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FCC TASKFORCE

NEWSLETTER

An international collaborative initiative solely dedicated to **quality improvement in NICU Family-Centered Care**.

In This Issue

FAMILY-CENTERED CARE
TASKFORCE

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Parenting in the NICU, Part 2

Jessi Barnes, MSN, RN, RNC-NIC, NPD-BC, C-ELBW

Content Warning: If you have experienced the NICU as a parent, please take care when reading.

The nurse shows us how to open the little doors on the box with our baby inside. My hands are shaking as I gently touch my tiny, sweet baby with the pad of my index finger. Avery seems impossibly small and a little bit sticky. Are babies supposed to be sticky? The nurse rushed to put her hand on mine and firmly said "Be gentle! They don't like stroking!" I wasn't stroking. I was shaking. I couldn't stop, so I removed my hand and squeezed my eyes tight to keep from crying. My partner, Cameron, meekly asked "Can we talk to him? Can he even hear us?" The nurse answers them, but I don't really hear it. All of my energy is focused on trying to be okay. I have no way to define what okay even means right now. It feels like a weight is pushing down on me, cementing me to the floor. I remind myself to smile and relax my face. They can't know how hard this is for me. It seems so easy for them. I need to be strong. The look on Cameron's face is cloudy. It's full of worry, fear, and confusion. We've weathered a lot over the last 10 years, but I've never seen this look before. Cameron grabs my hand and leans their head to mine as we both stand there absolutely shellshocked. The nurse comes back and says that I need to step out because they need to do something sterile for our baby. I feel guilty leaving Avery again. The nurse reminds me to pump when I get back to my hospital room so I can bring milk when I come back. "Your milk is medicine!" she cheerfully calls after us and my partner wheels me back to my hospital room.

Join us as we walk through the NICU through the lens of the parents. This is a stylized representation based on a combination of experiences shared by multiple NICU parents. **As a professional in this space, we must attempt to gain insight from their perspective so we can continue to mold neonatal care from a foundation of equity-focused, family-centered, and trauma-informed care**. Reflect on whatever comes up for you as you read this series and let it help shape your practice.

To read Part 1, click here.

SUPPORTING FAMILIES IN GRIEF

NAVIGATING GRIEF IN THE NICU

SAHRA CAHOON, LOVE FOR LILY &
ERIKA GOYER, NATIONAL PERINATAL ASSOCIATION

> “Grief shows up in many ways, and we carry it in many forms… Grief is a complex, communal emotional response to a wide range of losses that extends beyond the death of an individual…”
>
> -First Peoples Wellness Circle

Those of us who work in and around the neonatal intensive care unit (NICU) know that—in spite of tremendous, significant advancements in neonatal care—few patients and families leave the NICU unscathed. In fact, for many families a NICU stay can be marked by a series of losses, both anticipated and unanticipated, ambiguous and blunt. How we experience those losses shapes who we become as parents, caregivers, and advocates.

If you care for NICU families, you probably already understand that no one is guaranteed a “good outcome” in the neonatal intensive care unit. Sometimes bad things happen. Sometimes a diagnosis shatters the future a family has envisioned. Sometimes babies die. When this happens, we suffer—sometimes together—but often alone.

As parents who have lived through the deaths of our own babies, we bring experiential perspectives to the discussion of grief and loss. As advocates who have been the companions to other families in their grief, those views have broadened. And as witnesses to the suffering of our colleagues, we have been activated to try to improve the systems we all work within.

HERE’S WHERE WE’LL START

- **LISTEN** It sounds simple—and yet it can be so challenging. Sitting in someone else’s puddle and hearing their sorrow can feel intense. One of the most powerful things that you can do is listen. When parents tell you how they feel, believe them. When they ask for a break or a moment, give them space. ♥ **We believe that there is no wrong way to grieve**.
- **USE THEIR BABY’S NAME** This tiny human often holds someone’s whole world in their little body, and the name this family chose has meaning. Parents often find comfort in hearing their child’s name and knowing they will be remembered.

See more tips here.

HERE’S WHERE WE’RE GOING NEXT

We are committed to learning together and exploring a deeper understanding of grief in the NICU and how we all experience and process it.

We are compiling a list of resources and articles to help you and your organization as you move towards more responsive, respectful, trauma-informed family-centered care practices.

We invite you to share your favorite resources, policies, and practices with us.

If there is a topic that you would like to see us cover, please email us:
Sahra at sahra@loveforlily.org and Erika at egoyer@nationalperinatal.org

MARCH ‘26 WEBINAR SUMMARY

BOB CICCO, MD

“Trust and Engagement in the AI Era: Advancing FCC Through Responsible Innovation”
with James Barry, MD, MBA

Jim is a neonatologist and president of NeoMind-AI, a corporation whose mission is to advance the ethical integration of artificial intelligence in pediatric and neonatal medicine. **He presented a comprehensive overview of the developing impact of artificial intelligence (AI) on healthcare in general, and specifically in neonatal care.** Some key takeaways from his talk include:

- It’s important for healthcare professionals to embrace new technology, but **we must learn how to use it properly**.
- AI deep learning models can be useful in helping clinicians to better evaluate vast amounts of digital data and better “connect the dots” of how to interpret this data.
- **AI can be a useful “assistant” to both healthcare professionals and families** in establishing diagnoses, cutting down on documentation time to allow for more face-to-face interaction, and allowing families to better understand their child’s condition.
- Patients and families are accessing AI models to answer medical questions at a rapidly advancing pace. However, analysis shows AI answers were often “incorrect” when recommending a patient did not need to see a doctor or go to the ER.
- We must recognize that healthcare professionals do more than “diagnose.” **There is a partnership between a patient/family and their healthcare team that transcends any value provided by deep learning AI models.** We cannot let AI interfere with either the human connection between a patient/family or the trust that develops between a provider and their patient/family.

This session was extremely enlightening for anyone unaware of how rapidly AI is progressing in the healthcare setting. The bottom line is that **we must accept and embrace that this new technology will continue to grow and we must ensure that, as it does, it is safe, effective, based in science, well evaluated, and integrated into our care with human authority.**

Did you miss this session? Watch the recording here.

CHECK OUT OUR NEW WEBSITE!

If you haven’t checked it out yet, please visit our new and improved website. We hope you love the new look as much as we do, and we are grateful to smallTalk NICU Egg System for sponsoring this project.

A Multicenter, Collaborative Initiative Dedicated to Quality Improvement in NICU Family-Centered Care

Our Network

3444	80	49	9
Members Worldwide	Countries	United States	Canadian Provinces

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EDIBJ IN THE NICU

EQUALITY VS. EQUITY

JESSI BARNES, MSN, RN & MIA MALCOLM, BS, CDFT

Equality and equity are not the same thing. They don't want the same outcome and don't have the same intentions in the NICU space. Equality seeks to provide everyone with the same resources—and while that sounds "nice," it's not helpful or sustainable. **Equity acknowledges that families have different circumstances, needs, and starting points, and allocates the exact resources they need to reach the shared desired outcome.**

The principle of equity in healthcare spaces, specifically in the NICU, aims to provide everyone with a fair and just opportunity to achieve their highest level of health. It requires removing obstacles like poverty, discrimination, and lack of access to quality care, ensuring that systemic barriers are addressed to eliminate health disparities based on social, economic, or environmental factors. In the NICU, an example might be lack of equity in transportation support. Charging NICU parents and families for parking means some families will face financial hardship to participate in their child's care or may not be able to participate at all. Another example might be when parking vouchers are provided but only if families live 'X' number of miles away from the hospital. There's an assumption that proximity to the hospital somehow implies access or availability of resources. **Equity is the cornerstone of family-centered care. When families' needs are addressed on an individual basis, they are more likely to feel seen, heard, and supported to continue participation in their child's care.**

Reflect on this visual aid created by the Robert Wood Johnson Foundation that features a human-centered design based on feedback from the community they serve. Please visit their page to learn more about this image and the 'why' that led to them updating this visual.


EQUALITY:
Everyone gets the same–regardless if it's needed or right for them.

EQUITY:
Everyone gets what they need–understanding the barriers, circumstances, and conditions.

rwjf

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CHECK OUT OUR POSITION STATEMENT

The Family-Centered Care (FCC) Taskforce affirms and advocates for the principles of equity, diversity, inclusion, belonging, and justice (EDIBJ) as foundational to high-quality, compassionate, and just neonatal care. **We believe that every family in the neonatal intensive care unit (NICU) deserves care that honors their identity, recognizes their individual needs, and promotes trust, healing, and resilience.**

Visit our website to learn more and explore how your unit can mitigate harm for marginalized families

TRAUMA-INFORMED CARE CORNER

EASE: A DIFFERENT WAY TO HOLD CARE

MARY COUGHLIN, MS, NNP, NCC-E, TRAUMA INFORMED PROFESSIONAL

In trauma-informed care, we often speak about safety, trust, and honoring choice. But there is another question that sits just beneath all of it, one we don't always name. Not *what or who is right* but: *do people have EASE (Equitable Access to Support and Education) for all care journeys*. **Because when we step into the realities of care, whether in infant feeding, the NICU, or beyond, we quickly realize that the conversations we tend to have are often shaped by tension.** Breastfeeding or formula. Policy or practice. Guidance or lived experience.

And yet, when we collapse complexity into these kinds of either/or frames, **we risk losing sight of what people actually need in the moments that matter most**. We know, without question, that breastfeeding offers profound biological and relational benefits. We also know that global organizations have worked to establish guidance intended to protect infant feeding practices and promote public health. And yet, at times, these **broader frameworks can feel distant from the realities clinicians and families are navigating every day where decisions are complex, resources are limited, and competing priorities are constant.**

Not all parents can breastfeed, not all infants can receive breastmilk, and **every family deserves to be met with support that is safe, informed, and free from judgment**. And then there is the reality of the systems we work within.

Many of the people leading, teaching, and shaping this work are doing so voluntarily, offering their time and energy because they believe deeply in what is possible in the NICU and the world. The infrastructure required to sustain organizations, education, and collaboration is real. It requires resources. It requires support. It requires decisions that are not always simple.

Even the most well-intended systems and guidelines cannot fully account for the lived realities unfolding at the bedside and in families' lives. At the same time, there is a growing call across our field to look more closely at alignment, transparency, and the conditions that shape care.

These are not opposing forces. They are the conditions of the landscape we are navigating. And this is where trauma-informed care stretches us. Because it does not ask us to simply notice complexity; it asks us to respond to it. It asks us to move from awareness into agency. If something feels misaligned, the work is not only to name it, but to wonder: what else might be possible here?

EASE (Equitable Access to Support and Education) invites us to look more closely at the conditions that make care possible. It invites us to ask:

- Is there equitable access to meaningful support?
- Is education clear, compassionate, and grounded in both science and lived experience?
- Are people being met with dignity, or with pressure and judgment?

EASE: A DIFFERENT WAY TO HOLD CARE

CONTINUED FROM PAGE 5

MARY COUGHLIN, MS, NNP, NCC-E, TRAUMA INFORMED PROFESSIONAL

When EASE is present, care in whatever form it takes can feel supported, informed, and grounded. When it is not, people can feel overwhelmed, judged, or alone. Clinicians can feel stretched, uncertain, or constrained by systems that do not fully reflect the realities they are navigating.

While EASE is explored here through the lens of infant feeding, it extends far beyond it. It reflects a broader condition of care; one that applies wherever individuals and systems intersect. Because **across all settings, the ability to provide thoughtful, responsive care depends not only on intention, but on whether equitable access to support and education is truly in place.**

In many ways, this reflects what we already know through the B.U.F.F.E.R. framework; that how we show up matters deeply. EASE extends that understanding, inviting us to **consider not only how we relate, but whether the conditions around us make that kind of care truly possible.**

Trauma-informed care not only asks us to recognize these gaps but to respond with creativity, courage, and a shared responsibility to build something better. Because this work is not about ideology. It is about people. It is about the parent making decisions under pressure, often with incomplete information and deep emotion. It is about the infant whose needs must be met in real time, without delay. It is about the clinician who is holding science, ethics, and humanity all at once.

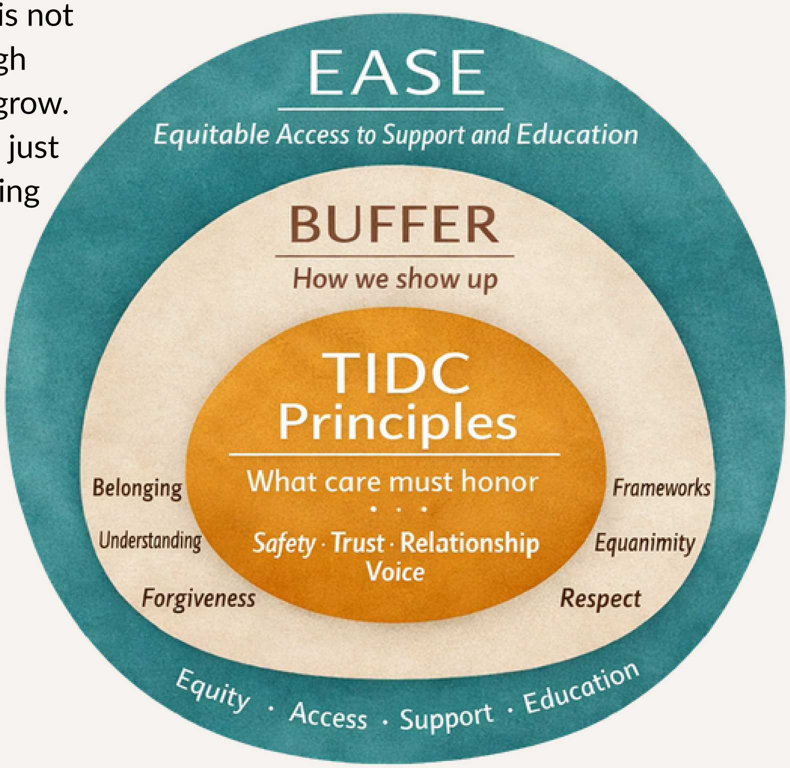
Trauma-informed care asks us to meet each of them with dignity. With honesty. With presence. Not perfectly, but consciously. Because trust is not built on perfection. It is built over time, through transparency, reflection, and a willingness to grow. And perhaps this is the deeper invitation. Not just to navigate complexity…but to create something new within it.

A Reflection

- Where in your own work do you see EASE present?
- And where might there be an opportunity to create more of it for the people you serve, for your colleagues, and for yourself?

With hugs and hope,
Mary

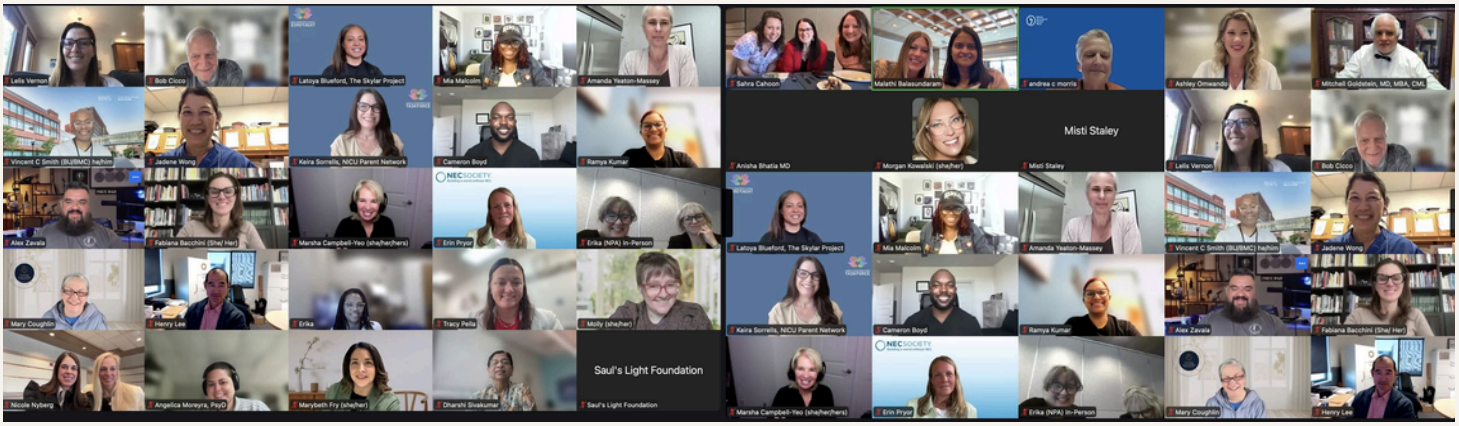
Layers of Trauma-Informed Care:



LEADERSHIP TEAM UPDATE

MALATHI BALASUNDARAM, MD & MORGAN KOWALSKI

The FCC Taskforce's Executive Council held its first quarterly meeting of 2026 on March 26th with 37 members joining virtually via Zoom and in-person at National Perinatal Association's conference in Coeur d'Alene, Idaho. Thank you to Kristy Love for accomodating our group!



Introducing The FCC Taskforce
Dads & Partners Engagement Committee

Seen, Heard, Included

The Family-Centered Care Taskforce is proud to introduce the Dads & Partners Engagement Committee, a new committee dedicated to advancing the inclusion, support, and engagement of dads, partners, and non-birthing caregivers in family-centered care.

Co-chaired by Cameron N. Boyd, MD, and Alex Zavala, this committee brings together clinical leadership and lived experience to help elevate voices that have too often been overlooked in the care journey.

Family-centered care is strongest when dads, partners, and non-birthing caregivers are intentionally included, supported, and engaged.

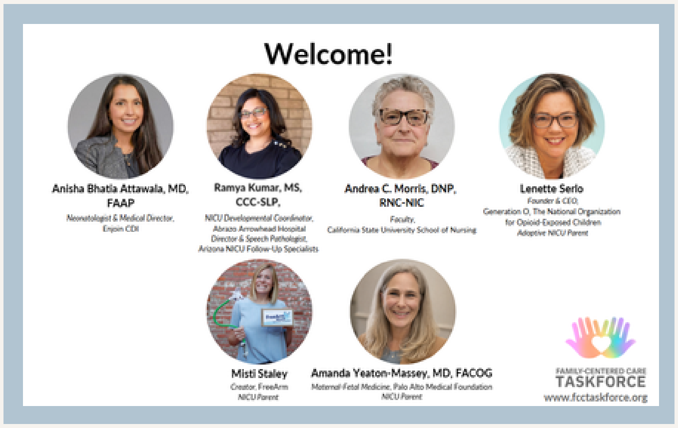
We are excited to introduce our new **Dads & Partners Engagement Committee** co-chaired by Cameron Boyd, MD and Alex Zavala of The NICU Dad! Together, they will **advance the inclusion, support, and engagement of dads, partners, and non-birthing parents in the NICU.**

Projects in Our Pipeline:

- Presence Study Toolkit
- FCC Scholars
- Quality Improvement Foundations Course for Family Partners - Thank you, VON!
- Dads and Partners Screening and Support Cohort
- Creation of Fiscal Stewardship Committee
- Silent Signals in the NICU Toolkit

It was so wonderful to be together in person in beautiful Coeur d'Alene!

We welcomed **six** new Executive Council members with dynamic areas of expertise and diverse lived experience!



Welcome!

Anisha Bhatia Attawala, MD, FAAP
Neonatologist & Medical Director,
Enjoin CDI

Ramya Kumar, MS, CCC-SLP,
NICU Developmental Coordinator,
Abrazo Arrowhead Hospital
Director & Speech Pathologist,
Arizona NICU Follow-Up Specialists

Andrea C. Morris, DNP, RNC-NIC
Faculty,
California State University School of Nursing

Lenette Serlo
Founder & CEO,
Generation O, The National Organization for Opioid-Exposed Children
Adoptive NICU Parent

Misti Staley
Creator, FreeArm
NICU Parent

Amanda Yeaton-Massey, MD, FACOG
Maternal-Fetal Medicine, Palo Alto Medical Foundation
NICU Parent

www.fcctaskforce.org

THANK YOU FOR READING

FCC Taskforce Leadership

Malathi Balasundaram, MD
Founder & Executive Director

Morgan Kowalski, NICU Parent
Director of Operations

Keira Sorrells, NICU Parent
Director of Impact & Strategy

Organizational Partners

27 family-led organizations
50 healthcare-based organizations

Connect

Membership

3,400+ members
49/50 U.S. States & Puerto Rico
9/10 Canadian Provinces
80 Countries
Join us, membership is free!

Our listserv is a closed and moderated, intended to foster meaningful collaboration and information sharing within our community. We are mindful of email fatigue and strive to keep communications thoughtful, relevant, and purposeful.

Mission Statement

We support NICUs as they begin or strengthen Family-Centered Care in their units.

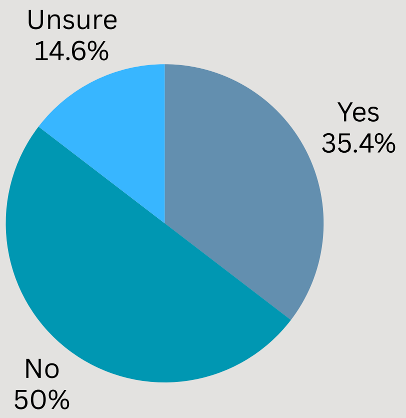
Why We Exist

To address the challenges that exist in implementing FCC practices, we offer free educational webinars with engaging, live Q&A sessions and free monthly FCC Community Exchange sessions.

Our key strength is equal partnership between clinicians and Family Partners in everything we do.

In a survey of 48 NICUs across the U.S., 65% said they don't have an active FCC Committee in their unit.

Does your NICU currently have an FCC Committee?



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We're grateful to our contributors who **donate their time and expertise** to our publication!

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