



Putting Care at the Center 2021

Action-oriented tools to build family trust for improved care for children with medical complexity

Friday, October 22, 2021 2:50pm – 3:35pm ET

Boston University School of Social Work
Center for Innovation in Social Work & Health

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This project is 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.
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***Boston University School of Social
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Family Voices

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Poll Time!

Which option best describes your role?

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

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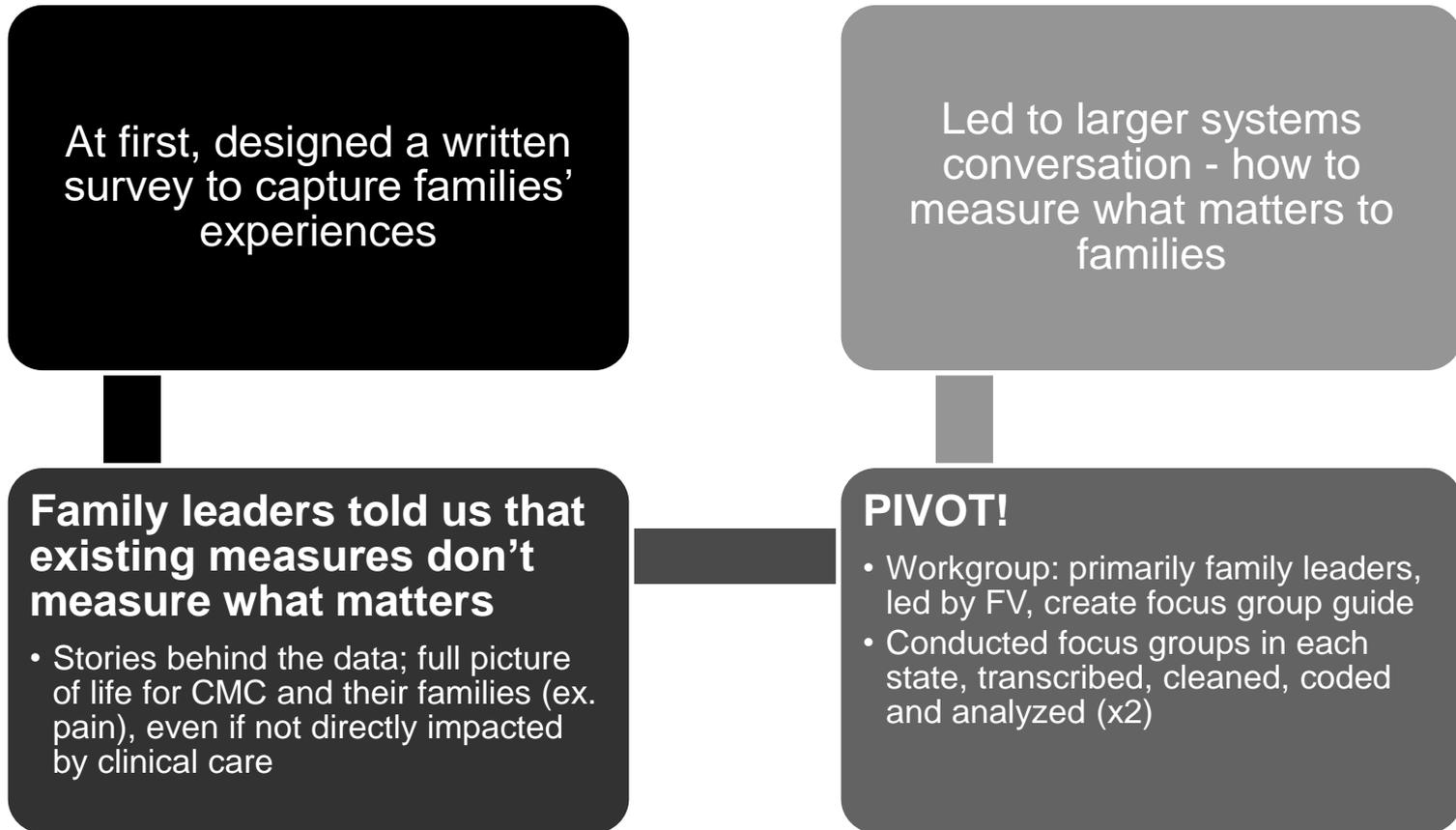
*For families of CMC, seeing the transformative power of lived experiences of **trauma** tied to improvement-oriented actions actively builds trust over time, and ultimately promotes healing.*



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Measuring child quality of life, family well-being and unmet need – PIVOT!



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Family Focus Group Process and Methods

Focus on child quality of life and family well-being

Interview guides developed **Family Focus Group Workgroup**, majority of whom were family leaders

First round of focus groups conducted by all 10 state teams between mid-2019 and early-2020

- Round 2 from late 2020- early 2021 being analyzed currently

90-120 minute conversations

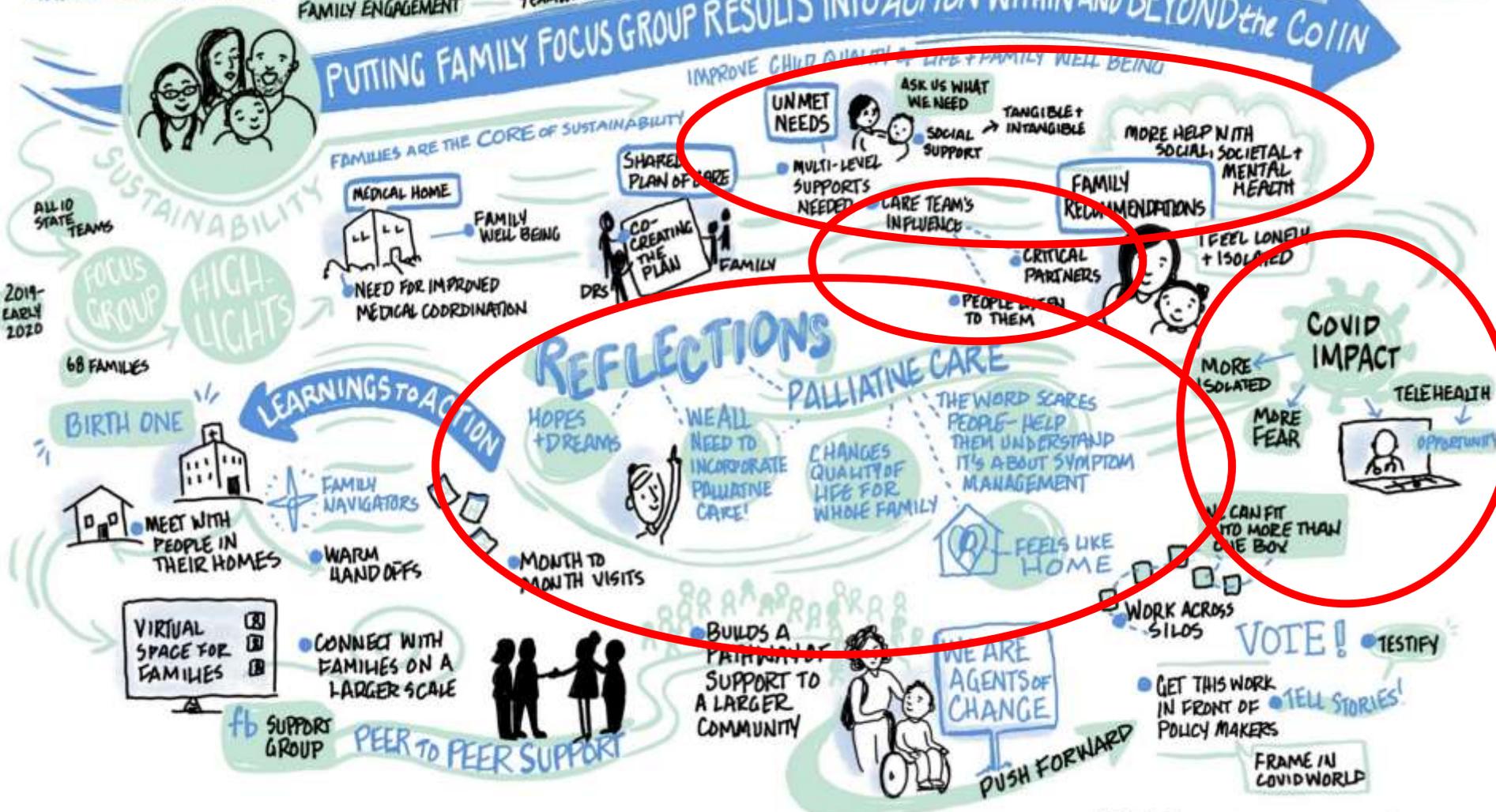
- Between 2 and 16 participants per group
- Total of 68 families participated across 10 states

Transcribed, coded, and analyzed by BU evaluation team



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PUTTING FAMILY FOCUS GROUP RESULTS INTO ACTION WITHIN AND BEYOND the CoiIN

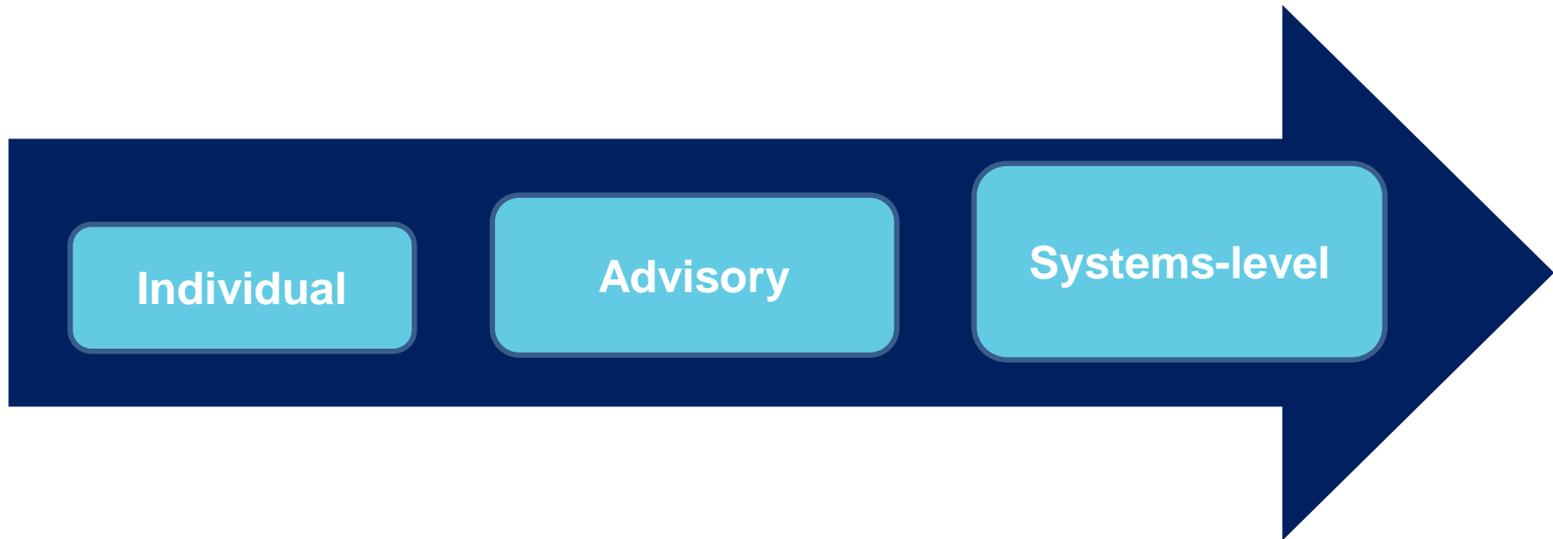


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FamilyVoices.org



Levels of Family Engagement



Family Engagement in Systems Tools



Domains of Family Engagement



Commitment

Families are included in all systems-level initiatives that impact the organization's policies, programs, services, and practices.



Transparency

Family leaders can easily access and understand the information they need to participate effectively.



Representation

Family leaders reflect the diversity of the community served by the organization.



Impact

Family leaders' ideas are incorporated at the systems level to improve policies, programs, services, and practices.

3 Ways to Use the FESAT

1 Plan

Families and staff can use the FESAT to learn if families have the information and supports they need to participate, partner, and contribute to decision-making groups.

- Compare perspectives on how family engagement is going.
- Identify what is working well.
- Identify areas for improvement.

3 Improve

What should we do?

How are we doing?

How can we do better?

2 Assess

Child- and family-serving organizations can use the Checklist in the Family Engagement in Systems (FES) Toolkit to establish family engagement processes.

- Identify supports already in place to ensure meaningful family engagement.
- Explore strategies and resources for additional ways to encourage and support family engagement.

Families and staff can use the FESAT and FES Toolkit to track progress in family engagement efforts.

- Complete the FESAT and use the results as a baseline score.
- Identify an area for improvement and select a strategy from the FES Toolkit that can help.
- Complete the FESAT again at scheduled intervals and compare results to the baseline.



Questions and Discussion

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Thank you!

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- Bethlyn Houlihan, MSW, MPH – bvergo@bu.edu
- Cara Coleman, MPH, JD – ccoleman@familyvoices.org
- Mary Jo Paladino, MSA – mpaladino@familyvoices.org
- Download the FESAT tools: <https://familyvoices.org/fesat/>
 - Contact Beth Dworetzky at bdworetzky@familyvoices.org with questions



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