

# 1: Status for parents as essential caregivers

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The bond between a parent and their infant is unlike any other. Infants and their parents are biologically co-regulated, deeply intertwined in ways that science continues to reveal.

## Awareness

Research consistently shows that when this relationship is nurtured and supported, the outcomes are positive and meaningful.

For infants, it means improved cognitive development, reduced neurological stress, improved weight gain, and greater physiological stability.

For parents, it improves mental health, reduces toxic stress and anxiety, fosters stronger clinical decision-making for their infant, betters the transition to the parents' care at home, and leads to stronger family functioning and overall well-being.

Yet when an infant has a medical condition that requires stabilization and therapy after birth, they are taken to a NICU. Separation between infants and their families has become an inherent part of NICU care, and many NICU policies and care practices further disrupt the vital infant-parent connection.

**This separation represents the most significant trauma any newborn mammal can experience.**

Why does this happen? Why are parents often viewed as passive observers rather than essential care providers? The answers likely lie in deeply rooted systemic issues.

## CHAPTER 1 KEY POINTS

### Awareness

- Parent-infant bond drives health outcomes
- Separation in NICU disrupts biological regulation
- Parents are essential caregivers, not visitors

### Assessment

- Review policies, signage, and staff language
- Identify barriers to parent recognition and inclusion
- Evaluate tone, inclusivity, and accessibility of communication

### Action

- Form an interdisciplinary implementation team
- Engage families early and revise policies
- Conduct assessments and co-design strategies
- Sustain leadership, equity, and collaboration

The modern system for neonatal health care developed with the important goal of improving medical outcomes for infants, but

**the patriarchal model used in the process of development has historically undervalued the role of families in clinical settings.**

In addition, neonatal healthcare systems continue to grapple with how to best address social influencers of health that intersect with harmful implicit bias and racism, language barriers, and other factors important to family presence within the NICU. While progress has been made, this perception of families as observers remains entrenched and urgently needs to be overturned. Parents are far more than gestational carriers or passive participants waiting to bring their infants home.

**Parents are biologically wired to provide the safety, care, and nurturance their infants need, even in the most stressful and traumatic environments. Parents are not optional—they are essential members of the life-saving healthcare team.**

It is imperative to reframe the role of parents in neonatal care. They must be empowered, supported, and coached to step confidently into their role as essential caregivers. This paradigm shift acknowledges what we already know at a biological and emotional level: parents are critical to their infant's survival and long-term well-being, and their role should be treated with the same respect and urgency as any medical intervention.

**The power of a parent's touch, voice, and scent cannot be replicated by medical interventions.**

## Assessment

NICUs can reinforce the essential role of parents as caregivers in multiple ways, including unit policies on parent presence, signage and documents displayed in the NICU, and consistent communication from healthcare professionals.

**A key first step in assessment is to conduct a critical appraisal of all these elements in your unit.**

### Policy Evaluation

- Is this policy specific to the NICU, or is it the same hospital-wide policy?
- How are parents and family members described in the policy?
- Does the policy use the term visitor when referring to parents? If so, can it be revised to use the term essential caregiver presence or parent presence to reflect the role of parents accurately?
- Is “family” defined broadly (parents, guardians, chosen family, support persons)?
- Does the policy use inclusive language that recognizes diverse family structures?
- Are there any restrictions on family presence at the bedside?

### Signage Evaluation

- Does the language on signage feel welcoming, supportive, and inclusive? Is the language free from jargon or acronyms that may be confusing to families?
- Does the tone feel welcoming, respectful, and supportive, or does it feel restrictive and rule-driven? Is the message phrased positively (on what families can do) rather than negatively (on what they cannot do)?
- Is the language accessible to people with different literacy levels?
- Are materials available in the primary languages spoken by families in your NICU?
- Does the wording avoid assumptions about family structure (e.g., using “parents and caregivers” instead of only “mother/father”)?
- Are signs placed where families, not just staff, can easily see them?

"I sat on the sidelines of my babies' care for weeks. I was terrified and disconnected. I didn't feel I had the right to claim the title of mother. My body had failed to keep my triplets safe: how could I call myself a mother? Our care team understood this. Ever so gently and consistently, they pulled me in. They engaged me in caring for my babies and helped me see, and affirmed, that I was not an extra in their lives. I was the lead!"

## Parent Recognition Evaluation

- How do healthcare professionals in your unit typically refer to parents?
- Could more accurate language be used to reflect parents as essential partners in care?
- As you round with the healthcare team, walk through the unit, and talk with bedside nurses, what language do you notice being used? Could it be more inclusive or respectful?
- How does your unit currently recognize and support parents in their role as essential caregivers for their NICU infants?
- What opportunities exist to further strengthen this recognition and support?
- Are the terms visit or visitor ever used to describe parents?

## Action

Gaining unit-wide support for recognizing parents as essential caregivers requires commitment from every member of the healthcare team

This effort is much like building trust—it must be nurtured through consistent, intentional actions. Even one negative interaction, however unintentional, can quickly erode trust and leave parents feeling excluded rather than valued as essential members of their baby’s healthcare team.

*Consider using this guide in your assessment:*

Institute for Patient and Family Centered Care

## Formation of an Interdisciplinary Implementation Team

**Purpose:** To oversee assessment, planning, and execution of strategies that embed family-centered principles and recognize parents as essential care providers.

*Begin sharing information about the NICU and ways families can engage as early as possible.*

### Team Composition

- Family partners (former NICU parents)
- Representatives from nursing, neonatology, therapy (physical, occupational, speech, music), lactation, social work, etc.
- Unit leadership and hospital administrators

### Responsibilities

- Assess current unit culture, policies, and practices
- Identify barriers and facilitators to parent-provider partnerships
- Develop and implement unit-specific strategies
- Provide ongoing leadership and accountability

### Early Family Engagement

- Begin sharing information about the NICU and ways families can engage as early as possible, especially during antenatal counseling when a NICU stay is expected

### Policy Review and Revision

- Ensure all written policies, procedures, and guidelines explicitly recognize and support parents as integral members of the healthcare team
- Policies should state: “Parents are recognized as essential care providers and partners in their infant’s care.”

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### Conduct a Comprehensive Assessment

- Utilize validated tools or internal surveys to gather feedback from families and staff
- Assess understanding, practices, and barriers related to family engagement
- Hold interdisciplinary review sessions in a trauma-informed, inclusive, and psychologically safe setting
- Ensure diverse voices, particularly from parents and underrepresented groups, are centered and valued

## **Strategy Development**

- Use assessment findings to co-design interventions tailored to the local context and culture of the NICU
- Incorporate input from current and former NICU families, as well as bedside staff and operational leaders
- Benchmark against best practices from peer institutions
- Identify systemic and logistical barriers (e.g., staffing, space, language)
- Prioritize strategies that promote sustainability and equity

## **Sustained Collaboration and Leadership**

- Continue to meet regularly to monitor implementation progress
- Identify local champions for family-centered care practices
- Identify future areas for improvement and innovation
- Institutionalize the role of families as essential care providers in all levels of NICU policy, care, and decision-making

## Resources

Effect of family integrated care on physical growth and language development of premature infants: a retrospective study. *Translational Pediatrics*, (2022). 11(6), 965–977.

<https://doi.org/10.21037/tp-22-210>

Early disruption of the mother–infant relationship: effects on brain plasticity and implications for psychopathology. *Neuroscience & Biobehavioral Reviews*, (2003). 27(1-2), 73–82.

[https://doi.org/10.1016/S0149-7634\(03\)00010-1](https://doi.org/10.1016/S0149-7634(03)00010-1)

Parents as the Primary Caregivers for Their Infant in the NICU: Benefits and Challenges. *NeoReviews*, (2014). 15(11), e472–e477.

<https://doi.org/10.1542/neo.15-11-e472>

Parent-identified barriers to pediatric health care: a process-oriented model. *Health Serv Res*. 2006 Feb;41(1):148-72.

<https://doi.org/10.1111/j.1475-6773.2005.00455.x>

The Authoritarian Reign in American Health Care. *Policy, Politics, & Nursing Practice*. 2010;11(1):71-79.

<https://doi.org/10.1177/1527154410372973>

The Surgeon and the Mother. *New England Journal of Medicine*. 2021 Jan 28;384(4):302-3.

<https://doi.org/10.1056/nejmp2029239>

Consensus Statement: Essential Care in the NICU during the COVID-19 Pandemic Significance. (2021).

[https://www.nationalperinatal.org/files/ugd/209d80\\_b42c2f061f664fc3b7acf7f35706dc6d.pdf](https://www.nationalperinatal.org/files/ugd/209d80_b42c2f061f664fc3b7acf7f35706dc6d.pdf)

Position Paper: Continuous & Uninterrupted Family Presence in the NICU.

<https://nicuparentnetwork.org/wp-content/uploads/2025/06/Continuous-and-Uninterrupted-Family-Presence-in-the-NICU.pdf>

Examples of hospitals that have changed their “visiting policies”.

<https://www.ipfcc.org/bestpractices/profiles-of-institutional-change.html>

Criteria for Exemplar Hospitals

<https://www.ipfcc.org/bestpractices/Better-Together-Exemplar-Hospitals-Criteria.pdf>

Why Partnering with Parents in the Neonatal Unit is the Key to Everything

<https://nidcap.org/why-partnering-with-parents-in-the-neonatal-unit-is-the-key-to-everything/>

Trauma-Informed Developmentally Supportive Care

[https://www.academia.edu/116239034/Trauma\\_Informed\\_Developmentally\\_Supportive\\_Care](https://www.academia.edu/116239034/Trauma_Informed_Developmentally_Supportive_Care)

Tiny Humans, Big Lessons: How the NICU Taught Me to Live with Energy, Intention and Purpose, 2022.

<https://pagetwo.com/book/tiny-humans-big-lessons/>

The Incubator Podcast - Mary Coughlin, RN Trauma Informed Care in the NICU

<https://www.the-incubator.org/post/038-mary-coughlin-rn>

The Empowering NICU Parents' Podcast - Trauma-Informed Care in the NICU with Mary Coughlin

<https://podcasts.apple.com/us/podcast/trauma-informed-care-in-the-nicu-with-mary-coughlin/id1551624574?i=1000568866434>

Studying caregiver-infant co-regulation in dynamic, diverse cultural contexts: A call to action - PMC

<https://doi.org/10.1016/j.infbeh.2021.101586>