



FROM THE SCIENCE DESK

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The Ripening of NIDCAP and the Emergence of Coaction

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The Newborn Individualized Developmental Care and Assessment Program (NIDCAP) is often acknowledged as “the gold standard” for all systems of developmental care in newborn intensive care units (NICUs). Without question, NIDCAP is the most comprehensive, in-depth, structured, integrative and detailed system in the world of NICU care. NIDCAP standards of care and the certification of practitioners are overseen by the NIDCAP Federation International (NFI). The NFI can boast about 2,000 certified professional practitioners. NIDCAP Training Centers, now 31 of them, have spread across North America, South

America, Europe, Scandinavia, the Middle East, Japan, and Australia. In addition, eight certified NIDCAP Nurseries – hospital units that represent physically and administrative-ly the high standards and processes of this brand of family-centered care to support prematurely born infants.

The NIDCAP statistics (cited above) are impressive and they are sobering. NIDCAP is known and recognized worldwide. It has dedicated practitioners and grateful families, some of whom have become public and political advocates for this system of care. Yes, NIDCAP has grown and spread, but it remains miniscule in relation to the scale

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“The families I have worked with, taught me my most important lessons.”

—gretchen Lawhon

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of need – with some 12 million premature births around the world each year!

There are numerous analyses, past and present, aimed at understanding and overcoming the barriers and inertial forces that impede NIDCAP and other developmental care systems from playing more prominent roles in NICUs. Often targeted are barriers related to staffing, including training, expertise, professional hierarchies, parental absence or resistance, financial limitations, medical biases, systemic resistance, and lack of scientific understanding.

The story to be briefly told here is about identifying ways in which science can help guide and support the adoption of developmental care in NICUs and beyond.

NIDCAP and Science

NIDCAP has a rich, historic relationship with science. The NFI website provides summaries of NIDCAP history. We can jump from the early years to milestones around 1980, when Dr. Heidelise Als described her “synactive theory” and also published an application of the theory as the basis of systematically assessing the developmental status of prematurely born infants.¹ Drawing from the brain and behavioral sciences of that era she applied many of the important ideas and tools of those days. NIDCAP itself was “born” in the 1980-1982 time-frame, depending on how we measure its gestation and birth.

“NIDCAP has spread across diverse cultures and healthcare systems.”

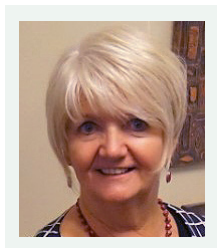
Here I posit that when NIDCAP began it was “ahead of its time” with respect to science. It emphasized the infant’s relation to the NICU environment. It incorporated sensory and physiological systems and recognized how stress reactions modulated basic functions and interacted with states of arousal and attention. Homeostatic regulations, including self-regulation were seen as vital functions and as markers of development. Early on, brain development was identified as a key variable relevant to prematurely born babies and became a process to protect and to measure as an indicator of developmental success. NIDCAP addressed its core ideas with research studies that measured success with standard medical markers, and neurobehavioral scales. And NIDCAP focused attention on parenting and parent-infant exchanges.

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Editorial

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Leading the Charge: NFI’s Path to Excellence



From its earliest beginnings to its emergence as a global organisation, the NFI has forged a path to excellence through visionary leadership, strong family partnerships, and continual strategic evolution. In this issue, Jeff Alberts reflects on NIDCAP, science, and the remarkable maturation of NIDCAP into a truly global movement. The growth of the NFI is reflected not only in its history, but also in the individuals who shaped the organisation and those now carrying its vision forward.

We celebrate the contributions of gretchen Lawhon, an early founder and enduring force behind NIDCAP, whose leadership continues to inspire new generations. Today, members such as Nadine Griffiths, the new Director of the Learning Center, alongside Susanna Pissarra from Portugal and Beverley Hicks from England, are advancing this important work across international settings.

As developmental care expands globally, Carole Kenner and Carol Jaeger highlight its reach into Africa through a

Community of Neonatal Nursing Practice, demonstrating how developmental care principles can strengthen outcomes within local communities.

At the heart of the NFI remain families and their stories. Laetitia van der Elst, a mother from Belgium, shares her traumatic experience, reminding us that listening deeply to families is essential. The NFI continues to be built on trust, compassion, and meaningful relationships between families and professional caregivers.

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The Evolution of NIDCAP

Like a living body, as NIDCAP grew, it differentiated, undergoing changes in form and functions, but it has maintained its core structures. NIDCAP has spread across diverse cultures and healthcare systems. It is now expressed in multiple languages. It has “ripened” and has acquired some new flavors. We see actions and perceptions linking infant and caregiver. We see touch mutually nurturing baby and mother. When one touches, one touches oneself. We see interdependence beyond mere interactions. There is interdependence among the systems that, together, create homeostasis. There is interdependence between mother and baby and among baby and its family. These are all examples of *coaction*.

Such coactions are the emergent information that guides subsequent development. From such arrays of interdependence emerges information that enables a baby to develop within the environment of a mother’s body, in the same way that the family develops itself through its many interdependencies. I think these are examples of a ripened NIDCAP view. It’s not just a particular act performed at a specific rate

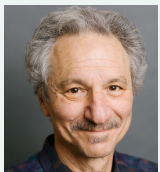
or manner that’s important. Acts by themselves are entities. What’s important are acts that are elicited by the action of one and that elicit a response from the other, which in turn is an act that elicits a responsive act, and so on, each is dependent on the other. From such interdependent acts created by their contexts emerges *coaction*.

Interestingly, in the same timeframe that NIDCAP evolved, science changed. Scott F. Gilbert, a prominent embryologist and brilliant synthesizer, characterized a “radical discontinuity” from what he calls the ‘old’ 20th Century Biology with the science that he labels “21st Century Biology”.² Twentieth Century Biology is a biology of “entities and objects”, which are considered as *the* level of explanation. A prime example is the assertion that genes make a body. This fable persisted for decades, relying on metaphors of genes as “programs” of information, or on the idea that there are genes that are “for” intelligence, strength, or generosity.

The biology of “objects and entities” has given way into a science of *relations and process*. Professor Gilbert deems 21st Century Biology a biology of *dialectical interactions*,

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Editorial Board



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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.



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with “dialectical” denoting a back-and-forth dialog between interdependent players – the immature, undifferentiated cells, for example. “Interdependent” signals something more than mere interaction, because the sides *depend* on each other and *act on each other*. The action of the one determines the action of the other, over and over. This is *coaction*. No separation here. This is a biology in which things do not exist as separate entities. They come to exist and differentiate through mutual dependence and coaction with others. No “program” or pre-determined “instructions” needed. The kind of “information” that guides development is not in the genes or any of the cells, per se. It is in their *interactions* with each other! This kind of information emerges from the interactions. Thus, we see development taking shape and differentiating *through* relationships and *in* relationships.

The Ripening of NIDCAP

If I have succeeded in holding your focus during this super-fast journey through a recent history of ideas, you may get a tantalizing sense that the thinking underlying NIDCAP practice and that of 21st Century Biology are similar, maybe even *very similar*. If so, where has this brought us, and what might it mean?

Yes, I see meaningful similarities. Early in NIDCAP’s life, it was already a well-defined system, practiced in a few, well-controlled and similar contexts. It was feasible to conduct Randomized Controlled Trials (RCTs) in which NIDCAP-directed care was provided systematically to groups of prematurely born infants (in accord with appropriate criteria for inclusion and exclusion) and the outcomes (appropriately defined and selected) were compared to a similarly-composed group of prematurely born infants receiving standard care. The findings in these papers, supported and extended by other workers in other settings, showed that Very Low Birth-weight (VLBW) preterm infants who received NIDCAP care developed more favorably in terms of more rapid transition to oral feeding from parenteral feeding, reduced intensive care and shorter hospitalization, lower incidence of necrotizing enterocolitis (NEC), bronchopulmonary dysplasia and intraventricular hemorrhage (IVH), and improved weight gain, enhanced autonomic and self-regulatory function, lower stress in parents and improved quality of care. The development of EEG parameters matching those of full-term babies, and later, at 9 months, improved Bayley scores in the NIDCAP-directed babies compared to those in the standard care control group.^{3,4,5}

Earlier, I noted that NIDCAP has “ripened” and changed. All living systems do. During my reading and reflections in preparing the present essay, it was impressive to encounter a Letter to the Editor from a group of excellent Swedish researchers (and clinicians) entitled, “Evaluating neonatal developmental care”⁶ in which they stated presciently and insightfully, “*Because of the complexity of the intervention, evaluation of NIDCAP is complicated and it is difficult to achieve an optimal experimental design*

“As its name says, NIDCAP is individualized, first and foremost. Thus, in an experimental study, the independent variable is, by definition, inconsistent. It’s individualized, varying with each baby in each moment.”

compared with studies involving, for example, different drug treatments or modes of ventilation.” (author’s emphasis).

Westrup and colleagues were identifying a problem with RCTs in relation to complex systems. RCTs and other empirical methods for assessing interventions in clinical settings are ill-suited to interventions that include multiple, complex independent variables and/or a variety of dependent measures, especially when they are presented at different levels of analysis and time scales (*see Footnote 1*). All these are typified by interventions such as NIDCAP.

Future Challenges

As its name says, NIDCAP is *individualized*, first and foremost. Thus, in an experimental study, the independent variable is, by definition, inconsistent. It’s individualized, varying with each baby in each moment. Scientifically, it is important to have specifiable, repeatable, isolated entities as independent variables. Individualized care is different. The tool should match the problem. RCTs and other tests designed for entities do not work well here. For NIDCAP to shine as a type of intervention, we have to learn how to articulate the powers of this type of system. There can follow a clearer view of the appropriate forms of empirical testing. These will not look like a traditional RCT. But they must be rigorous and acceptable as a stringent test. Such acceptance will depend on a clear explanation and demonstration.

It is time for an assessment of NIDCAP as a ripened system. The role of science is important in contemporary NIDCAP. Medical interventions are evidence-based, and it is our responsibility to create the kinds of knowledge that demonstrate effectiveness and that explain the mechanisms of the effectiveness. That is how science flexes its muscles.

As I noted earlier, science has an important role in opening NICUs to developmental care. It must be evidence-based,

and sensitive clinical insights can illuminate how we can design and apply appropriate metrics to developmental care that will shape interventions to be applied and valid measures to be taken. This process itself will be coaction! Now is the time for the observations, discussions and formulations. Let the science emerge and help move NIDCAP forward.

Footnote 1. As a reminder: In such studies, *independent variables* are the factors that are presented or manipulated by an experimenter to test their effects, and would likely represent the “cause” of an effect that arises as a function of that independent variable. In contrast, the dependent variables would be those representing the “effects” that change, based on the independent variable.

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gretchen Lawhon, PhD, RN, FAAN, is a pioneer and lifelong advocate for the NIDCAP approach, with over 40 years of influence. Her commitment to this evidence-based care has transformed NICU practices and outcomes worldwide, making the future brighter for infants and families. gretchen mentors and inspires healthcare professionals and future leaders in developmental newborn, infant, and family care. – *Deborah Buehler, PhD, President, NFI.*



The Beginning

NIDCAP was an incidental side effect of our first behavioral intervention research. Dr. Als and I were in a meeting with Rita Gibes, the NICU Nurse Administrator, who suggested that we could teach others how to use the observation sheet that Heidi had created as she observed infants at the bedside in that first research study.

In fact, it was Rita Gibes who suggested the acronym of NIDCAP in that meeting.

My first realization of the value of NIDCAP was when it occurred to me that, as a NICU nurse, I no longer had to know the right or best way to care for an infant. NIDCAP provided me with the infant's language. If I merely listened to and respected each infant's voice, I could follow their guidance in how I cared for them and adjust my handling based on whether it was effectively supporting them. I thought this gave me freedom and felt much relief that the infant would guide me, and I, alone, did not have to know what to do.

Changes to NIDCAP Over Time

I have been using NIDCAP for the past forty-four years, both in terms of the observation and meaning of an infant's behavior as well as the philosophy of acknowledging the vulnerability and strength of each infant. There have been ongoing changes and evolution in NIDCAP due to the theory's dynamic nature and the ever-evolving ideas of NIDCAP professionals. The dynamic nature of the synactive theory, as the foundation of NIDCAP, includes the continuous interaction among the subsystems of development within the infant, as well as the continuous interaction between the infant's internal and external environments. I see this same process at each level of the relationships and systems surrounding the infant and family, health care professionals, the newborn intensive care unit system, the hospital, the community, and the global context.

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The more concrete changes over time involve greater clarification of the family context of each infant; the addition of the experience of each NIDCAP trainee doing an Advanced Practicum given to us by Elsa Sell and Susan Mangan; utilization of NIDCAP journal pages to enhance our reflective process; the NIDCAP Nursery program; and the gradual implementation and adaptation of NIDCAP with special care and full-term nurseries, newborns requiring cardiac surgery, pediatric intensive care, and prolonged acute care settings to name a few.

The Biggest Drivers of NIDCAP (and APIB)

The members of the NIDCAP Federation International, Inc. Board of Directors work consistently to keep NIDCAP and APIB at the forefront internationally. In addition, the editors of the *Developmental Observer* share our work with the public by publishing research and interesting aspects of our work. The NIDCAP and APIB trainers continually work toward further education and training for both NIDCAP and APIB professionals and trainers. However, the heart of the drivers of NIDCAP and APIB are those utilizing it in clinical practice. This meets the NFI mission and literally changes the lives of infants and families.

The Main Advantage of APIB

The major advantage of using the APIB in clinical practice is that it provides the most comprehensive picture of the infant's

strengths and vulnerabilities. It is an excellent screening tool for any specific vulnerability in an infant. In my own practice, there have been a few times when my concern following an infant's APIB has led to further investigation, with a new diagnosis not yet made because the subtle behaviour was only picked up by the APIB. For me, the greatest advantage of the APIB in clinical practice is its use as a demonstration for parents of their son or daughter's individual strengths and challenges, which leads to excellent discussions about ways to support the infant.

The Early Days of the NFI

As I recall, the motivation was to formalize and protect the NIDCAP and APIB work. Since 1990, we had been meeting annually to deepen our knowledge together and ensure the highest quality in our training. We met in conjunction with the Contemporary Forums Developmental Interventions of the Newborn conference. Our stand-alone annual NIDCAP meetings began in 1991. Ten years later, we formalized our organization. A lot of time was spent together in 2000 at the 11th Annual NIDCAP Trainers meeting in Sweden, strategizing and planning the NFI. Our international membership was increasing, and Dr. Als wanted to safeguard our work. Five of us were founding members of the NIDCAP Federation International, Inc Board of Directors and took responsibility for a tremendous amount of organizational work. The work was especially difficult because none of the five of us had the desired expertise and struggled to find it and learn what was needed.

The Most Rewarding Experiences of My Career

By far, the most rewarding experiences of my career were the relationships I formed with infants and families. I can honestly say that it is the families I have worked with that taught me my most important lessons. I still learn from Heather, my first neonatal primary patient, who was born in 1980 at 28 weeks. An infant in our first behavioral intervention study, born in 1982, taught me about the fragility of an early born infant at the age of three years, with her dependence on a reliable, structured routine. Because I have learned so much from those I have cared for, I often share their stories when I teach about NIDCAP. The synactive theory, that Dr. Als provided us, is an amazing foundation, which, for me, is explicated in the lived experiences of infants and families I have had the privilege of collaborating with in newborn intensive care and beyond.

A First Editor of the *Developmental Observer*

There were a few of us in the NFI who were very interested in having a newsletter that we could share throughout the world to publicize our work. In 2007, at the 18th Annual NIDCAP Trainers meeting in Brest, France, Rodd Hedlund, Deborah Buehler, and I assumed formal responsibility for creating the NFI newsletter, which we named the *Developmental Observer*. Rodd took the lead, and Deborah and I worked with him to

develop regular columns and entice colleagues to provide articles. For the first few years, we had some funding, and the *Developmental Observer* came out as a beautiful glossy document, which we mailed out to individual NFI members and Training Centers. Once the cost became prohibitive, we went virtual. After 19 years, I retired from my position as an editor and am very appreciative of Kaye Spence for her leadership in maintaining and enhancing the quality of this valued product.

Envisioning the Future

It is imperative that the NFI embrace a reflective and dynamic evolution in leadership. The initial founding members of the NFI Board built a strong foundation, and the organization will be strengthened with the succession and nurturing of new leaders. Having served on the NFI Board since its founding in 2001, I chose to step down after 18 years in the spirit of modeling and encouraging this transition. New and diverse perspectives and leadership styles will build on the strong foundation, fostering growth while maintaining the excellent quality rooted in our academic and scientific approach. Trusting an innovative leadership approach may enhance our growth and global standing as the original and premier newborn individualized developmental care and assessment program.

By far, the most rewarding experiences of my career were the relationships I formed with infants and families. I can honestly say that it is the families I have worked with that taught me my most important lessons.

NIDCAP will endure as the foundation and core of all developmental programs that have evolved in recent decades. Assuring the understanding of the beauty and complexity of the Synactive Theory, as well as appreciating and preserving the comprehensive nature of the NIDCAP report, will guarantee the strength and longevity of our training and education.

The *Developmental Observer* continues to thrive under the leadership of dedicated editors. With ongoing passionate

contributors, it will endure with excellent quality and expanding reach. It is a beacon which illuminates the depth and comprehensive approach inherent to NIDCAP and the NFI.

The NIDCAP Trainers Meetings

My initial role in organizing and planning the Annual NIDCAP Trainers meetings just seemed natural for me as Co-Director of the National NIDCAP Training Center and working so closely with Dr. Als. Once the NFI was incorporated and I was Vice President, I took on the role as a formal responsibility within the Program Committee. After about 15 years, I welcomed Jean Powlesland to join me in planning the Annual Trainers meetings and then relinquished my role to others. Our participants at the annual meetings have increased greatly over the years. I used to know every single person, and that is unfortunately no longer the case. It is difficult to experience the loss of some of our pioneer members, obviously Heidi, Kathy Vandenberg, and some who no longer attend, including Rodd Hedlund, Jim Helm, Melissa Johnson, to name a few.

The meeting is a wonderful and valuable format for bringing all of us together, getting to know one another, and sharing our work. That purpose remains as effective despite the large number and little time. Over the last few years, it seems to me we have spent just as much of our time together on other developmentally supportive programs as on NIDCAP, which dilutes our ability to forward our NIDCAP work. It might be better to have a true NIDCAP meeting, totally dedicated to our work, which could be followed by a meeting that includes the many other developmentally supportive programs that share the theoretical foundation of the synactive theory.

A Typical Clinical Day

Currently, I have reduced my clinical hours to 20 hours a week with the responsibility to be aware of each infant in the newborn intensive care unit who needs a developmental consult, making the infant's first transitional follow-up appointment prior to their discharge, using the APIB to evaluate infants in our transitional follow-up program, and maintaining our database on every infant seen. A typical day for me involves spending a couple of hours checking on each NICU baby on the computer, then evaluating seven–14 infants, depending on the day. I feel incredibly fortunate to have my position and find tremendous pleasure and pride in my work. I am often amazed that I can be paid to assess an infant and support his or her parents in caring for them. It is especially fun when siblings are present, and I can include them. I end every session by asking each family member how they would complete the sentence "I am so proud of my son Alton because....."

Thoughts as a NIDCAP/APIB Leader

NIDCAP has been a part of my very being since it began.

NIDCAP has been a part of my very being since it began. The NIDCAP approach of assessing another person, appreciating their vulnerability, and building on their strength is my approach to every other person.

The NIDCAP approach of assessing another person, appreciating their vulnerability, and building on their strength is my approach to every other person. The key to forming meaningful relationships, both professional and personal, is understanding the other person's lived experience. I am extremely grateful for the opportunity I have had over the past forty-four years and plan to continue evolving within the NIDCAP framework for as long as possible.

Some Personal Reflections

Growing up in an Irish Catholic military family of 13 children instilled in me loyalty to family, a strong work ethic, and a mandate to serve others. I thrive on my relationships with others and feel great satisfaction when my intervention has been helpful. Because my NIDCAP journey began so early in my career, just within 5 years of becoming a nurse, NIDCAP is ingrained in the fiber of my being. Appreciating where a person is on the continuum of development, supporting their vulnerability, and facilitating their emerging strengths became my approach, both personally and professionally as a nurse. I strongly identify with being a nurse and the inherent care for others in a holistic manner. This concept is quite similar to the synactive theory. Allegiance to my family has always been a priority to me. I never changed my name when married 50 years ago. The NFI has been my professional family for more than four decades. Both my personal and professional families have had annual meetings that I have facilitated for about 20 years each. What inspires me is, quite simply, helping others in any way I can. If my support improves another person's life, I feel an inner joy. When I work with families in the newborn intensive care unit, I feel honored to share in the intimacy of their parent-infant relationship, and when I am able, to facilitate their better understanding and appreciation of their son or daughter through the APIB, I feel tremendous satisfaction and pleasure.



Celebrating 25 Years of the NFI Honoring the Past, Shaping the Future

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Column Editors: Livia Nagy-Bonnard and Debra Paul

In this deeply moving Family Voices contribution, a mother shares the story of her son, born far too soon, and the profound impact of separation, communication breakdowns, and missed opportunities for connection in the neonatal setting. Through her words, we are invited into the raw and intimate reality of those first hours and days—marked by uncertainty, longing, and a powerful instinct to be close to her baby.

This narrative does more than recount a personal tragedy. It challenges us to reflect on how care is delivered, how communication is experienced, and how parental roles are supported—or unintentionally diminished—during one of the most critical moments in a family's life. The absence of timely information, barriers to early contact, and fragmented support systems emerge not only as individual experiences, but as systemic issues that continue to affect families worldwide.

At its core, this story is a call to action. It underscores the importance of zero separation, early and sustained skin-to-skin contact, and consistent, compassionate communication. It reminds us that parents are not visitors, but essential partners in care. It also highlights how lived experience can become a powerful driver for change, as this family later transforms their grief into advocacy and support for others.

We are grateful to the authors, Laetitia and Michel for the courage to share this story—one that will resonate with families and professionals alike, and that calls us to do better, together.

A Struggle for Life

Laetitia van der Elst

Noah's Ark Belgium <https://www.noahsark.be/>

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It is 10 p.m., and I am here, my head resting on my arm, gazing at my baby, separated from me by this plexiglass. I do not dare touch him, stroke him, or show him my presence and my love. I do not want to disturb his sleep.

I am exhausted and, at the same time, full of energy, completely overwhelmed. There is only one thing I want: to make myself very small, tiny enough to fit inside the incubator and join my baby, who was born this afternoon at 3:20 p.m. I would give anything to sleep peacefully beside him and feel that we are reunited.

I already wish I could forget the first hours after Noah was born. I was kept in the delivery room for a curettage, and I was separated from my baby. Just one kiss, as if to make up for tearing us apart. I give up my place so Michel, his father, can go and support our son with his presence. They are in a tiny adjoining room, already too far away from me. Then, when the team comes to take Noah, he is transferred without his father or mother, despite our requests. My heart is broken. Who will welcome our son?

At that late hour, I could feel how unstable I was, and no one came to explain anything to me. The events of the day replayed in my mind, but I could not make sense of them. It was impossible to piece together what had happened, what was still happening, what I was feeling, and what was going on around me. Eventually, I returned to my assigned bed and met



Laetitia and her husband, Michel, with Noah

the night nurse. In our brief exchange, I told her that my son had arrived earlier and was in the neonatal unit. She offered to finish her rounds and come back to see me afterwards. I agreed. Confident in my ability to adapt, I thought I could wait a little longer.

And yet, if only I had known. The nurse came to explain how to express my milk and collect the precious colostrum, 12 hours after giving birth. How is it possible that newborns have to wait to receive those few drops of gold, so crucial in supporting their development? Drops that, when collected in time, also help establish milk production and breastfeeding. To make matters worse, I was still hearing, “Anyway, downstairs in the neonatal unit, they’ll explain things differently.” What was I supposed to rely on? I was lost. Who could I trust?

The future of my lactation became a constant struggle. A struggle to produce enough milk for my baby, a struggle to understand what milk I had to take back home and what had to remain at the hospital. Endless waiting, standing in line to use one of the two pumps in a closed, small room, following the three-hour schedule, and being ready before going off alone to isolate myself and comply with the rules. Again and again, I fought sleep under that unbearable strobe-like light. It was only 10 days later that I learned about lactation consultants in the unit.

I longed to have Noah close to me, to make up for the time we had lost, to smell him, to feel his body move against mine, to look at him. None of these was possible, as if he were born at term. All my instinctive desires had to disappear, and the lack of explanations, too often contradictory, didn’t help my milk come in, nor did it bring me peace.

The spontaneous bond I felt, expressed in the words “My baby” right after he was born, was a cry from the heart that surprised even me. I had so many questions, since the child I carried had been conceived through science and egg donation, after treatment 20 years earlier. It was only months later that I realized my pregnancy had not lasted six months, but nearly 20 years of hope, carrying within it the dream of pregnancy and of a baby at last.

After days spent in sterile rooms, after years of traveling across the world and to its farthest reaches, I tried to find my place in this tsunami. It hit like a tidal wave, sweeping away my peaceful shore, completely unpredictable and mercilessly violent. I knew the hospital. I knew what it meant to be a patient. And yet all my bearings had vanished. My intuition had to bend to staff demands and protocols. I became like a puppet, asking nurses what I was allowed to do, instead of being supported in my role as a mother.

I had to wait two days, two endless days, before I had my first skin-to-skin contact with my son. Despite my desire and my repeated requests, I still remember the answer: “I don’t have time for that, I have to take care of other babies first.” Today, with hindsight and experience, how can we make zero separation from birth a reality for all newborns, especially the most vulnerable, as recommended by the WHO?

Our son was born in 2019 at 28 weeks, weighing 1.15 kg. Born in haste, he could not receive surfactant to help his lungs develop. He was doing well at birth, and yet his condition



Noah

worsened over time. Going home and leaving my son behind was an ordeal. Away from him, it was impossible to rest or take care of myself. I spent all my time worrying about him and waiting to return to his side. He was my long-awaited treasure, my compass. I was like a needle spinning without direction, an anchor drifting away.

A breakdown in communication

As time passed, communication with the unit became more difficult, more contradictory, and less responsive to my needs. After 15 days of struggle, trying to find a routine, discovering my role as a first-time mother, communicating with the caring team, experiencing my son’s first moments, and marveling at this miracle, the staff decided that I needed to calm down and take medication.

When I refused, I was sent for a meeting to the emergency psychiatric unit of the hospital, which didn’t understand why I was there. This very long, exhaustive day, without being with my baby, trying to justify my state of tiredness, ended with a night in one of the emergency psychiatric rooms before the court order the next morning. They decide to observe me in a psychiatric hospital, which means isolation. The decision I couldn’t understand, the opposite of what I was fighting for, to be with my baby. I was in hell. Michel, my husband and our son discovered I was removed from the hospital by force, like a dangerous person, a murderer, handcuffed and wrapped in the system.

Medical authority overrode my repeated pleas to stay with my son. Already fragile because of his prematurity, his condition deteriorated. He developed Necrotizing Enterocolitis (NEC). He underwent emergency surgery for the first time.



Noah

His father was alone. After pleading with the unit, my mother was allowed to come in and be with Noah. She refused to hold him skin-to-skin because she believed that was my place, not hers. After eight days of struggle, each of us on our own, the three of us were finally reunited. I could look at Noah, watch him, connect and barely touch him. He was not well enough to return to his parents' skin. And yet he needed only one thing, our presence, our flesh. I missed him so much. My whole body was crying out with hunger.

After a second intestinal surgery, an extraordinary fight against pain, and the terrible absence of his parents, a hospital-acquired infection took his earthly life. After 48 days in the neonatal unit, the only home he had known, we left the hospital empty-handed, leaving his body in the cold room. Only our tears still testified to his presence in our lives.

The Aftermath

After 69,000 minutes of life in the neonatal unit, Michel and I had become complete strangers to this world. There was no further contact from the hospital, no desire to know what had become of us. The whole new routine vanished, the flame of hope went out, the wave receded, taking with it what little strength remained. Within 10 days, a farewell ceremony was organized, to honor the arrival of our miracle before he slipped into the void.

How do you survive and heal after such a traumatic experience? How do you absorb such an accelerated fragment of life, come to understand your emotions, and above all, open the floodgates enough to let the traumatic pieces rise to the surface? Limiting the damage and finding meaning in that existence are their own challenges. That is how, barely a year

later, in 2020, after finding no organization able to support us, we created Noah's Ark Belgium, an association that began by supporting and accompanying parents in neonatal units.

Step by step, we became aware of the existing network. First, GFCNI (Global Foundation for the Care of Newborn Infants), founded by Silke Mader, brought us into contact with our peers, a large international family in which everyone has lived through a story connected to neonatology. Meeting scientists such as Nils Bergman was a turning point in our understanding of our own story and in beginning our advocacy for zero separation. Learning about developmental care, such as NIDCAP, made us realize the gap between knowledge and practice. A whole new world opened before us.

As parents, we believed that everything was being done for the best, for the very best for our baby. And yet the reality is different. How many barriers are still in place to separate, rather than bring together?

Fast Facts

Colostrum and Preterm Infants

- ✓ A preterm newborn should receive colostrum as soon as possible, ideally within the first 1 to 6 hours after birth. Colostrum is packed with concentrated immune factors and nutrients that are vital for protecting an immature system.
- ✓ Early administration of buccal colostrum was associated with better outcomes in neonates who also developed sepsis.
- ✓ The administration of oral colostrum in preterm infants is safe and feasible and does not result in any adverse events such as NEC, LOS, VAP, or mortality.

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Column Editors: Livia Nagy-Bonnard and Debra Paul

Dans cette contribution profondément émouvante de Family Voices, une mère partage un bout de son histoire – leur histoire de parents avec leur fils né bien trop tôt. Elle aborde l'impact profond de la séparation, des ruptures de communication et des occasions manquées de créer du lien dans le contexte néonatal. À travers ses mots, nous sommes invités à entrer dans la réalité brute et intime des premières heures et des premiers jours – marqués par l'incertitude, le manque et un instinct puissant d'être au plus près de son bébé.

Ce récit va bien au-delà d'un témoignage personnel. Il nous invite à réfléchir à la manière dont les soins sont dispensés, dont la communication est vécue, et dont le rôle des parents est soutenu – ou parfois, involontairement, diminué – à l'un des moments les plus critiques de la vie d'une famille. L'absence d'informations en temps voulu, les obstacles au contact précoce et les systèmes de soutien fragmentés apparaissent non seulement comme des expériences individuelles, mais aussi comme des problématiques systémiques qui continuent d'affecter des familles à travers le monde.

Au cœur de ce récit se trouve un véritable appel à l'action. Il souligne l'importance du zéro séparation, du contact peau à peau précoce et continu, ainsi que d'une communication fluide et empreinte de compassion. Il nous rappelle que les parents ne sont pas des visiteurs : ils sont des partenaires indispensables des soins. Il met également en lumière la manière dont l'expérience vécue peut devenir un puissant moteur de changement, lorsque cette famille transforme son deuil en engagement et en soutien pour les autres.

Nous sommes reconnaissants envers l'autrice, Laetitia, et son mari Michel, pour le courage de partager cette histoire – une histoire qui résonnera auprès des familles comme des professionnels, et qui nous appelle à faire mieux, ensemble.

Et qui invite à questionner notre façon de travailler. Pour faire mieux, pour les parents vivant cette expérience traumatique et pour offrir le meilleur à tous les nouveau-nés vulnérables.

Un Combat Pour La Vie

Laetitia van der Elst

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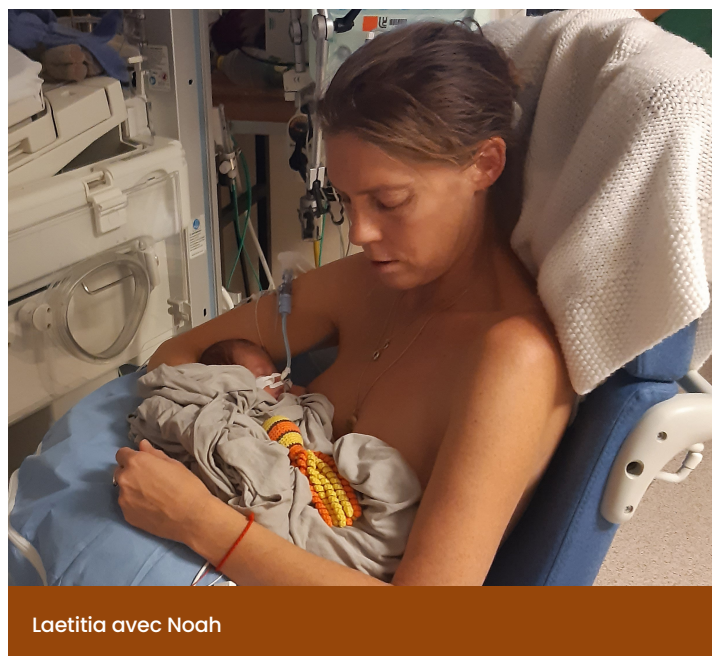
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Il est 22h et je suis là ; la tête appuyée sur mon bras à contempler mon bébé séparé de moi par ce plexiglas. Je n'ose pas le toucher, le caresser, lui témoigner ma présence et mon Amour, je ne veux pas le déranger dans son sommeil.

Je suis épuisée et à la fois pleine d'énergie, toute chamboulée. Je ne voudrais qu'une chose, me faire toute petite, minuscule pour rentrer dans la couveuse et rejoindre mon bébé qui est né cette après-midi à 15h20. Dormir apaisée avec lui et nous sentir rassemblés.

Je voudrais déjà oublier les premières heures qui ont suivi la mise au monde de Noah. Gardée par le corps médical en salle d'accouchement pour un curetage et séparée de mon bébé, il a été emmené loin de moi. Juste un baiser comme pour se faire pardonner de nous séparer. Je me sacrifie pour que papa aille soutenir notre fils de sa présence. Ils sont dans une micro-salle annexe, trop loin de moi déjà. Puis, transféré avec l'équipe venu chercher Noah, il part sans son père ni sa mère malgré nos demandes ; mon cœur est brisé. Qui va accueillir notre fils ?

A ces heures tardives, ma position instable se fait sentir et personne ne vient vers moi pour me donner d'explications.



Laetitia avec Noah

Le film de cette journée défile dans ma tête qui ne comprend pas. Impossible de mettre en lien tous ce qui s'est enchainé et s'enchaîne encore avec mes émotions et ce qui se passe. Finalement, je remonte retrouver le lit qui m'a été attribué et y croise l'infirmière de nuit. Dans notre court échange, je lui dis que mon fils est arrivé tout à l'heure et est dans l'unité néonatale. Elle propose de finir sa tournée et viendra me voir après. Chose que j'accepte. Certaine de mes capacités d'adaptation, je peux bien attendre encore un peu, ...

Et pourtant, si j'avais su ! L'infirmière vient m'expliquer comment tirer mon lait, prélever le colostrum si précieux ... 12h post accouchement. Comment est-ce possible que ce soit aux nouveau-nés de patienter pour recevoir quelques gouttes d'or, ces quelques gouttes si cruciales pour initier leur développement ? Quelques gouttes qui prélevées à temps vont favoriser la montée de lait et l'allaitement ! Pour couronner le tout, j'entends encore : « De toute façon en bas, en néonate, ils vous expliqueront les choses encore autrement ». A quoi dois-je me fier, je suis perdue et à qui faire confiance ?

Le futur de ma lactation a été une lutte permanente. Lutte pour arriver à avoir assez de lait pour mon bébé, lutte pour comprendre quel lait je devais ramener à la maison et lequel devait rester à l'hôpital. Attente interminable à faire la file pour utiliser un des deux tire-lait dans une des 2 micro-salles réservées à cet effet, respecter les 3 heures et être prête avant d'aller m'isoler seule pour être conforme au règlement. A moult reprises, j'ai lutté contre le marchand de sommeil malgré la lumière stroboscopique insupportable. C'est seulement 10 jours plus tard que j'ai appris l'existence des conseillères en lactation dans le service.

J'aurais tant voulu avoir Noah près de moi, rattraper ce temps éloigné, sentir son odeur, son corps bouger sur moi et porter mon regard sur lui. Rien de tout cela n'était possible comme s'il était né à terme. Tous mes désirs instinctifs devaient disparaître, ajouté à un manque d'informations et trop souvent contradictoires, cela ne favorisait ni ma montée de lait, ni mon apaisement.

Ma connexion spontanée exprimée par : « Mon bébé » alors qu'il venait de naître, a été un cri du cœur dont je fus étonnée. J'avais beaucoup de questionnement puisque le bébé que je portais avait été conçu par la science. Les suites de traitements 20 ans auparavant me rendant stérile, seul un don d'ovocyte pouvait permettre une grossesse. C'est des mois plus tard que j'ai découvert que cette dernière n'avait pas duré 6 mois mais près de 20 années d'espoir à chérir la venue d'une grossesse et d'un bébé.

Après des jours en chambre stérile, des années à parcourir le monde et les contrées, j'essayais de trouver ma place dans ce tsunami. Venu tel une lame de fond balayer ma plage paisible, de façon totalement imprévisible et d'une violence impitoyable. Je connaissais pourtant l'hôpital, ce qu'est d'être patient



Noah

et pourtant, tous mes repères avaient disparu. Mon intuition devait se plier aux desideratas du personnel, aux protocoles. Je devenais un pantin à demander ce que je pouvais faire aux infirmières plutôt que d'être soutenue dans ma place de maman.

J'ai dû attendre 2 jours, 2 jours interminables avant d'avoir un premier contact en peau à peau avec mon fils. Malgré mon désir et mes demandes, je garde en mémoire, la réponse de : « je n'ai pas le temps pour cela, je dois m'occuper d'autres bébé avant ». Aujourd'hui avec le recul et l'expérience, comment faire pour appliquer la zéro séparation dès la naissance pour tous les nouveau-nés et les plus vulnérables comme le recommande l'OMS ?

Notre fils est né en 2019, à 28 semaines de grossesse avec 1kg150. Né dans la précipitation, il n'a pu recevoir de surfactant pour développer ses poumons. Il se débrouillait pourtant bien à la naissance puis sa santé s'est empirée avec le temps. Rentrer chez moi et abandonner mon fils a été une épreuve. Loin de lui, impossible de me reposer et de m'en occuper. Je passais mon temps à m'en préoccuper et attendre de revenir près de lui. Il était mon trésor tant attendu, ma boussole ; j'étais tel une aiguille qui tourne sans trouver sa direction, une ancre partant à la dérive.

Une communication défaillante

Au plus le temps passait, au plus la communication avec le service était devenue complexe, contradictoire et sans réponse à mes besoins. Après 15 jours de lutte pour trouver une routine, découvrir ce qu'est devenir maman une première fois et le rôle de maman en néonate composant avec l'équipe soignante, essayer de vivre les premières fois de mon fils, émerveiller devant ce miracle, l'équipe a estimé que je devais me calmer, prendre des médicaments.

Quand j'ai refusé, j'ai été envoyée pour une consultation au service psychiatrique d'urgence de l'hôpital sans qu'il ne comprenne pourquoi j'étais là. Cette journée interminable, épuisante, sans pouvoir être auprès de mon bébé, essayant de justifier mon épuisement, s'est terminée par une nuit dans une des chambres d'urgence psychiatrique avant la décision de justice rendue le lendemain matin. A été décidé une mise en observation dans un hôpital psychiatrique, soit une mesure judiciaire d'isolation. Décision incompréhensible. Totalement contraire à ce dont je me battais pour ... être avec mon bébé. J'étais en enfer comme Michel mon mari et notre fils découvrant que j'étais éloignée de l'hôpital par la force, tel une personne dangereuse, une meurtrière, ... les menottes aux poignets j'étais prise au piège du système.

Le pouvoir médical a eu raison de mes demandes incessantes pour rester auprès de mon fils. Déjà fragilisé par sa prématurité, sa santé s'est dégradée. Entérocolite nécrosante (NEC). Il a subi une opération d'urgence une première fois. Son père était, seul. Après imploration du service, ma mère a pu rentrer pour être auprès de Noah. Elle a refusé de le prendre en peau à peau puisque pour elle c'était ma place et non la sienne. Après 8 jours de luttas chacun de notre côté, les trois d'entre nous avons finalement pu être réunis. J'ai pu revoir Noah, l'observer, me connecter à lui et le toucher, à peine. Il n'allait pas assez bien pour retrouver la peau de ses parents. Et pourtant il n'avait besoin que d'une chose, notre présence, notre chair. Et moi, j'avais viscéralement besoin de lui. Toute ma physiologie criait famine !

Après une seconde opération de l'intestin, un parcours exemplaire dans son comportement face à la douleur, un manque crucial de ses parents, une bactérie hospitalière a eu raison de sa vie terrestre. 48 jours en unité néonatale pour unique maison. Nous sommes repartis bredouille de l'hôpital laissant sa dépouille en chambre froide. Seules nos larmes exprimaient encore sa présence dans nos vies.

Les conséquences

Après 69 000 minutes de vie en unité néonatale, Michel et moi étions devenus de total étranger à ce monde. Plus aucun contact avec l'hôpital qui n'a pris la peine de savoir plus sur nous. Toute la nouvelle routine envolée, la flamme d'espoir soufflée, la vague repartie avec ce qu'il restait d'énergie. En dix



Michel et Noah

jours a été organisée la cérémonie d'adieu, rendre hommage à la venue de notre miracle avant la glissade vers le néant.

Comment survivre et guérir après une telle expérience traumatique. Intégrer cette tranche de vie en accéléré, découvrir nos émotions et surtout ouvrir les vannes pour faire remonter à la surface les éléments traumatiques. Limiter les dégâts et trouver du sens à cette existence est un challenge. C'est ainsi qu'à peine un an plus tard en 2020 n'ayant trouvé d'organisation pouvant nous soutenir, nous avons créé Noah's Ark Belgium. Association qui a commencé par un soutien et accompagnement des parents qui sont en unité néonatales.

De fil en aiguille nous avons pris connaissance du réseau existant. Tout d'abord GFCNI (Global Foundation for the Care of Newborn Infants) fondé par Silke Mader a été la rencontre avec nos pairs, cette grande famille internationale où chacun a vécu une histoire liée à la néonate. Rencontrer des scientifiques dont Nils Bergmann a été une des pierres angulaires pour comprendre notre histoire et démarrer notre plaidoyer pour la Zéro Séparation. Entendre parler des soins au développement NIDCAP nous a fait réaliser la faille entre les connaissances et les mises en application. Un univers s'ouvrait à nous, ...

En tant que parents, à nos yeux tout semblait être fait pour le mieux, visant le meilleur pour notre bébé. Et pourtant, la réalité est autre, Combien de barrières existe-il pour séparer plutôt que de réunir ?

Global Perspectives of Developmental Care – Africa

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The Council of International Neonatal Nurses, Inc. (COINN) developed a Community of Neonatal Nursing Practice (CoNP)-an online repository for evidence-based guidelines, training materials, and resources and a space for collaboration among participants. The aim was to fill a known gap: access to consistent, standardized training and education, and to evidence-based best practices for those caring for the small and sick newborn and family. The CoNP focused on sub-Saharan Africa, primarily Ghana, Kenya, Nigeria, and Zambia, where the neonatal morbidity and mortality were high. To improve neonatal health outcomes, the World Health Organization (WHO) produced the “Roadmap on Human Resource Strategies to Improve Newborn Care in Health Facilities in Low-and Middle-income countries.”¹ This document calls for upscaling the workforce caring for small and sick newborns and for creating a new cadre of neonatal nurses.¹ To that end, COINN developed evidence-based education/training materials.

COINN’s first focus was on a standardized 12 module neonatal orientation for post-diploma nurses, followed by preceptor training, a preceptor manual, and advanced neonatal nursing practice. During the two-year grant* period 2022-2024, 332 participants from 158 countries engaged in the courses and materials. In 2025, the number grew to over 180 countries, with another 99 participants in the courses. These courses focus on physiology and care management, especially in low-resourced countries. This content includes skin-to-skin care, Kangaroo Mother Care (KMC), and neuroprotective measures. Evidence-based guidelines are stressed in all these areas.

Webinars offered presented materials on clinical challenges in newborn care including infant-and family-centered developmental care (IFCDC). One webinar was on the “Parental Experience with KMC from Ghana, Rwanda, and Zambia”. Another one focused on “Neurodevelopmental Care.” KMC was among the early topics, especially immediate KMC (IKMC) and its link to improved neonatal outcomes. The WHO IKMC Study group,² in 2021, conducted a randomized, controlled trial in Ghana, India, Malawi, Nigeria, and Tanzania. The infants in the five hospitals weighed between 1,000 and 1,800 grams. Findings demonstrated that the mortality rate among those receiving IKMC was lower during the neonatal period than in the control group. Adejuyigbe and colleagues³ in 2023, examined the impact of continuous KMC



Father with baby in Ghana practicing Kangaroo Mother Care (KMC)

(CKMC) starting immediately after birth. They found that neonatal outcomes were better when started immediately rather than after a few days. Survival was improved, as was neuroprotection. KMC is part of the WHO⁴ recommendations for preterm or low birthweight infants. Yet, according to Ireso and Estifanos⁵ recent qualitative study of 14 participants, six mothers and eight neonatal providers, only 10% of the preterm or low-birth weight infants in Ethiopia, despite national support, receive KMC. The barriers often outweighed the benefits.⁵ Some of the barriers included: a lack of knowledge and/or motivation to provide KMC, healthcare delivery infrastructure, comfortable space, and short maternal lengths of stay.⁵ KMC promoters included quality improvement studies, visual aids to demonstrate correct KMC, and support for mothers.⁵

Leake and colleagues conducted a systematic review of family integrated care (FiCare).⁶ Their findings indicated that while staff saw the value of this type of care, the barriers, such as the healthcare delivery system, impeded implementation.⁶ Promotion of family integrative care requires strong leadership and policies that support the staff in the implementation.⁶ Families must be supported through education and demonstration of care techniques.

To date, the CoNP has attracted participants from more than 180 countries. Evidence-based materials and guidelines for care of the small and sick newborn and their families embrace neuroprotection and developmental care. The WHO recently published the updated KMC practice guide⁷ to promote KMC implementation globally. Despite strong evidence of KMC's impact on newborn outcomes,⁸ the availability of these materials and the incorporation of the principles into education courses and webinar implementations still lag behind. Families and staff do not always receive education regarding developmental care.

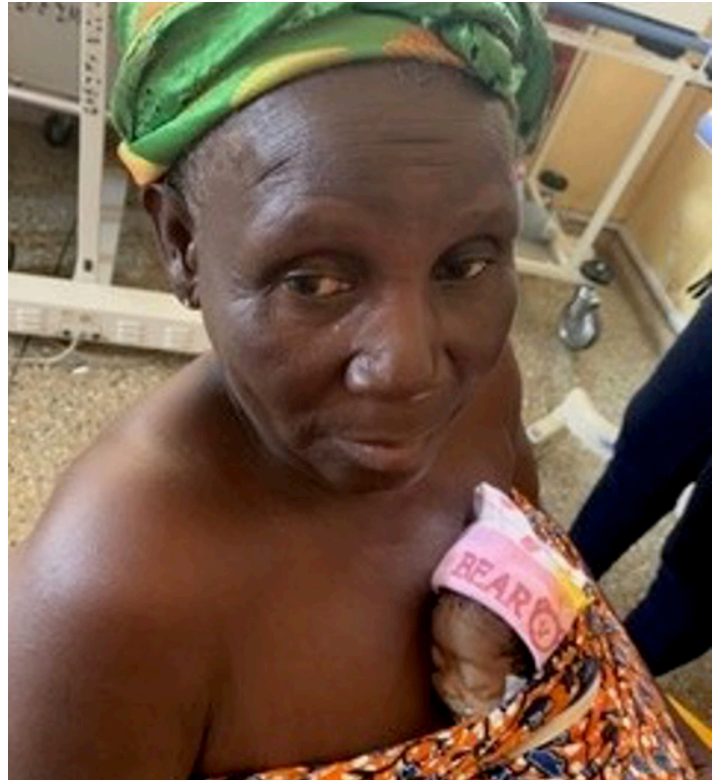
Partnerships to Improve Care

COINN and the CoNP have partnered with various organizations to improve skills in this area. These partnerships, which include the Global Foundation for the Care of Newborn Infants (GFCNI), NEST 360#, World Health Organization (WHO), International Pediatric Association (IPA), Family-Centered Care Taskforce (FCC), and participation on working groups such as the Consensus Committee on Infant-and Family-Centered Developmental Care (IFCDC) provide a strong voice to promote the implementation of infant and family-centered developmental care and neuroprotection into daily care practices. Sharing resources on the CoNP platform with cross-linkages with other organizations not only increases the impact of the CoNP, but also the other organizations associated. Partnerships with parent groups are critical as they must be considered part of the care team. During the CoNP conferences and visits to neonatal units in Africa, COINN witnessed firsthand how mothers were encouraged to participate in care, especially in KMC as illustrated in the photos; one is with a father, the other a grandmother.

The CoNP originally focused on Africa, however, due to the CoNP's Global Technical Advisory Committee, which had interprofessional representatives from many of the global maternal child partnership and the rising use of the infant-and family-centered developmental care (IFCDC) standards and competencies,⁹ COINN and IFCDC were invited to present to a group of policymakers and neonatal professionals in Nepal. The purpose of this meeting and follow-up webinar was to solicit governmental and professional support for IFCDC. This is but one example of the CoNP's impact outside Africa.

Promoting Infant and Family Centered Developmental Care

IFCDC is universal to all people in all low-, middle-, and high-income countries. The principles of IFCDC reflect a



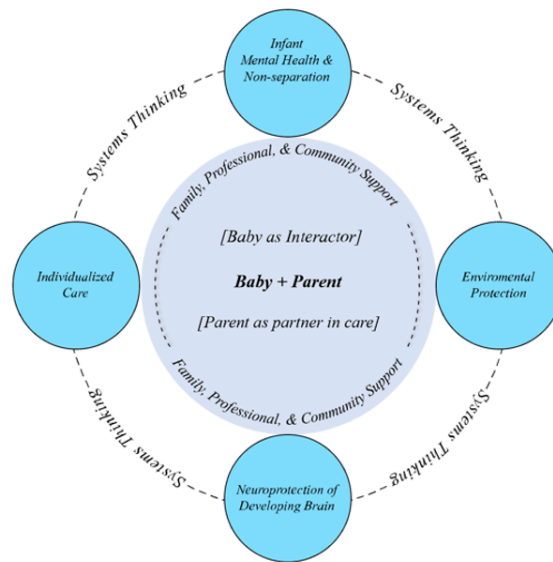
Grandmother helping with skin-to-skin care.

holistic concept of a respectful and inclusive healthcare culture advocating the non-separation and co-regulation of the baby and parents, recognizing the baby as a competent interactor and communicator, and supporting parents as essential partners and shared decision-makers in the baby's neuroprotective care. The use of a systems-thinking process guides the vision, policies, culture, environment, interprofessional structure, team collaboration, practice, education, fiscal accountability, continuous improvement, and evaluation of care.¹⁰ The evidence-based practices of IFCDC include: reducing infant pain using non-pharmacologic interventions and managing parent/family stress; positioning and light touch of the baby; safe sleep and gentle arousal of the baby; skin-to-skin contact/KMC with intimate family members; and the management of baby-led feeding, eating, and nutrition delivery using mother's own milk or human milk.^{11,12}

There are environmental factors that affect the healing and well-being of the baby and their parents/family, and support the neurodevelopment of babies in complex settings like Newborn Intensive Care Units (NICUs).¹³ Space is essential for parents and healthcare staff to interact with the baby, as are privacy and safety, to enable skin-to-skin contact. A comfortable air temperature promotes relaxation and warmth, so parents can gently touch their baby without triggering a startle response. When relaxed and comfortable, the baby can sense body position, movement, contact with surfaces, and begin to develop coordination and balance. Environmental factors that

Figure 1: Revised model of IFCDC developed by the Consensus Committee of the Recommended Standards, Competencies, and Best Practices for Infant and Family Centered Developmental Care in Intensive Care

- ▶ **Systems Thinking**
- ▶ **Baby + Parent**
 - Baby as competent interactor
 - Parent as partner in care
 - Support of family, professionals, & community.



- ▶ **Infant Mental Health & Non-Separation**
- ▶ **Individualized Care**
- ▶ **Neuroprotection of the developing brain**
- ▶ **Environmental protection**

can adversely affect the baby are noise, loud sounds, bright light, and/or strong scents. Adjusting environmental factors to promote comfort and relaxation can support the baby's neurodevelopment and the parents' well-being.

Shown in Figure 1 is the revised model of IFCDC developed by the Consensus Committee of the Recommended Standards, Competencies, and Best Practices for Infant and Family Centered Developmental Care in Intensive Care.¹⁴

The benefits of IFCDC provide short- and long-term support to the baby and parents/family.^{15,16} The non-separation of the baby and parent(s) at birth, and the continued unlimited presence with the baby, allow the baby to attach and co-regulate with the mother. Connection with the baby has been shown to reduce parent stress by allowing parents to experience the baby's initial care at/ following delivery, rather than moving the baby and mother to separate units/ areas for care. Parents are less depressed about the reality of not delivering a healthy baby if they remain present and engaged with their baby. Skin-to-skin connection stimulates the mother's milk production and increases the likelihood of successful breastfeeding. This improves the baby's physical growth and neurologic outcomes.

Parent partnership with the healthcare team provides education and coaching with parents/family members on care planning, decision-making, and competent caregiving practices. Further, the positive relationship between the parents and healthcare team members has been shown to enhance job satisfaction of healthcare partners.¹⁷⁻¹⁹ Continuous monitoring and use of targeted interventions can enhance KMC²⁰ and other IFCDC practices.

The adoption of Infant and Family Centered Developmental Care

Families, health professionals, and policymakers are collectively advancing the adoption of infant- and family-centered developmental care. Instruments such as the CoNP will facilitate and accelerate implementation through their broad online accessibility. Strategic partnerships with other organizations further strengthen opportunities for disseminating information and promoting best practices.

At the core of these efforts are infants and their families. COINN remains steadfast in its advocacy for neuroprotective care and affirms the family's role as a central partner in the care process. Through sustained collaboration, infant- and family-centered developmental care will be recognized and integrated as an essential standard of care.

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- # NEST360 is an international alliance of clinical, biomedical, and public health experts from 23 leading institutions and organizations in Africa.



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.



Nadine Griffiths, Director of the NIDCAP Learning Center

NIDCAP Learning Center

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The NIDCAP Learning Center is a dedicated space where members of the NIDCAP community, the broader community of healthcare professionals, and families can access a range of free and paid resources to support care in newborn and infant settings. The website will feature diverse content, including videos, interactive learning activities such as webinars, and practical resources. New content will continue to be built to support knowledge development both within and beyond the NFI community.

Through the Learning Center, access to education grounded in NIDCAP principles will be expanded by supporting their integration into newborn and infant care across diverse settings. A key goal is to promote equitable access to high-quality, evidence-based resources that enable healthcare professionals to embed NIDCAP-informed practices into their care. The Learning Center also seeks to strengthen families by providing accessible, reliable information aligned with NIDCAP principles, supporting their active involvement in care and decision-making.

The vision for the Learning Center

The vision for the Learning Center is to become an internationally recognised hub for high-quality education grounded in NIDCAP. The aim is to develop engaging, evidence-informed resources that are responsive to the diverse needs of learners across the global newborn and infant community. A key focus is to support the sustainability and growth of NIDCAP training internationally by complementing existing programs and expanding access to foundational and advanced learning opportunities.

The Learning Center is a valuable resource for NIDCAP trainers, healthcare professionals, and organizations, providing tools and materials that support education, clinical practice, and ongoing professional development. Importantly, it seeks to foster a connected, collaborative learning community that promotes the

consistent application of NIDCAP principles and supports continuous improvement in newborn and infant care worldwide.

The Director of the NIDCAP Learning Center

I am genuinely excited to take on the role, both professionally and personally. It presents a valuable opportunity to apply my skills and experience to support the NFI's work and contribute to the ongoing development and dissemination of education grounded in NIDCAP principles.

I have a strong background in clinical education, underpinned by a master's degree in clinical education. My experience as a Nurse Educator in the clinical setting involved developing and delivering educational curricula and leading the design of a range of eLearning programs. I have had the opportunity to work across multiple learning management systems, which has strengthened my adaptability in digital education environments. In my current role as an academic, I support both undergraduate and postgraduate students, enriching my understanding of contemporary teaching and learning practices across a range of settings.

Involvement of NFI Members in the Center

The Learning Center is designed to be for, and representative of, the entire NFI community. There will be ongoing opportunities to participate in creating content and learning activity development, and members are encouraged to keep an eye out for calls for contributions and collaboration. Members are warmly encouraged to become involved by contributing to content development, reviewing and providing feedback on resources, and suggesting priority areas for future development. By engaging with the Learning Center, members can play an important role in shaping a dynamic, relevant, and high-quality content that reflects the collective expertise of the NFI community.

Susana Pissarra, MD

DOI: 10.14434/dov19i2.43411

Senior Neonatologist at a Level III University Newborn Intensive Care Unit, Porto, Portugal.



Susana Pissarra, MD

I am a Senior Neonatologist at a level III University Newborn Intensive Care Unit, where I devote my professional life to the care of critically ill and extremely preterm newborns. My clinical work spans complex prematurity, neonatal surgery, congenital anomalies, highly specialized intensive care, and the clinical coordination of the Human Milk Bank, always with a focus on integrating develop-

mental and family centered principles into everyday practice.

My involvement with NIDCAP began very early in my career, at the São João NIDCAP Training Center, Porto. The NIDCAP philosophy echoed my own empathic and thoughtful way of living and relating to others.

I believe that the power of NIDCAP lies in its invitation to truly see each newborn, to observe carefully, listen deeply, and respond to the infant's unique cues with sensitivity. Individualized developmental care is not simply a technique, but a much-needed way of recognizing the newborn as a whole person, already communicating, already deserving of respect, and already shaping the caregiving relationship.

It is this perspective that aligns so profoundly with the message of *The Little Prince*, the book that has so deeply

influenced me since my childhood. The story's timeless lesson — “*What is essential is invisible to the eye; one sees clearly only with the heart*” — echoes the foundation of NIDCAP. Just as the Little Prince learns to perceive beyond the surface, NIDCAP invites caregivers to look beyond monitors and diagnoses and to see the subtle signs through which each baby expresses comfort, stress, readiness, or fatigue. NIDCAP is the clinical expression of this ability to “see with the heart”: observing with intention, acting with gentleness, and honoring the individuality of every infant and family. As in *The Little Prince*, where the time and presence dedicated to the rose made her uniquely important, NIDCAP reminds us that it is the time, attention and attuned presence we offer each newborn and family that truly shape our relationship with them and supports their development.

I am a strong advocate for family partnership in the NICU, ensuring that parents are not visitors, but essential participants in their baby's developmental journey. This commitment extends to my roles in training, mentorship, and research, through which I work to strengthen a culture of neuroprotective, relationship based care in my unit.

Guided by my personal philosophy — “*I'm in the business of making people happy!*” — I try to bring humanity, presence, and warmth to the NICU environment, supporting families through vulnerable and transformative moments, helping them discover the strength of their connection with their baby, even in the smallest, most subtle signs. I also support and empower professionals, nurturing their growth in confidence, sensitivity, and developmental understanding as they care for newborns and their families.



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.

Beverley Hicks

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Beverley Hicks

I work as the Developmental Specialist and Clinical Specialist Neonatal Occupational Therapist at University College London Hospital and UK NIDCAP Training Centre in central London. I am also a senior faculty member for FINE Training UK.

I was first introduced to the concept of NIDCAP and the synactive theory during a training session led by Inga Warren in 2004. I was working at the Royal Brompton and Har-

field NHS Trust, a tertiary cardiothoracic centre at the time and found that I couldn't understand why the little preterm infants with us for PDA ligations didn't behave like babies born at term. Inga's NIDCAP talk was a moment I will never forget and opened my eyes to preterm behaviour. I was lucky enough to get a job working as a neonatal OT at St Mary's Hospital and then the UK NIDCAP Training Centre with Inga in 2005. I started my NIDCAP training in 2008 with Gillian Kennedy and had the privilege of learning directly from Heidelise Als during my APiB training.

The most important aspects of NIDCAP are observing behaviour, helping to understand the baby's unique characteristics, and then using this with the baby's parents and the wider neonatal team. The detailed observation using the scan sheet reduces subjectivity, helps me focus on the connections between the baby's behaviour and medical needs, and gives me the opportunity to support caregiving to make the baby more comfortable.

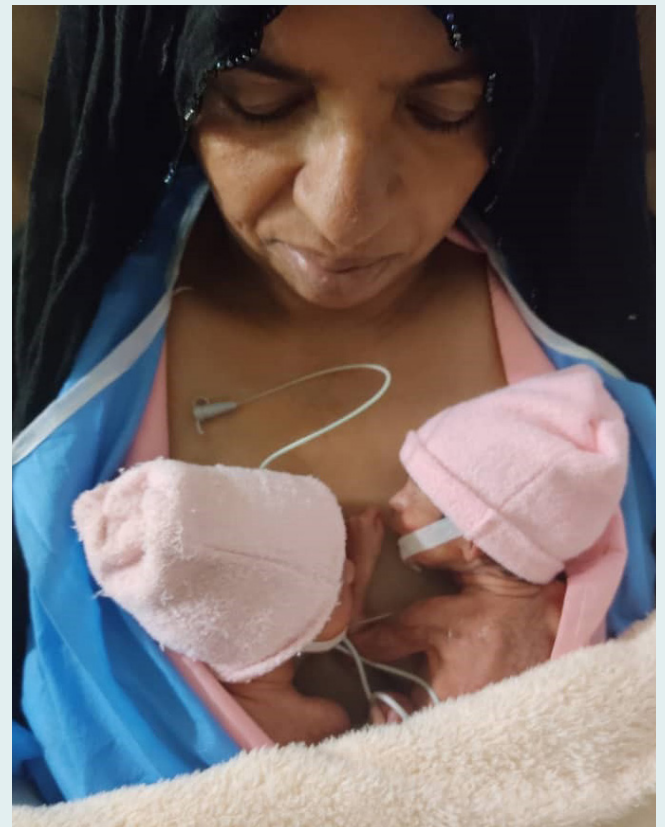
One of the first books I read when I started working on the neonatal unit was *Sent Before My Time: A Child Psychotherapist's View of Life on a Neonatal Intensive Care Unit* by Margaret Cohen. I remember so vividly the chapter on families with twins in the NICU and how torn they are between the "well twin" and the one who might not survive. It openly explored the emotional side of working with parents in neonatal care.

My philosophy on life is that family is the most important thing and that you never know what life will throw at you when you least expect it. My partner became acutely unwell last year while we were in Europe skiing and had two months

in two hospitals in the UK with major open-heart surgery. The experience reminded me how fragile life is and how important it is to prioritise your time with family.

I love making things and usually have a project on the go – I made so many crochet animals during the COVID-19 lockdown, and I made quilts that almost all my friends and their children have. I enjoy being outdoors and look forward to the ski season, where we travel to Italy for a week of beautiful scenery and exhausting skiing.

I would love to be back at home in Zimbabwe, but could I have a time machine as well? My childhood was such a happy one, and I am so grateful that I grew up in Africa. I would love to be back right now under the huge African sky, in the heat, with the beautiful landscape around me.



Iran, used with permission

NIDCAP Care in the Moment
Togetherness, Iran

What the Web says about NIDCAP

In 2026, the latest evidence for the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) strongly reaffirms its role as a superior, evidence-based approach to reducing early life stress and improving long-term outcomes for preterm infants, their families, and clinicians. As of April 2026, research continues to emphasize that NIDCAP protects the rapidly developing brain from NICU-related environmental stress.

Key Evidence Highlights in 2026:

- **Improved Clinical and Neurobehavioral Outcomes:** Evidence confirms NIDCAP reduces the duration of mechanical ventilation, accelerates weight gain, and shortens hospital stays.
- **Reduced Complications:** Implementation of NIDCAP-based developmental care is associated with lower rates of severe intraventricular hemorrhage (IVH), late-onset sepsis, and retinopathy of prematurity (ROP).
- **Family-Centered Impact:** NIDCAP increases parental confidence and competence, reduces stress, and fosters better infant-parent relationships.
- **Brain and Physiological Development:** The program is shown to improve neurodevelopmental scores, enhance feeding efficiency, and support better pain management, with strong links to improved thermoregulation via kangaroo mother care.
- **Implementation in Specialized Care:** Recent 2026 studies (e.g.,) show that implementing NIDCAP principles (such as 24/7 parent involvement, environmental noise/light control) is effective even in challenging, low-resource settings, as shown by studies in Ukraine.
- **Expanding Scope:** NIDCAP principles are being increasingly applied to specialized areas, such as caring for infants with congenital heart disease, to protect their fragile brain development, as advocated by 2026, 2025 guidelines from the American Heart Association and American Academy of Pediatrics.



Key 2026 Events and Developments:

- **25th Anniversary of NFI:** The NIDCAP Federation International (NFI) is celebrating its 25th anniversary in 2026, highlighting over four decades of research that validates the program's effectiveness.
- **2026 International Neonatal Conference (INAC):** The conference (November 2026) will focus on translating developmental care evidence into practice.
- **NIDCAP Nursery Certification:** The NIDCAP Nursery Program continues to be recognized, notably by the European Foundation for the Care of Newborn Infants (EFCNI) as a "Lighthouse Project" for high-quality care environments.

The NIDCAP approach is increasingly seen as a "biological therapy" and is becoming a standard for all NICU care, rather than a specialized intervention, aiming to optimize both survival and long-term quality of life.

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