

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.

Part Two:

**‘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.

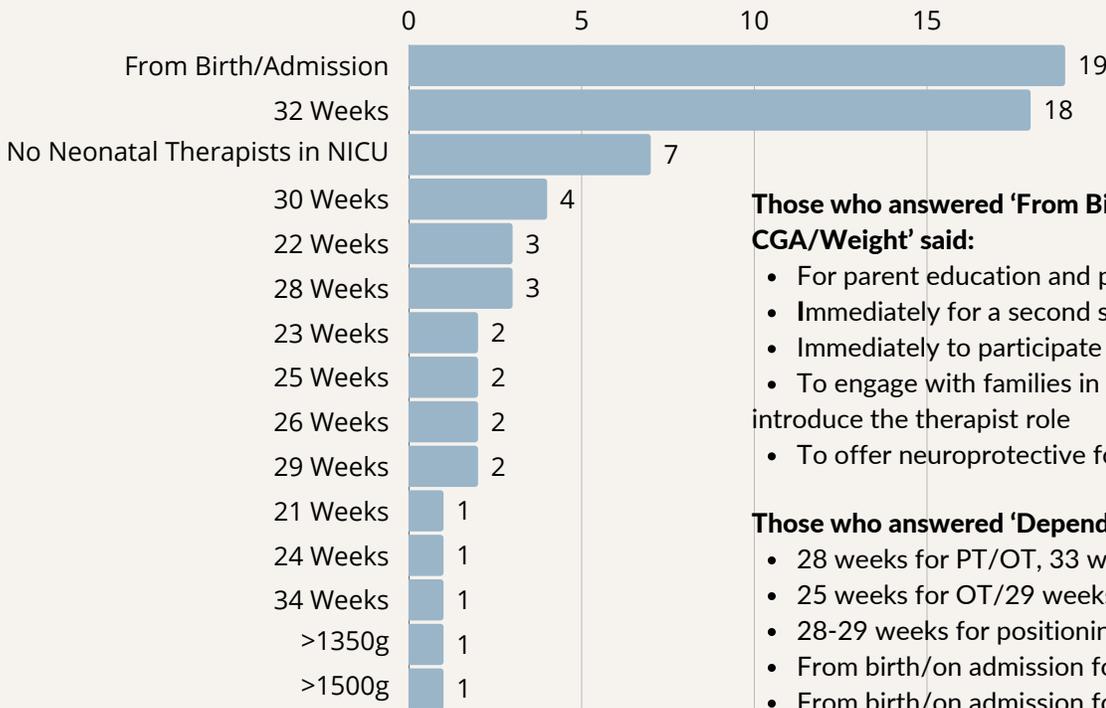
“This is different than where I was before. It’s still too bright and very loud. Apparently, we’re in the NICU. It’s a special place for people like me who need extra help after we’re born. I really miss Mom. She said she will come be with me as soon as she can. Dad is around here somewhere. I heard him ask how big I was. I’m small for my age, whatever that means. I’d like to think I’m on my own growth curve! I’ve learned that there are a lot of people in the NICU here to help me. I’m not sure what most of them do, but they all keep talking around me. I wish there was a way to turn down the volume. This thing on my face is so tight that it hurts a little bit. Ahh, that person fixed it. Thank you, kind stranger! Now I can open my eyes a little bit. There’s Dad! He looks scared. I’m okay, Dad! I’m doing my best. This being a person thing is much harder than I expected. Breathing and beating my heart at the same time is exhausting. Where’s a placenta when you need one, right? He says he has to leave for them to get me settled. I don’t know why he can’t stay. He can help me go to sleep like he usually does. These people might know a lot about babies like me, but they’re passing up a real opportunity here sending my Dad away. Ouch! Someone’s pulling my arms and legs straight and I can’t move them. It’s for something called ‘lines,’ but it really feels unnecessary. I sure hope this is all over soon. I miss my parents. They have to miss me, too.”

Join us as we continue to follow baby Aria and her family’s experiences in the NICU. It is easy to get wrapped up in the tasks & technology in the NICU, and **we as healthcare providers must remember to center the personhood of the infant and their family. Staying connected with our shared humanity helps us make lifesaving decisions from a place of empathy and connectedness.**

If you missed Part One (Aria’s birth) in Volume 8, catch up [here!](#)

SEPTEMBER POLL RESULTS

In September, we asked:
At what corrected gestational age/birth weight do neonatal therapists engage with infants in your unit?



Those who answered 'From Birth/Admission Regardless of CGA/Weight' said:

- For parent education and procedural support
- Immediately for a second set of hands and positioning
- Immediately to participate in two-person cares!
- To engage with families in the first week of life and introduce the therapist role
- To offer neuroprotective four hands care

Those who answered 'Dependent on Type of Therapy' said:

- 28 weeks for PT/OT, 33 weeks for SLP
- 25 weeks for OT/29 weeks for SLP
- 28-29 weeks for positioning/30 weeks for positive touch
- From birth/on admission for OT/31-32 weeks for SLP
- From birth/on admission for OT/32 weeks for PT/34 weeks for SLP

Neonatal Therapy Cheat Sheet:

- OT = Occupational Therapy
Focus: Developmental care, sensory processing
- PT = Physical Therapy
Focus: Positioning, infant massage, motor skill development
- SLP = Speech-Language Pathology
Focus: Feeding, communication

Resources:

- [SENSE Program](#)
- [National Association of Neonatal Therapists](#)



Thank you!

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

OCTOBER POLL

Thank you for helping us learn more about neonatal therapists in the NICU!

If you are a neonatal therapist with an active role in Family-Centered Care implementation in your NICU, please share how you were able to get involved/be included. Do you have any advice for neonatal therapists experiencing pushback around their presence in the NICU? [Click here](#) to share!

SEPTEMBER WEBINAR REVIEW

“Improving Family Engagement in the NICU: The Colorado Experience” with Sunah Susan Hwang, MD, MPH, PhD

In her talk, Susan shared how CPCQC (Colorado Perinatal Care Quality Collaborate) created their DEFINE (Data Driven Engagement of Families to Improve the NICU Experience) Colorado Program in 2019 to center families in the NICU as active members and collaborative partners in the healthcare team.

Susan cited two studies that took place in Colorado NICUs to highlight barriers to family engagement in the NICU. First a study by Palau et al. showed that fewer Spanish-speaking NICU parents correctly identified the diagnosis of their infants, and that Spanish-speaking parents were still receiving updates about their infant in English. A second study by Borque et al. showed that several social determinants (income, travel time, lack of childcare) were negatively associated with maternal time spent in the NICU. To address these barriers, **the DEFINE Colorado Program made it their aim to improve family engagement as reported by parents and to decrease disparities in family engagement.** They also adopted an equity-focused quality improvement strategy where they stratified data according to sociodemographic factors, families and community partners were compensated as stakeholders, root causes of inequities were identified and named, and the focus was improving systems.

The Colorado Perinatal Care Quality Collaborative has several programs in place in addition to DEFINE:

- [CHoSEN](#) (Colorado Hospitals Substance Exposed Newborns)
- [Colorado Maternal Mental Health Collaborative](#)
- [FIRST](#) (Family Integration to ReStore Trust)
- [IMPACT BH](#) (Improve Perinatal Access, Coordination, and Treatment for Behavioral Health)
- [MOMS+](#) (Maternal Overdose Matters Plus)

Overall, the CPCQC and DEFINE are excellent examples of incorporating the voice and perspectives of NICU parents and caregivers in high-level data-driven quality improvement. To learn more, visit [DEFINE - CPCQC](#).

“ICU baby’s Work to Optimize NICU Health Literacy & Transportation Support” with Elizabeth Simonton, JD, Co-Founder & CEO of ICU baby

Elizabeth spoke about the programs available to NICU families in South Florida through her non-profit organization, [ICU baby](#) which she founded in 2014 after her son Bennett was admitted to the NICU. ICU baby’s goal is to provide emotional, financial, and informational support to NICU families which is accomplished by supplying meals, essentials, peer mentorship, educational resources, bereavement support, foster care kits, reading programs, and more.

ICU baby created **TAP (Transportation Assistance Program)** after learning that some families were not at their baby’s bedside due to lack of reliable transportation. By creating a solution for overcoming this huge barrier, Elizabeth and ICU baby are making parent presence and Family-Centered Care in hospitals across South Florida possible. Parents have expressed that TAP has helped them better connect with the medical team and be there for their baby in the NICU. Additionally, ICU baby created **NEST (NICU Empowerment Support Tools)** to increase health literacy among NICU parents. NEST is completely free to parents in participating hospitals and offers an introduction and guide to the NICU via a guidebook, parent portal, and app in the three most prevalent languages in South Florida (English, Spanish, and Haitian Creole).

ICU Baby’s work has been extremely impactful for NICU families in South Florida. To learn more, check out their website: [ICUbaby.org](#)

Click [here](#) to watch a recording of this event!

TRAUMA-INFORMED CARE CORNER

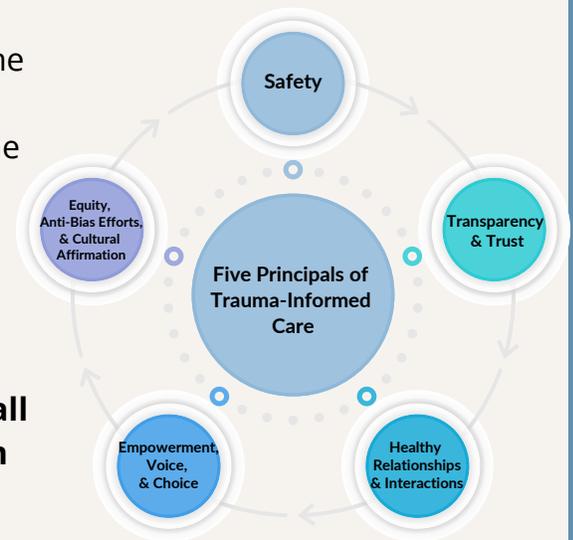
PUTTING FAMILIES AT THE HEART OF NICU CARE

WITH MARY COUGHLIN, MS, NNP, NCC-E

Welcome back to the Trauma-Informed Care Corner! I'm so glad you're continuing this journey with me as we explore what it truly means to support families in the NICU. As many of you know, the NICU is more than a clinical space – it's a place where families are often experiencing some of the most vulnerable moments of their lives. That's why embracing family-centered, Trauma-Informed Care is so vital. It's about recognizing that **the tiniest patients and their families are on this journey together, and we as care providers, are partners in that process.**

Let's talk about family engagement for a moment. When we say "engagement," it's not just about having families present – it's about inviting them into the care experience in a meaningful way. Picture this: a family not only observing their baby in the NICU but being an active part of the care team, feeling empowered, heard, and respected. When we bring families into the fold, we create a sense of belonging and trust, both crucial elements in a trauma-informed approach. After all, **when families feel like they truly belong, they're better able to support their baby's healing, and they feel more equipped to handle the challenges that come their way.**

But we also have to acknowledge that not every family has the same path into this experience. For some, the barriers - whether it's transportation, language, or simply navigating the overwhelming world of medical information - can make engagement feel impossible. That's where we, as compassionate caregivers, can step in with thoughtful solutions. **Simple acts like offering transportation assistance or providing health information in clear, accessible language can make a world of difference. It's all about meeting families where they are and helping them feel empowered, no matter their circumstances.**



This is where Trauma-Informed Care really shines. It encourages us to view every interaction through a lens of compassion and understanding. By recognizing the potential stress and trauma that families face, we can offer support that not only helps their baby but also helps them as a whole family. When we do that, we're not just providing care, we're building resilience. We're creating a space where healing happens not just in the medical sense, but in an emotional and psychological sense, too. So, as we continue to reflect on how we can best serve families in the NICU, let's keep this at the forefront: **Engagement is about partnership. It's about ensuring that every family feels welcomed, supported, and empowered to take an active role in their baby's care. Together, we can create NICU environments where families and babies thrive, both in the moment and long after they leave our care.**

Until next time, **let's keep striving to put families at the heart of everything we do.**

Hugs, Mary

HOW DO YOU KNOW YOU'RE TRULY DEVLIERING FCC IN THE NICU?

NICU FCC MEASURES REDCAP SURVEY

We are excited to share that our NICU FCC Measures REDCap Survey pilot is ready to launch! Our journey to develop this assessment tool is has been a collaborative effort spanning 17 months of dedicated work by FCC Taskforce leadership, including our diverse Executive Council of Family Partners and multidisciplinary Healthcare Partners, and researchers.

Why Your NICU Should Participate:

1. Once your survey is completed, you'll receive results automatically and will have the option to review them with FCC Taskforce leadership
2. You'll have the opportunity to collaborate with other NICUs to join topic-specific quality improvement work

Survey Makeup:

1. NICU Framework/Infrastructure
2. Family Support
3. Family Integration into Care
4. Family Integration into QI & Processes
5. NICU Environment
6. Staff Education
7. Balancing Measures

"Your participation directly impacts the promotion of FCC as a culture and standard of care."

-Keirra Sorrells, Founder & Executive Director of [NICU Parent Network](#)

"By participating in this survey, you are supporting parental mental health for families in the NICU"

-Kelli Kelley, Founder & CEO of [Hand to Hold](#)

"The NICU environment that FCC creates is crucial for families to have a positive NICU experience."

-Alex Zavala, Founder of [The NICU Dad](#)

To learn more, [click here](#) or scan the QR code to watch a brief video from Family Partners on our Executive Council. →



To receive the survey link, [click here](#) or scan the QR code to register. →



This work is supported by an educational grant from Chiesi Inc. USA and a SEED Partnership Award from Stanford Impact Labs.

FCC TASKFORCE OFFICE HOURS

The FCC Taskforce holds **monthly Office Hours to discuss challenges around implementing FCC practices and brainstorm strategies for overcoming them.** Office Hours are facilitated by both Family and Heathcare Partners from our Executive Council and include a variety of topics relevant to beginning or strengthening FCC in the NICU. Click [here](#) to register, it's free to join!

Upcoming Sessions:

- Tuesday, October 22nd @ 9am PT/12pm EST
- Thursday, November 21st @ 9am PT/12pm EST
- Tuesday, December 17th @ 9am PT/12pm EST



THANK YOU FOR READING

FCC Taskforce

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Mission Statement

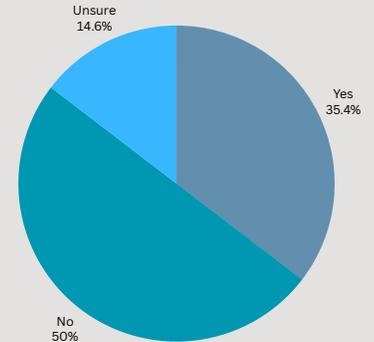
We exist to equip and support NICUs as they seek to begin or strengthen Family-Centered Care in their units.

Why We Exist

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.

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

Does your NICU currently have an FCC Committee?

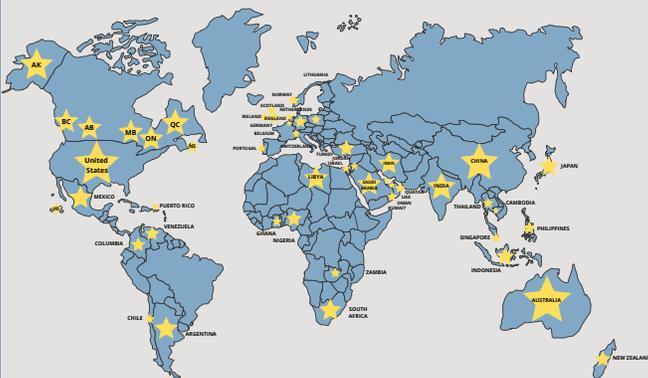


Our key strength is equal partnership between Clinicians and Family Partners in everything we do.

Organizational Partners



Membership



1500+ members
48/50 U.S. States & Puerto Rico
8/10 Canadian Provinces
57 Countries
Join us, membership is free!



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