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> "Recognizing that change takes time and that solutions need to be adapted to local conditions."
>
> *-Joan Neergaard Larsen*

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FAMILY VOICES

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Every Moment Matters: From the Other Side of the Incubator

Lucie Žáčková

Mother of Ella, Executive Director of Nedoklubko, Czech Republic
Family Member, NIDCAP Federation International

Column Editor: Livia Nagy-Bonnard

In this deeply personal piece, Lucie Žáčková (Nedoklubko, Czech Republic) takes us back to the birth of her daughter Ella, born at 25 weeks. 16 years ago. I am very happy to share Lucie's story in this issue, because it captures something at the heart of this column: every baby communicates, every parent has a role, and every moment matters.

Sixteen years ago, I stood beside an incubator and looked at my daughter through its transparent wall. Her name was Ella. She weighed 730 grams and measured only 33 centimeters. She had been born at 25 weeks and three days of pregnancy, almost fifteen weeks before her due date.

That very morning, I was still at a work meeting, discussing an important event. My pregnancy had been uncomplicated, and I was only beginning to imagine slowing down and preparing for our baby's arrival. Just a few hours later, at 2:28 in the afternoon, Ella was born. There had been no time to prepare, not even enough time for antenatal corticosteroids to help mature her lungs.

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When I woke after the delivery, I no longer had a pregnant belly, but I did not have my baby with me either. I did not even know if she was alive. That feeling has never completely left me.

A Mother Beside the Incubator

When I first saw Ella, she was ventilated, fed through a tube and connected to monitors and lines. Her body looked impossibly small. In the first days, her weight dropped from 730 grams to around 580 grams.

Suddenly, my world became very small too. There was the incubator, the monitors, the milk I tried to express and the medical information I struggled to understand.

Above all, there was one question that followed me everywhere: *Will my baby survive?*

But alongside that fear was another question: *What can I do for her?*

The doctors knew how to keep her alive, the nurses knew how to care for her tiny body, and the machines helped her breathe. I had to learn what it meant to be a mother in this completely unexpected world.

The nurses encouraged me to talk to Ella, so I did. Through the wall of the incubator, I told her about the world waiting for her outside the hospital, about her little bed at home and about everything we would do together one day. Perhaps I was trying to convince her that she would make it. Perhaps I was trying to convince myself.

> **"I was doing something that only I could do for my daughter. I was her mother.**

I came to the hospital every single day. I did not miss one of the 77 days Ella spent there, and neither did her father. We were both there every day. I expressed milk for her, sat beside her, and gradually learned how to participate in her care and touch such a tiny baby. I celebrated every gram gained and feared every complication.

When Ella was stable enough, I was finally able to hold her skin-to-skin. She was 21 days old. Once we could start kangaroo care, I wanted to do it every day. Having Ella on my chest changed something fundamental. For a while, the incubator and the machines moved into the background, and I could

(continued on p.3)

Editorial

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Seeing, Listening, Connecting



This issue highlights the work of NIDCAP Professionals and Family Advocates as they support newborns and their families in their everyday work.

The world of newborn intensive care raises many ethical questions. Michael Van Manen challenges us to consider the impact of pain and suffering on newborns and their families. NIDCAP Professionals have a unique opportunity to use observation and reflection to improve the experiences of both newborns and their families. Joan Neergaard Larsen from Denmark demonstrates this beautifully by focusing on keeping mothers and babies together, while Lisa Kleinz from the USA describes how she uses her NIDCAP lens to improve oral feeding.

We then journey with two parents, Kylie Pussell and Yamile Jackson, as they visit newborn units across Europe to explore practices in peer support and skin-to-skin care. Their experi-ences remind us of how much we can learn when we listen to families and recognize them as advocates for their babies.

Our Family Voices column, as always, provides an insightful perspective on families' experiences. Lucie Žáčková tells us the story of Ella with a reflection on changes over 16 years.

I am also delighted to welcome back our Poets Corner, with Julia Giesen sharing a thoughtful reflection on the experience of tube feeding.

There is much to explore and reflect on in this issue, and I hope you enjoy reading it as much as we have enjoyed bringing it together.

In 2027, *The Developmental Observer* will celebrate its 20th anniversary. To mark this special milestone, I would love to hear from you. What has the publication meant to you? Which articles, stories or themes have stayed with you over the years? And what have you found particularly interesting or valuable?

Please share your stories with us as we look back on twenty years of T*he Developmental Observer*.



Kaye Spence AM FACNN
Senior Editor – Developmental Observer
Adjunct Associate Professor
Australasian NIDCAP Training Centre/
University of Western Sydney



Cover image by: Petre Sztahovits

simply feel her warmth and her tiny body against mine. I was doing something that only I could do for my daughter. I was her mother.

What I Understand Differently Today

Looking back, I realise that many elements of what I now recognise as developmental and family-centered care were already part of our experience sixteen years ago. At the Department of Neonatology at the General University Hospital in Prague, parents were not simply expected to stand outside and watch. I was encouraged to express breast milk, and as Ella's condition allowed, we gradually became involved in her care and practiced kangaroo care.

It would therefore be wrong to describe neonatal care sixteen years ago simply as a world in which parents were kept at a distance. Many of the people who cared for Ella already understood something fundamental: her parents mattered.

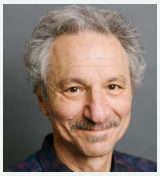
What I did not have then was the language I have today. I did not know the term "developmental care" and had never heard of NIDCAP. I did not understand how deeply a premature baby's developing brain is influenced by the environment,



Ella in intensive care

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Editorial Board



Jeffrey R. Alberts, PhD, is Professor of Psychological and Brain Sciences at Indiana University -- Bloomington (USA). Jeff is also a NIDCAP Professional and blends his lab studies with similar research at Cincinnati Children's Hospital Medical Center.



Diane Ballweg, MSN, is the Developmental Specialist at WakeMed Hospital in Raleigh, North Carolina, USA. Diane's writing and editing experience also includes reviewing for several peer reviewed journals and authoring several journal publications and book chapters related to developmental care.



Deborah Buehler, PhD, has a degree in developmental psychology and is a NIDCAP Master and APIB Master Trainer with expertise in developmental care within newborn and infant intensive care nurseries. Her work has focused on NIDCAP research, education and mentorship, and awareness. Deborah has authored and co-authored papers and manuals pertaining to NIDCAP care.



Sandra Kosta, BA, NFI Executive Director of Administration and Finance, has been an Associate Editor for the *Developmental Observer* since 2007. As a Research Specialist at Boston Children's Hospital, Sandra has co-authored several papers on the effectiveness and long-term outcomes of NIDCAP Care.



María López Maestro, MD, is a Neonatologist at the Hospital 12 de Octubre in Madrid, and is a NIDCAP Trainer and Member of the National Committee for the implementation of Developmental Centered Care in Spain. Maria has 10 research works. *https://orcid.org/0000-0002-0545-6272.*



Lívia Nagy-Bonnard, is Founder and Vice-President of the Melletted a Helyem Egyesület Association for preterm babies in Hungary. Livia is a patient expert for the European Patients' Academy on Therapeutic Innovation, a member of the Global Foundation for Care of Newborn Infants, and a member of the Parent Advisory Board and is a member of the Family Advisory Council of the NFI.



Debra Paul, OTR/L, is an Occupational Therapist and NIDCAP Professional at Children's Hospital Colorado in Aurora, Colorado and the Column Editor for the Family Voices section for the *Developmental Observer*. Debra writes policies and guidelines which requires succinct writing and an eye for editing.



Kaye Spence AM is a Clinical Nurse Consultant and clinical researcher with numerous publications in peer reviewed journals and several book chapters and is a peer reviewer for eight professional journals. She is a NIDCAP Professional and past Editor of *Neonatal, Paediatric* and *Child Health Nursing*. *https://orcid.org/0000-0003-1241-9303*

or how much a baby communicates through behavior. I simply knew that I wanted to be close to Ella.

Today, NIDCAP provides me with a framework for understanding what I intuitively experienced as a mother. It explains why observing an individual baby's signals matters; why touch, light, sound, positioning and sleep matter; why skin-to-skin contact is much more than a beautiful bonding experience; and why parents should be supported in becoming confident partners in their baby's care.

Progress is not always about replacing the past with something completely new. Sometimes it is about understanding more deeply why the things we were already doing mattered, improving them as our knowledge grows and making sure every baby and family can benefit from them.

Parents Are Not Visitors

My experience as Ella's mother became the beginning of another journey. During her hospitalization, I encountered Nedoklubko, a Czech parent organization supporting families of babies born prematurely. I received information and, perhaps even more importantly, the feeling that there were people who understood what our family was going through. Later I wanted to give something back and gradually became involved with the organization. Today, I serve as its Executive Director.

For more than a decade, I have listened to hundreds of mothers and fathers. Their stories are different, yet the emotions are remarkably similar: fear, guilt, helplessness, and often the same question I once asked myself:

> *Does my baby really need me when there are so many professionals around who know much more than I do?*

My answer today is unequivocal: *yes.*

Parents are not visitors to the NICU. They are part of their baby's environment, development and care. Medical technology can save a premature baby's life, but it cannot replace a parent's voice, smell, warmth, touch and presence.

We sometimes say in Nedoklubko that extremely premature babies need to be "carried to term on their parents' chest." The incubator is essential technology, but whenever medically possible, a parent's body is also part of the baby's developmental environment.

From Survival to Development

Neonatal medicine has achieved extraordinary things, and Ella is one of them. The tiny 730-gram baby I watched inside an incubator is now sixteen years old. When I look at her today, I sometimes find it almost impossible to connect the young woman standing in front of me with that tiny body surrounded by tubes and wires.

I will always be grateful to the doctors and nurses who saved her life. But gratitude should not prevent us from asking how care can become even better. The question is no longer only: Can we save this baby? We can also ask:



Lucie with her daughter, Ella, now age sixteen

> *How can we protect this baby's developing brain, relationships and emotional security while we save their life? And how can we protect the family at the same time?*

This is where NIDCAP has become so important to me. It is not simply another intervention to be fitted between medical procedures. It is a way of seeing the baby as an individual human being with their own behavioral language, and the parents as essential partners who are learning that language alongside the professionals.

In September 2025, I attended the NIDCAP Trainers Meeting in Copenhagen and became a Family Member of the NIDCAP Federation International. Sitting among people who had devoted their professional lives to developmental care, I kept thinking about the young mother I had been sixteen years earlier, standing beside an incubator and trying to understand her place in this new world.

If I could go back to her today, I would tell her to watch Ella and learn her language. I would tell her that her voice matters, her touch matters, and that her chest is a place of care. Most importantly, I would tell her: *You are not standing beside her treatment. You are part of it.*

A Message to Healthcare Professionals and to Families

There is something I would like every professional working in neonatal care to know: parents remember you. They may forget medical terminology, numbers or test results, but they remember the person who helped them touch their baby for the first time. They remember the nurse who moved a chair closer to the incubator, the doctor who spoke to them as partners and

the person who told them, "Your baby knows your voice." They remember being invited in, and they remember the moments when they felt they did not belong.

Developmental care does not live only in protocols. It lives in everyday moments: in lowering a voice, dimming a light, noticing a baby's stress signal, protecting sleep, supporting skin-to-skin contact or helping frightened parents become confident in caring for their child. These moments tell the baby and the family: *You belong together.*

After sixteen years of working with families, I believe this cannot depend on the philosophy of a single hospital or the sensitivity of a single exceptional doctor or nurse. It needs to become the standard.

And to parents standing beside an incubator today, I want to say this: at first, you may feel that everyone in the room knows your baby better than you do. Perhaps they know more about the medicine, but there is something only you can bring. Your relationship with your child.

Learn to observe your baby. Ask how you can participate. Offer your voice, your hands, your milk if possible, your chest and, above all, your presence. Do not underestimate the quiet moments simply because they may not look like treatment. They matter.

Sixteen years after Ella's birth, I believe that the future of neonatal care is not a choice between sophisticated medicine and human closeness. We need both. The smallest and most fragile babies deserve the best technology, science and professionals. At the same time, they deserve gentleness, individualized care, and to have their families close to them.

My daughter taught me this long before I knew there was a name for it. Today, NIDCAP gives me the language to describe what she was telling us all along:

See me. Listen to me. Protect me. And keep the people I know and love close.

Every baby communicates, every parent has a role, and every moment matters.

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National NIDCAP Training Center
NIDCAP Trainer
Children's Hospital of University of Illinois NIDCAP Training Center
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SECRETARY

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email: *mandy.daly@inha.ie*

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email: *livianagybonnard@hotmail.com*

Fátima Clemente, MD
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Co-Director, São João NIDCAP Training Center
email: *clemente.fatima@gmail.com*

María López Maestro, MD
NIDCAP Trainer, Madrid, Spain
email: *mariamaestro@gmail.com*

Monique Oude Reimer, RN
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Juzer Tyebkhan, MBBS
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Director, Edmonton NIDCAP Training Centre
email: *juzer.tyebkhan@albertahealthservices.ca*

Dorothy Vittner, PhD, RN, FAAN
Senior NIDCAP Trainer
West Coast NIDCAP & APIB Training Center
email: *dvitt8@gmail.com*

STAFF AND CONSULTANTS

Sandra Kosta, BA
Executive Director of Administration and Finance
email: *sandra.kosta@childrens.harvard.edu*

Bonni Moyer, MS, PT
Director, NIDCAP Nursery Program
email: *Bmoyer12@gmail.com*

Nadine Griffiths, RN, PhD
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email: *learning@nidcap.org*

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Using My NIDCAP Lens to Support Oral Feeding

Lisa Kleinz MA, SLP/L, CNT
Director of Education, Dr Brown's Medical, USA

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An Introduction to a New Lens

I remember when I first started my NIDCAP training in 1997. After beginning my career at a Level 4 Children's Hospital as a Speech Pathologist, I accepted a new role as the Developmental Care Specialist for the Newborn Intensive Care Unit (NICU). Looking back, I realize that early in my career, I approached feeding through a very 'assessment/recommendation' and compartmentalized lens: Receive a feeding consult, read the chart, feed the baby, tell the nurse and provider my recommendation (then the family), and move on to the next patient.

My initial NIDCAP training with gretchen Lawhon, and later recertification with Jen Hofherr, transformed the way I approached my work. It changed how I fed infants, how I entered the NICU space each day, and how I communicated with nurses, the medical team, and the family.

NIDCAP taught me to observe, understand, and respond to infants' behaviors and cues. It showed me how to support development by fostering parent-infant relationships, collaborating with teams to influence hospital culture, and providing education, coaching, and support to staff. Honestly, it was like receiving a new pair of eyes.

Do I remember the first baby I fed in the NICU as a speech pathologist? No. But with my new NIDCAP lens, I vividly remember the first infant and family truly observed. I shall call her Emily.

Peering into the incubator, before, during, and after care, I saw things I had never noticed before. The subtle movements she made in response to light when the nurse lifted the incubator cover. The way her tiny hands reached into the air, searching for something stable during care. For the first time, I wasn't simply watching what was happening; I was beginning to understand what Emily was communicating. That experience also changed the way I interacted with the nurses and the families. Instead of immediately offering my assessment, I found myself asking questions:

"What did you notice about Emily during that time?"

"What do you think she was trying to tell us?"

Those conversations invited shared observation and reflection. Rather than positioning myself as the expert with the answers, as NIDCAP training encouraged, I became a partner in understanding the infant. This is how I learned to see the baby through a different lens.

Nearly 30 years later, although my role has changed from hospital clinician to the Director of Education at Dr. Brown's Medical, I still practice through the same NIDCAP lens. I may no longer spend every day in the NICU, but every educational program I help develop and every hospital team I support is influenced by what NIDCAP first taught me – to observe before acting, to understand before intervening and to see the infant and the family as active participants in every caregiving experience. NIDCAP is the foundation of the care we now provide, including feeding.



Mother parenting her baby

The Synactive Theory Is At the Core of Everything We Do

When I was introduced to the Infant-Driven Feeding® Program (IDF™) years later, it felt familiar. The principles that had reshaped the way I observed infants through NIDCAP were there again – watch the baby first, understand what the baby is communicating, and allow those observations to guide care. With every interaction, I learned to use the lens of the Synactive Theory subsystems to read everything about the baby, and those subsystems build on one another. A baby who doesn't yet have autonomic stability may not be able to show attentional/interactive capacity on their own. Later, the feeding interaction became another opportunity to apply the Synactive Theory in a practical, teachable way. How could I expect a baby to feed 'well' if they didn't have autonomic or motoric stability?

Shared Language With an Observational Tool That Requires Training

One of the greatest gifts NIDCAP gave our team was a shared language. The Naturalistic Observation Tool helped us learn to see the same behaviors, describe them consistently, and build care plans together. But the tool alone wasn't enough. It required educational mentorship and repeated practice before it became meaningful.

I often compare it to surgery. Give a surgeon an excellent instrument without training, and it is unlikely to be used well. Give the surgeon years of knowledge without the appropriate instruments, and the knowledge has nowhere to go. Meaningful practice requires both the right tools and the education to use them effectively.

NIDCAP paved the way for parent involvement in developmental care and programs such as the IDF™ Program.

"IDF™ didn't just help me learn how to feed my baby; it helped me learn how to parent my baby."

This comment, which a parent recently shared with me, immediately took me back to what I learned through NIDCAP decades earlier. The goal of family-centered, developmental care isn't solely to teach professionals to care differently. It's about shifting the whole orientation of care from task-oriented to relationship-centered, with families at the center as members of the care team rather than visitors. Whether through NIDCAP or IDF™, the goal is the same: helping families discover that they already know their baby. They simply need someone to help them learn their baby's unique language.

The International Effect of NIDCAP

As I visit hospitals around the world today, I continue to see the influence of NIDCAP. Developmental care has become a shared goal across countries and cultures, yet feeding practices remain remarkably inconsistent. Recent international studies demonstrate tremendous variations in how infants are assessed, when feeding begins, and how feeding decisions are made.[1,2] Hospitals are increasingly seeking structured approaches that preserve individualized care while ensuring consistency across caregivers. It is often through that search that they discover the Infant-Driven Feeding® Program.

Models for Change

Years ago, NIDCAP Trainers gretchen Lawhon and Jen Hofherr both handed me something far more valuable than another clinical skill. They handed me a new way of seeing.

I no longer spend my days standing beside the same incubators I once did, but every hospital I visit, every educator I teach, every family I meet, and every conversation about infant feeding is still viewed through the same NIDCAP lens.

Conclusion

The view outside my window has changed. However, the lens has never changed.

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Mission

The NFI improves the future for all infants in hospitals and their families with individualized, developmental, family-centered, research-based NIDCAP* care by providing and assuring the quality of NIDCAP education, training and certification for professionals and hospital systems. *(Adopted 31 June 2025)*

The Newborn Individualized Developmental Care and Assessment Program (NIDCAP) Model

- Infants are considered individuals, person, collaborators, in care, supported and nurtured by their parents enhancing their healthy overall development wellbeing and full potential.
- Families are considered infants key nurturers, advocates and primary caregivers as well as collaborators in care decisions.
- Infants, families and professionals are integral partners of the health care team.
- Hospital environment and culture supports and nurtures infant and family relationships, and promotes individualized strengths, health, growth, and development.
- The NFI provides the framework for NIDCAP care with educational resources, formal training and mentoring to healthcare professionals and families.

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Keeping Mothers and Newborns Together in Highly Specialized Care: Reflections From a Clinical Research Context

Joan Neergaard Larsen, PhD

Clinical Nursing Specialist and researcher at Copenhagen University Hospital - Rigshospitalet, Department of Neonatology. Danish NIDCAP Training and Development Center, Copenhagen, Denmark

Introduction

In newborn and obstetric care, much attention is rightly given to ensuring safe and effective treatment for both mothers and newborns. Over time, this has led to highly specialized services, often organized in separate departments with distinct clinical expertise. While this structure supports advanced care, it also creates a situation where mothers and newborns are frequently separated in the first hours or days after birth, particularly in case of clinical deterioration.

This manuscript reflects on that situation. Drawing on insights from my PhD thesis on mother–newborn couplet care in single-family rooms.[1] I explore how separation has become part of routine care, how alternative approaches are being considered, and the practical and professional challenges involved in keeping mothers and newborns together in more complex clinical settings.

The research program comprised four complementary studies, moving from experiences and professional perspectives to clinical evidence and national implementation (*Figure 1, page 9*). Together, the studies explore different aspects of mother–newborn couplet care and the conditions that may support its implementation in highly specialized care.

Rather than arguing for a single solution, the aim is to share reflections from working and researching in this field, where intentions to support families are strong but structural and clinical realities can make this difficult in practice.

Separation as Part of Routine Care

In many hospitals, the organization of postnatal care means that mothers and newborns follow different clinical pathways if either requires specialized treatment. A mother may remain in an obstetric ward recovering from surgery, while her newborn is admitted to a neonatal unit. This division is not unusual; it reflects the structure of healthcare systems and the distribution of professional expertise.[2]

From a clinical perspective, this arrangement often makes sense. It allows each patient to receive care from professionals with the appropriate skills and resources. However, from a family perspective, it can be challenging. The early postnatal period is a time when families begin to get to know each other, and physical closeness can play an important role in establishing breastfeeding, bonding, and parental confidence.

As described in the thesis, separation during this period may also be associated with emotional strain for parents, particularly when combined with medical uncertainty. At the same time, it is important to acknowledge that separation is rarely a deliberate choice; it is often the result of organizational structures and clinical priorities that are not easily changed.

The Idea of Keeping Mothers and Newborns Together

In recent years, there has been increasing interest in care models that aim to reduce or avoid separation between mothers and newborns. Concepts such as "zero separation" and mother–newborn couplet care reflect a shift toward viewing the mother and newborn as a connected unit rather than two separate patients.[3,4]

Early skin-to-skin contact is one of the most widely studied aspects of this approach and has been associated with improved physiological stability, breastfeeding outcomes, and early bonding.[5,6] In this sense, closeness is not only relational but also clinically relevant. Early skin-to-skin contact may therefore serve as a proxy for physical closeness.

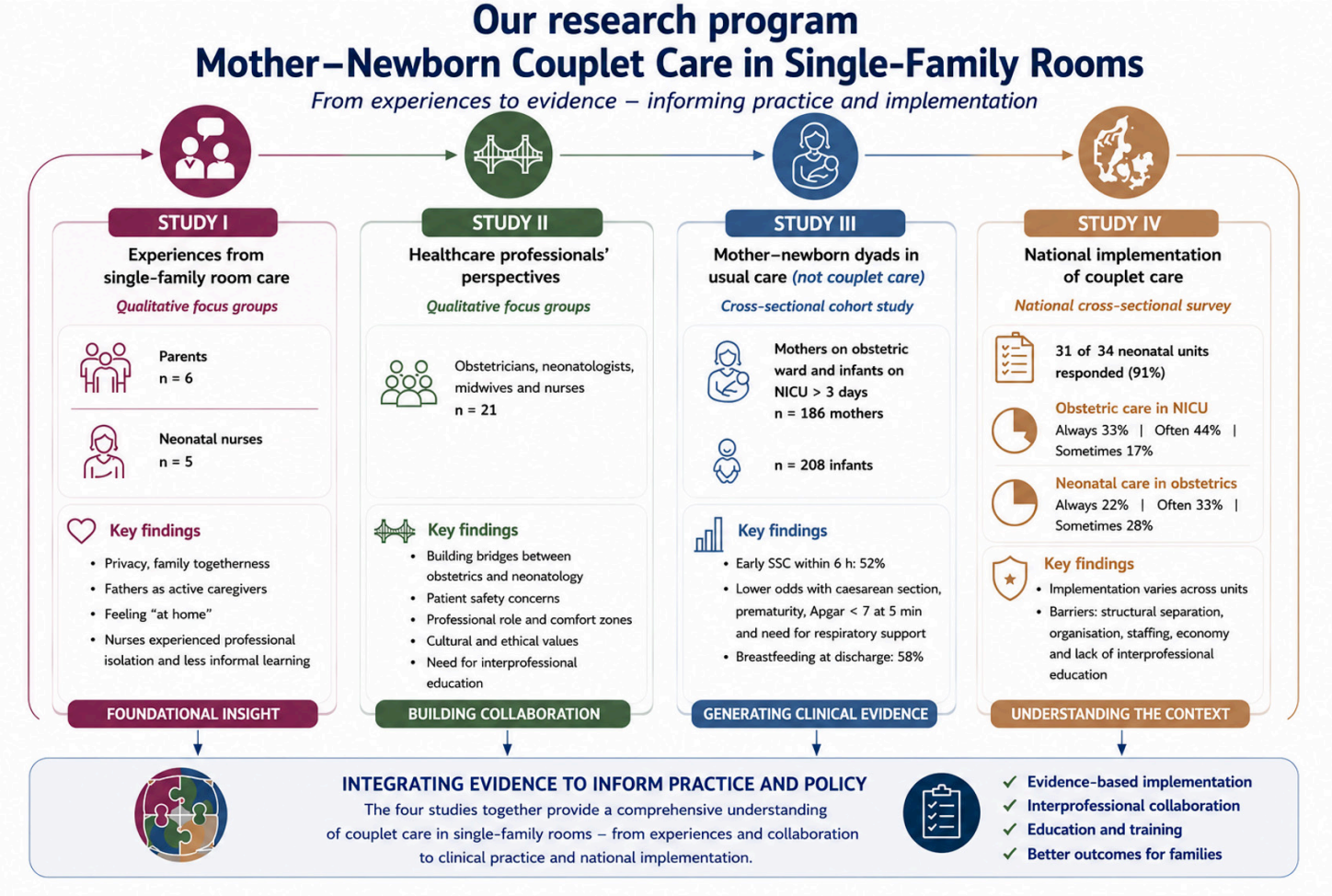
In principle, this approach is relatively straightforward: mothers and newborns remain together in the same room, even when one or both require treatment. In practice, however, it raises several questions. How can care be organized so that both patients receive appropriate monitoring and treatment? How should responsibilities be shared across professional groups? And how can this be done without compromising patient safety?

These questions are particularly relevant in highly specialized settings, where both mothers and newborns may have complex clinical needs. Much of the existing evidence on couplet care comes from less-intensive settings, and there is still limited knowledge about how such models function in more complex contexts.

Single-Family Rooms as a Possible Setting

One way to support closer contact between families is to use single-family rooms (SFRs). These rooms allow parents to stay with their newborn throughout the hospital stay and are increasingly used in newborn care.

Figure 1



In the qualitative part of the thesis, parents described these rooms as offering privacy and a sense of control over their environment.[7] They appreciated being able to spend time together as a family and to develop their roles as parents in a private room. Some also described how the setting made it easier to involve partners or co-parents more actively in care.

At the same time, healthcare professionals described a more mixed experience. While they valued the quieter environment, some also reported feeling more isolated and less able to maintain an overview of patients. Concerns were also raised about maintaining competencies in more decentralized settings.

These findings suggest that physical space can influence how care is experienced, but it does not, in itself, resolve the challenges of integrating care across disciplines.

Clinical Considerations

Clinical factors play a significant role in whether early contact between mothers and newborns is possible. In the thesis, a cross-sectional study examined associations between maternal and newborn conditions and early skin-to-skin contact within the first six hours after birth.[8]

The findings showed that early contact was less likely in cases involving cesarean section, preterm birth, low Apgar scores, or the need for respiratory support. These are common conditions in specialized settings and illustrate why separation can be difficult to avoid in practice.

At the same time, the study showed that fathers or co-parents often played an important role in providing early skin-to-skin contact when mothers were unable to do so immediately. This points to the potential for involving the wider family in supporting early contact, even when circumstances are not ideal.

Overall, these findings highlight that the question is not simply whether separation should be avoided, but how care can be adapted to support contact in different clinical situations.

Working Across Professional Boundaries

Another important aspect of couplet care is collaboration between obstetric and neonatal teams. In many hospitals, these specialities operate with separate staff, leadership structures, and routines.

Infant- and family-centered developmental care has long emphasized the importance of involving parents as active participants in care. Extending this approach to include both mother and newborn within the same care context adds another layer of complexity.

In the thesis, healthcare professionals described both opportunities and challenges related to closer collaboration.[9] On the one hand, working more closely together was seen as meaningful and potentially beneficial for patients. On the other hand, it also raised questions about roles, responsibilities, and professional identity.

Some participants expressed uncertainty about working outside their usual area of expertise, while others highlighted differences in clinical approaches and priorities. These findings suggest that implementing couplet care involves not only logistical changes, but also adjustments in how professionals understand their work and collaborate with others.

Organizational Conditions

Beyond individual experiences, organizational factors also play a key role. The national survey included in the thesis showed that elements of couplet care are already present in many Danish hospitals, but that practices vary widely depending on local conditions.[9]

Common challenges included physical departmental separation, differences in staffing levels, and a lack of shared training. In some cases, mothers could receive care in neonatal units, or newborns could receive care in obstetric wards, but this was often limited to specific situations.

These findings suggest that while the idea of keeping mothers and newborns together is widely supported, its implementation depends on a range of practical factors that are not always easy to address.

The Role of Education

Several participants in the studies emphasized the importance of education in supporting changes in practice.[10] This included both formal training and opportunities for informal learning across disciplines.

Interprofessional education was seen as particularly important for building understanding of each other's roles and for increasing confidence in managing situations that involve both maternal and newborn care. At the same time, education alone is unlikely to be sufficient. It needs to be supported by organizational structures that allow staff to apply what they have learned in practice.

A Gradual Approach

Given the complexity of the setting, a gradual approach to implementing couplet care may be more realistic than attempting large-scale changes all at once. In the thesis, a stepwise strategy is suggested, in which care models are first introduced for less complex cases and then expanded as experience grows.

This approach allows for adaptation over time and provides opportunities to identify and address challenges as they arise. It also acknowledges that not all situations will be suitable for keeping mothers and newborns together, and that flexibility is needed.

> **"Working with these questions has highlighted how strongly healthcare systems are shaped by structures that are often taken for granted.**

Reflections

Working with these questions has highlighted how strongly healthcare systems are shaped by structures that are often taken for granted. Separation between mothers and newborns is not necessarily questioned in everyday practice, even though many clinicians recognize its limitations.

At the same time, efforts to change this are not straightforward. They involve balancing different priorities, including patient safety, staff competencies, and family needs. In this context, it may be more helpful to think of couplet care not as a fixed model, but as an ongoing process of adaptation. NIDCAP-directed developmental care, grounded in Als' Synactive Theory of Development,[11] may offer a useful framework for this process by encouraging individualized care based on careful observation of each newborn's behavioral cues while recognizing parents as essential partners in care. This perspective complements the organizational ambitions of couplet care by reminding us that keeping mothers and newborns together is not only about reducing physical separation but also about adapting care to the unique needs of each newborn and family.

The findings from this research do not suggest that separation can or should always be avoided. Rather, they point to the importance of considering when and how to support closer contact, and what conditions are needed to make this possible.

Conclusion

The organization of postnatal care in highly specialized settings presents a challenge: how to provide advanced treatment while also supporting the relationship between mothers and newborns.

Mother-newborn couplet care offers one way of addressing this, but its implementation requires attention to clinical,

organizational, and professional factors. Single-family rooms, interprofessional collaboration, and targeted education may all play a role, but none is sufficient on its own.

A gradual and context-sensitive approach may be necessary, recognizing that change takes time and that solutions need to be adapted to local conditions.

Ultimately, the question is not only how to organize care, but how to balance different aspects of what is considered important in the early postnatal period. This remains an area where further research and practical experience are needed.

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NIDCAP Care in the Moment

Precious



In 2027, The *Developmental Observer* will celebrate 20 years since it started. We are looking for contributions from the members. We are interested in your thoughts, reflections, ideas and what you have liked about the *Developmental Observer* over the 20 years.

Send to Kaye Spence, Senior Editor at *kayenfi@gmail.com*.

From Presence to Practice: Integrating Skin-to-Skin (Kangaroo) Care and Peer Support Across Settings

Observations from NICU Visits and Global Parent Organization Engagement

Kylie Pussell OAM, *CEO and Co-founder of Miracle Babies Foundation (Australia)*
Yamile C. Jackson, *PhD, PE, PMP—founder of Kangaroo Care Day® and the engineer behind The Zaky® (USA)*

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The 2026 Global Foundation for the Care of Newborn Infants (GFCNI) Parent Organization Summit was held in Germany. More than 70 leaders representing parent organizations from 32 countries came together to learn, exchange experiences, and collaborate around a shared goal: improving care and outcomes for premature and sick babies and their families. Because traveling from Australia involved such a significant journey, I arranged additional visits to learn from and share with parent organizations across the global GFCNI network. Yamile Jackson joined me from the United States, and we began our Newborn Intensive Care Unit (NICU) trek in Munich, Germany before traveling to Prague, Czech Republic.

Our NICU Trek included meetings with parent organizations across five countries—the Czech Republic, Bulgaria, Hungary, France and the Netherlands—alongside visits to six NICUs: two in Munich, Germany, two in the Czech Republic, and one each in Sofia, Bulgaria and Budapest, Hungary.

During our NICU Trek, we were able to share both our passions: mine (Kylie) in peer support and Yamile's in Skin-to-Skin (Kangaroo) Care. We both have lived experience of newborn care and, now with adult children, can share our learning and the sometimes-lifelong impacts of having a premature baby. Peer support and Skin-to-Skin (Kangaroo) Care have critical roles in improving care and outcomes for babies receiving newborn care and their families.

Our aim across the countries we visited was to highlight a shared commitment to improving outcomes for babies and families through connection, safety, peer support and family-centered care—during the NICU stay and beyond.

What Was the Highlight of Our Trip?

Kylie – For me, it was the people. Connecting, learning and sharing are things I love to do. On this trip, I met so many dedicated people working with newborns and so many new parents overjoyed to be with their babies. The friendships and the time spent with international colleagues, now friends in their own countries, were very special.

Yamile – The highlight was the connection with Kylie, parent leaders, clinicians, and parents currently experiencing their NICU journeys, as well as the opportunity to connect with nature and experience new surroundings. Across parent organizations, we are united by lived experiences, by the trauma of the NICU, and by a shared promise that families who come after us will experience something better. Each of us brings personal and professional perspectives that equip us to advocate in different ways while working toward the same goal: that babies are held, protected, and supported, and that parents are recognized not as visitors, but as essential members of their baby's care team. The NICU journey does not end at discharge. Its impact continues—and often shapes the work we choose to do.



Kylie Pussel (center) and Yamile Jackson (second left) in the NICU in Sophia, Bulgaria

What Were the Key Takeaways From the NICU Visits?

Kylie – In Munich, Germany, the NICUs were located in large hospitals with spacious corridors, all designed to create a calm environment. The corridors were very quiet; it was not a bustling scene, as some hospitals can be. The units were well-equipped with state-of-the-art equipment and had adequate staffing, although few parents were present. The NICUs were very quiet.

In Prague, the Czech Republic, the NICUs were also very nicely designed. I really liked the images and family atmosphere, with a strong focus on beautiful images of premature and sick babies. I felt this brought a sense of normality to the unit for families. The doctors were very open and keen to do more to support parents and promote inclusion. There were some parents present, but fewer parents were at the cot side than I would have expected.

In Sofia, Bulgaria, the NICU was smaller and much busier. There were many families gathered outside the hospital, with photographers, flowers and balloons ready to celebrate babies'

births and discharges. This was very special to see, but also a reminder that families miss out on this celebration when their baby goes to the NICU, and the interval from birth to discharge can be many weeks or even months. There were not many staff members, and the nurses had many babies to care for. The mothers were happy to spend time with their babies, although more space and chairs would enable them to stay longer.

The maternity hospital with the NICU in Budapest, Hungary, was another large building with wide corridors. The unit was busy, with many parents and their babies. The doctors were very involved and interested in both the babies and their parents. There was a strong focus on Kangaroo Care and on keeping babies and parents together.

Yamile – Across all the NICUs, the consistency of commitment stood out. Every team was dedicated and doing everything possible within its environment.

These observations reflect systems—not individuals.

Three patterns emerged:

1. **Parent presence is not always fully enabled.** Access, space and comfort varied. In some settings, parents were present but not fully supported to remain at the bedside, and fathers were rarely seen, often reflecting structural barriers rather than a lack of desire. The intention to support families was evident in most NICUs we visited, though it was not always consistently reflected in practice. In Sofia, for example, parent participation was limited to very short, scheduled periods. Local parent leaders shared that, while progress has been made over time, important barriers remain—including physical layout constraints, limited space and resources, and variability in how parents are integrated into care. This does not reflect a lack of commitment—families, clinicians and parent organizations are working within the realities of their environment—but rather a combination of system design and longstanding practices that can unintentionally limit parent participation. When parents are recognized as part of the care team and supported with appropriate space, guidance and trust, they can participate more fully in their baby's care, including Skin-to-Skin (Kangaroo) Care.
2. **Skin-to-Skin (Kangaroo) care is valued but not consistently integrated.** Although the evidence supporting Skin-to-Skin (Kangaroo) Care is well established, its integration into routine practice remains variable across settings.
3. **Nursing workforce pressures are universal.** All NICUs identified staffing challenges that influence how care is delivered. Despite this, the care team's commitment to babies and families was evident in every setting.

How Could Practice Be Improved?

Some settings had very high baby-to-nurse ratios. Improving neonatal care requires sustained investment in nursing recruitment, education, retention, staffing, and working conditions. Nurses support families at the bedside and care for babies when parents cannot be present. Their role is essential not only to clinical outcomes, but also to parent confidence, participation, and mental health.

More encouragement is needed to help parents feel comfortable and included, so they can spend more time with their baby. This could include transport or accommodation support, space at the cot side, and facilities that make families feel welcome to stay for longer periods.

> **When parents are recognized as part of the care team and supported with appropriate space, guidance and trust, they can participate more fully in their baby's care, including Skin-to-Skin (Kangaroo) Care.**

Many improvements can be achieved through system design:

- Support parent presence through simple environmental changes.
- Integrate safe and trauma-informed Skin-to-Skin (Kangaroo) Care for both parents into routine practice.
- Create a shared, evidence-based understanding among clinicians, families, and parent organizations of the importance of family presence, infant behavioral cues, and Skin-to-Skin Care.

In response, Yamile is working with NICU parent organizations to expand the book *When Your Heart Touches Mine: The Power of Closeness*[1] into additional languages—building on its English and Spanish editions—to support a consistent, trauma-informed and evidence-based understanding of Skin-to-Skin (Kangaroo) Care for families and clinicians.

When understanding is aligned, implementation becomes more consistent. Frameworks such as the Synactive Theory, NIDCAP and family-centered care can guide individualized, developmentally supportive care and meaningful parent participation.[2–5]

What Impressed Us About the NICUs?

We were both equally impressed with the rooming-in arrangements at some hospitals. Wards dedicated to parents and babies, once high-level intensive care was no longer needed, enabled families to spend weeks together with medical support. The design and family atmosphere of some were very special.

All of the NICUs we visited highlighted how special the people who work in newborn care units are. Their dedication and passion for helping babies achieve the best possible clinical outcomes were clear. All countries face challenges and obstacles, and doing the best possible under the circumstances is sometimes very hard. However, this can also bring a unique perspective on finding magic in what is available. It is important to highlight how practice can evolve over time when parent organizations and clinical teams work together to support parent involvement.

> **"Newborn care continues to improve globally, and medical advances are progressing rapidly. We must ensure that parent inclusion and parent mental health remain essential parts of that progress.**

What Does This Mean for the Future of Newborn Care Globally?

Newborn care continues to improve globally, and medical advances are progressing rapidly. We must ensure that parent inclusion and parent mental health remain essential parts of that progress. As the way we support and equip families to care for their babies evolves, we must continue working together to improve outcomes for babies and families.

Conclusion

The evidence and our lived and professional experience have convinced us that connection is not a luxury—it is essential. Parents are not visitors; they are fundamental to their baby's regulation, development, and long-term well-being.

Parent Organizations are essential partners in newborn care. Their lived experience, expertise, peer support, trust, advocacy, and continuity complement clinical care in ways healthcare professionals alone cannot replicate. They should therefore be supported, resourced, and formally integrated into neonatal systems as partners—not treated as optional services or kept at the margins of care.

The intention to support families was evident in the NICUs we visited. Yet separation can be physiologically and emotionally stressful for both babies and parents.

The gap is not willingness; it is consistency. Systems must reliably enable family presence, participation, connection, and access to peer support—not as optional additions, but as essential components of newborn care.

The evidence is clear. The commitment is present. The opportunity is to make connection and support consistent—for every baby, every family, every day.

Perhaps we should no longer ask only: *"How many hours of Skin-to-Skin (Kangaroo) care did this baby receive today?"*

We must also ask: *"How many hours did this baby spend separated from their family, without access to the regulatory, emotional, and relational support their family could provide—and what did the system do to prevent or reduce that separation?"*

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Declaration of Interests

Yamile C. Jackson is the founder and owner of Nurtured by Design, Inc., which develops The Zaky® products and provides consulting, education and implementation support related to Kangaroo Care and neonatal care. She is also the founder of International Kangaroo Care Awareness Day (May 15), observed annually. No commercial product was evaluated in this article. Kylie Pussell is the CEO and Co-founder of Miracle Babies Foundation, Australia. The authors declare no other relevant competing interests.

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AN ETHICS LENS

Ethical Reflections on Pain and Suffering in the NICU

Michael van Manen MD

Department of Pediatrics, John Dossetor Health Ethics Centre, University of Alberta, Edmonton, Alberta, Canada.

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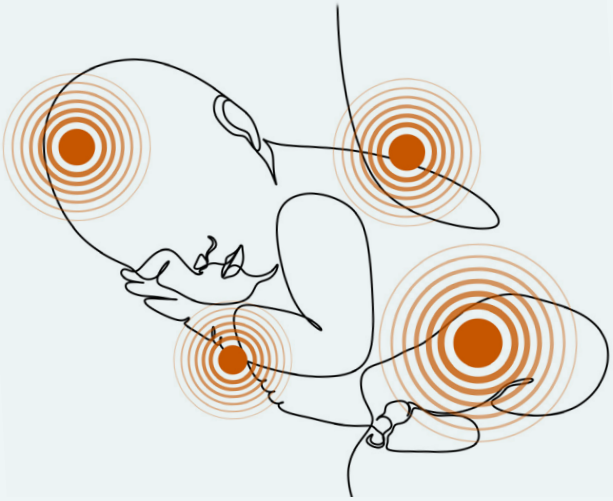
Is she in pain?
—It's difficult to say.
Do you think he is suffering?
—We are doing everything we can.

Pain and suffering: perhaps there are no two words with less ethical weight for newborn intensive care. Readers of the *Developmental Observer* know that infants in the Newborn Intensive Care Unit (NICU) are not infrequently subjected to procedures like blood draws and line insertions in addition to events such as being ventilated on high distending pressures, having enteral feeds held in anticipation of elective procedures, or being placed in an incubator, at times, without a proper nest or other physical support. We all agree that newborns have the right to analgesia and other measures aimed at pain relief; and hopefully, as well, that infants should not endure suffering. But what are the meanings of pain and suffering? At what point does pain become suffering? Can a newborn suffer without pain?

Trying to Get a Hold of the Meaning of Pain and Suffering

Let us begin by considering the etymology of pain and suffering to understand what language itself can tell us. The word "pain" comes from Middle English and Old French, ultimately tracing back to Latin *poena* (penalty, punishment) and Greek *poine* (payment, penalty), connecting the experience of pain to the concepts of paying for something or facing a punishment.[1] In comparison, the word "suffer" comes from Latin *sufferer* (to bear or to endure), relating the idea of suffering to the act of being weighed down by something unpleasant.[1] While there is semantic overlap between these words, it may be said that there is an exactitude to pain, while suffering refers to something more expansive.

Turning to the literature, we may appreciate that aspects of pain and suffering transcend the body. For example, Cicely Saunders' notion of "total pain" includes physical, emotional, social, and spiritual aspects of distress,[2] and William Fordyce's description of pain as "transdermal" points to causes of pain within and beyond the boundaries of the body.[3] In comparison, the International Association of the Study of Pain (IASP) defines pain as: "An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual



or potential tissue damage".[4] And expands on this definition with six key notes:

- Pain is always a personal experience that is influenced to varying degrees by biological, psychological, and social factors.
- Pain and nociception are different phenomena. Pain cannot be inferred solely from activity in sensory neurons.
- Through their life experiences, individuals learn the concept of pain.
- A person's report of an experience as pain should be respected.
- Although pain usually serves an adaptive role, it may have adverse effects on function and social and psychological well-being.
- Verbal description is only one of several behaviors to express pain; inability to communicate does not negate the possibility that a human or a nonhuman animal experiences pain.[4]

In comparison, Eric Cassell's historic article "The Nature of Suffering and the Goals of Medicine" is credited as forefronting a holistic understanding of suffering:

> Suffering is experienced by persons, not merely by bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychological entity. Suffering can include physical pain but is by no means limited to it. The relief of suffering and the cure of disease must be seen as twin obligations of a medical profession that is truly dedicated to the care of the sick.[5]

Suffering here is related to pain, and yet distinct in its origins and remedies: "Suffering can be relieved, in the presence of continued pain, by making the source of the pain known, changing its meaning, and demonstrating that it can be controlled and that an end is in sight".[5] Following, it would seem that we think of pain as a medical problem and suffering as an existential consequence that may involve untreated pain.[6]

> "The challenge for the NICU is if we regard suffering as needing a certain cognitive capacity to be manifested or contained, we are stuck in a dichotomy: infants do not suffer as the result of pain or all pain for them is suffering.

The challenge for the NICU is if we regard suffering as needing a certain cognitive capacity to be manifested or contained, we are stuck in a dichotomy: infants do not suffer as the result of pain or all pain for them is suffering. Here, there is a risk of devaluing the experiences of newborns, even if we recognize them as having social and psychological dimensions to their lives.[7,8] Neonatology certainly has a history of neglecting pain and suffering, whereby infants were viewed as too underdeveloped to have such experiences, or their bodies were viewed mechanically so these experiences were not seen, or quite simply their subjective experiences were viewed as secondary to other aims.[9,10,11] In comparison, there is a large volume of physiologic and behavioral research which supports the assertion that even the most premature of infants have nociceptive systems involved in pain and suffering experiences.[12,13,14] We also recognize that pain, as well as the medications used to address it, may have measurable (potentially adverse) effects on newborns in the short and longer term.[15,16] This raises ethical concerns related to proportionality: the harms and benefits of treating or not treating pain. Still, our developmental knowledge of those born premature, those with congenital differences, and those with critical illness is truly in its infancy. It would seem that we are in an aporia: We should assume newborns have pain and suffering experiences in the NICU, and yet, there is an equivocality to the subjective nature of these experiences. We may consider: What comes from languaging newborns' experiences, that is, giving their experiences words? From choosing to use words like pain and suffering when we incompletely understand their experiential life?

The Ethical Necessity of Naming Pain and Suffering

Some 20 years ago, when I was a pediatric resident, I recall my NICU attending telling me that we do not need to worry about anesthesia when performing lumbar punctures on infants. If I recall his argument correctly, he said that because the spinal cord of newborns is not fully myelinated what we observe as far as a behavioral response is only reflexive in nature. Now, I appreciate that even back then there was evidence that newborns may benefit from analgesia for this procedure, yet providing analgesia was not routine practice.[17] What also speaks to this matter is that research regarding analgesia for lumbar puncture was generally not oriented to what newborns may endure, but instead whether analgesia would increase the likelihood of healthcare providers being successful in performing the procedure.[18] So, perhaps, we should not be self-congratulatory that research which ultimately led to more widespread use of analgesia for newborns was centered on newborns' subjective experiences. I write this not to devalue this research nor using basic science and empirical knowledge as a basis for clinical judgement; but instead, to point out how we may pass over the experiential lives of newborns when we cease considering its existence.

Still, we can only wonder, consider, or speculate what conscious perception entails for newborns when they undergo a lumbar puncture or another procedure (i.e., there is a schism between nociception and perception knowledge). This does not invalue attempts to bring the experiential life of newborns to words but instead intensifies them. Language does not simply lift meaning to our awareness; it also lifts a world into presence as a hermeneutic event: to reflect on or otherwise think through it.[19] Said differently, words such as pain and suffering afford reflecting on what infants endure in the NICU. In comparison, at times, our words may obfuscate newborn's experiential life through objectification. For example, for the infant started on midazolam who becomes more agitated, restless, cries, or displays other such behaviors, we may use the label of "paradoxical reaction." In comparison, we may name the jitteriness, shuttering, or other signs of stress that may evolve to physiologic instability in a preterm infant as "disorganized behavior." The point is that some of our language, paradoxical reaction and disorganized behavior as examples, risks passing over the sensuality of a newborn's possible experiences. Such words lack experiential weight compared to words like pain and suffering, or other words like fear, distress, and trauma.

So, by naming pain and suffering, we may orient to the possible experiential life of a newborn. Here, we may recognize that the language we use to talk about newborns is not a unified, closed, or static system, but instead exists in a "sharing of voices" responding to the "sharing of hermeneutic instances" in which there is no cogent interpretation.[20] Said differently,

although individual nurses, physicians, and others may see different things when it comes to interpreting a newborn as experiencing pain or suffering, using the words of pain and suffering affords ethical dialogue oriented to our intersubjective sense of what these phenomena may involve. In comparison, although we may achieve some measure of consistency by utilizing observational behavioral scales, the scales themselves rate behavior rather than perception.[21]

We should recognize that care programs, such as NIDCAP, which focus on infants' behavioral cues have promise to address pain and/or suffering. For example, there have been studies exploring the positive impact of the provision of NIDCAP on infant's tolerance of retinopathy of prematurity eye examinations.[22,23] Studies such as these sidestep our inability to precisely grasp the subjective experiences of newborns to focus on objective measures such as heart rate, oxygenation saturation, facial expression, and so forth. So, NIDCAP should be recognized in its utility to respond to behavioral cues which are read as communicative of infants' well-being.[24] Interpretation here is not a disengaged reading of the behavior of a newborn; rather, we as a community are ethically present, sharing in situations, being-together, where interpretation signals a directedness, exposedness, openness to an existence outside ourselves.

Recognizing the intersubjective nature of these experiences, we may say that raising the possibility of pain and suffering is only possible if medical care is not simply given procedurally, mechanistically, or otherwise distanced from a concern for the possible experiential meaning of the experiences we point to by terms like pain or suffering. And we should also recognize how using such words generally requires an empathic understanding and a qualitative questioning: a "focused human attention and sincere commitment to the infant's comfort".[25] For an ethics of NICU, we believe that children have something akin to these experiences, even if such a belief is in some sense cast from faith. To language their experiences constatively does not mean reducing their subjectivity to adult terms or making them little adults. Rather, it means wondering about their being in the world with words.

Concluding Thoughts

We gain little and risk much by questioning whether newborns experience pain, recognizing that the word pain labels a manifold of subjective uncomfortable, difficult, unpleasant (painful) experiences. In comparison, suffering is conceptually challenging if we insist on suffering requiring a certain developmental capacity to contort the meaning of pain into a specific psychological entity that we label as suffering. My worry is if we reduce all pain to suffering, we risk not recognizing certain experiences as hard on a child. Nor should we indulge in hermeneutic arrogance and say that newborns cannot suffer because their developmental capabilities differ from our own.

We perhaps should wonder what questions are most helpful to ask when it comes to considering an infant as experiencing pain or suffering. Instead of inquiring abstractly or conceptually into an infant's capacity for pain and suffering, perhaps we should focus in a caring way to constatively ask what newborns live through. NIDCAP is a possible paradigm for orienting to an infant's world recognizing that behavior is read as an interpretation of experience. Even if we cannot fully answer questions of the experiential life of a newborn, we must act in a way that shows we are sensitive to different possible answers. What does it say about us when we go to examine a baby who has just managed to fall asleep? What does this say about how we regard their world and our place in it? What emotions are we comfortable naming for a newborn? Is it simply pleasure or pain? Is pain truly the opposite of pleasure? If we are prepared to describe them as suffering, does this too have a converse? We should consider which experiences we are potentially supporting newborns in having. We also should contemplate how languages describe newborns as in pain or suffering, and for what sake they speak these words.

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POETS CORNER

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They Unravel (or "Just a Tube Feed")

Julia Giesen

As time goes on
The more we see
The harder it is
To simply be

To walk away
While the tube feeds run
While in their beds
Like a setting sun

… They unravel

First they squirm
Blink their eyes
Stick out their tongues
Let out some cries

Their breathing slows
With longer pauses
Then speeds up again
From unseen causes

Their faces red
Like the break of dawn
They let out a cough
Then a great big yawn

They grimace
They sneeze
Their lips bubble
Then wheeze

They sink in their beds
As the world slips away
And across the room
Our minds might stray

Away from them
Lying in their cots
Out of sight
Out of our thoughts

But when we stay
See their story begin
The veil lifts from our eyes
And the truth seeps in

… They unravel

A reflection on Candice C's FINE 2 assignment

May 28, 2026

Expressions of interest are called for interested members to join the Editorial Board in 2027.

We are seeking enthusiastic members to contribute to the future direction of the Developmental Observer. You will be required to attend ZOOM meetings three times a year, contribute to the content and provide feedback on each issue. In addition you will be asked to contribute to the reviewing of manuscripts to determine appropriate content.

Please send your expressions of interest and your bio to:

Kaye Spence, Senior Editor.
kayenfi@gmail.com
by December 1st 2026.



Celebrating 25 Years of the NFI

Honoring the Past, Shaping the Future

Listening and Supporting Infants, Families and Professionals
Transforming Care Worldwide

13, 14, 15* October 2026

0800 - 1600 EDT

Online Meeting

Hosted by NIDCAP Federation International

(Full meeting attendance is by invitation only)

***October 15, One Day Conference Open to All**

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Recent 2026 research on developmental care and the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) emphasizes family-integrated models, reduced infant length of stay, and improved neurobehavioral stability, though structural barriers like nurse workloads remain challenging.[1,2,3,4]

Clinical and Developmental Outcomes

- Reduced Morbidity: Studies highlight shorter durations on ventilators, faster weight gain, and decreased overall hospital length of stay for high-risk preterm infants.[1]
- Physiological Stability: Environmental modifications—such as keeping sound levels below 45 decibels, reduced lighting, and proper postural swaddling/nesting—improve infant sleep quality and cardiorespiratory stability.[1,2,3]
- Neurofunctional Progress: Routine neurobehavioral assessments show improved self-regulation and better early motor, visual, and auditory milestones.[1,2]

Family Integration and Parental Well-Being

- Kangaroo Mother Care & Co-Regulation: Research underscores the biological and psychological benefits of continuous skin-to-skin contact, promoting maternal attachment and cerebral perfusion in the newborn.[1,2]
- Parental Empowerment: NIDCAP training actively decreases maternal anxiety and boosts confidence in handling and feeding premature infants, lowering readmission risks post-discharge.[1,2]

Implementation and System Challenges

- Multidisciplinary Training: Effective NIDCAP adoption requires system-wide staff training to interpret infant behavioral cues accurately and adapt care plans.[1]
- Barriers to Scale: Recent evaluations point to persistent hurdles in routine NICU settings, including nursing shortages, high workloads, financial limitations, and lack of standardized department guidelines.[1]

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Samantha Butler
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Celebrating NIDCAP on the Web in 2026

In **2026**, the web reflects major milestones, global expansions, and active scientific discussions surrounding **NIDCAP** (Newborn Individualized Developmental Care and Assessment Program).

1. 25th Anniversary of the NFI

The **NIDCAP Federation International (NFI)** is officially celebrating its **25th Anniversary (2001–2026)**. The organization is using this milestone year to honor its legacy, celebrate its community of 31 global training centers, and push forward new initiatives for individualized, family-centered neonatal care.

2. Major Events and Conferences

- **37th Annual NIDCAP Trainers Meeting:** The NFI will host its annual meeting culminating in an **Open One-Day Online Conference on October 15, 2026**. The event focuses on "Honoring the Past, Shaping the Future" and is open to clinicians, researchers, and family advocates worldwide.
- **JNN 2026 (Paris):** NIDCAP took a prominent spot at the 55th National Neonatology Conference (*Journées Nationales de Néonatologie*) in Paris in March 2026. A dedicated session highlighted newborn behavior and individualized developmental care, led by prominent European NIDCAP trainers, Sandra Lescure and Delphene Durant.
- **The 12th Council of International Neonatal Nurses (COINN) Conference 2026 (Darwin, Australia):** NIDCAP Intersection, the conference features prominent speakers championing family-centered neurodevelopmental care. Among them is Nadine Griffiths, a Senior NIDCAP Trainer and lecturer, presenting on how developmental care is shaping the future of neonatal nursing practices.

3. Global Expansion & Awareness

- **World NIDCAP Month (March 2026):** Celebrated under the theme *"NIDCAP Care Around the World,"* March 20, 2026, marked World NIDCAP Day. The campaign focused heavily on teaching, encouraging, and supporting parents as essential pillars of the NICU care team.



- **New Training Center Updates:** Digital updates highlight newly implemented care standards, including the newly updated **NICU facilities at the CHU St Pierre / Brussels NIDCAP Training Center** in Belgium.

4. Scientific and Research Discussions

The medical community continues to place heavy weight on the clinical outcomes of NIDCAP. While foundational NIDCAP resources emphasize its proven benefits on early brain structure, shortened hospital stays, and parent-infant bonding, peer-reviewed literature in 2026—including a recent systematic review and meta-analysis of randomized controlled trials—continues to spark debate by pointing out a lack of definitive evidence regarding long-term, multi-year neurodevelopmental fixes. Despite this, the clinical focus on sensory management (sound levels under 45 decibels, maternal scent, and controlled movement) remains a core theme in modern NICU design.

NIDCAP TRAINING CENTERS

AMERICAS

North America

CANADA

Edmonton NIDCAP Training Centre
Stollery Children's Hospital
Royal Alexandra Site
Edmonton, AB, Canada
Co-Directors: Andrea Nykipilo, RN and Juzer Tyebkhan, MB
Contact: Juzer Tyebkhan, MB
email: *Juzer.Tyebkhan@ahs.ca*

UNITED STATES

St. Joseph's Hospital NIDCAP Training Center
St. Joseph's Hospital and Medical Center Phoenix, Arizona, USA
Director and Contact:
Bonnie Moyer, MS, PT
email: *bmoyer12@gmail.com*

West Coast NIDCAP and APIB Training Center
University of California San Francisco San Francisco, California, USA
Director and Contact:
Deborah Buehler, PhD
email: *dmb@dmbuehler.com*

Children's Hospital of University of Illinois (CHUI) NIDCAP and APIB Training Center
University of Illinois Medical Center at Chicago
Chicago, Illinois, USA
Director and Contact:
Jean Powlesland, RNC, MS
email: *nidcapchicago@gmail.com*

National NIDCAP Training Center
Boston Children's Hospital
Boston, Massachusetts, USA
Director: Samantha Butler, PhD
Contact: Sandra M. Kosta, BA
email: *nidcap@childrens.harvard.edu*

NIDCAP Cincinnati
Cincinnati Children's Hospital Medical Center
Cincinnati, Ohio, USA
Director: Michelle Shinkle, MSN, RN

South America

ARGENTINA

Centro Latinoamericano NIDCAP & APIB
Fernández Hospital
Fundación Dr. Miguel Margulies and Fundación Alumbrar, Buenos Aires, Argentina
Director and Contact: Graciela Basso, MD, PhD
email: *basso.grace@gmail.com*

OCEANIA

AUSTRALIA

Australasian NIDCAP Training Centre
The Sydney Children's Hospitals Network Westmead, Australia
Co-Directors: Nadine Griffiths, MN and Hannah Dalrymple, MBBS
Contact: Nadine Griffiths, NIDCAP trainer
email: *SCHN-NIDCAPAustralia@health.nsw.gov.au*

EUROPE

AUSTRIA

Amadea NIDCAP Training Center Salzburg
University Clinic of the Paracelsus Medical University, Salzburg, Austria
Director: Elke Gruber, DGKS
Co-Director: Erna Hattinger-Jürgenssen, MD
Contact: Elke Gruber, DGKS
email: *elke.gruber@salk.at*

BELGIUM

NIDCAP Training Center Ghent, Belgium
University Hospital Ghent, Belgium
Director: Prof Dr Sophie Vanhaesebrouck, PhD, NIDCAP professional
Nursing Director and Contact: Margo Rogge, NIDCAP professional
email: *margo.rogge@uzgent.be*

The Brussels NIDCAP Training Center
Saint-Pierre University Hospital
Free University of Brussels Brussels, Belgium
Director: Inge Van Herreweghe, MD
Co-Director: Marie Tackoen, MD
Contact: Delphine Druart, RN
email: *delphine_druart@stpierre-bru.be*

UZ Leuven NIDCAP Training Center
Leuven, Belgium
Director: Anne Debeer, MD, PhD
Co-Director: Chris Vanhole, MD, PhD
Contact: An Carmen
email: *nidcaptrainingcenter@uzleuven.be*

DENMARK

Danish NIDCAP Training and Development Center
Aarhus University Hospital, Aarhus N, Denmark
Director: Tine Brink Henriksen Professor, MD, PhD
Co-Director: Tenna Gladbo Salmonsen, RN, MScN
Contact: Eva Jørgensen, RN
email: *Nidcaptrainer@gmail.com*

Danish NIDCAP Training and Development Center, Copenhagen
Copenhagen University Hospital, Rigshospitalet
Copenhagen, Denmark
Director: Jannie Haaber, RN
Co-Director: Porntiva Poorisrisak, MD, PhD
Contact: Jannie Haaber, RN, NIDCAP Trainer
email: *nidcap.rigshospitalet@regionh.dk*

FRANCE

French NIDCAP Center, Brest
Medical School, Université de Bretagne Occidentale and University Hospital, Brest, France
Director: Jean-Michel Roué, MD, PhD
Contact: Sylvie Minguy
email: *sylvie.bleunven@chu-brest.fr*

French NIDCAP Center, Toulouse
Hôpital des Enfant Toulouse, France
Director and Contact: Sandra Lescure, MD
email: *lescure.s@chu-toulouse.fr*

Saint-Brieuc NIDCAP Training Center
Saint-Brieuc – Paimpol – Tréguier Hospital Center
Saint-Brieuc, France
Director: Marie-Cécile Andro-Garcon, MD
Contact: Aurélie Guillou, RN
email: *aurelie.guillou@armorsante.bzh*

DCAP Training Centre Hospitalier de Valenciennes

Valenciennes, France
Director: Sabine Rethore, MD
Co-Director: Juliette Barois, MD
Contact: Peggy Laurant, RN
email: *p.laurant@orehane.fr*

GERMANY

NIDCAP Germany, Training Center Tübingen

Universitätsklinik für Kinder- und Jugendmedizin
Tübingen, Germany
Director: Christian Poets, MD, PhD
Contact: Birgit Holzhüter, MD
email: *birgit.holzhueter@med.uni-tuebingen.de*

ITALY

Italian Modena NIDCAP Training Center

Modena University Hospital, Modena, Italy
Director: Alberto Berardi, MD
Contact: Natascia Bertoncelli, PT
email: *natascia.bertoncelli@gmail.com*

Rimini NIDCAP Training Center

AUSL Romagna, Infermi Hospital, Rimini, Italy
Director and Contact: Gina Ancora, MD, PhD
Co-Director: Natascia Simeone, RN
email: *gina.ancora@auslromagna.it*

THE NETHERLANDS

Sophia NIDCAP and APIB Training Center

Erasmus MC-Sophia Children's Hospital
Rotterdam, The Netherlands
Director: Nikk Conneman, MD
Co-Director and Contact: Monique Oude Reimer, RN
email: *nidcap@erasmusmc.nl*

NORWAY

NIDCAP Norway, Ålesund Training Center

Ålesund Hospital, Ålesund, Norway
Director and Contact: Unni Tomren, RN
email: *nidcap@helse-mr.no*

PORTUGAL

São João NIDCAP Training Center

Pediatric Hospital at São João Hospital
Porto, Portugal
Director: Hercília Guimarães, MD, PhD
Co-Director and Contact: Fátima Clemente, MD
email: *nidcapportugal@gmail.com*

SPAIN

Barcelona NIDCAP Training Center: Vall d'Hebron and Dr Josep Trueta Hospitals

Hospital Universitari Vall d'Hebron, Barcelona, Spain
Director and Contact: Josep Perapoch, MD, PhD
email: *jperapoch.girona.ics@gencat.cat*

Hospital Universitario 12 de Octubre NIDCAP Training Center

Hospital Universitario 12 de Octubre, Madrid, Spain
Director: Carmen Martinez de Pancorbo, MD
Contact: María López Maestro, MD
email: *nidcap.hdoc@salud.madrid.org*

Sant Joan de Déu Barcelona NIDCAP Training Center

Sant Joan de Déu Hospital Barcelona, Spain
Director and Contact: *Ana Riverola, MD*
email: *ariverola@hsjdbcn.org*

SWEDEN

Karolinska NIDCAP Training and Research Center

Astrid Lindgren Children's Hospital at Karolinska University Hospital
Stockholm, Sweden
Director: Agnes Linnér, MD, PhD
Co-Director: Siri Lilliesköld, RN, MS
Contact: Ann-Sofie Ingman, RN, BSN
email: *nidcap.karolinska@sll.se*

Lund-Malmö NIDCAP Training and Research Center

Skane University Hospital
Malmö, Sweden
Director: Elisabeth Olhager, MD
Contact: Pernilla Stenman, RN
email: *nidcap.sus@skane.se*

UNITED KINGDOM

UK NIDCAP Centre

Department of Neonatology, University College Hospital, London, UK
Director: Giles Kendall, MBBS, FRCPCH, PhD
Contact: Beverley Hicks, OT
email: *beverleyann.hicks@nhs.net*

MIDDLE EAST

ISRAEL

Israel NIDCAP Training Center

Meir Medical Center
Kfar Saba, Israel
Co-Directors: Ita Litmanovitz, MD and Dalia Silberstein, RN, PhD
Contact: Dalia Silberstein, RN, PhD
email: *daliasil1960@gmail.com*

ASIA

JAPAN

Japan National NIDCAP Training Center

Seirei Christopher University, Shizuoka, Japan
Director: Tomohisa Fujimoto, PT
Co-Directors: Kanako Uchiumi, RN, MW, Noriko Moriguchi, MSN, RN, PHN, IBCLC and Yoko Otake, RN
Contact: Tomohisa Fujimoto, PT
email: *fusan.mail@gmail.com*



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