

NEWSLETTER

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

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FAMILY-CENTERED CARE
TASKFORCE

Subscribe to our mailing list and visit our website to learn more about our advocacy efforts, read testimonials from our members, watch webinar recordings, and access free resources on all things Family-Centered Care.

'Aria's Journey: Connecting Through Our Shared Humanity' by Jessi Barnes, MSN, RN, RNC-NIC, NPD-BC, C-ELBW

Content Warning: The following is an artistic interpretation of what being a premature baby could be like. If you've experienced a preterm birth, please take care when reading.

"Wow, it sure is noisy in here, I thought while floating in my warm, comfortable environment. That thumping has gotten a lot faster and the voices sound different, more rushed and scared. I wonder what's going on. All of a sudden, the warm fluid I was floating in is gone and someone is touching me. It's so cold and bright. Where is the person I was with before? They seemed so kind. I don't like it here. Can't they put me back? The brightness is overwhelming, so I squeeze my eyes shut as hard as I can. Who knew I could do that? Why is it so cold? Do people out here like it like this? I'm trying to stay warm, but I can't. The new voices are telling me it will be okay. I'm trying to believe them, but I really wish those familiar voices were here. They always made me feel loved and calm. What is this thing on my face? That air is so harsh. I am grateful that it helps me breathe better though. It's so weird here.

Wait! I hear the voices from before. Mom? Dad? Are you there? Can you help me? The deeper voice gets closer. He says his name is Dad. Apparently, my name is Aria. I feel a new touch. It's soft, gentle, and warm. It's him! He says I'll get to see Mom soon, too! The other voices are talking to him now. Something about going somewhere special for me because I came out too early. I'm not sure what that means. I was just fine in there. They're the ones who took me out! Now the new voice is moving me. Dad says I'm going to meet Mom. I am so excited, but I still wish it was warmer in here. Oh, I hear her! She sounds scared. It's okay, Mom! I'm right here. I'm just on the outside now. I'm not sure what's going on either, but we'll figure it out together like we always have!"

It is easy to get wrapped up in the tasks and technology of the NICU. **We as healthcare professionals must remember to center the personhood of the baby and their family. Staying connected with our shared humanity helps us make lifesaving decisions from a place of empathy and connectedness.**

MAY POLL RESULTS

In May, you supported our advocacy work by helping us understand your unit's policies around primary caregiver presence in the NICU! 75 centers answered the following question: **Does your unit allow unrestricted access to primary caregivers?**

76% said Yes to unrestricted caregiver access, 24% said No

We're thrilled to learn that most survey respondents allow unrestricted caregiver access in their units, however **there's still work to be done toward reaching zero separation between NICU babies and their families, especially where it concerns change of shift.** Share these results with your team to gain buy-in around encouraging primary caregivers to remain present at shift change.

"Parents excluded during invasive procedures."

"No access during change of shift."

"If parents are present already, we do not ask them to leave at shift change, however if they are not already present, parents cannot come in for an hour in the morning and an hour in the evening [during shift changes]. Banded caregivers can stay without restrictions, however any additional visitors have to leave at 8pm once hospital visiting hours end."

"Closed for 30 minutes at change of shift."

"Visitation allowed 22hr/day. Closed for one hour at nurse change in shift. Only 2 [allowed] at the bedside at a time and one must be banded caregiver."

"It is not policy, but the staff (medical and nursing) will not allow parents to be at bedside for an admission or for a sterile procedure (including line change) - despite much effort in stopping them from doing this."

"No access during change of shift (6:30-7:30am/pm.)"

"[No access] only when sterile procedures are occurring in one of our large bay-type rooms where part of the room is closed."

"Parents are only visitors allowed right now. Must step out during nursing change of shift or when rounding on other patients."

"Parents and designee (usually grandparents) allowed 24/7 but have to step out at 7am and 7pm for nursing change of shift. Other visitors allowed 9am-9pm."

"No access during shift change twice a day. No sleeping, food, or drink allowed."

"Mothers are not allowed to be in the NICU for the first 24 hours of life if they are on magnesium."

"Primary caregivers may stay at the bedside during line changes, PICC insertions, etc. but may not come and go during these times."

"2x shift change closing unit for 1 hour - UGG!"

Thank you!

Thank you to those who responded to our May Poll! **To view all of the helpful answers we received, click [here](#).**

JULY POLL

Does your unit educate paid and/or volunteer Family Partners on implicit bias, emotional support, and/or how to navigate challenging situations? Click [here](#) to answer and help us support centers who are integrating Family Partners into the care provided for inpatient NICU families!

MAY WEBINAR REVIEW

“Family-Team Dynamics in the NICU: How Bias Can Threaten Optimal Communication” with Tamorah Lewis, MD, PhD

***This presentation was not recorded and will not be summarized due to the sensitivity of material shared; however, we would like to highlight the **resources** Tamorah Lewis, MD, PhD suggested. These materials are invaluable and can be found under the [Resources tab](#) on our website:

1. [Becoming an Antiracist Neonatal Community](#) (Abstract)
2. [Recalibrating the Use of Race in Medical Research](#) (Article)
3. [Race and Genetic Ancestry in Medicine – A Time for Reckoning with Racism](#) (Article)
4. [Teaching the Social Determinants of Health: A Path to Equity or a Road to Nowhere?](#) (Abstract)
5. [Clinical Framework for Dismantling Antiracist Racism in the Clinic Room](#) (Abstract)
6. [NeoReviews EDI Case Series Discusses Inequities in the NICU](#) (Article)
7. [Addressing the Elephant in the Room: Microaggressions in Medicine](#) (Article)
8. [Implicit Bias in Pediatrics: An Emerging Focus in Health Equity Research](#) (Article)
9. [Racial Equity Tools](#) (Toolkit)
10. [Dealing with Racist Patients](#) (Video)

“NICU Parents Need A Hand to Hold: Early Intervention Mental Health Services Improves Outcomes for Parent & Baby” with Kelli Kelley, *Founder & CEO*, [Hand to Hold](#)

Kelli Kelley shared how her lived experience as mom of 24-week infant, Jackson, and 34-week infant Lauren, led her to found Hand to Hold, a non-profit organization that provides free mental health support for NICU parents. Kelli spoke of the fear, relief, grief, and joy that accompanied the birth, hospitalization, and discharge of her son 24 years ago. Although Jackson’s medical team provided great medical care, there were few if any mental health resources available to NICU parents at the turn of the century. In fact, at one point during her discharge from the postnatal ward, Kelli was asked to not cry for her NICU baby so as not to upset moms with term infants nearby.

Thankfully, we now openly acknowledge that the NICU experience can be traumatic. When the NICU community helps care for a NICU parent’s mental health, there can be immense benefits for both the parent and infant. Hand to Hold specifically offers flexible and easily accessible resources for parents who either have or had a baby in the NICU or who have lost a baby in the NICU. These resources range from virtual support groups and counseling in English and Spanish to in-person support from Family Support Specialists in the NICU and after discharge home.

Hospitals without formal parent peer support or mental health support resources can refer parents to Hand to Hold. The Hand to Hold [app](#) serves as a safe place for parents to share their stories and access educational resources. The feedback from both parents and medical professionals has been exceedingly positive, stating that Hand to Hold provides a vital service and often fills the critical gap of providing mental health support to parents.

We are grateful to Kelli for sharing her experience as a NICU parent to Jackson and Lauren, and about the many invaluable resources [Hand to Hold](#) provides!

TRAUMA-INFORMED CARE CORNER

WITH MARY COUGHLIN, MS, NNP, NCC-E

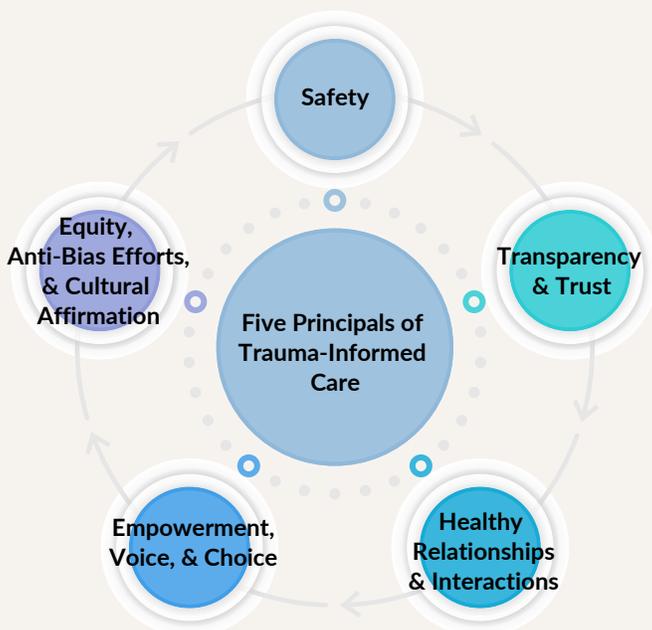
In the Neonatal Intensive Care Unit, every interaction can significantly impact the fragile lives of newborns and their families. Implicit bias—unconscious attitudes or stereotypes that affect our understanding, actions, and decisions—can subtly but profoundly undermine communication in this critical environment. Utilizing a trauma-informed framework is essential to recognize and mitigate these biases, ensuring that every family receives equitable care and support.

Implicit bias in the NICU can manifest in various ways; clinicians may communicate differently with families based on their backgrounds or they may make assumptions about a family's understanding and needs. For instance, a parent's concern might be dismissed due to stereotypical beliefs about their socioeconomic status or education level, leading to a breakdown in communication and care. Such biases can erode trust, create misunderstandings, and exacerbate the already high levels of stress and trauma experienced by NICU parents.

To combat this, NICU teams must be trained to recognize and actively address their biases. Trauma-Informed Care principles emphasize safety, trust, healthy relationships, empowerment, and equity (see the figure below). Applying these principles can help create a more inclusive environment where every family feels heard, respected, and valued.

Equally important is the provision of early mental health services for NICU parents. The NICU experience can be deeply traumatic, and parents often struggle with a variety of feelings that can lead to anxiety, depression, and PTSD. With mental health support, parents can process their emotions, build a repertoire of effective coping strategies, enhance their decision-making capabilities, and foster healthy parent-infant attachment and bonding that ultimately enriches their baby's developmental outcomes.

By addressing implicit bias and offering robust proactive mental health support, we can improve communication and outcomes in the NICU, ensuring that all babies and families receive the compassionate, equitable care they deserve.



Resources

- Educate yourself and your staff on implicit bias using this [Anti-Racism & Equity Toolkit](#) from the American Academy of Pediatrics.
- Participate in the Institute for Perinatal Quality Improvement's [28 Day Anti-Racism Challenge](#).
- Watch our May 2024 Webinar [recording](#) to learn about [Hand to Hold's](#) early intervention mental health services.
- Watch our July 2023 Webinar [recording](#) to learn how [Mammha](#) is closing gaps in mental health care in NICUs (begins 01:08:20 on the recording).

THE IMPORTANCE OF DISCHARGE PREPARATION FOR NICU FAMILIES

WITH JESS DAIGLE, MD, FAAP, NICU PARENT

“The hospital did not tell me in advance my baby was being discharged. I got a call at 1:30 p.m. telling me to be at the hospital before 8 p.m. that same day.” You may think, “Really?!”, yet I have heard many families share similar experiences. I was a practicing physician when I had my son at 31 weeks gestation, and despite my clinical training I found it incredibly challenging to transition home with only 24 hours’ notice. How can we expect families of medically fragile infants who aren’t accustomed to the medical realm to feel prepared to transition home with even shorter notice of discharge?

It is imperative that clinicians and staff are well-organized and allow ample time for NICU discharge education to avoid poor infant health outcomes and families feeling unprepared and anxious around handling their baby's unique medical and developmental needs. Discharge education provides parents with the knowledge and skills they need to provide ongoing care for their fragile infants at home and gives them confidence as caregivers.

Below are **5 steps** to ensure parents feel more prepared for the transition home:

- 1. Early Discharge Education:** Start educating parents and family caregivers about their baby’s diagnoses, care, and what the transition home will look like well in advance of discharge. Shift the culture in your unit to make early discharge education the expectation rather than the exception.
- 2. Hands-On Training:** Involve parents in hands-on care under the supervision of NICU staff to build confidence and competence. Empower families to embrace their role as caregivers with the ability to handle their baby’s care despite medical fragility.
- 3. Regular Updates:** Provide consistent updates on baby’s progress and expected discharge time more than 48 hours prior to discharge so parents can mentally prepare and get their home ready.
- 4. Comprehensive Discharge Checklist:** Use a detailed discharge checklist covering all aspects of home care including feeding, sleeping, medication, and emergency contacts.
- 5. Post-Discharge Support:** Arrange follow-up appointments and provide contact information for lactation consultants, pediatricians, perinatal mental health support, and NICU support groups.

FCC TASKFORCE OFFICE HOURS

The FCC Taskforce holds **monthly Office Hours to discuss challenges around implementing FCC practices and provide strategies for overcoming them.** Office Hours are facilitated by both clinicians and Family Partners from our Executive Council and include a variety of topics relevant to beginning or strengthening FCC. Click [here](#) to register!

Upcoming sessions:

Thursday, July 25th @ 9am PT/12pm EST
Tuesday, August 27th @ 9am PT/12pm EST
Thursday, September 26th @ 9am PT/12pm EST



THANK YOU FOR READING

FCC Taskforce

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Mission Statement

We exist to equip and support NICUs as they seek to begin or strengthen Family-Centered Care in their units.

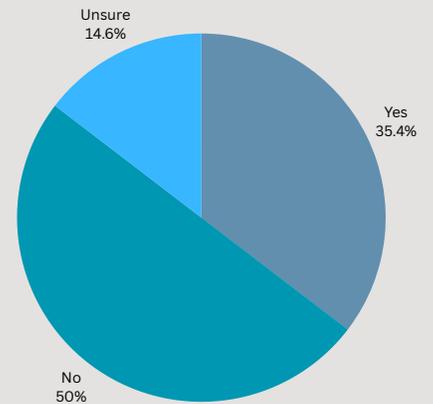
Why We Exist

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

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

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

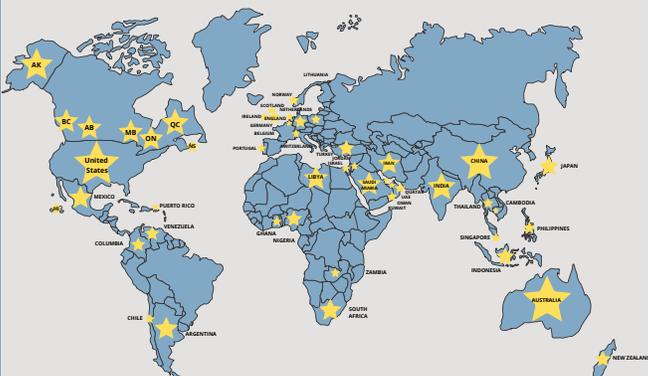
Does your NICU currently have an FCC Committee?



Organizational Partners



Membership



1300+ members
48/50 U.S. States & Puerto Rico
41+ Countries
Join us, membership is free!



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