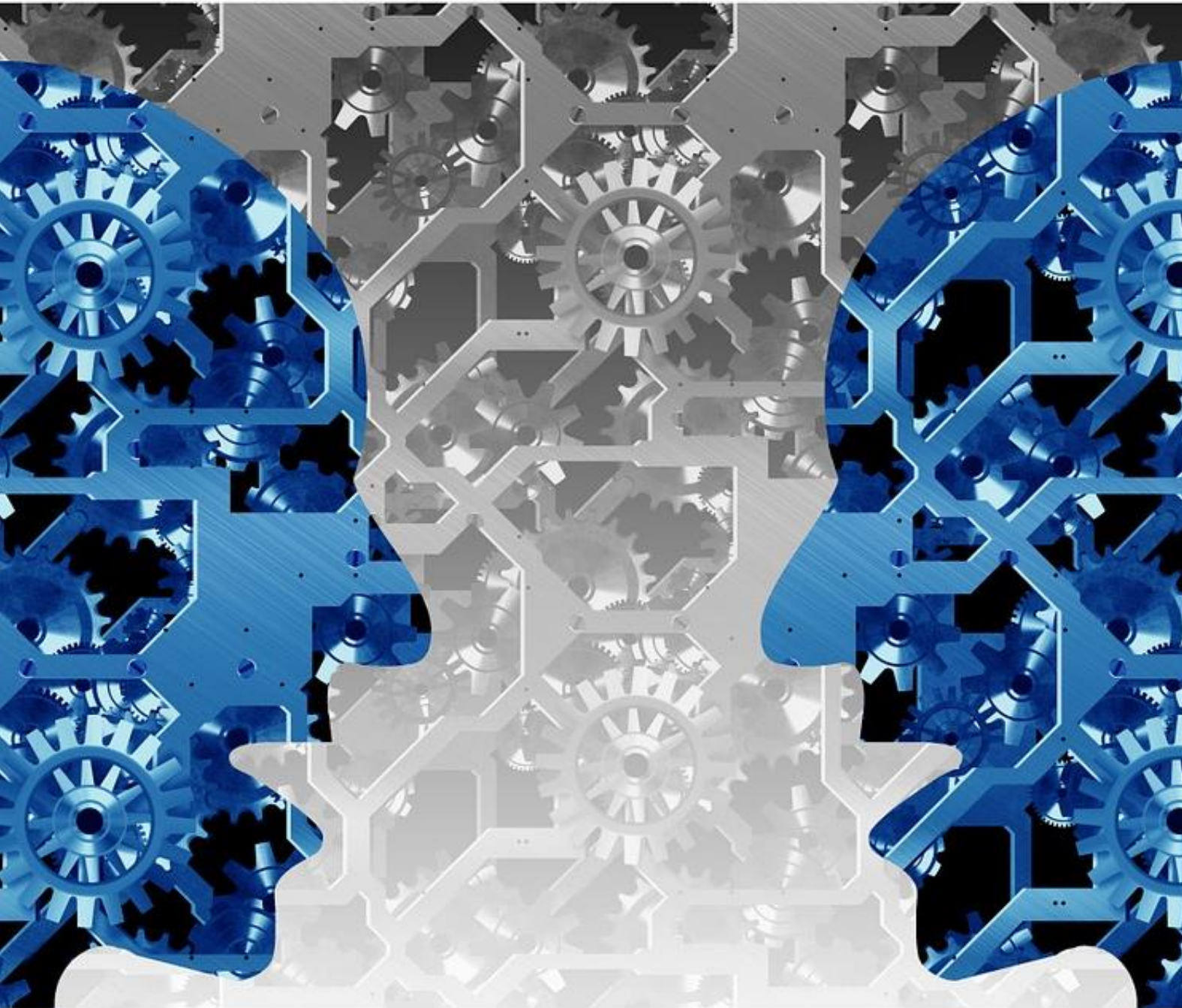
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Going into Breakouts

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

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





Group Share Out

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

Next Virtual Café: Health Equity and Anti-Ableism Through Family Partnership

Wed, Oct 30, 4-5p ET

Discussants:

Michelle White, MD, MPH

Duke University

Nikki Montgomery, MA, MEd, GPAC

Family Voices

****Reg link in chat!**



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Future Café Topics

- Sustainability and Strategic Partnerships

Dec 4, 2024 4-5p ET

****Register and access prior recordings and synthesized highlights and handouts (as avail.) through our website**

<https://ciswh.org/project/cmc-virtual-café>



Evaluation Survey

Link in the chat box:

https://bostonu.qualtrics.com/jfe/form/SV_3I4JC4FDj2lvCaa



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Contact Us!

- Nikki Montgomery
nmontgomery@familyvoices.org
- Katie Huth
Kathleen.Huth@childrens.harvard.edu
- Jay Berry
Jay.Berry@childrens.harvard.edu

