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FCC TASKFORCE NEWSLETTER

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

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FAMILY-CENTERED CARE TASKFORCE

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Parenting in the NICU, Part 4

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.

I'm prepping to go back to the hospital to see Avery. My doctor says I'm supposed to eat and stay hydrated, but the booklet I was given says I can't eat or drink in the NICU. What do I do? Do they have a microwave or a refrigerator? Maybe I'm not supposed to stay long enough to eat? I have no idea how to do this. I tried to stay home, but Cameron thinks it will be good for me to be in the NICU with Avery. That's easy for them to say! I've got a bag full of books, my headphones, a water bottle, and a sack lunch. I feel like I'm going to my first day of school. The pumping and postpartum supplies are off-theme. What happens if I need more pads? Maybe I should put a few more in my bag. I've never questioned myself this much before. Who knew leaving the house could be this stressful? I don't know how many times I can do this.

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. To read Part 3, click here.

NAVIGATING GRIEF IN THE NICU

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

The Grief No One Sees: Grief & Loss When Your Baby Is Alive

When a baby is admitted to the NICU, the world often responds with relief...
"At least they're in good hands." "At least they're alive."
But many parents quietly carry something heavy that doesn't fit those words. **GRIEF.** 💔
And while grief is something we associate with death, it is so much broader.

Grief is the natural response to any significant loss, and **THE NICU IS FULL OF LOSSES.**

Why would a parent grieve when their baby is living?
What could parents feel they have lost?

SO MUCH. 💙 Often the last weeks of pregnancy, the birth they pictured, and the moment of carrying a healthy newborn out the hospital doors.

There are many tiny losses along the way, too. The loss of privacy, their sense of control, pieces of their identity, learning to parent through monitors, alarms, and shift changes.

Grief ripples out and touches so many places. And **when your baby is alive** — and **the world is telling you to be grateful** — **acknowledging that grief can be challenging**.



Researchers have given names to some of what families feel.

- **AMBIGUOUS LOSS** describes grief with no death and no closure, where your baby is here but the life you expected is not.
- **ANTICIPATORY GRIEF** is mourning a loss that hasn't happened yet, the fear that rises with every update and every uncertain forecast.
- **CHRONIC SORROW** is the grief that returns in waves, at setbacks, at missed milestones, and long after discharge — whenever the distance between "what should have been" and "what is" becomes visible again.
- **DISENFRANCHISED GRIEF** is grief that others don't recognize as legitimate, which can leave parents feeling they have no right to their pain.

None of these are signs of weakness or poor coping. 💙 **They are normal responses to an abnormal, frightening situation** – and they often overlap within a single day.

For those who care for NICU families,
ONE OF THE MOST POWERFUL THINGS YOU CAN DO IS STOP TRYING TO FIX A PARENT'S FEELINGS.



Next time... Being a Companion to a Family That is Grieving.

SEPTEMBER '26 WEBINAR SUMMARY

BOB CICCO, MD

"Accessible Pregnancy Action Plan" with Kara Ayers, PhD, **"Supporting Parents with Diabilities: Inclusive Multidisciplinary Care for Lactation and Beyond"** with Alesha Thomas BS, IBCLC, and **"Disability Inclusion in Neonatal Settings"** with Amy Rule, MD, MPH, FAAP.

This insightful panel **highlighted the challenges parents with disabilities face during pregnancy, in the NICU, and after discharge, and provided actionable strategies to reduce barriers and support families in their vital roles.** They also showed healthcare professionals how to think about disability more inclusively and without bias, helping them communicate better with families. Lessons to be learned from this session include:

- Almost **7% of parents** in the United States have disabilities! People with disabilities are less likely to have a job or receive preventive healthcare. They are also more likely to live in poverty, face high healthcare costs, and experience mental illness or premature death.
- A peer facilitator who understands the stigma that can come with disability can help pregnant people with disabilities **create a written document to communicate their needs and preferences** during pregnancy and a NICU stay.
- A pregnancy action plan for a parent with disabilities must be both **empowering and practical**, identifying the environments and care practices that matter most to that parent.
- **Ongoing review and dialogue** between parents and healthcare professionals can help ensure that pregnancy action plans for parents with disabilities succeed.
- **Parenting is an occupation** whose job description changes as a child ages. **Parents with disabilities encounter many barriers in performing vital parenting activities, yet they bring essential strengths and love that are key to their child's development**. Great parents still need support, even more so when they have a disability.
- Common barriers for parents with disabilities include negative attitudes and healthcare professionals' limited knowledge of their needs. **We need more disability education in healthcare.**
- Transdisciplinary care is essential in helping parents with disabilities perform key activities, such as positioning and breastfeeding. A parent with a physical disability will usually know what to do but struggle with how to do it.
- Supporting parents with disabilities must focus not only on the disability but also on **identifying and acknowledging parental strengths**.
- Medicine has a history of accepting ableism, which we must strive to reverse.
- In one study, 80% of more than 25,000 healthcare professionals exhibited implicit bias toward people with disabilities.
- While most in healthcare view disability as a "pathology" or "something wrong," healthcare professionals need to appreciate that disability has social and psychological dimensions. **"Disability" does not equal "illness."**
- **We should not be afraid to use the words "disability" or "disabled." Rather, we need to use them with respect and in a way that counteracts ableism.**
- Using a **biopsychosocial lens** allows for social acceptance of people with disabilities while still recognizing the need for medical support.
- "Disability" means different things to different people. Labeling babies as "mild," "moderate," or "severe" without knowing a family's background or views may work against the goals of social acceptance and inclusion.

SEPTEMBER '26 WEBINAR SUMMARY

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The webinar's central lesson was simple: we can build a more supportive and inclusive model of disability by recognizing our own biases and by seeing people as people, not as their disabilities. And most importantly, **everyone should understand that all people need support and deserve respect and affirmation.**

Did you miss this session? Watch the recording here.

EDIBJ IN THE NICU: *INCLUSIVITY, DIVERSITY IN ACTION*

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

Inclusion is diversity in action. It means actively seeking, understanding, and applying how families say they want to be included in their child's care. It starts with asking families not only how they want to be involved, but what being a parent means to them, what matters to them, and how we can work together to make it happen. The choice is theirs. **Inclusion is not about checklists or checking boxes; it is about building relationships**. Families have to feel safe enough to be vulnerable and share their wants and needs around what is a traumatic experience.

The NICU is a source of trauma for families, whether they recognize it in the moment or not. **Practicing inclusion is one way clinicians can lessen the weight of that trauma.** When inclusion does not happen, **exclusion adds another layer on top of an already traumatic experience**. Once families are shut out of the parenting process, it is hard to come back; the effects are, at times, irreparable. Parents want to parent their children in the NICU, but when they are not allowed to be who they instinctively know themselves to be, it creates uncertainty and mistrust and erodes their confidence in their ability to parent, both in and out of the NICU.

Below are two examples of how inclusion impacts family-centered care practice in the NICU:

Example 1 - Inclusive Feeding

The baby is a 33-weeker, and the parent has identified that they want to provide human milk exclusively for their child. When there are concerns about the baby's growth, the parent is insistent that they are not going to feed their child formula under any circumstance.

Your colleague says, "They just need more education on feeding in the NICU", but you decide to lead with curiosity to better understand where this parent is coming from. When you ask them to share more about why providing human milk is so important to them, they say, "It was always the plan. When I found out I was pregnant, I knew this is what I wanted for my baby. I even found milk banks in my area and spoke with my sister about saving her milk in case I needed it. I do not want my care plan for my baby to change just because we had to come here. This is how I know how to be a mom, so this is what I will do."

You end the conversation by thanking the parent for sharing and that you appreciate the way that they are showing up to advocate for their child. You let them know that you will discuss options around donor human milk if it is needed.

DIVERSITY, INCLUSIVITY, DIVERSITY IN ACTION

CONTINUED FROM PAGE 4

Example 2 - Resisting Exaggeration

The road to inclusion is sometimes daunting for clinicians, because the idea of parents getting to make a decision or being present during stressful clinical situations causes them to jump to an exaggerated outcome. **Sharing power with a family does not mean that they have unlimited reign in the NICU.** Safety will always be a priority for all parties: baby, parents, and clinicians. Consider the following clinical scenarios:

- A baby who has had a clinically unstable course is worsening, and the parents request to be present during the code event. This request does not mean that they want to intubate their baby or perform compressions; they only want to be present for the life their baby has. **Their presence is the ask. No more, no less.**
- A parent arrives at the NICU, and the nurse tells them they can come see their baby—but then they have to leave, because it's time for a sterile fluid change. Consider that the parent wants that process to stay sterile and safe for their baby too. How is a parent at the bedside—wearing a hat and mask—any different from the clinicians walking around the space? **They only want to be present with their baby.**

Inclusion doesn't mean all control is relinquished. There is no threat to your role or expertise. Inclusion introduces diversity of thought, which allows for collaboration and trust building between families and clinicians. **Inclusion is a call to evaluate how to dismantle the hierarchy of relationships in the NICU.**

TRAUMA-INFORMED CARE CORNER

BEFORE THE WORDS, THERE IS US

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

As clinicians, we bring our whole lives into the NICU: our worries, responsibilities, losses, fatigue, and the experiences that shape how we respond under pressure. Some days, finding a compassionate word takes more effort than anyone else can see. Babies and families experience both our care and us. How we show up becomes part of their experience of being cared for.

Jean Watson reminds us that "Nursing has a global covenant with humanity". Her words invite us to remember the trust placed in us to sustain caring, healing, and wholeness, especially when these are threatened. **Although rooted in nursing, that invitation speaks to everyone entrusted with another person's care.** Watson also describes an ethic of belonging. We bring that ethic into everyday practice: recognizing babies, families, colleagues, and ourselves as people whose dignity matters, even when needs differ or interactions become difficult. This is the shared humanity at the heart of relational stewardship, which is all about **taking responsibility for how our presence and interactions shape safety, dignity, trust, and belonging.**

BEFORE THE WORDS, THERE IS US

CONTINUED FROM PAGE 5

A moment to arrive: Before entering a room, beginning a conversation, or laying hands on a baby, pause briefly to notice how you are arriving to the moment. Is your jaw tight? Is your breathing hurried? Are you bracing, distracted, impatient, or disconnected? These observations can help us recognize our own regulation or dysregulation with curiosity and compassion.

For just a second, feel your feet on the floor, release tension where you can, and breathe. Notice the baby, the family, the moment, and ask yourself: What am I bringing into this encounter? What support do I need? An intention might be simple: **"May I bring steadiness, curiosity, and kindness."**

These moments offer opportunities to cultivate equanimity or the capacity to remain open, steady, and responsive amid uncertainty, distress, or strong emotion. I see equanimity as a wellspring of trauma-informed developmental care and our capacity to be the buffer. It grows through practice, reflection, supportive relationships, and working conditions that sustain us.

Words that open connection: Watson's understanding of caring as meaningful action becomes tangible in everyday exchanges. **Our words can communicate judgment or invite understanding**:

- When we might want to say: "The Parents aren't involved", try: **"How would you like to parent at the bedside and what support would help you?"**
- When we might say: "I already explained that," try: **"This is a lot to take in, what can we go over together?"**
- When the words: "Calm down" try to escape your lips, try: **"I can see this is upsetting, what do you most need us to hear?"**

Open-ended questions make room for parents' knowledge, concerns, and preferences: "What are you noticing about your baby?" "What feels most important for me/us to understand today?"

Practice asking one question at a time, allowing for silence, and remembering to listen before explaining. Then agree on next steps together and follow through. **Parents deserve compassionate care whether they want to talk, need time, or remain distressed.**

Returning with humility: We can be compassionate and tired, committed and imperfect. When our words cause hurt, we can repair: **"I'm sorry, that was dismissive. Let me try again."**

Caring for others and sustaining ourselves belong together. Connection can replenish our sense of meaning, while workplaces must commit to providing the kind of support compassionate practice requires. Over the next month or two, try one intentional pause and one curious question. Notice what changes in the encounter and what changes within you.

Take care and care well,
Mary

REFLECTION & RESPONSE GUIDE

Recommended Reading:

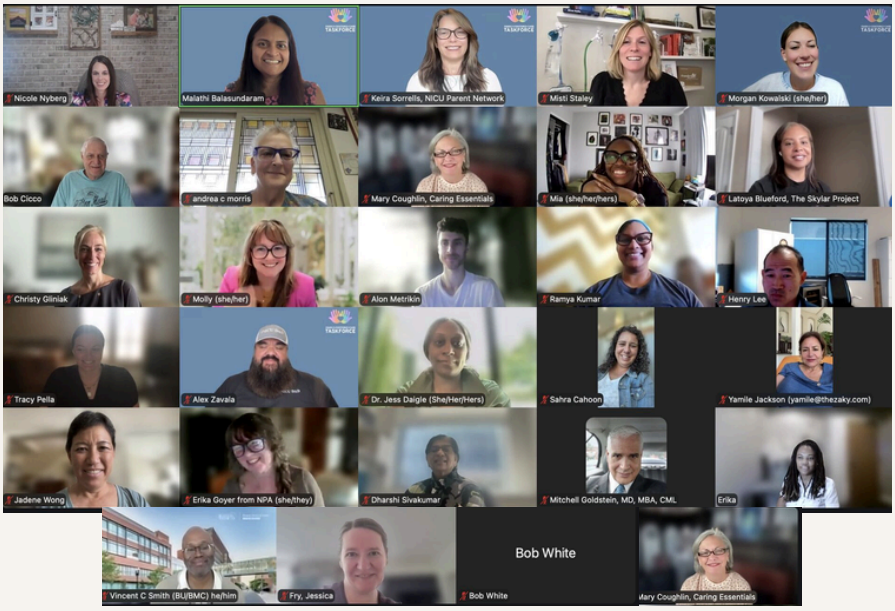
Watson, J. (2020). Nursing's global covenant with humanity – unitary caring science as sacred activism. Journal of Advanced Nursing, 76, 699-704. https://doi.org/10.1111/jan.13934

LEADERSHIP TEAM UPDATE

MALATHI BALASUNDARAM, MD & MORGAN KOWALSKI

The FCC Taskforce's Executive Council held its third quarterly meeting of 2026 on September 22nd with 29 members joining despite busy Fall schedules and conference travel.

We discussed **modifying our 2027 Webinar schedule to accomodate our growing membership's needs**. Stay tuned on when those will be taking place!



Our Board of Directors has stepped into their roles! Here's who's taking on what:

President



Ashley Omwando, MBA
FCC Committee Member
El Camino Health NICU
NICU Parent

Vice President



Robert Cicco, MD
Retired Neonatologist,
Pittsburgh, PA
Former Associate Director,
West Penn Hospital NICU

Membership Chair



Erika Goyer, BS
Co-Founder,
Academy of
Perinatal Harm Reduction
Co-Chair,
Family Advocacy Network
Director of Communications,
National Perinatal Association
NICU Parent

Secretary



Jadene Wong, MD
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Treasurer



Mitchell Goldstein, MD, MBA, CML
Professor of Pediatrics
USC Keck School of Medicine
Division of Neonatology
Children's Hospital Los Angeles
Editor in Chief,
Neonatology Today

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

IMPORTANT DATES

November

Prematurity Awareness Month

November 15th: World Prematurity Day
***Note! The World Health Organization has moved World Prematurity Day from November 17th which is World Cerival Cancer Elimination Day

December

December 7-13: National Influenza Vaccination Week

HAPPY Holidays

Are we missing something? Email us!

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.

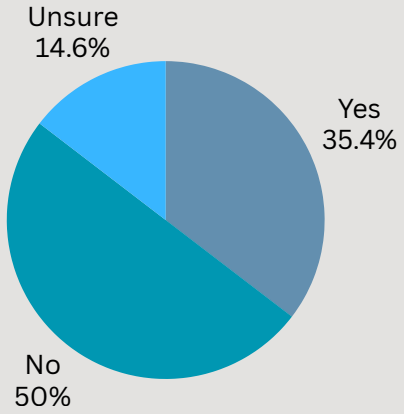
Why We Exist

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



3,900+ 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.

Newsletter Committee

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