

The Future of Care for Children with Medical Complexity

**Session #1: Where Are We Now &
Where Do We Need To Go?**

March 27, 2024

Discussants:

Meg Comeau, MHA

Cara Coleman, JD, MPH

Bethlyn Houlihan, MSW, 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: 15 min presentation + 5 min Q&A + 40 min facilitated discussion
- Family partners co-leading every session
- Discussion questions and analysis by an interdisciplinary faculty



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!

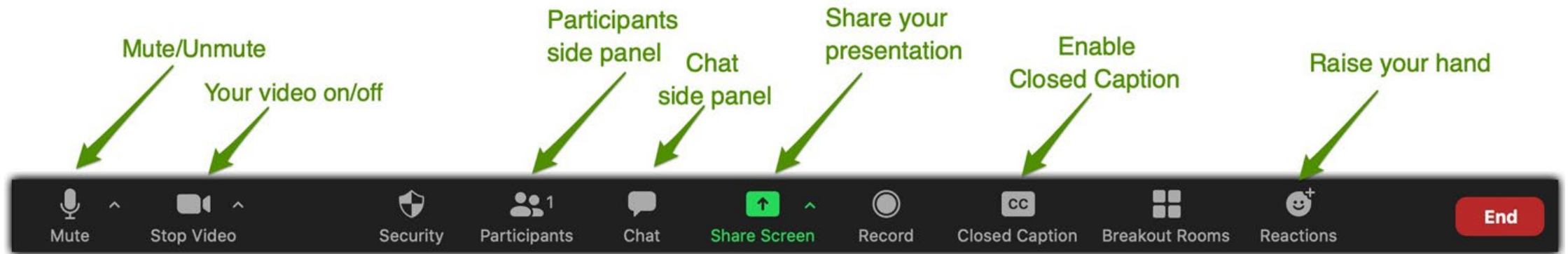
This meeting is being recorded and the
chat transcript will be saved



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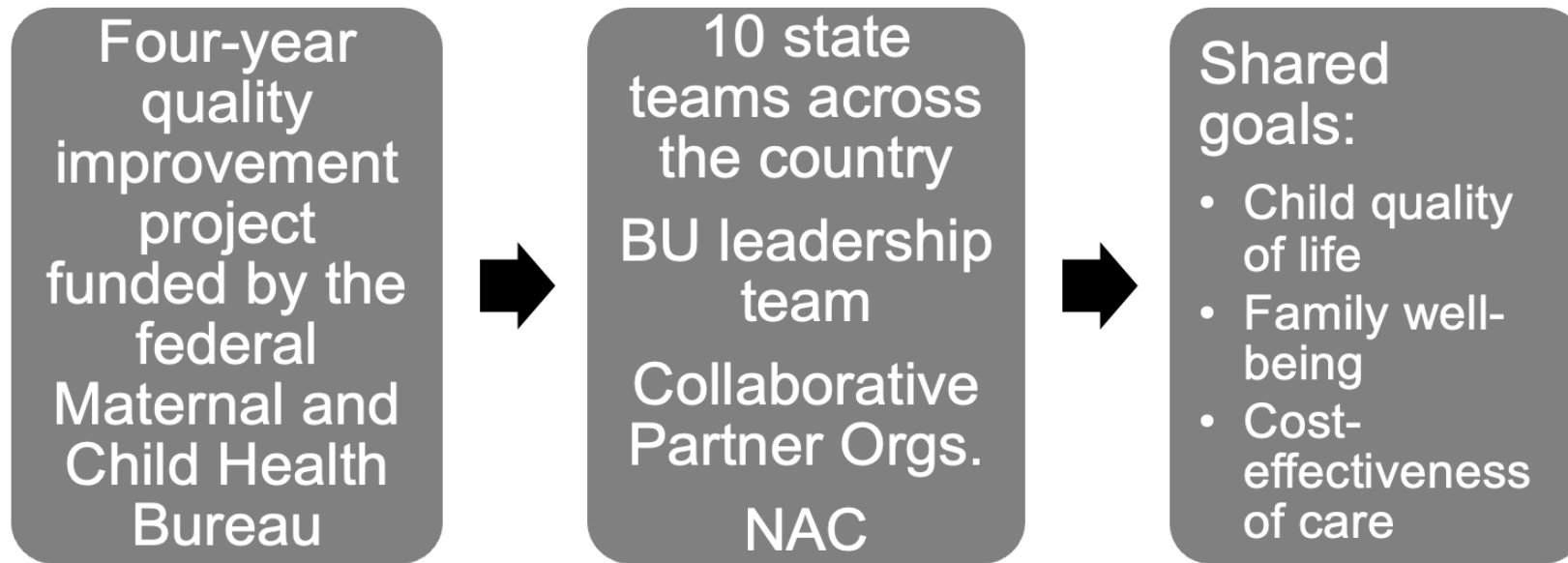
Zoom Platform Please Use Your Camera & Mute Your Line



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Collaborative Improvement and Innovation Network to Advance Care for Children with Medical Complexity (CMC CoIIN)



This project was supported by the Health Resources and Services Administration (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 endorsement be inferred, by HRSA, HHS or the U.S. government. Anna Maria Padlan, HRSA/MCHB Project Officer



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Major High-level Project Findings

- The value of family partnership at all levels
- Knowledge of and access to social supports and community-based resources are essential but limited for CMC and their families
- Need for broader support networks for CMC families and regular referral mechanisms
- Families raising CMC often require mental health supports but cannot access them
- Broader disability awareness and education are needed to increase inclusion and mitigate bias
- Progress is being made in coordinating care (operationally), but its effectiveness is difficult to measure



Major Recommendations

Essential elements of a well-functioning system of care for CMC:

- Integration of **primary palliative care principles** as standard practice
- Patient- and family-centered/driven **measures**
- **Holistic perspective** (whole child/family)
- Family-driven **care coordination** – accountable, measurable, robust



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Major Recommendations, continued

- Access to high-quality **home- and community-based services** are prioritized equally with clinical care
- Child- and family-serving **agencies coordinate and collaborate** on the local, state and federal levels to lessen fragmentation and stretch resources
- Interdisciplinary teams which include **peer supports** are the standard in care for CMC, rather than the exception



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Blueprint for Change: A National Framework for a System of Services for CYSHCN

Want to learn more about the Blueprint?
Read the *Pediatrics* Supplement Issue from June 2022

Need help around the Blueprint?
Visit the National Center for a System of Services for CYSHCN website



Critical Areas for a Well-Functioning System



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Current Landscape

GROUP ACTIVITY:

- We will all type into the chat **BUT DO NOT HIT SEND YET**
- Everyone take a moment to type in:
 - a link to a favorite CMC resource **OR**
 - one way you are working to advance care for CMC
- On my count of 3, we will all press “SEND” together
- Enjoy the waterfall of chat responses



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Bias, Discrimination, Ableism and the Role of Narratives in Care of CMC, Families and Care Team



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Facilitated Discussion – Cafe-Style!

- Aim: To consider together actionable strategies, resources, and leverage points for change
- Grab your coffee!
- “Our Whole Life is a Quality Improvement Project”
- Collective **impact**: It’s going to take ALL of us; we ALL matter
- Collective **wisdom**: Stay together to learn altogether
- 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 discussion alive visually



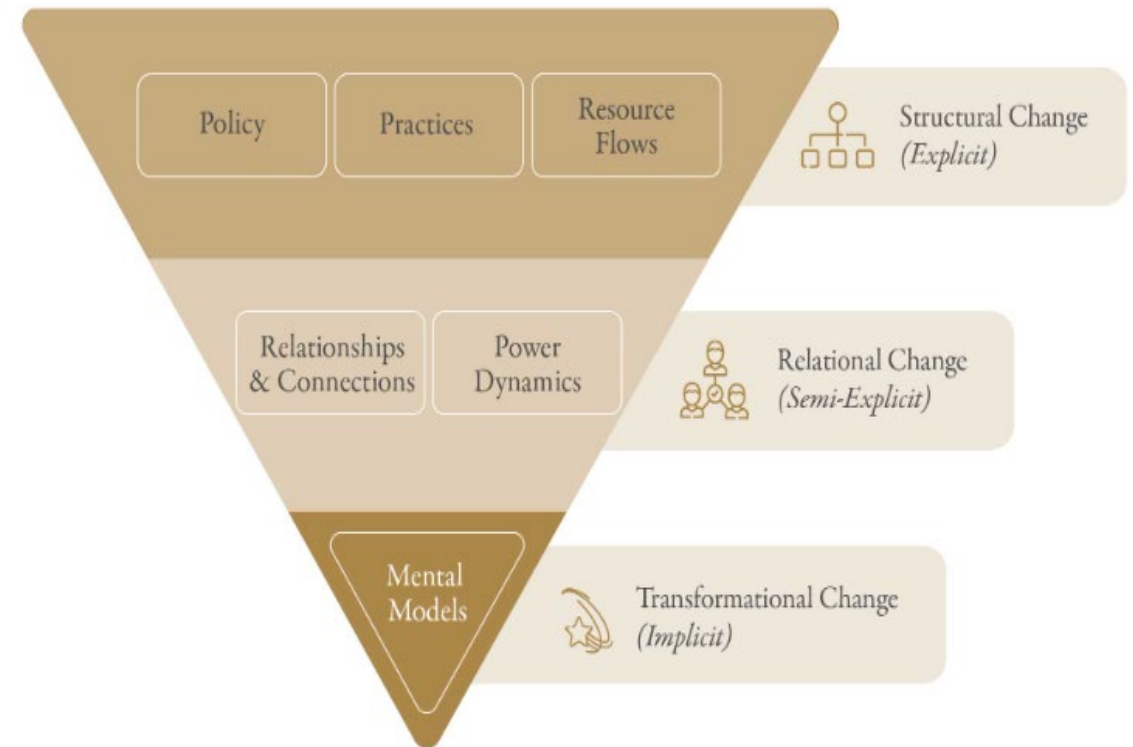
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Six Conditions of Systems Change



Q1. “Where can the smallest change make the biggest difference?”
~Hugh Macleod



Source: <https://www.chandlerfoundation.org/social-investor/systems-change-why-it-matters-and-isnt-just-a-buzzword>



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Q2. How can we think about innovation and improvement differently so as to get improved and/or new results?



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Q3. How do we leverage care innovation and bring it to scale so there's more collective power behind it?



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Q4. How will we know we're asking the right questions - and that we're listening in ways that matter?



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Future Café Topics

- Unmet Needs - May
- Policy Opportunities - July
- Research Priorities - September
- Health Equity and Anti-Ableism - November
- Sustainability and Strategic Partnerships - December



Next Virtual Café:
***Humanism in Clinical Care to Meet Whole
Child/Family Needs***

Wednesday, May 29, 4-5p ET

Discussants: Dennis Kuo, MD, MHS; Bethlyn Houlihan,
MSW, MPH; Cara Coleman, JD, MPH

[Register here](#) to attend the second café.

Remaining dates coming soon!



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Evaluation Survey

Link in the chat box:

[https://bostonu.qualtrics.com/jfe/form/SV_dai2O
LIAgp6uCeq](https://bostonu.qualtrics.com/jfe/form/SV_dai2O
LIAgp6uCeq)



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Contact Us!

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