

NEWSLETTER

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

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Parenting in the NICU

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.

*Join us as we walk through the NICU through the lens of 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 parents' 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 the following and let it help shape your practice.*

As we walk through a set of dark wooden doors, we are greeted with a pastel banner that says, "Welcome to the NICU!" with ducks and teddy bears. I don't want to be here. I want my baby to still be safely inside of my body growing and kicking me from the inside. Someone greets us and tells us to wash our hands for one full minute to keep our baby safe. A clock counts down the seconds as I wash my hands with the hospital soap that smells so procedural. Don't they understand that of course I want to keep my baby safe? It's all I've ever wanted, and now I have to share that responsibility with all these strangers. Don't get me wrong, they seem nice enough and like they want to help us. Everyone is smiling and there are pastel nursery decorations everywhere. Still, I can't shake the feeling that I don't want their help no matter how nice they are. I look at my partner and realize they are just as scared as I am. I wonder if I can hold their hand while we walk to our baby or if we'd have to wash our hands again. I decide not to just in case. Someone is walking us to our baby's bedside now. I can feel my hands start to shake and tears well in my eyes. The nurse introduces herself and encourages me to step up to the giant box where our baby is hidden in a bunch of cloth and things that don't look like they are safe for them to sleep in. The nurse is talking and smiling, but I have tunnel vision and my focus is entirely on my sweet, fragile baby who looks so alone in that giant box. My partner squeezes my shoulder as we take a step forward. I guess they decided to risk it on washing their hands again.

SUPPORTING FAMILIES BEYOND DISCHARGE

THE HIDDEN GRIEF OF GOING HOME: SUPPORTING EMOTIONAL READINESS AND CAREGIVER CONFIDENCE

JESS DAIGLE, MD, FAAP, NICU PARENT

While discharge planning often focuses on teaching, checklists, and medical stability, many families carry a quieter truth: the hidden grief of leaving the NICU. **Discharge is often celebrated as a moment of relief; yet for many parents, it also brings fear, sadness, and a profound sense of disorientation.** The NICU becomes a place of structure, support, and predictability; stepping away from that environment can feel like losing the safety net that helped them navigate some of the most vulnerable moments of their lives.

This grief does not reflect a lack of readiness. It reflects the weight of transitioning from shared caregiving to full responsibility at home. Parents may appear outwardly confident while quietly asking themselves, “How will I do this on my own?” **Emotional readiness must be viewed as a core component of family-centered discharge—not an optional add-on.**

NICU teams can support families by normalizing these mixed emotions and preparing them for the emotional landscape of the first days and weeks at home. Families benefit from knowing that grief, anxiety, and uncertainty are common and do not mean they are unprepared. They benefit from practical strategies they can use when these feelings arise, such as:

- Pausing to take a breath during overwhelming moments
- Grounding themselves with simple routines
- Writing down questions for their pediatric provider
- Connecting with parent support networks and NICU follow-up programs that understand the complexities of the journey

Another important aspect of emotional readiness involves **preparing families for the reality that outpatient providers may adjust the care plan they learned in the NICU.** Even small changes can make parents feel confused or uncertain. NICU teams can empower families by explaining that **evolving guidance is normal as babies grow**—and encouraging parents to ask clarifying questions rather than assume they “got something wrong.”

When NICU teams support both the emotional and practical dimensions of going home—and equip families with realistic expectations and self-advocacy tools—discharge becomes more than a clinical milestone. It becomes the beginning of confident, connected parenting. **Families deserve to leave the NICU not only with instructions, but with a sense of capability, community, and hope for the next chapter.**

Free Support for Families of NICU Graduates:

- [Counseling Program in Partnership with BetterHelp for During or After the NICU, Project NICU](#)
- [Parent Groups and Resources, NICU Alumni](#)
- [Specialized Coordinator for Families Recently Home from the NICU, Postpartum Support Int’l](#)
- [Virtual Support Groups, Hand to Hold](#)

JANUARY '26 WEBINAR SUMMARY

BOB CICCICO, MD

"Breaking Down Professional Silos to Improve Infant-Parent Outcomes in Neonatal Care" with Christy Gliniak, PhD, OTR/L, CNT, CPXP, NTMTC and Sue Ludwig, OTR/L, CNT

Sue opened the session by sharing how a relationship with a NICU mother shaped her understanding of the critical role occupational, physical, and speech therapists play when they work together. This experience inspired her to lead the creation of an organization dedicated to strengthening the quality, value, and collective voice of neonatal therapists. Together, Sue and Christy highlighted **key lessons they've learned about breaking down silos and fostering meaningful collaboration to improve outcomes for babies in the NICU:**

- Breaking down silos doesn't mean putting everyone into one role; it means **recognizing and valuing the unique perspectives, training, and skills each profession brings to improving outcomes**
- Families are a silo of their own and offer **essential expertise and insight** into their child's care
- **When professionals work in isolation, families bear the consequences** of fragmented care, mixed messages, loss of trust, and delayed decision-making
- A baby's development is influenced by multiple systems, and recognizing this shapes how we work within our own roles and alongside others
- Building a collaborative team requires cooperation, coordination, communication, and coaching
- Collaboration across professions allows for a more holistic understanding of the baby and family
- **Everyone involved in NICU care plays a vital, though often different, role in achieving positive outcomes; moving from silos to collaboration is essential**

"The Power of "How Are You?": Strengthening Support for Fathers and Non-Birthing Parents in the NICU" with Cameron Boyd, MD and Michael Swain

Cameron and Michael delivered an in-depth presentation on **how to establish a successful Dad's group in the NICU and why these groups are essential for supporting fathers and other non-birthing parents.**

Key takeaways from the session included:

- Michael, a veteran NICU dad, shared his two NICU experiences (20 years ago and 11 years ago), emphasizing that **no two NICU admissions are the same and that a previous NICU stay does not prepare a parent for another**
- Societal expectations that "this is as hard for Dad as it is for Mom" often result in limited resources designed specifically for fathers
- In reality, **fathers experience stress, anxiety, and depression that may be as significant, and sometimes more persistent, than what mothers experience**
- Providing clear information, including fathers in decision-making, encouraging participation in skin-to-skin care, and practicing family-centered care can reduce negative mental health outcomes for all parents
- Both short-term and long-term financial stressors may disproportionately affect fathers
- A dedicated Dad's Group is one of several effective ways to increase engagement with non-birthing parents
- Data presented showed that Dad's Groups are well received, offer meaningful educational opportunities, and help fathers become more actively involved in their baby's care
- Bottom line: **while we often ask how mom is doing, we must also remember to ask how dad, or any non-birthing parent, is doing and how we can support them throughout their NICU journey.**

Both sessions highlight that **achieving optimal outcomes in the NICU requires a dedicated team effort that respects and values every member of the care team (including birthing and non-birthing parents) and equips them with the tools and opportunities to do their work well.**

Did you miss this session? [Watch the recording here.](#)

EDIBJ IN THE NICU

A FOUNDATION FOR FAMILY-CENTERED CARE

JESSI BARNES, MSN, RN, RNC-NIC, NPD-BC, C-ELBW & MIA MALCOLM, BS, CDFT

As NICU parents, we understand that the NICU is uniquely positioned to influence the patient/family experience and their understanding of what healthcare is. For some families, their birthing experience and the NICU are their first interaction with the medical system—you are the prelude to their medical story. **For other families who have had extensive interactions with the healthcare system, they may be coming to the NICU with medical trauma that is personal, familial, generational, or ancestral. For them, the NICU can be a watershed moment allowing them to reflect on their past experiences and for you to earn their trust.**

In addition to the more trauma-informed, compassion-centered reasons that EDIBJ should be foundational to the care you provide, there is also a business case for prioritizing these principles. The reality is, it starts before that family even enters the NICU. The birthing experience is impactful to a family's origin story, whether positive or negative. **Practicing with EDIBJ principles in mind sets the stage for a more inclusive birth that mitigates the possibility for trauma.** Birth-related trauma shows up with the family and their baby in the NICU and does not end there. Trauma from the NICU will follow them for the rest of their lives.

Throughout this series, we are going to break down the **core tenets of this work:**

- **Equity:** Addressing disparate individual outcomes caused by systemic inequalities
- **Diversity:** Acknowledging the many different ways individuals and groups identify (socio-economic status, language of origin, education, etc.) and how the intersection of those identities shapes their perspective
- **Inclusion:** Intentionally considering not only the needs of individuals/groups but also their wants and desires
- **Belonging:** The action of inclusion
- **Justice:** The action of equity through systemic changes via policy, resource allocation, dismantling structures, individual removal, etc.

We plan to share real examples, practical guidance, and present the business case for establishing an EDIBJ foundation. **Our hope is that you take a moment to reflect on how you show up and the impact it has on your peers, your path, your patients, and their families.**

In the Spring Newsletter, we will unpack equity—what it is, what it is not, and why it is important to family-centered care.

CHECK OUT OUR MONTHLY POLLS

We invite you to check out our Monthly Polls and submit your question for a future poll!
Past topics include formal reading programs, trauma-informed care education, staff & family debriefs after adverse events, and more.

[View All Polls & Responses](#)

[Submit Your Poll Question](#)

TRAUMA-INFORMED CARE CORNER

TRAUMA DOES NOT BEGIN AT ADMISSION: A TRAUMA-INFORMED REFLECTION FOR FAMILY-CENTERED CARE

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

In family-centered care, we often speak about the NICU as a traumatic environment, and rightly so. The sights, sounds, uncertainty, separation, and loss of control can profoundly affect infants, parents, and clinicians alike. And yet, there is something equally important to name: for most families, trauma does not begin at admission. **Families arrive in the NICU carrying stories that long predate the hospital—stories shaped by generational and intergenerational trauma, by cultural and racialized histories of medical harm or exclusion, by chronic stress related to poverty, immigration, discrimination, or environmental exposure, and by prior pregnancy loss, infertility, or complicated reproductive journeys.**

The NICU may be the place where trauma becomes visible, but it is rarely where it begins.

When this broader context is not held, even well-intentioned care can misinterpret what families are expressing. Grief may be labeled as emotional dysregulation. **Vigilance can be mistaken for anxiety. Advocacy may be perceived as “difficult behavior.” Withdrawal might be read as disengagement rather than protection.** These responses are often not signs of pathology. They are adaptations shaped by experience, history, and survival. **Trauma-informed, family-centered care asks us to pause before correcting, managing, or redirecting and to wonder instead what this response may be protecting. This may sound simple, but it is often insightful to quietly ask ourselves:**

- What story might this family be carrying that I cannot see?
- What has this parent already survived before arriving here?
- How might history, culture, or prior harm be shaping how they show up today?
- What would it mean to meet this moment with curiosity rather than correction?

This kind of reflection does not slow care down. It deepens it.

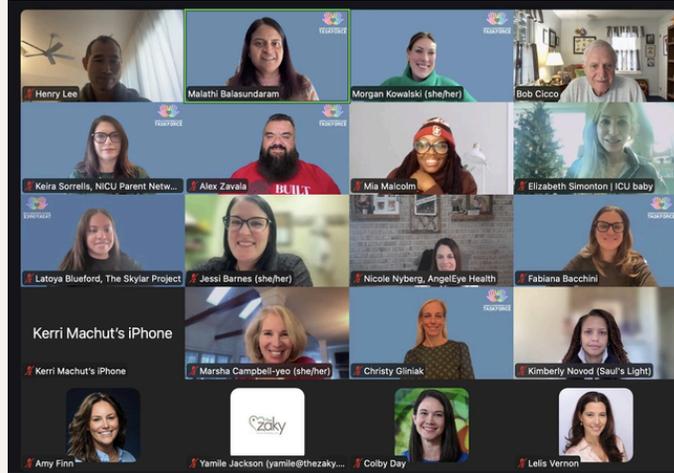
When we acknowledge that trauma does not begin at admission, family-centered care expands. It moves from engaging families in care to honoring the realities that surround and shape that care. Safety, trust, voice, and dignity are not created solely through policies or checklists. They are built through attunement, humility, and relationship—moment by moment.

Trauma-informed family-centered care is not about having all the answers. It is about widening the frame. **If we want families to feel seen, heard, and respected in the NICU, we must be willing to look beyond the moment in front of us to the histories, systems, and lived experiences that walk in with them. Because care is never neutral. And neither is context.**

LEADERSHIP TEAM UPDATE

MALATHI BALASUNDARAM, MD & MORGAN KOWALSKI

The FCC Taskforce's Executive Council held its fourth and final quarterly meeting of 2025 on December 10th with 21 members joining virtually via Zoom!



Non-Profit Status!!!

The Family-Centered Care Taskforce has received non-profit, 501(c)3 status!

Thank you to Mitch Goldstein for helping us secure grant funding through his nonprofit, Loma Linda Publishing over the last three years.



We are excited to share that the **FCC Taskforce has received non-profit, 501(c)3 status!** A huge thank you to Mitch Goldstein whose nonprofit Loma Linda Publishing has served as our fiduciary home over the last three years.

Join us in welcoming our newest Organizational Partners!



We are excited to share that our monthly office hours sessions are **changing to accommodate a growing audience and desire for FCC implementation strategies.**

Quality Improvement Committee

Co-Chairs



Colby Day, MD
Associated Professor of Pediatrics,
Division of Neonatology,
University of Florida Jacksonville



Lelis Bauzá Vernon, S.Q.I.L.
State Family Leader, Florida PQC
Editorial Board, AAP Publications
Clinical Advisor, AAP, SoNPM
Faculty Family, Vermont Oxford Network

- Integrating FCC into quality improvement
- Support opportunities for small group quality improvement work



Quality Improvement has remained an important foundational aspect of our work. Our newest committee will **support efforts to integrate FCC into QI.**

2026 Office Hours FCC Community Exchange

Every 3rd Thursday at 11am PT/2pm EST

Open Forum

- January 15th
- March 19th
- May 21st
- July 16th
- September 17th
- November 19th

A casual opportunity to share your unit's specific barriers to implementing FCC practices and brainstorm solutions for overcoming them with your peers and FCC Taskforce leadership.

Mini-Presentations

- February 19th
- April 16th
- June 25th
- August 20th
- October 15th
- December 14th

Learn from members who have successfully implemented an area of FCC during a short presentation followed by question and answer.



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

Newsletter Committee

Co-Chairs

Bob Cicco, MD
Morgan Kowalski

Contributors

Jessi Barnes, MSN, RN, RNC-NIC
Mary Coughlin, MS, NNP, NCC-E
Jess Daigle, MD, FAAP
Mia Malcolm, BS, CDFT
Jadene Wong, MD

Membership



3,000+ members
49/50 U.S. States & Puerto Rico
9/10 Canadian Provinces
79 Countries
Join us, membership is free!



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Mission Statement

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

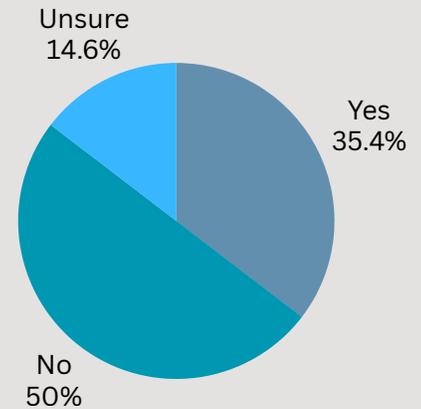
Why We Exist

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?



Organizational Partners



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