

NEONATOLOGY TODAY

Peer Reviewed Research, News and Information in Neonatal and Perinatal Medicine



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Family Centered Care September Column

Morgan Kowalski

“Equity, Diversity, Inclusion, and Belonging Work Our Equity, Diversity, Inclusion, and Belonging Committee is in the process of authoring a position paper to highlight our organization’s commitment to health equity.”

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Family-Centered Care Taskforce

The **first** international, multicenter, collaborative initiative solely dedicated to neonatal family-centered care (FCC).

Our Mission:

We support NICUs as they begin or strengthen family-centered care in their units.

Why We Exist:

We exist to address the challenges that exist in implementing FCC practices by providing free education, quality improvement opportunities, and resources.

Who We Are:

Our key strength is equal partnership between multidisciplinary healthcare professionals and Family Partners (former NICU parents) in everything we do.

Core Leadership Team



Malathi Balasundaram, MD **Keira Sorrells, NICU Parent** **Colby Day, MD, NICU Parent** **Morgan Kowalski, NICU Parent**

Family Partners



Fabiana Bacchini **Lelis Bauzá Vernon** **Latoya Blueford** **Sahra Cahoon** **Jennifer Canvasser** **Nishan Degnarain, MPA** **Amy Finn**
Molly Fraust-Wylie **Marybeth Fry** **Yamille Jackson, PhD** **Erika Goyer** **Mia Malcolm** **Necole McRae**
Erika Mendence **Katrina Moline** **Kimberly Novod** **Betsy Pilon** **Elizabeth Simonton** **Alex Zavala**

Healthcare Partners



Daphna Barbeau, MD **Jessi Barnes, MSN, RN, RNC, NIC, NPO, BC, CELEW** **Marsha Campbell-Yeo, RN, BN, NNP, BC, PhD, FAAN** **Robert Cicco, MD** **Mary Coughlin, MD, NNP, NCC-E** **Jessica Daigle, MD** **Jessica Fry, MD**
Christy Gliniak, PhD, OTR/L, OMT, CPSP, NMT/MTC **Mitchell Goldstein, MD** **Luann Jones, DNP, APRN, NNP, BC, NE, BC** **Henry Lee, MD** **Lily Lou, MD, FAAP** **Kerri Machut, MD**
Nicole Nyberg, MD, APRN, NNP, BC **Dharshi Sivakumar, MD** **Vincent Smith, MD, MPH** **Kimberly Stobbe, LCSW** **Bob White, MD** **Emily Whitesel, MD**

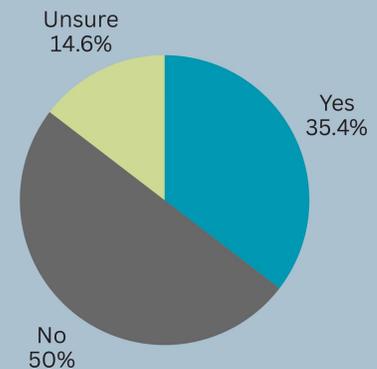
What is Family-Centered Care in the NICU and why does it matter?

Family-Centered Care in the NICU is a model of care that recognizes **parents and families as essential partners in their baby's health and healing**. Instead of seeing parents as "visitors," family-centered care positions them as core members of the care team, with unique expertise about their child

FCC has been **clinically proven to improve infant health outcomes, parental mental health, and family well-being**. It's directly linked to lower mortality rates, shortened length of stay, and fewer readmissions.

Despite its benefits, **FCC practices still aren't fully adopted in the NICU**. In a survey of 48 NICUs across the US, 65% of respondents said they don't have an FCC Committee in their unit.

Does your NICU currently have an FCC Committee?



Fun Fact

Family Partners **co-design, co-lead, and co-author** our research projects, advocacy work, and quality improvement projects! They are **equally represented** in each of our webinars, office hours sessions, and quarterly newsletter publications.



fctaskforce.org



FAMILY-CENTERED CARE TASKFORCE

Organizations Supporting Our Work

- 55 national & international partners
- 22 family-led organizations
- 33 healthcare-based organizations

→ We are actively seeking State Quality Collaboratives to join our network of support! [Email us](#) to learn more.



Our Membership

- 2,600+ members
- 49/50 U.S. States & Puerto Rico
- 9/10 Canadian Provinces
- 71 Countries
- Growth ~100 members/month!

Join us, it's free!



Heard from Members:

"Thank you for all your hard work in engaging NICU teams all around the country on this Taskforce! Our unit has been able to share our FCC team's efforts as well as benefit from the availability of rich information-sharing to help us refine our family-centered care processes in our NICU."



FAMILY-CENTERED CARE TASKFORCE

Our Free Educational Webinars

Learn how clinicians, researchers, and Family Partners are implementing mental health screenings, increasing instances of skin-to-skin care, optimizing neuroprotection, addressing bias, and more.



Fun Fact

Each of our webinars has been recorded and made available on our [YouTube Channel](#). We even post the slides on [our website!](#)

Webinar Database



Our Free Monthly Office Hours Sessions

Who? Facilitated by one Healthcare Partner and one Family Partner from our Executive Council and attended by members like you!

What? An informal meeting where members can bring their unit's specific challenges and barriers around implementing family-centered care practices and brainstorm solutions for overcoming them with their peers.

Where? Zoom! These sessions are not recorded so folks can feel safe sharing.

Why? Don't reinvent the wheel! Modify what's worked for other units to suit your own.

Heard from Members: **"Hearing real life experiences is so impactful for us all as clinicians who have never lived in the shoes of NICU families! Thank you all for your vulnerabilities and sharing so that we can all learn."**

Register Here



Our Free Quarterly Newsletter Publications

Authored by a diverse group of healthcare professionals and Family Partners, these are full of actionable and practical takeaways.



All Issues



Fun Fact

Units who print and post our newsletter in their staff spaces report higher success achieving buy-in around FCC practices!



**FAMILY-CENTERED CARE
TASKFORCE**

Advocacy Work

We are in the process of creating a **comprehensive, interactive toolkit based on the 13 recommendations uncovered by the PRESENCE Study**. Each chapter is authored by one healthcare professional and one family partner.

The spark:

The negative impact of restrictive parental presence policies in NICUs during the COVID-19 pandemic.

Rationale

- Hospitals restricted parental access leaving babies without a parent or a support person, even during extreme illness or death.
- Significant variations existed in parental access policies, even in the same city.
- Parents reported higher negative mental health outcomes during the restrictions.

The response:

Co-created best evidence practice recommendations regarding parental presence in NICUs during pandemics caused by respiratory pathogens such as COVID-19.

How we got there:

Consensus Panel: A diverse group of individuals with expertise related to the project.

Values, preferences, and evidence guided our recommendations

- Step 1: Gathered impact data (via national surveys) from parents/caregivers, healthcare providers, and NICU leadership
 - Step 2: Completed literature review
 - Step 3: Identified 50 potential recommendation items
 - Step 4: Conducted two rounds of Delphi surveys. Participants (n=55) rated and ranked each item on importance
 - Round 1: Rated 50 items (on scale of 1–5)
 - Round 2: Ranked the top 20 items of Round 1 (from 1–20)
 - Step 5: Presented rapid evidence synthesis of the benefits and potential harms for the top-rated items to the consensus panel. Collaborated each item on a Strong or Conditional recommendation based on strength of evidence and value.
 - Step 7: Asked panel members: Do you agree with including this item as a national recommendation?
- Consensus was reached if at least 80% of the panel agreed to add the item

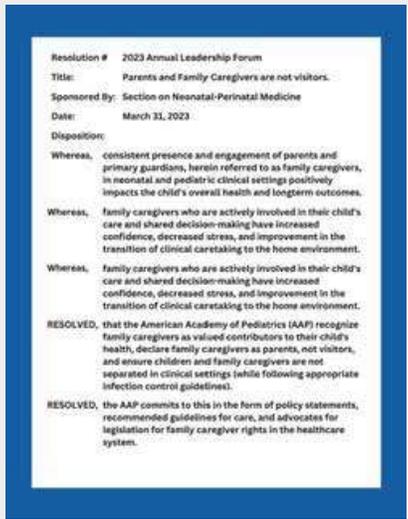
Consensus practice recommendations regarding parental presence in NICUs during pandemics

caused by respiratory pathogens such as COVID-19.

Parent/Caregiver(s) should have:

- Status for parent/caregiver(s) as **essential caregivers**
- Unrestricted access to provide skin-to-skin contact for their infants in the NICU.
- Unrestricted access to breastfeed and to receive breastfeeding supports (including early hand expression, pumping and pumps, encouragement, and lactation support) for their infant in the NICU.
- Uninterrupted access to mental health and psychosocial support services while their infant is admitted to the NICU.
- Uninterrupted access to attend medical rounds while their infant is admitted to the NICU.
- Inclusion in co-designing/decision-making for parent-related NICU policies (e.g., infection control, response planning), including NICU parent partners and advocates.
- Unrestricted access to provide hands-on care tasks for their infant in the NICU.
- Unrestricted access to provide healing touch for their infant in the NICU.
- Unrestricted, in-person access to attend medical rounds while their infant is admitted to the NICU. Virtual care services may be preferred, based on the local context or if parent need/parent preference warrants it.
- Unrestricted, in-person access to mental health and psychosocial support services while their infant is admitted to the NICU. Virtual care services may be preferred, based on the local context or if parent need/parent preference warrants it.
- Uninterrupted access for two parents/caregivers to be present while their infant is admitted to the NICU.
- Unrestricted access to food and allocated spaces to eat/drink while their infant is admitted to the NICU.
- Unrestricted access to use communication devices (their own or hospital devices) for remote connectedness and support (with partners, family, peers, etc.) while they are in the NICU with their infant.

Call to Action: Consistent nationwide evidence-based recommendations must be implemented to support the health and well-being of infants and their parents, ensure equitable care, and navigate future infection control crises.



Our Advocacy Committee submitted a resolution to the AAP Leadership Conference titled **“Parents and Family Caregivers are Integral Members of the Patient Care Team” (#36)** supported by the Section on Neonatal-Perinatal Medicine (SoNPM).

Equity, Diversity, Inclusion, and Belonging Work

Our Equity, Diversity, Inclusion, and Belonging Committee is in the process of authoring a **position paper to highlight our organization's commitment to health equity**.

“Silent Signals in the NICU: Ensuring Nonverbal Communication is Family-Centered” Educational Toolkit

Project Timeline: January 2026 – December 2026

Project Description:

Parents of infants in the Neonatal Intensive Care Unit (NICU) face profound emotional and practical challenges, including stress, fear, and uncertainty about their infant's health and their own role in the care process. In such a vulnerable state, every interaction and message from the care environment carries heightened weight. **Silent signals—such as posted signage, institutional policies, bedside visuals, and even the arrangement of the physical environment—often shapes a family's first impression of care and indicates their place within the NICU.** While these tools are designed to inform, organize, and support clinical workflows, **they can unintentionally undermine family-centered care (FCC)** when they emphasize restrictions, highlight barriers, or implicitly discourage parental engagement.

To address this, we are developing a comprehensive, evidence-informed educational toolkit that will set best practices for silent signals in the NICU to ensure all nonverbal communication is family-centered. Authored by 12 members from our Executive Council of multidisciplinary healthcare professionals and family partners (former NICU parents) diverse in their lived experiences and backgrounds, this project will encompass multiple domains:

- Signage and visual cues that can either welcome and empower families, or discourage their presence and participation at the bedside
- Auditory cues such as alarms and overhead announcements that affect the emotional tone of the unit
- Policies that either promote or inadvertently hinder family partnership
- Physical NICU environment and its accessibility, including tailored provisions for families with non-English language preferences and for parents with disabilities
- Design and content of the NICU webpage as a gateway to family engagement
- Staff behaviors and body language in everyday interactions

By creating a unified framework that addresses these diverse but interconnected elements, we will provide NICUs with actionable strategies to create an environment where every message—spoken or unspoken—reinforces partnership, inclusion, and family-centered care.

We are seeking funding to support the development, design, and dissemination of this toolkit to ensure nonverbal communication is family-centered across the U.S. and abroad.

Project Components:

- Dedicated Interactive Webpage on FCC Taskforce Website
- Introductory and Closing Chapters
- Six Chapters Aligned with Ensuring Nonverbal Communication is Family-Centered
 - Written Content
 - Assessment Tools
 - Implementation Strategies
- Resource Library
- Subject Matter Expert Consultants
- Robust Toolkit Dissemination



We're in the early stages of creating a comprehensive educational toolkit titled **“Silent Signals in the NICU: Ensuring Nonverbal Communication is Family-Centered”** which will encompass multiple domains:

- 1) Signage and visual cues
- 2) Auditory cues
- 3) Policies
- 4) Physical NICU environment & accessibility
- 5) NICU webpage
- 6) Staff behaviors and body language

The goal of this project is to provide units with actionable strategies to **ensure every message, spoken or unspoken, reinforces partnership, inclusion, and FCC.**



FAMILY-CENTERED CARE
TASKFORCE

2024-2026 Quality Improvement Work

Our aim for 2024-2026 is to use quantitative and qualitative research methodologies to create **metrics for family-centered care in the NICU** and to explore **FCC practice implementation at a scale that exceeds prior studies**.

99 NICUs around the globe have participated in our comprehensive NICU FCC Measures survey which was developed by multidisciplinary healthcare professionals, researchers, and family partners. 45 NICUs agreed to an interview to discuss their unit's successes and challenges in implementing FCC practices, and in 2026, interview participants will have the opportunity to engage in topic-specific quality improvement work to overcome their unit's unique barriers.

We're grateful to Stanford Impact Labs for supporting our project! [Click here](#) to learn more about this work.

7 Categories of NICU FCC Measures Uncovered by FCC Taskforce:

1. NICU Framework/Infrastructure
2. Family Support
3. Family Integration into Care
4. Family Integration into QI & Processes
5. NICU Family Environment
6. Staff Education
7. Process Measures

2023 Quality Improvement Work

We are thrilled to share that among the 22 global NICUs participating in our 2023 quality improvement work, we exceeded our goals by **increasing the percentage of units with an active NICU-specific FCC Committee from 18% to 59%, and the percentage of NICUs with an active Family Advisory/Partnership Council from 18% to 45% in just 12 months!** Units who had the most success consistently participated in small group benchmarking opportunities where they were encouraged to share their barriers to implementing FCC practices and brainstorm strategies for overcoming them and attended our free educational webinars while encouraging their colleagues to do the same.

[Click here](#) to read an open access manuscript about this project!

SMALL GROUP 1

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Lurie Children's Hospital of Chicago
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CEO & Co-Founder, ICU Baby



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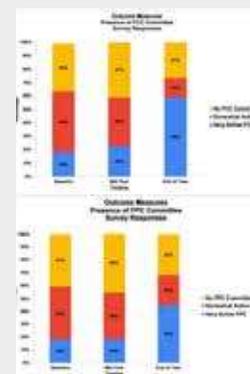
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Chair, Family Advisory Committee CPQCC



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Connect with Us!

Follow and tag us in your FCC-related work so we can easily share!



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LinkedIn



Bluesky



Facebook



Instagram



X

Become a Member



Visit our Website



Our Resources tab is full of relevant articles, policies, guidelines, toolkits, videos, podcasts, and more.

Monthly Column

Check out our [monthly FCC column](#) in Neonatology Today!

Monthly Polls

Submit a question and we'll collect answers from our robust membership!

Submit a Question



All Polls & Responses



Previous polls have focused on couplet care, supplemental communication with families, mental health screenings, doula presence, engagement of Family Partners, and more.

Sponsor Us

Support our organization's work with an industry sponsorship at Supporter, Advocate, Champion, or Trailblazer level. [Reach out to us](#) to learn more.

Interested in a **focus group** with the FCC Taskforce's Executive Council of Healthcare & Family Partners? [Email us!](#)

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