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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 3

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.

Today is discharge day—for me, not for Avery. How am I supposed to leave him here by himself? He's so impossibly small. What if something happens? He can't tell us. I think fondly about the comforts of home and Rascal, our dog. Immediately, I feel guilty for thinking even just for one second of leaving my baby. It could be months before Avery is able to come home. Am I supposed to just return to normal life? My life before his birth feels foreign to me. I don't want to go back, even if I could. Cameron walks with me to see Avery before we leave. They look so tired. We both do, I'm sure. I'm deeply grateful that Avery's nurse tonight gives us space after updating us. Space is all I crave now. Avery looks like he's in a terrarium, but we are, too. The lack of privacy is maddening. These curtains don't shield much. I sneak in a gentle touch to Avery's tiny hand. Bless him for not alarming anyone because I didn't ask first. I hope he knows that I'm his mom. I'm still wrapping my mind around that transition myself. As we prepare to leave, his nurse offers me a hug (I decline) and shares that while she has never been in this position, she can only imagine how hard it must be. I appreciate the gesture, I really do. I would give anything to only be imagining all of this. Cameron thanks her while I somberly walk to the door. The childbirth classes and pamphlets didn't prepare me for this feeling. I'm not supposed to leave without my baby. Everything about this feels wrong.

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 professionals 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. To read Part 2, click here.

NAVIGATING GRIEF IN THE NICU

SAHRA CAHOON, Love for Lily & **ERIKA GOYER**, National Perinatal Association

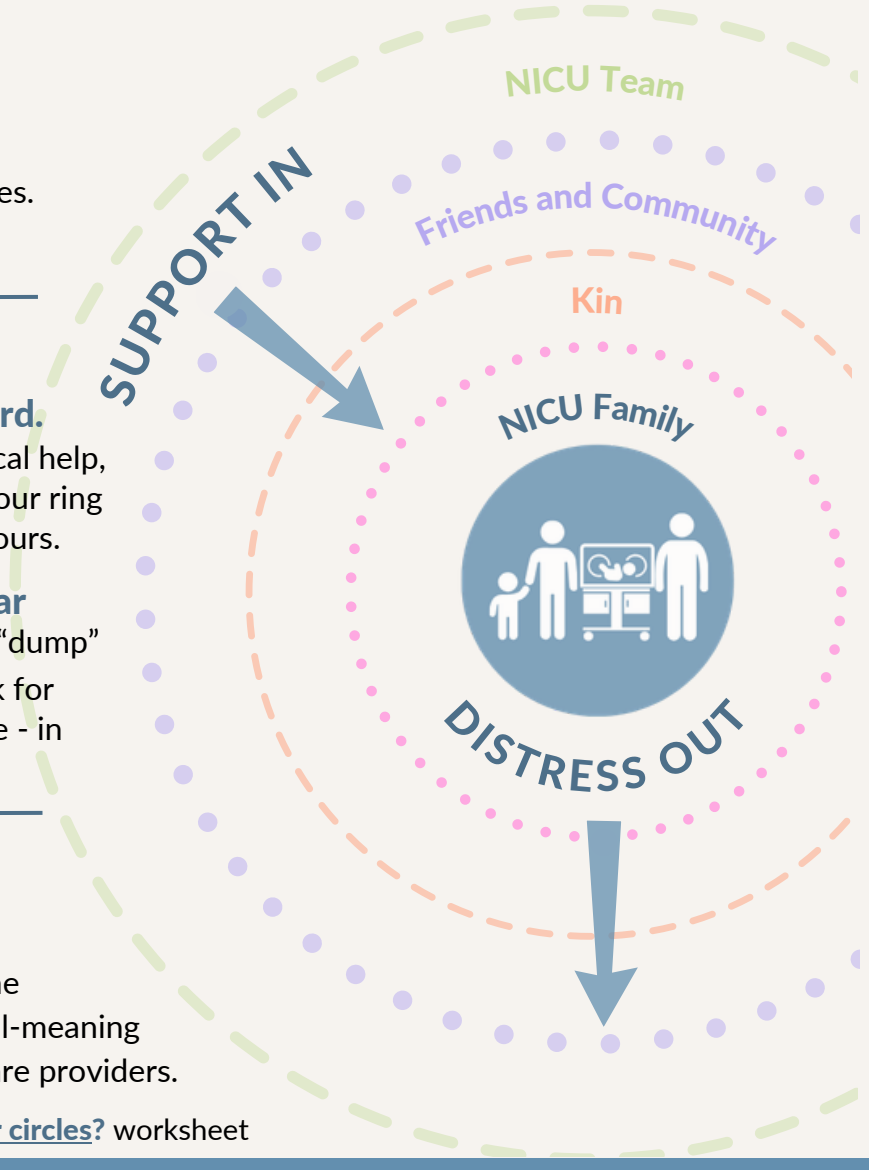
When supporting families in the NICU, remember this phrase **Comfort in. Dump out.**

We read it years ago in the Los Angeles Times. It's simple, practical, useful advice. And it was the answer to the persistent question from NICU staff during our annual bereavement support trainings. **"I want to help. How do I not say or do the wrong thing?"**

Psychologist Susan Silk calls it the **Ring Theory**

- **Draw a circle.** In that circle is the family who is in crisis or who is grieving.
- **Now draw a larger circle.** Those are the people closest to the family. Grandparents. Siblings. Auties. Uncles. Cousins. Kin.
- **The next circle** is their closest friends and community. They provide practical support during times of crisis.
- **We are in the circle of NICU providers and staff.** Nurses, neonatologists, therapists, peer support specialists, and NICU psychologists care for babies & families.

Read more on the Ring Theory



The Rules:

- **Comfort and support flow inward.** Your role is to offer validation, practical help, and emotional support to people in your ring or in the rings that are smaller than yours.
- **Distress, worry, anxiety, and fear flow outward.** Your goal is to only "dump" - vent at, complain to, worry with, ask for reassurance, or seek help from people - in rings larger than your own.

Why?

In the NICU, this model helps protect traumatized parents from taking on the burdens, anxieties, and distress of well-meaning friends, extended family, and healthcare providers.

Who's in your circles? worksheet

JULY '26 WEBINAR SUMMARY

BOB CICCO, MD

"Parent Perspectives: Clinician Communication" with Latoya Blueford and Tracy Peila, MA, LMHP, EdS and **"Breaking Bad News: Helping Families When They Need It Most"** with Anthony Orsini, DO, FAAP

After sharing stories of losses both mothers experienced in the NICU, Latoya and Tracy provided valuable insights that clinicians can utilize to improve their communication skills not only with families in the NICU setting, but also in any professional encounter. Following this discussion, Anthony provided a clinician's perspective on how we can improve our communication skills, especially while breaking bad news. Some important highlights include:

- It's not just what a clinician says, but **how they say it**. Nonverbal communication like eye contact, facial expressions, and body language allows a family to know he or she is "present" during a conversation. And **it's just as important to "be present" after the conversation is over**.
- Clinicians should **always sit during a conversation with families**. It's an essential part of that nonverbal communication that is oftentimes overlooked!
- How a clinician talks to a family can either help empower that family to manage their NICU stay or add to the stress and pressure that a family already feels.
- While it is imperative that a clinician always speaks the truth, ***how*** that truth is spoken always matters.
- While a clinician can't always be perfect in what he or she says, **communicating in a compassionate and caring way** can overcome some of that imperfection.
- It is important that clinicians know the families they are speaking to and talk on a level that families understand. **There are no "standard scripts" that can be used for everyone!**
- Having difficult conversations does not come naturally to any clinician. And it should not be viewed as a task that must be done. Rather, it is a **skill that must be taught, honed, and mastered**. No one is inherently "good" at it without this training.
- In addition to individual training, the **culture of a NICU** can prioritize that staff communicates in a way that is sensitive to family needs.
- There is a difference between merely giving information and communicating. Clinicians must not merely give information and leave. Rather, that i**nformation must be part of a conversation that is carried out with empathy, clarity, and purpose**.

This session served as a reminder to all of us that **how we communicate plays a major role in establishing trusting relationships between families and clinicians**. This is especially true in difficult and stressful situations that are so common in the NICU setting. Honing communication and listening skills must be a **continual part** of a clinician's ongoing education if they are to develop effective partnerships with the families they serve.

Did you miss this session? Watch the recording here.

EDIBJ IN THE NICU: *DIVERSITY, HONORING DIFFERENCES*

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

What does diversity actually mean? At its core, diversity is about variety—in people, places, and perspectives.

- **Diversity in people** includes a wide spectrum of races, ethnicities, genders, languages, ages, cultures, and beliefs.
- **Diversity in places**—especially in healthcare—means designing environments like the NICU, PICU, CICU, or ED to meet specific clinical and family needs.

Simply put, diversity is about honoring differences.

But to honor someone, you first have to see them. That starts by creating psychological safety—building a space where patients, families, and staff can share their full stories without fear of judgment. When we understand someone's story, we can show up for them in ways that truly matter to them.

Here are two ways equity and diversity come together to drive compassionate, family-centered care:

Example 1 - Assessing Language Needs

A Spanish-speaking family asks through an interpreter how to complete their discharge CPR class. The schedule offers English classes Monday through Wednesday, from 12:00 PM to 3:00 PM or 4:00 PM to 7:00 PM. The Spanish option? Thursdays from 12:00 PM to 1:00 PM only.

On paper, it looks like a win—we have language options! But in practice, true accessibility is only being offered to English-speaking families. An English-speaking parent gets 18 hours of total class availability across multiple times of day, while a Spanish-speaking parent gets just one single hour. On top of that, while the hospital assumed Spanish was the most pressing need based on national trends, a closer look at local demographic data showed that Haitian Creole was actually the second most spoken language in their specific patient population.

This is where diversity without equity falls short. **Honoring differences means looking past surface-level checklists and designing care around the actual lives and languages of the families in front of us.**

Every family deserves access to care that is free from bias, discrimination, and fear-based practices. In the NICU, diversity also encompasses family structure and community, which often looks different than expected. Each family arrives with a distinct set of strengths and challenges regardless of their makeup.

Providing individualized, equitable care means recognizing and responding to those differences with humility and respect.

The goals of diversity include fostering creativity and innovation, strengthening decision-making, and building a more just and empathetic community.

EDIBJ IN THE NICU: *DIVERSITY, HONORING DIFFERENCES*

CONTINUED FROM PAGE 4

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

Example 2 - The Connection Between Being Seen and Feeling Safe

You are working on a quality improvement project to decrease the number of sticks for babies while placing PICC lines. You notice that one member of the PICC team has a significantly higher number of sticks for Black infants. When you ask them about it, they respond with "That can't be right. I do the same thing for every baby. I don't see color when it comes to my patients. My success rate is still the highest on the team."

This team member response highlights three critical misunderstandings:

- **Equity vs Equality:** Doing the "same thing" for every baby is not equal care, especially when the approach disproportionally benefits lighter skin tones. Darker skin may require different lighting or technology (transilluminator, etc.) to locate veins accurately on the first try.
- **Reframing Success:** A high success rate is not what is being discussed – the number of sticks it takes to achieve success is. A "high success rate" means very little if a Black infant had to endure 2-3 times as many sticks when compared to their white peers.
- **The Danger of Colorblindness:** Saying "I don't see color" may seem benign, but what it does is dismiss both physical and cultural realities of families. When families realize that their diverse identities are being ignored, under the guise of neutrality, trust evaporates. Choosing not to see a family's race, ethnicity, culture, etc., leads them to feel undervalued, which translates to an inherent lack of safety.

Both examples show that both equity and diversity are needed to truly see families and provide individualized care that accomplishes clinical care goals in ways that are important to and affirming of their family. Next time, we'll explore inclusion and how it helps operationalize equity and diversity.

IMPORTANT DATES

September

- NICU Awareness Month
- Newborn Screening Awareness Month

September 10: World Suicide Prevention
September 7-13: Maternal Suicide Prevention Week
September 15: Neonatal Nurses Day
September 12-18: Neonatal Nurses Week
September 20-26: Int'l Neonatal Therapy Week

November

- Prematurity Awareness Month

November 15: World Prematurity Day

October

- Pregnancy & Infant Loss Awareness Month
- Sudden Infant Death Syndrome (SIDS) Awareness Month

October 4-10: National Midwifery Week
October 10: World Mental Health Day
October 15: Pregnancy & Infant Loss Remembrance Day
October 25-31: Respiratory Therapy Week

Are we missing something?
Email us!

TRAUMA-INFORMED CARE CORNER

TINY RUPTURES, TINY REPAIRS

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

Trauma-Informed Care After We Get It Wrong

A parent asks a question during rounds. Someone answers quickly, turns back toward the team, and the conversation moves on. The parent grows quiet. Nothing dramatic happened. And yet, something happened.

Trauma-informed care is often described through the things we hope to do well: create safety, build trust, offer choice, listen deeply, communicate transparently, and foster connection. But what about the moments when we don't get it quite right?

We interrupt. We assume. We move too quickly. We use words that land differently than we intended. We decide without realizing someone important has been left out. These small moments of disconnection, also called relational ruptures, are part of being human.

Trauma-informed care isn't about relational perfection. It's about building the capacity to repair.

Repair Can Be Small

Repair doesn't necessarily require a lengthy conversation or formal apology. Sometimes it begins simply by noticing that something shifted and having the courage to turn toward it. A repair might sound like:

- "I don't think I really heard you. Can you tell me again?"
- "I moved too quickly. Let's try that again."
- "I realize we made that decision without you. What matters to you here?"
- "That didn't come out the way I intended. May I start again?"

These seemingly small moments communicate something much larger: You matter. Your experience matters. Our relationship matters enough for me to notice. When people have experienced trauma, uncertainty, powerlessness, or exclusion, that message can be profoundly important.

Importantly, rupture and repair do not occur only between two people. The conditions surrounding an interaction such as team culture, workload, policies, communication practices, hierarchy, and the larger care environment, contribute to both disconnection and reconnection. Repair is relational, and it also invites us to notice what else needs attention or change in order to more consistently (and sustainably) support connection.

A Practice to Carry with You

When an interaction with an infant, family member, or colleague feels different afterward, rather than immediately explaining it away, pause, notice, and get curious.

Was there a moment of disconnection here? Is there an opportunity for repair?

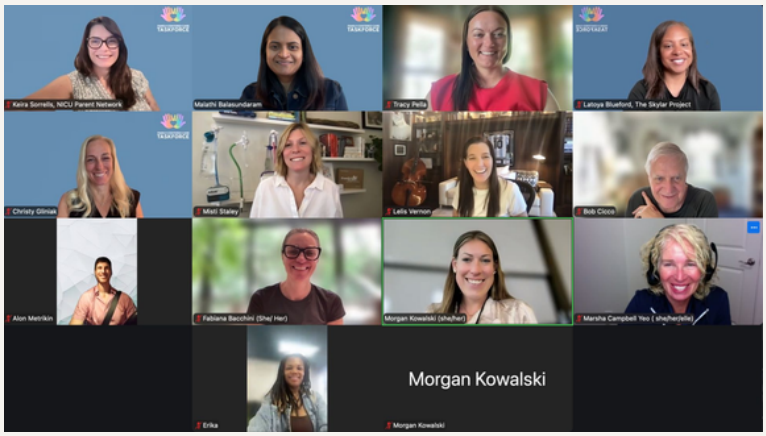
Healing relationships are not relationships without rupture. They are relationships in which we learn how to find one another again. This builds safety, trust and leads to true collaboration and partnerships.

Continue the Exploration

LEADERSHIP TEAM UPDATE

MALATHI BALASUNDARAM, MD & MORGAN KOWALSKI

The FCC Taskforce's Executive Council held its second quarterly meeting of 2026 on June 17th with 27 members joining virtually via Zoom and in-person at the International Gravens Conference in South Bend, Indiana.



Our first-ever exhibitor table featuring materials from Hand to Hold, Love for Lily, The NICU Dad, and Timeless Topics!

Executive & Advisory Council Members with our FCC Scholars!

2026 Accomplishments

- Released Equity, Diversity, Inclusion, Belonging, and Justice Position Statement
- Launched Presence Study Toolkit
- Established three new committees:
  - Dads and Partners Engagement
  - ROI of FCC
  - Quality Improvement
- Published Family Partnership Abstract

Projects in our Pipeline:

- Quality Improvement Foundations Course for Family Partners (Dec 2026) *Thank you, Vermont Oxford Network!*
- Silent Signals in the NICU Toolkit (Sept 2027)
- Dads and Partners Screening and Support Cohort (Dec 2027)

Thank you to each of our Executive & Advisory Council members who volunteer their time to support this work!

SHARE YOUR SUCCESS!

We are seeking **FCC implementation success stories** for our 2027 Community Exchange sessions! These are a fun way to **showcase your work and support your peers**. Check out previous sessions and email us to learn more.

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

30 family-led organizations
51 healthcare-based organizations

Connect

Mission Statement

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

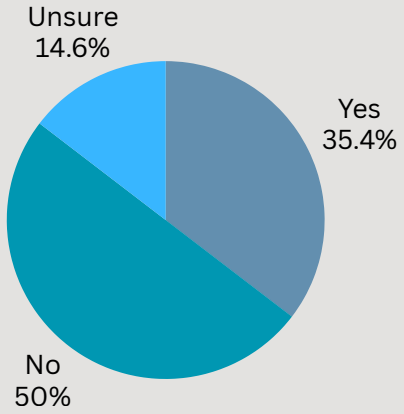
Why We Exist

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?



Membership

3,700+ members
50 U.S. States & Puerto Rico
9/10 Canadian Provinces
81 Countries
Join us, membership is free!

Our listserv is 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.

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