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FCC TASKFORCE 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

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Part Six: 'Aria's Journey: Connecting Through Our Shared Humanity'

by Jessi Barnes, MSN, RN, RNC-NIC, NPD-BC, C-ELBW, NICU Parent

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.

It's here! I finally get to break out of this place. I'm going home! I've heard so much about it. Mom and Dad have told me all about my room and my big brother at home. They say he's a dog, but I don't know what that means. I'll see soon enough, though! My helpers have been talking with Mom and Dad a lot. There are so many instructions for taking a baby home. How hard can it be? If we can survive this place together, we can do anything! I am going to miss my helpers. They've supported us all so much. I promised a few of them that I'd be on my best behavior and no more forgetting to breathe. I want Mom and Dad to focus on all the fun stuff about having a baby and not just the scary stuff. They've done enough of that already. If I'm honest, I'm a little nervous, too. I know we got this, but it'll be weird not being tethered to all these machines. I keep reminding myself that they were meant for me, and together we can ride out any storm. Here's to our next chapter together! I've got a world to see!

Practical tips for emotionally supporting a family through discharge:

- Share in the entirety of their experience – the excitement and the fear. They have spent their time in the NICU accepting their baby's need for medical intervention and support. It's all of a sudden being taken away. They need time to process that.
- Offer to document this very important milestone. Take (or encourage them to take) pictures and videos. Provide things for their baby book or however they plan to document their baby's journey. (It's okay if they don't have a plan!)
- Provide reassurance and support a warm handoff to their community providers through report, documentation, and connection.

Part One: Aria's Birth
Part Two: Aria's Admission
Part Three: Aria's First Time Skin-to-Skin
Part Four: Aria's First Time Breastfeeding
Part Five: Aria Bottle-Feeds

SUPPORTING FAMILIES BEYOND DISCHARGE: *OUTPATIENT ROLES IN THE TRANSITION HOME*

WITH JESS DAIGLE, MD, FAAP, NICU PARENT

Leaving the NICU is often mislabeled as a “happy ending,” but for many families it feels more like stepping into the unknown.

The monitors are gone, the team of nurses and doctors is no longer by their side, and parents suddenly carry the weight of caring for a medically fragile baby at home. Outpatient healthcare professionals are uniquely positioned to bridge this gap and make the transition less daunting.

With intentional guidance, reassurance, and coordinated care, discharge can shift from overwhelming to manageable, transforming the experience for both babies and families.

Here are **five ways** outpatient healthcare professionals can strengthen family-centered care after discharge:

1. Prioritize Clear, Consistent Communication

Revisit the NICU history at follow-up visits. Families appreciate when pediatric and family medicine providers acknowledge their baby’s unique journey, explain what to expect, and create space for questions. Validation builds trust.

2. Support Feeding and Growth Monitoring

Feeding challenges are common for NICU graduates. Early proactive guidance, whether through weight checks, lactation support, or feeding therapy referrals, prevents setbacks and reassures families. Clear education on growth goals empowers parents to track progress with confidence.

3. Promote Developmental Surveillance and Early Intervention

Encourage parents *not* to “wait and see.” Regular developmental screening and timely referrals to early intervention services optimize long-term outcomes and reduce parental anxiety. Position therapy as supportive, preventative care and not a sign of failure.

4. Address Mental Health and Family Well-Being

Screen parents regularly for postpartum depression, anxiety, and trauma related to the NICU stay. Connecting families with counselors, peer mentors, and community resources reflects holistic, family-centered care and prevents parents from feeling unseen.

5. Foster Collaborative Care

Proactively communicate with subspecialists, therapists, and community partners. When families see their care team working together, it reassures them that their child’s growth and their family’s adjustment are being supported on all fronts.

When outpatient healthcare professionals embrace these strategies, they not only safeguard the health of NICU graduates but also strengthen the resilience of families during one of the most vulnerable transitions of their lives.

SEPTEMBER ‘25 WEBINAR SUMMARY

WITH BOB CICCO, MD

“Screening Now: Standardizing Mental Health Assessments for NICU Parents” with Megan Paulsen, MD and Sarah Swenson, MD

A recent FCC Taskforce poll indicated that 47% of respondents do not screen for perinatal mood disorders or anxiety, while 37% screen only the birthing parent, and just 16% screen both birthing and non-birthing parents. Megan and Sarah presented a compelling case for why and strategies for how to increase these numbers:

- A baby’s medical progress doesn’t always match the parent’s emotional well-being—parents may still feel guilt or inadequacy even after positive outcomes and with strong supports.
- Social stress and inequities increase the risk of poor emotional and mental health for parents.
- Individual staff efforts help, but systemic approaches are needed to fully address parents’ emotional health in the NICU.
- Mental health screening must include effective referral systems for care.
- Non-birthing parents are also at risk and should be included in emotional health support systems.
- Informal screening can help early, but standardized ongoing screening is more effective—up to 80% of parents screened have a mental health concern.
- Parents emphasize the need for support around and after discharge since emotional health changes over time. Ongoing screening and follow-up are essential.
- Keep in mind that, “Neonatology isn’t just about saving babies, it’s about saving families!”

“Long-Term Outcomes: Preparing Families for Future Health” with Lauren Ingledow and Michelle Kelly, PhD, CRNP

Michelle and Lauren gave an excellent overview addressing the common misconception that preterm babies simply “outgrow” their prematurity. The session highlighted ways healthcare providers can navigate this widespread myth and better support families of premature infants:

- Families are often told their baby will “catch up,” which implies they are “behind” and overlooks each child’s unique path, strengths, and risks. Reframe language to emphasize individual growth patterns and celebrate strengths while acknowledging risks.
- Preterm birth carries lifelong risks—including lung problems, heart issues, and behavioral and learning challenges—even for babies born late preterm. Educate healthcare providers and families about the full spectrum of lifelong risks to ensure early screening and proactive care.
- While 85% of adults born preterm feel it affects their health, only 20% say healthcare providers see it as relevant. Incorporate patient perspectives into provider training to increase awareness and validate lived experiences.
- NICU staff must prepare parents and healthcare providers to understand long-term risks, recognize strengths, and support interventions that help children thrive. Develop family-centered discharge education and follow-up plans that highlight both risks and individualized supports.

These sessions encouraged us to rethink NICU care by promoting long-term health and well-being for babies and their families. Watch the recording here.

TRAUMA-INFORMED CARE CORNER

FROM THE NICU TO THE NATIONS: AN INVITATION TO COURAGOUS CARE

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

When I first began advocating for trauma-informed developmental care in the NICU, the focus was clear: how do we minimize stress, protect sleep for developing brains, and nurture parent-infant attachment? Over time, though, I realized something deeper: the NICU is not isolated from the world. **The inequities and systemic traumas that families carry with them don't disappear when they pass through our doors.** They are present in the stress of a parent who fears medical bills more than their own grief, in the exhaustion of a nurse stretched thin by staffing shortages, in the quiet weight of racism, misogyny, or poverty that bends lives long before prematurity.

Recognizing this can feel confusing, even frightening; it is tempting to tell ourselves, *"that's not my job"*. We want to believe we can leave "the outside world" outside and simply focus on the fragile babies before us. But the truth is, **systemic trauma always finds its way in.**

The NICU Is Not an Island
The walls may be white and sterile,
but they do not keep out the world.
Systemic trauma enters with every parent,
racism sits in waiting rooms,
inequity shadows the bedside.

We cannot swaddle away
a society's wounds.
But we can bear witness,
we can hold babies and families
in a circle of dignity,
and we can refuse to forget
that what happens outside
always finds its way inside.

To love the smallest among us
is to love the world they will grow into.
To heal here is to heal forward —
toward justice, toward belonging,
toward a future where care
is never confined to walls.

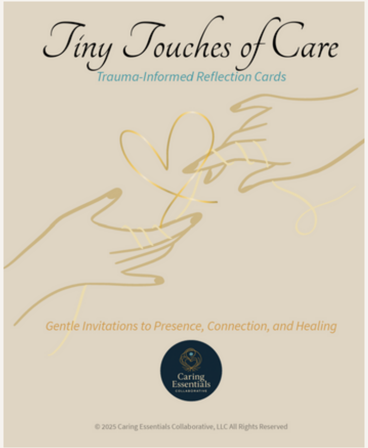
And here's the invitation: not to despair, but to dig deeper. To **reconnect with our values as healthcare professionals, yes, but even more as human beings**. To stretch ourselves toward love that is bigger than our comfort zone. To lean in where it feels risky. To live into the "you" who has been called to this sacred work.

Because trauma-informed developmental care is more than a clinical framework. It is a way of being that insists **dignity is non-negotiable, that healing is possible, and that love, for babies, families, colleagues, and even our nations, is our most essential medicine**.

We may not solve every societal wound, but by refusing to look away, by bringing our full humanity to the bedside, we plant seeds of justice and healing that ripple far beyond the NICU walls.

No matter where we practice, across regions, cultures, and nations, this shared commitment to dignity and healing binds us together. **Our work in each NICU is part of a larger movement toward a more caring world.**

Take care and care well,
Mary

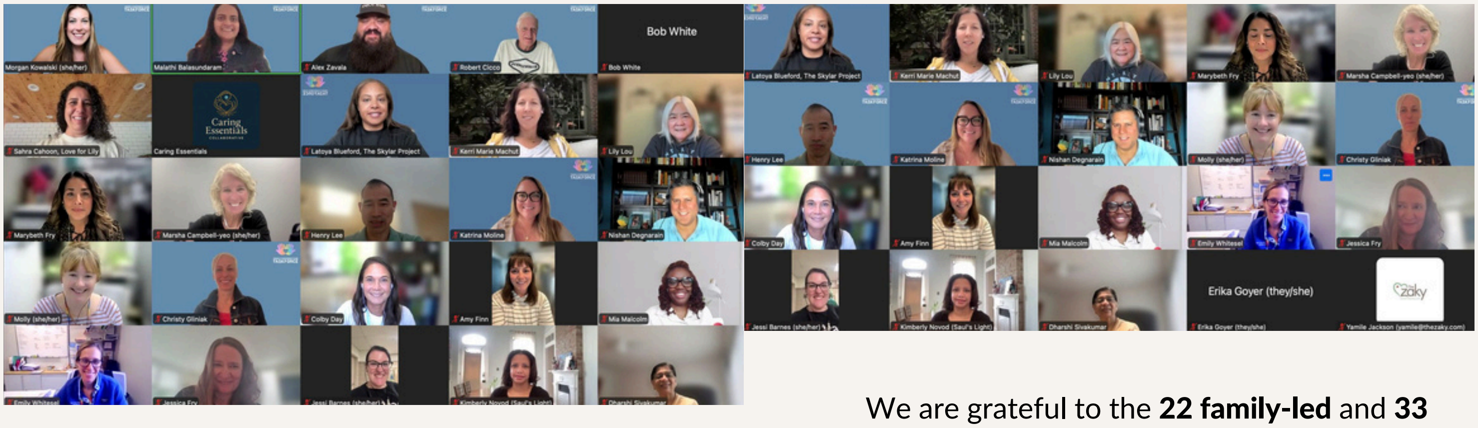


Click here to download a complementary resource: Tiny Touches Reflection Card deck

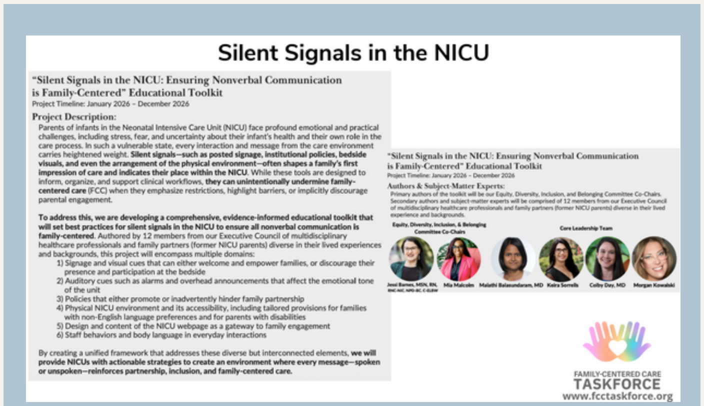
EXECUTIVE COUNCIL UPDATE

WITH MALATHI BALASUNDARAM, MD & MORGAN KOWALSKI

The FCC Taskforce's Executive Council held its third quarterly meeting of 2025 on September 24th with 32 members joining virtually via Zoom!



We are grateful to the **22 family-led** and **33 healthcare-based** organizations supporting our work by sharing our free educational webinars and office hours sessions!



Silent Signals in the NICU

"Silent Signals in the NICU: Ensuring Nonverbal Communication is Family-Centered" Educational Toolkit

Project Timeline: January 2026 – December 2026

Project Description:

Parents of infants in the Neonatal Intensive Care Unit (NICU) face profound emotional and practical challenges, including stress, fear, and uncertainty about their infant's health and their own role in the care process. In such a vulnerable state, every interaction and message from the care environment carries heightened weight. **Silent signals—such as posted signage, institutional policies, bedside visuals, and even the arrangement of the physical environment—often shapes a family's first impression of care and indicates their place within the NICU**. While these tools are designed to inform, organize, and support clinical workflows, **they can unintentionally undermine family-centered care** (FCC) when they emphasize restrictions, highlight barriers, or implicitly discourage parental engagement.

To address this, we are developing a comprehensive, evidence-informed educational toolkit that will set best practices for silent signals in the NICU to ensure all nonverbal communication is family-centered. Authored by 12 members from our Executive Council of multidisciplinary healthcare professionals and family partners (former NICU parents) diverse in their lived experiences and backgrounds, this project will encompass multiple domains:

1) Signage and visual cues that can either welcome and empower families, or discourage their presence and participation at the bedside
2) Auditory cues such as alarms and overhead announcements that affect the emotional tone of the unit
3) Policies that either promote or inadvertently hinder family partnership
4) Physical NICU environment and its accessibility, including tailored provisions for families with non-English language preferences and for parents with disabilities
5) Design and content of the NICU webpage as a gateway to family engagement
6) Staff behaviors and body language in everyday interactions

By creating a unified framework that addresses these diverse but interconnected elements, **we will provide NICUs with actionable strategies to create an environment where every message—spoken or unspoken—reinforces partnership, inclusion, and family-centered care.**

"Silent Signals in the NICU: Ensuring Nonverbal Communication is Family-Centered" Educational Toolkit

Project Timeline: January 2026 – December 2026

Authors & Subject-Matter Experts:

Primary authors of the toolkit will be our Equity, Diversity, Inclusion, and Belonging Committee Co-Chairs. Secondary authors and subject-matter experts will be comprised of 12 members from our Executive Council of multidisciplinary healthcare professionals and family partners (former NICU parents) diverse in their lived experience and backgrounds.

Equity, Diversity, Inclusion, & Belonging Committee Co-Chairs

Core Leadership Team

Jessi Barnes, MSN, RN, RNC-NIC, NPD-BC, C-ELBW
Mia Malcolm
Malathi Balasundaram, MD
Keira Sorrells
Colby Day, MD
Morgan Kowalski

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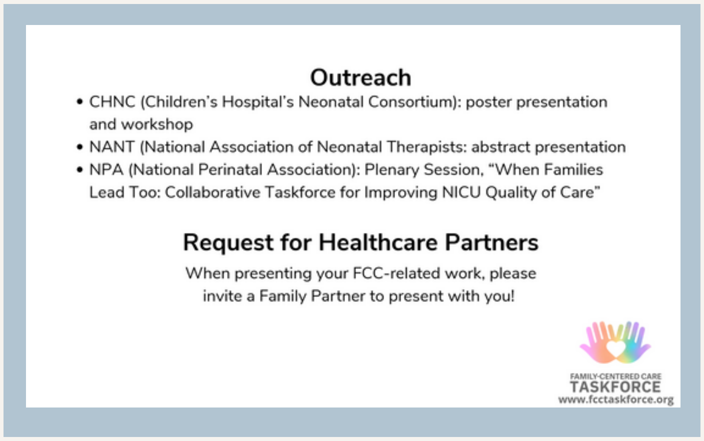
New Organizational Partnerships

Our Equity, Diversity, Inclusion, and Belonging Committee is in the early stages of creating an **educational toolkit to ensure all communication, spoken *and* unspoken, are truly family-centered**.

We will be attending **CHNC, NANT, and NPA** conferences to share our work. Come say hi if you'll be present!



Outreach

- CHNC (Children's Hospital's Neonatal Consortium): poster presentation and workshop
- NANT (National Association of Neonatal Therapists: abstract presentation
- NPA (National Perinatal Association): Plenary Session, "When Families Lead Too: Collaborative Taskforce for Improving NICU Quality of Care"

Request for Healthcare Partners

When presenting your FCC-related work, please invite a Family Partner to present with you!

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Coming Up Next:

- 2026 Webinar speakers
- Equity, Diversity, Inclusion, & Belonging position paper
- New & improved website!
- Interactive Presence Study Toolkit
- Publication on our NICU FCC Measures findings!

THANK YOU FOR READING

Mission Statement

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

FCC Taskforce

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Colby Day, MD
Keira Sorrells, NICU Parent

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Morgan Kowalski , NICU Parent

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Jess Daigle, MD, FAAP
Jadene Wong, MD

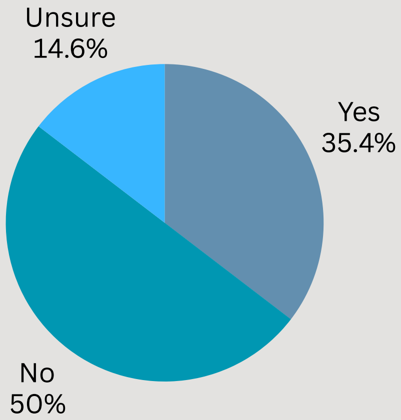
Why We Exist

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.

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 FCC Committee in their unit.

Does your NICU currently have an FCC Committee?



Membership

2600+ members
49/50 U.S. States & Puerto Rico
9/10 Canadian Provinces
71 Countries
Join us, membership is free!

Organizational Partners

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