nidcap FEDERATION INTERNATIONAL
voice of the newborn

Developmental
Observer

The Official Publication of the NIDCAP® Federation International

2025 | VOL 18 | NO. 2

> Just ten minutes of guidance can build parental confidence that lasts for years.
>
> *-Oleksandra Balyasna*

INSIDE

DOI:10.14434/DO.V18I2.41635

FAMILY VOICES

DOI: 10.14434/do.v18i2.41637

When Every Gram Counts: Reflections on My Daughter's Early Arrival

By Oleksandra Balyasna, Ukraine

I had never heard of preterm birth during any of the pregnancy preparation courses I took with my partner. A few days before giving birth to Diana, our daughter, I shared with my gynecologist that I was feeling inexplicably anxious. I didn't understand where that feeling was coming from. The doctors never mentioned the risk of premature delivery, so I was utterly unprepared, mentally and emotionally. After all, who expects to deliver a baby at 28 weeks?

My daughter was just over one kilogram when she was born. It was a cocktail of stress, shock, and uncertainty. I felt completely out of control, like I was the first person on the planet to deliver a baby so early, so tiny, so vulnerable, and so fragile. I had no idea how to reduce my daughter's pain or bring her comfort. It was not the kind of maternity experience I had ever dreamt of.

After delivering prematurely, I couldn't stop crying. Every time I tried to speak, my words dissolved into tears. What helped me was seeing a psychologist I had known before. On the third day after my baby's birth, I shared my biggest fears out loud and expressed everything I was feeling. That conversation was deeply comforting and brought me much relief. I didn't experience the "uncontrolled crying mode" again and felt much more emotionally balanced.

Visiting the NICU

At the time of Diana's birth, she spent time in the neonatal intensive care unit, the

(continued on p.2)

(continued from p.1)

perinatal center was still closed, and only an hour a day was allowed for us to visit her at lunchtime. During this hour, I also had to talk to the doctor about her medical treatment, get a new list of medical items I had to purchase for my baby, and bring in the pumped milk I was expressing. The time that was left was focused on connecting with my baby.

During my first visit, I could only watch my daughter from a distance through the glass of the incubator. On the third day, a nurse encouraged me to touch her skin, hold her tiny arm, and gently place my palm on her. Without guidance, I was terrified I might hurt her with all the tubes and catheters keeping her alive.

A particularly traumatic experience for me was being placed in a room with an empty bed, right next to rooms full of mothers who had delivered healthy, full-term babies. I could hear crying babies all around, while mine was in the intensive care unit. I felt utterly useless. *What can I do? Am I even a mother yet?*

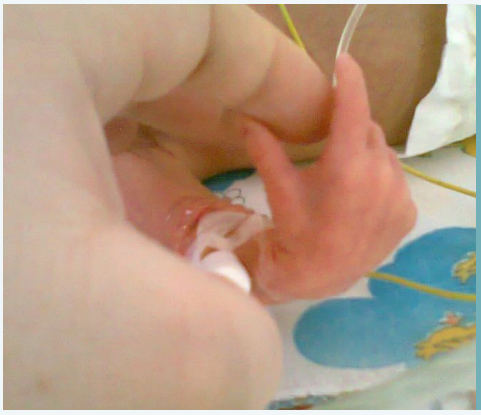
Learning how to gently touch Diana, respond to her behaviors, and build trust in our interactions became *one of the most emotionally meaningful experiences*. It also laid the foundation for her emotional resilience and future development. These small, sensitive interactions help babies born prematurely begin to regulate their senses and bond securely, essential for their neurodevelopment.

Learning how to gently touch Diana, respond to her behaviors, and build trust in our interactions became one of the most emotionally meaningful experiences.

My most memorable experience in the NICU

One of my strongest memories is hearing the words, *"You can kangaroo her now—hold her."* That half-hour of holding my daughter skin to skin was pure magic. While the NICU was busy all around me, I was in another world while I held my daughter, feeling her heartbeat, breathing in her scent, and bonding with her deeply for the first time.

At the time, I didn't fully understand the power of skin-to-skin care, but I instinctively understood how important it was. Later, I learned that kangaroo care supports the baby's ability to regulate heart rate and body temperature and even supports healthy brain development. If I had known more then, I would have done it more often, during the dedicated hour and as often as possible.



Supportive touch in the NICU, November 2012.

Navigating my fears in the NICU

My biggest challenge was to gain the confidence to touch my daughter. I was unsure if this was hurting her, and it took me some time to get comfortable with how to lift her, place her back into the incubator, or change her. She seemed so fragile.

As Diana grew, breastfeeding seemed intuitive for her. However, it was challenging to learn how to balance tube feeding, bottle feeding, and breastfeeding while she was not gaining weight rapidly. Bottle feedings were frustrating when it seemed the focus was on getting her to eat more, and then she would lose almost half of the feed by spitting up. We learned we had to be more patient and let Diana learn how to suck, swallow, and to increase the volume while breastfeed at the same time. By the time Diana was discharged home, she was only breastfeeding without tube feedings or bottle, which felt like a tremendous victory and an important milestone.

My family was my biggest support and was always next to me. My father, even though being scared of the small size of our daughter, was happy to support me with other tasks. For example, he washed, ironed, and disinfected all the clothes for our little fighter. My mom was cooking, and my sister was searching for tiny socks, clothes, and special pacifiers of a tiny size. Each day, Diana's father came to the hospital after his job to check on us. One of my fondest memories is when he came during the Christmas holiday wearing a Christmas hat and spent New Year's Eve with me and his daughter.

New challenges with the transition to home

After Diana's discharge home, our next challenge was finding the right family doctor who understood the specific needs of a premature baby. We had to organize the follow-up care ourselves: monitor her vision (retinopathy of prematurity), heart development, orthopedic assessments, and her neurological development. There was no follow-up center at the time, and it felt like a huge responsibility to build our own care system. Our biggest fear was: *Did we miss anything important?*

(continued on p. 4)

Cover image: Oleksandra Balyasna and her 5 month old daughter, Diana.. Used with permission.

Editorial

DOI: 10.14434/do.v18i2.41636

New Voices, Lasting Legacies

In this issue, we feature articles that explore NIDCAP training across diverse settings. Dalia Silbertstein shares her reflections on the NIDCAP Advanced Practicum (AP) in Spanish and English, challenging us to consider new perspectives on training approaches. Hannah Dalrymple offers insights from the viewpoint of a medical practitioner during her AP, guiding us through the challenges and triumphs of her experience. Jeffery Alberts challenges us to consider the hot topic of Delirium in the NICU.

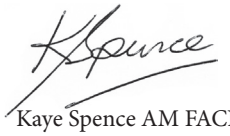
Angela Gregoraci contributes a thoughtful piece on implementing broader aspects of individualised developmental care based on the NIDCAP model. She highlights various strategies to support parents and staff, enriching our understanding of how this model can be applied. Oleksandra Balyasna, a mother from Ukraine, shares her journey and recommendations for supporting parents.

Continuing our ongoing feature introducing NFI members, this issue profiles Julia Giesen. Alongside the profile, we are privileged to share Julia's evocative poetry inspired by her experience with the Assessment of Preterm Infant Behaviour (APIB).

We also take a moment to say farewell and express deep gratitude to **gretchen Lawhon**, who is stepping down from the editorial team. gretchen has been a foundational member of the *Developmental Observer* since its launch in 2007. Her dedication and contributions have been extraordinary. Thank you, gretchen, for your enduring commitment and wisdom.

We welcome **Livia Nagy-Bonnard** to the editorial team as the Family Voices column co-editor. Livia brings a wealth of experience and a strong commitment to family-centred care.

As always, I welcome suggestions for features, content, and potential reviewers. Please don't hesitate to contact me—I would love to hear from you.



Kaye Spence AM FACNN

Senior Editor – Developmental Observer, Adjunct Associate Professor
Australasian NIDCAP Training Centre/ University of Western Sydney

Editorial Board

Building that follow-up network, finding a neurologist, orthopedist, or ophthalmologist, was overwhelming but essential. The earlier developmental concerns are identified, the better the outcomes with timely interventions. Regular checkups became a part of our new routine.

Support

The following were helpful to me during Diana's hospitalization in the NICU:

Peer-to-peer stories. Hearing other positive preemie stories gave me hope. I still remember the moment I saw a child return to the NICU with her parents. I couldn't believe that my tiny one-kilo baby could one day be like that.

A close friend of mine once told me she had been born prematurely. She's now a smart, beautiful lawyer with a kind heart. I called her and said: *"Tell me everything. How was it for you?"* Just hearing her story was deeply therapeutic. She reminded me that premature babies can survive, thrive, and shine, leaving no visible trace of being born too soon.

My recommendation to parents going through the NICU journey:

- While positive preemie stories can be supportive, peer groups are also very helpful. Check preemie parent organizations that operate locally next to you.
- It is important to prioritize getting mental health support. Ask for psychological support for you and your partner together. This is not something you go through daily, and any preterm labor is stressful.
- Involve your family and friends, whether this means having them babysit your older kids, cook, or perform other helpful tasks.
- Maybe your journey is not going as planned, but you are definitely not alone in it. Please feel the support of our huge community, which is behind parents who are going through or have similar experiences. Having other parents to talk to and share stories with is inspiring.

What could be helpful in the NICU:

- Invite parents to walk this journey together with the care team. Show them how to talk to and touch their baby, and how they can contribute to their baby's care. Just 10 minutes of guidance can build parental confidence that lasts for years.
- Provide access to peer support groups and display information in the unit so parents can view it.
- Offer psychological support and printed materials for families. This is a new, unfamiliar world for them, and knowing what they can do helps restore a sense of control and hope.

Oleksandra with her daughter Diana, aged seven.

"Our biggest fear was: Did we miss anything important?"

While in the incubator, our daughter moved a lot and showed her character. She speaks four languages fluently, likes to read books and history, write stories, draw, and collect stones.

Column Editors: Livia Nagy-Bonnard and Debra Paul

Diana fought bravely for her life as a fragile newborn—and today, she continues to show that same strength as they begin a new life in another country, far from home. Diana and her mom are now living as refugees after fleeing the war in Ukraine. Starting over in unfamiliar surroundings is never easy, but Diana's resilience reminds her mom every day of the power of survival, hope, and love. Her journey began in an incubator, surrounded by uncertainty, and now she walks forward with confidence and creativity, shaping a future full of promise.

OUR SPONSORS

Dr. Brown's Medical delivers valuable feeding solutions that help provide the best possible outcomes for all babies.

NIDCAP Federation International Board of Directors and Staff 2025

The INFA-Neo Program: Supporting Infants and Parents from the NIDCAP Perspective

Angela Gregoraci, PhD, Neonatologist and NIDCAP Professional

Trueta Hospital Girona, Spain

DOI: 10.14434/do.v18i2.41641

I recall when I began my NIDCAP training 12 years ago in Barcelona alongside my mentors, Graciela Basso, Josep Perapoch, and Fátima Camba. I read the *Nursery Assessment Manual* for the first time. This manual is a key instrument for evaluating the quality of a nursery's developmental orientation and care implementation. At that time, our average summary scale score was 2.5 on a 1-5 rating, and we were concerned about how to move forward and achieve a higher score. How can we consistently promote the best short- and long-term development for all infants and families, while supporting care professionals and staff in ensuring their personal and professional growth to implement relationship-based care effectively?

The answers came little by little...

In 2020, I received a grant from the Spanish Neonatologist Society and decided to travel to our European references in Infant and Family Centered Developmental Care (IFCDC)[1]—the Scandinavian countries. There, I met Stina Klemming, Liisa Lehtonen, and Sari Ahlqvist-Björkroth, and they all demonstrated to me that a successful integration of a neuroprotective, developmental, and supportive care philosophy is possible. I learned that the best chance for successful implementation requires patience, endurance, and persistence, and that a broader strategy, which reviews unit culture, enablers, and barriers to sustainability, is essential.[2]

For IFCDC to be implemented effectively, we must focus our efforts and attention on a) understanding infants' needs and rights through their behavioral communication and cues, giving the newborn a voice, as Dr. Als reminds us; b) supporting parental well-being and the infant's development through parent engagement; c) changing hospital culture through healthcare staff training and support.

The INclusion of FAmily in Neonatology Program (INFA-Neo) was developed at Trueta Hospital in Girona, a NIDCAP training center, to achieve these three main goals. Our philosophy is the NIDCAP philosophy. We use individualized care plans based on developmental assessments of an infant's behavior. A strength-based approach to healthcare recognizes the family as the constant in a child's life. It focuses first on the positive attributes, capacities, and resources of the infant, family, and community, rather than solely focusing on deficits and needs.

We were also inspired by other parenting interventions, such as Close Collaboration with Parents,[3] which routinely included parents in the observations to increase their knowledge and understanding of their baby's cues, which affect their interactions. Care recommendations were given to parents and shared with the healthcare team. Meanwhile, the entire staff was trained to observe infants together with the parents through the FINE program.

Joint observation with a mother

Trueta Hospital is the reference hospital for the Girona health region, attending 1,650 births annually, 56 of which are premature babies born at less than 32 weeks of gestation or less than 1,500 grams. Implementing the NIDCAP model in the Neonatology Unit of Trueta Hospital started in 2016 in collaboration with Vall d'Hebron Hospital in Barcelona, which is a NIDCAP training center and part of the PADEICS-NIDCAP program network,[4] an expert advisory program jointly promoted by the healthcare medical directors of the six hospitals affiliated with the Catalan Institute of Health. In this context, the INFA-Neo intervention was developed in 2023, focusing on integrating families and providing individualized developmental care for high-risk babies.

A specialized team leads the INFA-Neo program, comprising one full-time NIDCAP nurse, one part-time NIDCAP neonatologist, a psychologist, a pediatrician with FINE 2 training, and a local parents' association representative. It consists of common elements for all families and more specialized interventions for the most vulnerable infants born before 30 weeks of gestation. The principal components of the intervention are:

1. **Individualized developmental infant care:** Weekly joint observations of infants under 30 weeks with parents, focusing on understanding the infant's behavior.
2. **Parental guidance and education:** Weekly reflective sessions with parents of premature infants <30 weeks, led by one NIDCAP Professional. These sessions help parents learn to identify each infant's needs and characteristics, listen to parents' perceptions about their infant, and provide them with a psychological space to create a shared care plan and understand their unique journey to becoming parents. The goal is to build collaboration, integrating parents' observations about their infant's behavioral responses in caregiving decisions. The individual needs of infants and families, identified during these meetings, and the subsequent recommendations are shared with the staff to enhance their understanding and empathy for the parents' and infants' experiences, ultimately improving how developmentally centered care is provided.
3. **Parental presence and caregiving:** Progressive and individualized parent coaching at the bedside teaches parents the skills required to provide many aspects of their infant's care. Additionally, parents are invited to attend weekly parental classroom meetings, where they are educated by various specialists on different subjects. Families also have access to a library to encourage reading to their babies and a diary for entries about their baby's progress.
4. **Parental support:** The INFA-Neo team's psychologist provides individualized psychological support for parents and weekly family group therapy.
5. **Healthcare staff, time, and education:** Training and educational activities for all staff to foster a care culture in the Neonatal Intensive Care Unit (NICU) and enhance the healthcare team's skills in family and infant neurodevelopmental care.

Since May 2023, 48 infants born at or before 30 weeks' gestation have been born at our hospital. Of these, 36 were included in the INFA-Neo Program. Of the 28 pregnant women admitted to the obstetric ward before delivery, 25 (89%) received the first structured, interdisciplinary-focused antenatal meeting. During their NICU admission, an average of three meetings per family were held, and five NIDCAP care recommendations were shared with the healthcare team per family. Eighty-eight percent of infants had their first skin-to-skin contact with their parents within the first week, and 61% within the first 72 hours. Initially, families with significant language barriers were excluded, but given the multicultural nature of our population, we could not deny them the program's benefits. Therefore, we adapted and included 25% of the families. Forty-four percent of the infants discharged were on breast milk, and 20% received both breast milk and formula. Eleven families (44%) were also included in the home-hospitalization program after an average of 80 days of admission (38 weeks of postmenstrual age). One hundred percent of families followed up with the interdisciplinary consultation.

Reflective session with parents

Families said about the program:

> *"We knew it would be a long stay due to our little one's prematurity, but we always had the support of the entire staff, and that helped us a lot to know how to manage the situation." –Ailany's parents*

> *"It has been a tough experience, and day by day we have overcome our fear, and every day we have been more confident and more eager to reach the end of the road." –Darian's parents*

> *"Babies are put at the center and the rest are satellites, and that innovative and powerful approach that is NIDCAP always seeks the best for these little ones, including the importance of how to get families to also listen to them, to care for them, to also be protagonists in the process of their little ones' evolution." –Samara's mother*

Nevertheless, we still face many challenges. Some parents have experienced variable levels of individualized support in the unit, probably because not all staff have completed the Family and Infant Neurodevelopmental Education (FINE) 2 training and are not yet sensitive or receptive to the NIDCAP recommendations. Inconsistent practices have been identified as a barrier to implementing IFDCC. Inadequate facilities and unit design (our NICU is an open-bay unit without single-family rooms) make it difficult for families to be present. Additionally, the unavailability of interpreters and a lack of empathy make communication between staff and families challenging.

However, the cultural and attitudinal environment of IFCDC is more important than the physical environment. IFCDC can be successfully implemented, even in crowded NICUs with older facilities, if the clinical team is committed and willing to invest in creative solutions.[5]

Strong evidence shows that outcomes improve for infants

and families when families are involved in their hospitalized infant's care.[4] The NICU team cannot fully meet the infant's physical and developmental needs during hospitalization or adequately prepare families to care for infants after discharge without strong family engagement. A developmentally supportive philosophy of care leads to better health outcomes, improved patient and family experiences of care, better clinician and staff satisfaction, and wiser allocation of resources when families are fully integrated into the care delivery system and treated as essential and irreplaceable partners in all aspects of healthcare delivery—from the bedside to the health system boardroom.[2,5]

The INFA-Neo Program is a multidisciplinary intervention designed to support the development of pre-term infants, the parent-infant relationship, and the training of NICU staff throughout the entire pathway, including prenatal, birth, NICU, discharge, and follow-up care. It is still very young, but we are confident that it could facilitate the implementation of the NIDCAP model in our NICU and in other similar neonatal units. As Dr. Heidelise Als[6] said, "one infant and one family at a time; one nurse and one doctor at a time; one NICU and one hospital at a time; one city and one country at a time. This is the way to create the necessary change."

All quotes used with permission.

References:

1. https://newborn-health-standards.org/standards/standards-english/infant-family-centred-developmental-care/
2. Griffiths N, Spence K, Loughran-Fowlds A, Westrup B. Individualised developmental care for babies and parents in the NICU: Evidence-based best practice guideline recommendations. *Early Hum Dev.* 2019 Dec;139:104840. doi: 10.1016/j.earlhumdev.2019.104840. Epub 2019 Aug 21. PMID: 31445697.
3. Ahlqvist-Björkroth S, Axelin A, Lehtonen L. Close Collaboration with Parents-Implementation and effectiveness. *Acta Paediatr.* 2025 Apr;114(4):699-709. doi: 10.1111/apa.17210. Epub 2024 Mar 21. PMID: 38514910; PMCID: PMC11894782.
4. Perapoch J, Camba F, Gregoraci A, Anglès R, and the PADEICS-NIDCAP Group. NIDCAP: Always a journey. *Developmental Observer.* 2025, 18 (1): 20-21. DOI: 10.14434/do.v18i1.40895.
5. Franck LS, Axelin A, Van Veenendaal NR, Bacchini F. Improving neonatal intensive care unit quality and safety with family-centered care. *Clin Perinatol.* 2023 Jun;50(2):449-472. doi: 10.1016/j.clp.2023.01.007. Epub 2023 Mar 21. PMID: 37201991.
6. https://nidcap.org/testimonials

Welcome New Member of Editorial Team and Co-Editor of the Family Voices Column

Lívia Nagy-Bonnard

We are delighted to have Livia Nagy-Bonnard join our Editorial Team on the Developmental Observer as Co-editor of the Family Voices Column. Livia is Founder and Vice-President of the Melletted a Helyem Egyesület association for preterm babies in Hungary. She is the mother of four, including a son born prematurely at 27 weeks' gestation who is now a young adult living with multiple disabilities. Livia is a patient expert - EUPATI (European Patients' Academy on Therapeutic Innovation) Fellow, also a member of the GFCNI (Global Foundation for Care of Newborn Infants) - European Standards of Care for Newborn Health project's Parent Advisory Board and is an NFI (NIDCAP Federation International) Family Advisory Council member. Livia coordinates FINE (Family and Infant Neurodevelopmental Education) training in Hungary and received an EFCNI award for organising the adaptation of FINE for online training in Hungarian. She has completed FINE 2 and is currently involved in a FINE 3 quality improvement project on neonatal pain management at Semmelweis University Hospitals in Hungary. Livia brings a wealth of knowledge and connections to our team.

DOI: 10.14434/DOV17I3.39756

Julia Giesen MSc. SLP, R.SLP, S-LP(C)

I am Julia Giesen, a speech-language pathologist with 17 years of clinical practice working with pediatric patients in their homes, community programs, rehabilitation, and acute care settings. I am an Adjunct Professor in the department of Communication Sciences and Disorders at the University of Alberta. My primary role is as a feeding and swallowing specialist in the Philip C. Etches Neonatal Intensive Care Unit (NICU) at Stollery Children's Hospital. I am certified as a NIDCAP Professional and as an instructor and mentor for Family and Infant Neurodevelopmental Education (FINE). I draw on this learning to coach families and NICU staff in providing developmentally supportive, responsive care for infants.

I wrote this poem as a reflection after my first APIB (Assessment of Preterm Infants' Behavior) training session with Dr. Juzer Tyebkhan and Dr. Deborah Buehler. Juzer conducted the APIB on a little one who had been in our NICU for three months. His parents were in the room during the APIB. At the end, Juzer called his father over and he spoke to his son in his first (emotional) language. That evening, I reflected on what an APIB shows us; this is the result.

Julia Giesen

"Can you tell us your story?"

Hello, nice to meet you
Can you tell us your story?
How long have you been here?
What's it been like for you?

It's been all my life.
Three months to the day.
My mom and my dad
Have never gone away.

I see that you're sleeping,
Hard to do that in here.
With all the bright lights
And the sounds in your ear.

It's hard to keep going
Here all on my own
I try to keep breathing
But can't keep my tone.

Now warm hands around me
As my heart starts to race
Wrapping me in a blanket
My hands close to my face.

Speaking softly, speaking gently
Hold me close as I wake
A new face as my eyes open
And a few breaths I take.

Well hello, now I see you
Can we try a few things?
Can you stay here with me
Even when the apple rings?

You said, "Yes, I can try
I'll try all on my own
I'll show how far I've come
How much I have grown."

In these 90 days
Since the day I was born
With all of the milestones
That my necklace adorn.

And when it's enough
When it all becomes the same,
I hear my father's voice;
He's calling my name.

That's me! That's my dad!
I turn to my right
I smile so broadly
Then with all of my might.

I call right out to him
As his tears trace a line.
I'm here Dad, I hear you
I'm yours and you're mine.

Illustration VectorStock/gthd

The Transformative Power of NIDCAP: An Australian Medical Perspective

Dr Hannah Dalrymple, MBBS BSci(Med) FRACP MPH

Australasian NIDCAP Training Centre.

DOI: 10.14434/DO.V17I3.39757

I never planned to become a NIDCAP Professional. The first time I heard about the process, I thought it was too big a commitment to fit in amongst a busy medical role and motherhood to two young children. But life has a funny way of leading me to career decisions I don't expect. When I unexpectedly became a neonatologist in the Grace Centre for Newborn Intensive Care, I was immersed in the developmental care culture of the Australasian NIDCAP Training Centre. Slowly, I was integrated into the developmental care team, and as I witnessed the impact of the work, I was encouraged and supported to undertake the training. In Australia, only one neonatologist had previously been trained, and I saw it as an opportunity to extend my scope of practice into an important area of neonatology.

The NIDCAP process was transformative for me as a clinician and parent. While observing, I was self-conscious about my role as a neonatologist in the unit. I felt I was different from my fellow NIDCAP nursing trainees due to my preconceptions about the medical hierarchy. Observing and interpreting how clinicians cared for babies and their potential impacts felt uncomfortable. Still, I learned to lean into my relationships with curiosity and kindness, slowly becoming accustomed to guiding staff using my expanding knowledge and experience. I began to understand that our unit hierarchy differs from many departments, having a culture built on maintaining relationships with all staff, thanks to an incredibly inclusive head of department. As my boss would say, "It is for the babies," and that is the mantra that permeates the culture of the department.

Balancing the clinical complexity of our patients in a surgical NICU with normalizing experiences for the baby was also challenging. Towards the end of our reliability training, we observed a baby boy due to be discharged from the NICU that day. He was using *"a range of behaviours to communicate with his carers when he is not coping well with caregiving"*, displaying clear cardiac physiological vulnerability. Focusing on his strengths, I recommended normalizing feeding opportunities. Still, following transfer to the ward, he had a clinical deterioration, was readmitted to the Paediatric ICU (PICU), later deteriorated further, and eventually, he sadly did not survive. The niggling feeling during my observation that he wasn't coping was subtle and in retrospect I felt regret that I had not acted more strongly on this. It was an excellent reminder to trust those instincts when noticing subtle signs in babies, bringing a different perspective to my clinical decision-making.

Family cuddles on day 5 of life

Advanced Practicum

I was nervously excited to commence the advanced practicum (AP) component of the NIDCAP training. Leading into the AP, everyone had told me that being able to support a family throughout admission was such a valuable, enjoyable, and privileged undertaking, but I was anxious. My first observation of Keziah was a massive relief; I hadn't forgotten all I had learned during reliability training. The AP also brought new challenges, such as observing in units other than my own with nursing staff unfamiliar with neurodevelopmental care and the NIDCAP observation process. Following the postponement of surgery for Keziah, my second observation found me arriving fatigued and sweaty after cycling on an exercise bike carrying a former patient to raise money for our NICU. Of course, having missed the nursing care, it was my longest observation. I observed Keziah for 60 minutes while he was being breastfed, and his attentive parents performed care.

An excerpt from my reflection on the observation:

> *"The observation was prolonged and tiring due to the parents gently struggling to wake Keziah up for a feed. They interacted with him beautifully and were very gentle….. My biggest surprise during this observation was how the space and design of the room were more developmentally friendly…..*

The room noise and activity were lower… and there was a lot more space at the bedside allowing each of the parents to have a chair. ….. but much more clinical than Grace with no pictures on the walls. The nursing staff were both friendly and receptive to my presence, showing interest in developmental care learning….. different to my expectations."

I visited the family throughout the admission, even when not undertaking observations. The most challenging time was visiting Keziah when he was puffy and had an open chest post-bypass surgery. His mother was *"visibly very stressed and chewing her nails and bouncing her legs."* I knew from being on service at that time that the cardiology team was worried about him, too. It was difficult for me to see him like this, and I felt inadequately prepared to support his parents, who were finding it much harder. Although my medical summaries had always been a strength, according to my trainer, I felt voyeuristic in this period, having not worked in the PICU before and being out of my comfort zone clinically.

Challenges

My expectations were constantly challenged throughout this process, both in terms of what I expected from the hospital system and what I had expected from this beautiful family. They taught me that attentive, sensitive parenting can come naturally to any parents, despite the challenges of having an unwell baby, as this couple took everything in their stride. They were hungry for information and support, and despite feeling like I was imposing on them, I could provide additional care beyond the standard healthcare provision by the system. After discharge, I supported Mum with her questions via email and phone, despite the family being well-engaged with the hospital's ambulatory care service. This initially made me uncomfortable, as I felt it was beyond my scope, and I directed her to appropriate resources. However, my trainer pointed out that it reflected her trust in me and the development of a bond. The relationship I formed with this mother has endured, and I have seen Keziah twice in developmental follow-up, always to his mother's excitement. To my delight, his development is on track with Bayley's assessment at one year of age. I didn't expect my recommendations to have such an impact on the patient's family. Still, feedback was that *"everything was great"*, they *"learnt a lot"*, and input from a neonatology colleague that the *"incorporation of the NIDCAP recommendations made his care superior"* was very rewarding.

Completing the AP brought more challenges and frustrations, as it examined the systemic issues plaguing the provision of neurodevelopmental care in our healthcare systems. Despite evidence that high noise and activity are detrimental to patient outcomes, implementing change is challenging. Despite some quality improvement efforts in this area, it is very difficult to achieve traction. Sucrose usage for settling remains a problem, and significant areas of neurodevelopmental care require evidence before we can convince the rest of the neonatal healthcare community of the importance and need for simple interventions that support babies and families.

Developmental follow-up with Keziah and his mother at 3 months of age

An Achievement

At the end of the training process, I was surprised by how much I felt that NIDCAP certification was a significant achievement. My AP folder sits proudly on my office bookshelf, and the skills I've acquired through reflection and neurodevelopmental care continue to enhance my clinical career. This process showed me how simple changes can benefit babies and families in our care. It also showed me how important it is to meet the family where they are and support them through learning about their baby together. NIDCAP presents me with new challenges for ongoing learning through leadership and business skills as co-director of The Australasian NIDCAP Training Centre. In the future, I hope to encourage my medical colleagues in Australia to adopt neurodevelopmental care and its benefits for our young patients. As I wrote in my final reflections during the advanced practicum, *"I enjoyed the close relationship with the family, and they hold a special place in my heart. I often think of them and hope Keziah will thrive at home."*

Thank you to Keziah and his family for allowing me to be a part of their journey and for sharing their story and photographs.

Práctica Avanzada de la Formación NIDCAP: Tesoros Escondidos Para Aprendices y Entrenadores

Dalia Silberstein, PhD, RN

NIDCAP Trainer, Israel NIDCAP Training Center

DOI: 10.14434/DO.V18I2.41642

Mi percepción de la formación en el marco del modelo NIDCAP es la de un gradual recorrido de creciente acercamiento a las necesidades del bebé y su familia, así como una más profunda comprensión de la incidencia que tiene en ellas el equipo de profesionales que les cuida. Dicha idiosincrasia – la de gradual y creciente – es indispensable en un proceso de formación cuyo objetivo es comprender y cuidar la individualidad del bebé.

La formación del profesional NIDCAP consta de diversas fases.[1] Una vez que el profesional en formación (en adelante, "aprendiz") ha demostrado una apropiada conceptualización del comportamiento del bebé, y es capaz de formular adecuadamente sus observaciones y recomendaciones de cuidados, la fase siguiente en su formación es la Práctica Avanzada (en adelante, "PA"). La PA consiste en la observación periódica, siguiendo la metodología aprendida, del bebé y su familia, desde el ingreso a la unidad de cuidados intensivos neonatales (UCIN) hasta el alta hospitalaria y la transición al hogar.[2]

La PA es un importante punto de inflexión en el proceso de formación y un componente singular del mismo. Aprendices y entrenadores llegamos a la PA con un buen grado de ilusión y expectativa. Acompañados, tal vez, de interrogantes: ¿Seremos capaces de crear una genuina relación de apoyo y colaboración con la familia? ¿De qué manera evolucionará la misma? ¿Cuáles serán sus matices, a medida que transcurran las semanas? ¿De qué forma expresaremos, sea por escrito como a través de acciones y hechos, nuestro compromiso con el cuidado del bebé y su familia, y con el proceso de formación en sí mismo? ¿Podremos construir y asegurar esa envoltura contenedora al bebé, a sus padres, al aprendiz y a los profesionales de la UCIN, que propugna el modelo NIDCAP?[3]

Estas preguntas nos invitan a reflexionar sobre aquellas oportunidades menos aparentes o explícitas, aún por descubrir, que esta fase de la formación nos proporciona a aprendices y a entrenadores en igual medida.

Si llegamos con curiosidad, con la mente y el corazón abiertos, ¿qué "tesoros escondidos" podremos descubrir a partir de nuestra experiencia con la PA? Quisiera plantear en este artículo algunos de los que he descubierto a partir de mis propias experiencias de formación.

Una llamada a la individualidad

La PA abarca varias semanas. Se inicia en los primeros días tras el nacimiento, sigue en la hospitalización y el alta, y finaliza en el entorno familiar. Durante todo ese tiempo, el seguimiento longitudinal y periódico del bebé a través de las observaciones

Reflexionando sobre las observaciones durante la Práctica Avanzada

NIDCAP, nos aporta un mejor conocimiento de sus necesidades y nos compromete de una nueva manera con la promoción de su constante evolución y desarrollo.

La PA pone a prueba nuestra capacidad de adoptar, desarrollar y mantener a través del tiempo, un enfoque individualizado del cuidado. Esta etapa de la formación nos convoca a ajustar y afinar más aún esa capacidad, que veníamos desarrollando ya en etapas anteriores de la misma. Nos impulsa a adecuar más cabalmente nuestro análisis y a articular nuestras recomendaciones para este bebé que seguimos – que es específico y único. Nos sitúa en la necesidad de amoldarlas a sus capacidades y vulnerabilidades; a su evolución clínica; a su familia; a sus circunstancias irrepetibles y singulares.

Ser capaz de asegurar la individualización del cuidado[1] es la competencia central a desarrollar en la formación NIDCAP. Debido a ello, durante la PA, nuestra capacidad de mantener esa perspectiva de cambio y evolución que propugna la Teoría Sinactiva del Desarrollo,[3] se hace imprescindible y se pone en mayor evidencia. Importa tener presente que, como todos sabemos, de esta teoría surge el modelo NIDCAP.

Por el hecho de ser un pilar básico del modelo que estudiamos, es necesario que el aprendiz haya comenzado a desarrollar esta competencia ya en etapas tempranas de su formación, anteriores a la PA. No obstante, la habilidad del aprendiz de individualizar las recomendaciones y propuestas de cuidado se hace visible con mayor claridad durante la PA. En consecuencia, el

requisito de contar con la capacidad de individualizar el cuidado emerge aún con mayor magnitud en esta fase de la formación.

Una situación que ejemplifica lo que señalo es la recomendación de cuidados *"mantener el contacto físico cercano con su madre"*. Se trata de una recomendación presente en todas y cada una de las etapas que ha vivido el bebé desde su ingreso en la unidad. Ha sido relevante y crucial para el bebé al que estamos siguiendo desde el mismo momento de nacer, y constituye una necesidad que está presente, sin excepción, en cada una de las etapas de su hospitalización.[4] Sin embargo, la manera de abordarla y actualizarla para el bebé y su familia es distinta en cada etapa de su desarrollo. Hemos de anticipar que el abordaje de esa necesidad medular se transforme y evolucione en cada una de las observaciones que componen la PA.

Es, por tanto, de gran importancia que en dichas observaciones - que el aprendiz formula y el entrenador evalúa - seamos capaces de identificar y poner en evidencia esa singular evolución que presenta cada bebé, cada familia. Así, ateniéndonos al ejemplo anterior, si se tratase de un bebé en su segundo día de vida que se encuentra fisiológicamente inestable y medicamente lábil, puede que la recomendación "universal" antes propuesta, tome la forma singular de: *"Considera guiar a los padres en el modo de ayudar a su bebé a mantener una posición relajada, posando suavemente sus manos alrededor de su cuerpo, de tal forma que los pies y los brazos del bebé estén levemente flexionados y cercanos al cuerpo"*.

En observaciones futuras hemos de formular claramente (el aprendiz) e identificar (el entrenador) como aquella necesidad incuestionable, constante e inamovible, de *"mantener el contacto físico cercano con su madre"*, adquiere distintos matices. Tales matices son la manifestación inequívoca la de individualización. Por ello, deben quedar reflejados en la PA en unas recomendaciones de cuidados individualizadas que varían en función de los cambios producidos en el bebé y sus circunstancias, por ejemplo: su situación clínica; su capacidad de estar alerta o de organizar su postura; la competencia de sus padres; etc.

En definitiva, tal como he tratado de argumentar, la PA nos confronta, tanto a aprendices como a entrenadores, con el reto de la individualización. Es en esta etapa del aprendizaje en el que con mayor claridad podemos poner de manifiesto nuestra capacidad de percibir el cuidado de manera individualizada.

Este es el primero de los tesoros escondidos de la PA: la oportunidad sin igual que esta vía de aprendizaje ofrece al aprendiz y al entrenador. Al aprendiz le permite demostrar su *competencia para individualizar* sus apreciaciones y sugerencias. A su vez, le ofrece al entrenador la posibilidad de identificar y evaluar *el grado en que dicha competencia está en uso* durante el trabajo del aprendiz con él bebé y la familia.

Usos y desusos del lenguaje

Tal como he señalado, durante la PA se observa al bebé en el transcurso de varias semanas. Esa suerte de "relato" a través del tiempo acerca del bebé en interacción con su entorno, con su familia, y con los cuidadores profesionales, proporciona un contexto en el que examinar nuestro lenguaje y reconocernos en él. El texto de las observaciones brinda una oportunidad más para identificar la medida en que logramos ser facilitadores del desarrollo.

En definitiva, tal como he tratado de argumentar, la PA nos confronta, tanto a aprendices como a entrenadores, con el reto de la individualización. Es en esta etapa del aprendizaje en el que con mayor claridad podemos poner de manifiesto nuestra capacidad de percibir el cuidado de manera individualizada.

La PA posibilita una mirada amplia e integradora. Es en esta etapa de la formación NIDCAP en la que podemos examinar de forma más completa nuestro discurso y el lenguaje que manejamos. Abordaré esta percepción personal brevemente, con relación a tres ejes del cuidado que ya he mencionado: el bebé; los padres y los cuidadores profesionales.

Con relación al bebé, la PA nos sitúa en la necesidad de escoger con sensibilidad las palabras y expresiones que utilizamos para transmitir aquello que deseamos comunicar y enfatizar acerca del bebé y su desarrollo. Por ello, nos insta a prestar atención a cuán cabalmente se refleja en el lenguaje que utilizamos nuestra percepción del bebé como un ser competente.[5,6] En consecuencia, nos induce a explorar si hemos sido capaces de reflejar tanto sus fortalezas como sus vulnerabilidades. Explorar el lenguaje que utilizamos en la PA supone, en definitiva, valorar en qué medida aquello que expresamos se adhiere al modelo de cuidados que propugnamos.

Con relación a los padres y cuidadores profesionales, las directrices del programa de formación[1] nos instan a articular informes NIDCAP que: resulten claros y sostenedores para ellos; que les habiliten para comprender el lenguaje comportamental del bebé; que fomenten la creatividad y confianza de los padres y cuidadores para apoyar y promover el desarrollo del

bebé. Las directrices recomiendan, además, que aquello que comunicamos y escribimos impulse a los padres a sentir placer y seguridad en el ejercicio de su rol parental en el complejo entorno de la unidad neonatal.[2]

Nada de lo anterior puede lograrse sin el uso reflexivo de nuestro propio lenguaje, tanto en los informes escritos que componen la PA, como en el diálogo que entablamos con padres e integrantes del equipo profesional de la unidad. El lenguaje que utilizamos puede contribuir al crecimiento profesional y a la transformación de la cultura de cuidados de la unidad.

Desde mi perspectiva, es en esas notas del entrenador en las que radica otro tesoro escondido en la PA: el uso de un instrumento sencillo como plataforma desde la cual *propiciar el diálogo*.

Por todo ello planteo que, a la hora de valorar la PA, es conveniente responder a algunas cuestiones centrales en nuestro compromiso de apoyo al desarrollo del bebé. Entre ellas destacan, a mi entender, las siguientes: ¿Hemos sido capaces de transmitir fortalezas y vulnerabilidades inherentes al lenguaje comportamental del bebé? ¿Hemos sido suficientemente hábiles al articular los próximos pasos en su trayectoria de desarrollo? ¿Hemos hecho acopio de la sensibilidad y delicadeza necesarias para plantear unas recomendaciones de cuidados que contribuyan a su desarrollo? Finalmente, cabe también preguntarse si hemos realizado el indispensable proceso de introspección que nos permite priorizar nuestro rol de guías y posibilitadores del cuidado7, como parte integral de nuestra identidad profesional.

Aquí yace, entonces, un segundo tesoro escondido de la PA: *el lenguaje utilizado al escribir las observaciones y comunicarlas*, ofrece una ventana desde la cual apreciar las percepciones más genuinas y profundas que tenemos del cuidado que brindamos al bebé y su familia en el marco del modelo NIDCAP.

Construir el diálogo

Aprendices y entrenadores incorporan al proceso de formación NIDCAP sus propias percepciones y perspectivas del cuidado. Como entrenadores nos enfrentamos al reto de ser cálidos, sensibles y respetuosos, de identificar y comprender las percepciones de nuestros alumnos y hacer explícitas - al mismo tiempo - las nuestras, sin imponerlas y sin asumir que se dan por sentadas.

Una cuestión que me he preguntado desde mi rol como entrenadora NIDCAP es la siguiente: ¿Cómo puede iniciarse, promoverse y mantenerse vivo un diálogo que es necesario y vital, en una formación que por lo menos en parte, se lleva a cabo a distancia? En mi caso, he utilizado el recurso de notas escritas intercaladas en el texto del aprendiz. He utilizado dichas notas como una primera y muy básica plataforma desde la cual construir una base para el dialogo que se establecerá después, a través de conversaciones - en persona u online. Estas notas me han proporcionado un modesto cimiento desde el cual propiciar un diálogo reflexivo, abierto, y esclarecedor entre aprendiz y entrenador.

He aprendido, a su vez, que algunos aprendices pueden estar poco familiarizados con este "método" y que, acaso, puedan sentir cierta incomodidad al recibir un trabajo que incluye numerosas notas. Viniendo de sistemas educativos más o menos tradicionales, muchos hemos sido educados en la premisa que cuanto más impecable y con menos notas se nos devuelve un trabajo, mejor. Un trabajo que contiene muchas notas del profesor o mentor es – según dicha concepción – un trabajo menos logrado. Sin embargo, desde mi experiencia, las notas son vitales para propiciar la reflexión y el diálogo, y es por ello que procuro incluirlas. No hacerlo significaría, desde mi punto de vista, renunciar a un intercambio más abierto de ideas sobre lo observado acerca del bebé y su familia. A menudo he sentido la necesidad de explicar este punto de vista, y asegurar al aprendiz que estas notas son un elemento ineludible en la construcción de un dialogo más libre, que dará lugar a un más profundo aprendizaje.

Sin el intercambio y la mutua exposición de puntos de vista, el proceso de aprendizaje se empobrece.

Desde mi perspectiva, es en esas notas del entrenador en las que radica otro tesoro escondido en la PA: el uso de un instrumento sencillo como plataforma desde la cual *propiciar el diálogo*.

Enhebrar reflexiones

La práctica del modelo NIDCAP consiste en observar, articular lo que hemos observado y reflexionar acerca de ello. Las observaciones secuenciales de la PA nos permiten mirar de manera estructurada e individualizada el comportamiento del bebé y sus necesidades de desarrollo a lo largo del tiempo. Es la lectura de dichas observaciones la que permite al entrenador valorar lo que el aprendiz ha *observado e inferido*. Sin embargo, son las reflexiones escritas que se adjuntan a cada una de las observaciones de la PA las que otorgan al entrenador un atisbo de lo que el aprendiz *ha sentido y experimentado*. La reflexión, sustentada en los apartados que aporta la denominada "Journal Page"[8] de la formación NIDCAP, proporciona una ventana única al mundo interior del cuidador, en este caso el aprendiz.

La oportunidad de reflexionar que nos otorga la PA pone a prueba nuestra capacidad de pensar más libremente, de quitar

vallas a nuestra mente y plasmar con espontaneidad aquellos pensamientos que la observación ha despertado en nosotros. Puede que, en esa implícita invitación de la PA a la libre reflexión, radique su aparente complejidad. No es inusual que los aprendices manifiesten una cierta "dificultad para reflexionar". De hecho, a menudo han preguntado qué tipo de pensamientos sería pertinente incluir en esa sección de la PA.

Son la necesidad y el deseo de mirar una situación aparentemente conocida desde nuevas perspectivas, los que desencadenan la exigencia de reflexionar sobre la práctica profesional. Hacerlo requiere cierta dosis de introspección, sensibilidad y tolerancia. Por sobre todas las cosas, reflexionar significa estar en disposición de hacer una pausa, de frenar. Quizás en cada uno de estos atributos radica la dificultad de ejercitar la reflexión que se manifiesta, a veces, durante el proceso de formación.

Sin embargo, el imperativo de reflexionar que exige la formación NIDCAP es más sencillo de lo que pueda parecer a primera vista, si se aborda con genuina libertad. Mi consejo es aproximarnos al ejercicio de la reflexión con la mente – y sobre todo el corazón – abiertos. Permitirnos la libertad de considerar todo aquello que nos viene en mente a partir de la observación que hemos hecho. Que no impongamos límites estrictos, ni atendamos a un determinado método o estructura al hacerlo. Que hagamos un pequeño inventario de los pensamientos y sentimientos que cada observación ha despertado en nosotros. Llegados a este punto, que escojamos en cuál de ellos nos gustaría detenernos a reflexionar por escrito. Bastaría, desde mi punto de vista, con que el aprendiz aborde cada vez uno o dos "temas" de su inventario. Así, cada observación y su correspondiente reflexión nos obsequiarían seguramente con el tesoro escondido de descubrir un nuevo matiz, una nueva faceta en nuestro aprendiz.

Es así como al leer la PA, las reflexiones del aprendiz que acompañan las distintas observaciones se enhebran a través de nuestra lectura en una suerte de collar imaginario. Las reflexiones nos proporcionan una herramienta más para para *apreciar las diversas maneras en las que el aprendiz percibe al bebé, su trayectoria de desarrollo y las interacciones de cuidados que experimenta*.

Cultivar el orgullo

Uno de los principales objetivos de la PA es que el aprendiz aprenda a apoyar al bebé y su familia, así como al equipo profesional que colabora con ellos, para ayudarles a sentirse más competentes para cuidar a su bebé y favorecer su desarrollo.[1]

En mi práctica como enfermera desde la perspectiva del modelo NIDCAP, he identificado que una de las maneras más apreciadas y eficaces para brindar ese tipo de apoyo es cultivando el sentido del orgullo, tanto en los padres como en los profesionales. Son muchos los motivos para sentir orgullo y satisfacción en el día a día de una unidad neonatal. Por ejemplo: por los cuidados que se brindan; por la capacidad de individualizar las decisiones; por mantener el foco asistencial en el bebé y su familia; por las incipientes capacidades que día a día va mostrando el bebé, a pesar de la fragilidad de su prematuridad o de las complejidades médicas que pueda presentar.

La PA, con su metódico seguimiento del bebé a lo largo de varias semanas, nos permite situar ese orgullo en un primer plano, nos ofrece un ámbito en el que regocijarnos (tanto padres como profesionales) en los logros del bebé. La PA nos invita a enfatizar la alegría de formar parte del esfuerzo conjunto de ayudar a ese bebé y su familia a expresar su más óptimo potencial de desarrollo. En el complejo entorno de la UCIN, donde lo urgente puede a menudo quitar lugar a lo importante, la PA nos obsequia con otro pequeño tesoro: un contexto donde *detenernos, destacar y cultivar la alegría y el orgullo* por el bebé que cuidamos.

Conclusión

La PA de la formación NIDCAP proporciona una experiencia llena de oportunidades de aprendizaje tanto para aprendices como para entrenadores. Adquirir mejor competencia y habilidad para individualizar, utilizar más adecuadamente el lenguaje, reflexionar, fomentar el diálogo y cultivar el orgullo son - desde mi perspectiva - algunas de las más destacadas.

No obstante, las nociones y competencias que afianzamos en esta etapa de la formación no se limitan exclusivamente al ámbito de la PA, sino que, de hecho, la trascienden. Si somos capaces de proyectar más allá esas nociones y competencias, podremos ejercitarlas e implementarlas en otros contextos de nuestro ejercicio profesional. De esta manera, beneficiaremos y enriqueceremos cada una de las interacciones de cuidados en las que participemos, y cada una de las experiencias de aprendizaje que propiciemos. En este sentido, la PA encierra la potencialidad de convertirnos no solamente en profesionales NIDCAP, sino también en mejores cuidadores en el marco del equipo multidisciplinar de cuidados de la unidad neonatal.

Agradecimientos

Agradezco de corazón a María Maestro y Josep Perapoch, de la Federación Internacional NIDCAP, por aportarme sus valiosas reflexiones, incorporadas a este manuscrito. Y a Consuelo López, de la Universidad de Cádiz, por revisar este trabajo y sugerir importantes mejoras al texto.

Bibliografía

1. Als H. Program Guide. *Newborn Individualized Developmental Care and Assessment Program (NIDCAP): An Education and Training Program for Health Care Professionals.* Copyright, NIDCAP Federation International, 1986, rev 2009.
2. Als, H. *Guidelines for Advanced NIDCAP Practicum: Following an Infant and Family from Admission to Discharge and Transition to the Home.* Copyright NIDCAP Federation International, 2010.
3. Als H. Toward a synactive theory of development: promise for the assessment and support of infant individuality. *Infant Ment Health J*. 1982; 3(4):229–43. doi: CO;2-H 10.1002/1097-0355(198224)3:43.0.
4. Flacking R, Lehtonen L, Thomson G, Axelin A, Ahlqvist S, Moran V et al. Closeness and separation in neonatal intensive care. *Acta Paediatrica*, 2012; 101, 1032–1037.
5. Brazelton TB. Preface. Pediatrics, 2005;113, 632-633.
6. Tronick E. *The neurobehavioral and social-emotional development of infants and children.* 2007; W. W. Norton & Company. New York. London.
7. Als H & Gilkerson L. The role of relationship-based developmentally supportive newborn intensive care in strengthening outcome of preterm infants. *Seminars in Perinatology*, 1997; 21 (3):178-189.
8. Als H. Documentation of NIDCAP Observations: Journal Page. Copyright NIDCAP Federation International, 2018.

The Advanced Practicum in NIDCAP Training: Hidden Treasures for Trainees and Trainers

Dalia Silberstein, PhD, RN

NIDCAP Trainer, Israel NIDCAP Training Center

DOI: 10.14434/DO.V18I2.41643

My perception of training within the NIDCAP model framework is that of a gradual and increasing approximation to the needs of the infant and their family, as well as a deeper understanding of the professional team's impact on their care. This idiosyncrasy - gradual and increasing - is essential in a training process aiming to understand and care for the infant's individuality.

NIDCAP training consists of several phases.[1] Once the professional in training (hereafter, "trainee") has demonstrated an appropriate conceptualization of the infant's behaviour and can formulate appropriate observations and care recommendations, the next phase in training is the Advanced Practicum (hereafter, "AP"). The AP consists of periodic observations, following the learned methodology, of the infant and family, from admission to the neonatal intensive care unit (NICU) until hospital discharge and transition home.[2]

The AP is an important turning point in the training process and a unique component. Both trainees and trainers come to the AP with a good deal of excitement and expectation, and perhaps holding various questions in mind: Will we be able to create a genuine relationship of support and collaboration with the family? How will it evolve? What will be its nuances as the weeks go by? How will we express, both in writing and through actions and deeds, our commitment to the care of the infant and family, and to the training process itself? Will we be able to build and ensure the supportive envelope needed for the baby, the parents, the trainee, and the NICU Professionals that the NIDCAP model[3] advocates for?

These questions invite us to reflect on those less apparent or explicit opportunities, yet to be revealed, that this phase of training offers to both trainees and trainers.

If we come with curiosity, with open minds and hearts, what "hidden treasures" can we discover in our experience with AP? In this article, I would like to discuss some of those I have discovered in my own training experiences.

A call for individuality

The AP spans several weeks. It begins in the first days after birth, continues through hospitalization and discharge, and ends in the home environment. Throughout this time, longitudinal and regular follow-up of the infant through NIDCAP observations provides us with a better understanding of their needs; it engages us in a new way in promoting their ongoing evolution and development.

The AP tests our ability to adopt, develop, and maintain an individualized approach to care over time. This stage of training calls upon us to further adjust and refine that capacity, which we have been developing in earlier stages of NIDCAP training. It prompts us to refine our analysis further and to articulate our recommendations for this unique infant we are following. It places us in the need to tailor those recommendations to the infant's strengths and vulnerabilities, their clinical evolution, their family, and their circumstances.

Finding new ways to build a dialogue

The core competence to be developed in NIDCAP training is the ability to ensure the individualization of care.[1] Because of this, during AP, our ability to maintain the perspective of change and evolution advocated by the Synactive Theory of Development[3] becomes essential and more evident. It is important to remember that the NIDCAP model stems from this theory.

Since it is a fundamental pillar of the model we are studying, the trainee must have begun to develop this competence in the early stages of their training, prior to the AP. However, the trainee's ability to individualize care recommendations becomes more visible during the AP. Consequently, the requirement to individualize care emerges even more strongly at this stage of training.

A situation to exemplify this is the care recommendation *"maintain close physical contact with mother"*. This recommendation is appropriate for every stage of the infant's life. It has been relevant and crucial from the very moment of birth, and constitutes a need that is present, without exception, at every phase of the infant's hospitalization.[4] However, the way of addressing and updating it for the infant and family differs at

each developmental stage. We must anticipate that our approach to this core developmental need will change and evolve in each of the observations that make up the AP.

It is therefore very important that in these NIDCAP observations, which the trainee formulates and the trainer evaluates, we can identify and highlight the unique evolution of each infant and family. Thus, following the previous example, if it was a physiologically unstable and medically labile two-day old infant, the previously proposed "universal" recommendation above might take the singular form of: *"Consider guiding J's parents on how to help her maintain a relaxed position by gently placing their hands around her, so that J's feet and arms are slightly bent and close to her body."*

In future observations we need to clearly formulate (the trainee) and identify (the trainer) how that unquestionable, constant and immovable need *"to maintain close physical contact with his mother"* takes on different nuances. Such nuances are the unmistakable manifestation of individualization. Therefore, they should become apparent in the AP as individualized care recommendations that vary according to changes in the infant's circumstances, e.g., their clinical situation; their ability to be alert or organize their posture; the parents' competence, etc.

In short, as I have tried to articulate, the AP confronts both trainees and trainers with the challenge of individualization. It is at this stage of the training process that we can most clearly demonstrate our ability to perceive care in an individualized way.

This is the first of the AP's hidden treasures: the unparalleled opportunity that this learning path offers to the trainee and the trainer. It allows trainees to demonstrate their competence in individualizing their assessments and suggestions. In turn, it allows the trainer to identify and evaluate *the degree to which this competence is in use* during the trainee's work with the infant and family.

Uses and misuses of language

As previously pointed out, during the AP, the infant is observed over the course of several weeks. This kind of "narration" over time about the infant in interaction with their environment, their family, and the professional caregivers, provides a context in which to examine our language and to recognize ourselves in it. The written text of the observations provides a further opportunity to identify the extent to which we succeed in being facilitators of development.

The AP enables us to take a broad and integrative view. At this stage of NIDCAP training, we can more fully examine our discourse and language. I will briefly address this personal perception in relation to three components of care that have already been mentioned: the baby, the parents, and the professional caregivers.

Regarding the infant, the AP places us in a position where we must choose carefully the words and expressions to use in our communications (reports) about their development. It

In short, as I have tried to argue, the AP confronts both trainees and trainers with the challenge of individualization. It is at this stage of the training process that we can most clearly demonstrate our ability to perceive care in an individualized way.

therefore prompts us to pay attention to how fully our perception of the infant as a competent being is reflected in the language we use.[5,6] Consequently, it leads us to explore whether we have been able to reflect about their strengths and vulnerabilities. Exploring the language we use in AP, ultimately means assessing the extent to which it reflects the NIDCAP model of care.

Regarding the parents and professional caregivers, the training program guidelines[1] encourage us to articulate NIDCAP reports that are clear and supportive for them; that enable their understanding of the infant's behavioural language; and that foster their creativity and confidence to support and promote infant's development. The guidelines further recommend that what we communicate and write does encourage parents to feel pleasure and confidence in their parental role in the complex environment of the neonatal unit.[2]

None of the above can be achieved without the thoughtful use of our own language, both in written reports (which make up the AP) and in the dialogue we engage in with parents and members of the professional team. The language we use can, in turn, contribute to professional growth and to the transformation of the unit's culture of care.

Therefore, I suggest that when evaluating the AP, it might be helpful to answer some questions central to our commitment to support infant's development. Among them, the following stand out: Have we been able to convey the strengths and vulnerabilities inherent in the infant's behavioural language? Have we been sufficiently skillful in articulating the next steps in the infant's developmental trajectory? Have we mustered the necessary sensitivity and delicacy to suggest care recommendations that contribute to the infant's development? Finally, it is also worth asking

whether we have undertaken the necessary process of introspection that allows us to prioritize our role as guides and facilitators of care[7] as an integral part of our professional identity.

Here, then, lies a second hidden treasure of the AP: *the language used in writing down observations and communicating them* offers a window from which to appreciate the deeper and more genuine insights we have into the care we provide to the infant and family within the NIDCAP model.

Building a dialogue

Trainees and trainers bring their own perceptions and perspectives of care into the NIDCAP training process. As trainers, we face the challenge of being warm, sensitive and respectful, to identify and understand our trainees' perceptions and at the same time make our own perceptions explicit, without imposing them or assuming that they are taken for granted.

From my perspective, it is in these trainer's margin notes that lies another hidden treasure in the AP: the use of a simple instrument as a platform from which to *foster dialogue.*

A question I have asked myself in my role as NIDCAP trainer is the following: How can a dialogue that is necessary and vital, be initiated, promoted and kept alive in a training that is partly carried out remotely? In my case, I have used the resource of written margin notes inserted in the trainee's text. I have used these notes as a first and very basic platform from which to build a basis for a dialogue that will be established later, through conversations - in person or remotely. These notes have provided me with a modest foundation from which to foster a reflective, open, and enlightening dialogue between trainees and me.

I have learned, in turn, that some trainees may be unfamiliar with this "method" and may feel some discomfort at receiving a paper that includes numerous notes. Coming from traditional educational systems, many of us have been brought up on the premise that the more flawless and less marked a paper is returned to us, the better. A paper that contains a lot of remarks from the teacher or mentor is, according to that conception, a less successful one. However, in my experience, notes are vital to encourage reflection and dialogue, which is why I try to include them. Not to do so would mean, in my view, giving up to a more open exchange of ideas about what has been observed about the baby and family. I have often felt the need to explain this point of view, and to reassure the trainee that these notes are an inherent element in the construction of a freer dialogue, which will lead to deeper learning. Without the mutual exchange of perspectives, the learning process is impoverished.

From my perspective, it is in these trainer's margin notes that lies another hidden treasure in the AP: the use of a simple instrument as a platform from which to *foster dialogue*.

Threading reflections

The practice of NIDCAP consists of observing, articulating what we have observed and reflecting on it. The sequential observations of the AP allow us to look in a structured and individualized way at the infant's behaviour and developmental needs over time. It is reading these observations that allows the trainer to assess what the trainee has *observed and inferred*. However, it is the written reflections attached to each of the AP observations that give the trainer a glimpse of what the trainee *has felt and experienced*. Reflection, supported by the topics provided in the "Journal Page",[8] provides a unique window into the inner world of the caregiver, in this case - the trainee.

The opportunity to reflect what the AP affords, tests our ability to think more freely, to remove boundaries from our minds and spontaneously express those thoughts that the observation provoked. Perhaps it is in this implicit invitation to freely reflect that its apparent complexity lies. It is not unusual for trainees to express a certain "difficulty to reflect". Indeed, they have often asked what sort of thoughts would be pertinent to this section of the AP.

It is the need and desire to look at a seemingly familiar situation from new perspectives that triggers the demand to reflect on professional practice. Doing so requires a certain amount of introspection, sensitivity and tolerance. Above all, to reflect means to be willing to pause, to slow down. Perhaps in each of these attributes lies the difficulty of exercising reflection that sometimes manifests itself during the training process.

However, if approached with genuine freedom, reflection, an essential component of NIDCAP training, is simpler than it may seem at first glance. My advice would be to approach reflection with an open mind - and especially with an open heart. To allow ourselves the freedom to consider whatever comes to mind from the observation we have made. That we do not impose strict limits, nor do we necessarily adhere to a certain method or structure in doing so. Let us make a small "inventory" of the thoughts and feelings that each observation has awakened in us. At this point, let us choose which of them

we would like to pause and reflect on in our writing. It would suffice, in my view, for trainees to address one or two "themes" from their "inventory" in each observation. In so doing, each observation and its corresponding reflection would surely present us with the hidden treasure of discovering a new nuance, a new facet in our trainee.

Thus, as we read the AP, the trainee's reflections on each observation get threaded through our reading in a kind of imaginary necklace. These reflections provide us with another tool to *appreciate the various ways in which the trainee perceives the infant, their developmental trajectory and the care interactions they experience*.

Cultivating pride

One of the main goals of the AP is that the trainee learns to support the baby and family, as well as the professional team that collaborates with them, to help them feel more competent in caring for their baby and to promote their development.[1]

As a nurse practicing from the NIDCAP model perspective, I have identified that one of the most valued and effective ways to provide such support is to cultivate a sense of pride in both parents and professionals. There are many reasons to feel pride and satisfaction in the day-to-day life of a neonatal unit. For example: for the care provided; for the ability to individualize decisions; for keeping the focus of care on the infant and family; for the emerging abilities that the infant is showing day by day, despite the fragility of prematurity or the medical complexities they may present.

The AP, with its methodical follow-up of the infant over several weeks, allows us to bring that pride to the forefront, and offers us (both parents and professionals) an arena in which to rejoice in the infant's achievements. The AP invites us to showcase the joy of being part of the joint effort to help that infant and their family express their most optimal developmental potential. In the complex environment of the NICU, where urgency can often take the place of important experiences, the AP presents us with another small treasure: a context in which to pause, *to highlight and cultivate joy and pride* in the infant we care for.

Conclusion

The AP of NIDCAP training provides an experience full of learning opportunities for both trainees and trainers. Acquiring better competence and ability to individualize care, using language more appropriately, reflecting, fostering dialogue and cultivating pride are - from my perspective - some of the most salient ones.

However, the concepts and competences that we develop at this stage of NIDCAP training are not limited exclusively to the AP, but in fact transcend it. If we extend these concepts and competences further, we will be able to exercise and implement them in additional contexts of our professional practice. In this way, we will benefit and enrich each of the care interactions in which we take part, and each of the learning experiences that we facilitate.

One of the main goals of the AP is that the trainee learns to support the baby and family, as well as the professional team that collaborates with them, to help them feel more competent in caring for their baby and to promote their development.

In this sense, the AP holds great potential to turn us not only into NIDCAP Professionals, but also into better caregivers within the multidisciplinary care team of the neonatal unit and elsewhere.

Acknowledgement

I sincerely thank María Maestro and Josep Perapoch from the NIDCAP Federation International for providing me with their valuable reflections, which I incorporated into this manuscript. I also thank Consuelo López from the University of Cádiz for reviewing this work and suggesting important improvements to the text.

References

1. Als H. Program Guide. *Newborn Individualized Developmental Care and Assessment Program (NIDCAP): An Education and Training Program for Health Care Professionals.* Copyright, NIDCAP Federation International, 1986, rev 2009.
2. Als, H. *Guidelines for Advanced NIDCAP Practicum: Following an Infant and Family from Admission to Discharge and Transition to the Home.* Copyright NIDCAP Federation International, 2010.
3. Als H. Toward a synactive theory of development: promise for the assessment and support of infant individuality. *Infant Ment Health J.* 1982; 3(4):229-43. doi: CO;2-H 10.1002/1097-0355(198224)3:43.0.
4. Flacking R, Lehtonen L, Thomson G, Axelin A, Ahlqvist S, Moran V et al. Closeness and separation in neonatal intensive care. *Acta Paediatrica*, 2012; 101, 1032-1037.
5. Brazelton TB. Preface. Pediatrics, 2005;113, 632-633.
6. Tronick E. *The neurobehavioral and social-emotional development of infants and children.* 2007; W. W. Norton & Company. New York. London.
7. Als H & Gilkerson L. The role of relationship-based developmentally supportive newborn intensive care in strengthening outcome of preterm infants. *Seminars in Perinatology,* 1997; 21 (3):178-189.
8. Als H. Documentation of NIDCAP Observations: Journal Page. Copyright NIDCAP Federation International, 2018.

Delirium in the NICU: Seeing is Believing or Believing is Seeing?

Jeffrey R. Alberts, PhD
Indiana University, USA, NFI Science Committee, Associate Editor for Science

DOI: 10.14434/do.v18i2.41638

Delirium is recognized as a serious condition associated with hospital stays, especially in intensive care units (ICUs) and geriatric settings. Delirium is codified in the American Psychiatric Association's *Diagnostic and Statistical Manual* (DSM-5)[1] and in the World Health Organization's *International Classification of Diseases, Tenth Edition* (ICD-10).

The DSM-5 classifies delirium as a disorder of neurocognition. Symptoms are manifest as acute disturbance in attention, perception, awareness, and changes in cognition, indicating disorganization of thought, such as disorientation, alteration in language, and memory impairment. Other supportive features may be hallucinations or misperceptions, delusions, inappropriate or unsafe behavior, and lability in arousal and emotions, both of which may include hypoactive and hyperactive forms.

By definition, delirium is a syndrome of CNS dysfunction seen as a consequence of another prior medical condition.[2] Examples of such prior, physiologic causes may be from a toxin, disease, injury, medication or other iatrogenic factors. What we "see" is the result of these provocative conditions or events. The "seen" symptoms can be charted explicitly, using validated tools such as the Confusion Assessment Method for the ICU and the Intensive Care Delirium Screen Checklist,[3,4,5] which are considered easy, rapid screens.

These symptom descriptions convey the seriousness of delirium. Delirium diagnoses in adult ICU patients predict longer hospitalizations and subsequent increases in morbidity and mortality. Consequently, the syndrome has become a call for treatment plans and clinical trials for prevention and mitigation. Additionally, with reports of as many as 30 – 80% of patients experiencing hospital delirium (especially in ICUs), investigators have widened their investigations to examine different populations and age groups.[2, 6] Delirium is now reported in pediatric patients, and questions of treatment approaches, including pharmacological interventions are being tested.[5,6,7]

The foregoing summary brings us to the question introduced in the title of this essay: Does delirium arise in the NICU? There is urgency in this question because delirium is a syndrome that creates suffering and, importantly, regularly leads to additional morbidities and even to mortality. Furthermore, delirium is associated with ICU conditions and procedures, many of which prevail in the NICU! (Admission to an ICU or NICU often means separation and isolation; the restraints and stresses of mechanical ventilation are frequently cited as potential iatrogenic precursors, as are the after-effects of some sedatives, etc.).[7-10]

Image by Emanuel Angelicas

Maternal and Infant gaze

There is general acceptance that delirium can be discerned validly and reliably in medical and surgical wards, postoperative recovery areas, emergency departments as well as the ICUs and step-down units. It is reported in geriatric, adult, and pediatric populations. My survey of published reports of delirium in the NICU yielded a small number of case reports.[11,12]

Here, I will bring to the discussion some perspectives and considerations from the field of "developmental science". Though it is not a clinical specialty, I have found that this field has ideas to share with neonatology that are sometimes helpful

in pragmatic ways and often make useful contributions by stimulating fresh approaches and considerations. Let's give it a try.

We'll address two views which can be considered "opposing" perspectives. Admittedly, this is a simplification because each view is contained in the other. Nevertheless, for starters, let's go with the two "opposing" statements: Seeing is Believing and then Believing is Seeing, because an initial separation will help clarify the issues.

I emphasize that I am proceeding with caution and respect because I do not have direct professional experience with hospital delirium. The thoughts that I share here are reactions to the published literature, combined with decades of lab-based experience as a "developmental psychobiologist" working with perinatal animals (rats and mice). Additionally, I am a proud NIDCAP Professional, with approximately 10 years of experience in this specialty within NICUs.

Seeing is Believing

As officially codified in the DSM-5 and by other respected professional groups, delirium is defined as a syndrome of CNS dysfunction. It is understood as a neurocognitive disorder. What does "neuro" "cognitive" mean in this context? The "neuro" component refers to brain function (dysfunction or encephalopathy in the present discussion). Thus, we consider brain systems as the substrate responsible for the behavioral changes that are manifested. The "cognitive" component refers to some of the non-behavioral changes that contribute to the symptoms. These are changes in thinking, some emotions, perceptions, attention, focus, awareness, and orientation to people and things.

Cognitions themselves cannot be seen: they are inferred and interpreted. Cognitions are usually ascribed to "higher" functions of the mind and brain. As such, cognitive processes are localized in "higher" regions of the brain, particularly the cerebral cortex. Top of the list: Frontal Lobes for "executive functions" such as attention, emotional control, decision making; Broca's Area, in the left frontal gyrus, controlling speech production and word usage; Wernicke's Area, left posterior superior temporal gyrus, understanding meaning of words and sentences, and so on across the cortex where spatial regions cover the interpretation of sensory information as well as many aspects of movements. Together, these areas comprise the core cognitive processes. By observing and questioning a patient, healthcare specialists gather information to assess the status of mental function.

Of the various non-verbal indices of cognition, eye movements are particularly important. Much is known about the functional organization of the visual system, especially the neural controls and cognitive mediators of eye movements. Together, these "neuro" and "cognitive" features provide much of the behavioral and inferred cognitive functions that are interpreted in the standard screening tools for diagnosing delirium in hospital settings. Eye movements that do not fix on faces during interactions suggest social disconnection, eyes that do not track moving objects thus communicate lack of attention or signal disorientation from the present. As a result, Seeing is Believing in the recognition of delirium. The same measures guide choices of pharmacological treatments aimed at treating delirium symptoms. Perhaps not surprisingly, antipsychotic drugs and, more recently, the so-called "atypical" antipsychotic drugs have been the pharmacological treatments of choice for delirium.[9]

With a goal of identifying and capturing previously unrecognized cases of delirium, a widening evaluative net is being cast across a variety of hospital units.

Believing is Seeing

With a goal of identifying and capturing previously unrecognized cases of delirium, a widening evaluative net is being cast across a variety of hospital units. Consequently, delirium has been discerned in medical and surgical wards, postoperative recovery areas, emergency departments, step-down units, as well as pediatric ICUs[7] Predictably, this net now includes NICUs. At this point, published accounts of delirium in the NICU are limited to a small number of case reports, but the search is underway for the syndrome in NICU populations.[2, 9-12]

Certainly, any syndrome in the NICU that increases morbidities or is developmentally damaging should be identified. But there are reasons to question whether delirium, per se, is a valid diagnosis for newborns, especially those born preterm and who depend on newborn intensive care for weeks or months before reaching 40 weeks (postmenstrual age). There is value in accuracy and in avoiding labelling that can misguide interpretation or deflect focus. This is where developmental science can contribute.

A primary concern is that the current definitions, diagnostic criteria, and tools for defining delirium are based on adult cognition and behavior. A cognitive framework was initially constructed and refined around a syndrome of behavioral

phenomena we call delirium. This cognitive framework was then linked—by inference, not by direct data—to brain dysfunction ("encephalopathy" was an early label), and we have delirium as a neurocognitive disorder! It is said to manifest in pediatric units as with adults in ICUs and elsewhere, and emblematically with geriatric patients. I hasten to add that the Cornell Assessment for Pediatric Delirium (CAPD), a standardized instrument[14] is used, as are other bedside screens. The CAPD is an instrument designed within a cognitive framework. It represents a tacit belief that there are higher-level cognitive processes normally at work in the infant and that these can be provoked into dysfunction. With this belief framework in place, believing can lead to seeing. But is this real, or a kind of illusory 'sleight of hand' trick that we can play on ourselves?

Gaze has long been used in cleverly designed experiments to reveal infant abilities to detect, discriminate between, and recognize visual stimuli—all perceptual tasks.

It can be satisfying to see instances of direct continuity from the immature, unformed infant to the mature, differentiated, and integrated adult. But does such "developmental continuity" exist between the diagnosed delirium of children with that of adolescents, adults, and geriatric patients who share a terminologic diagnosis? Accurate, in-depth answers to this question are important because continuities in the disorder would enable tests of common treatments, whereas lack of continuities would immediately challenge the use of common treatments and, importantly, motivate further studies of the syndrome in the infant, adult, and intermediate stages.

Conveniently, the "neuro" side of neurocognition can contribute to this discussion of delirium. Gaze is a great example. Gaze refers to the movements that orient the eyes to a target and fix on it. Gaze has long been used in cleverly designed experiments to reveal infant abilities to detect, discriminate between, and recognize visual stimuli – all perceptual tasks.

But there has been a major shift: the same eye movements are now interpreted as cognitive processes. This has worked pretty well with adult subjects. In delirium, patients often fail to fixate on faces, and their eyes do not track novel objects. They fail to pay attention to people, speech, and their surroundings. Their words and thoughts become similarly disorganized. In adults and children with speech, this spectrum of deficient attention, loss of social connections, and failures of 'executive function' are linked to dysfunction of the cerebral cortex.

We have long known that the cortex is a late-developing structure, displaying multiple forms of immaturity in babies and toddlers and continuing to develop and undergo refinement as long as 20 years in humans! What we have not appreciated until recently is that the cortical control of eye movements and gaze is absent in infants! Yes, the infant's eyes move and can move in a coordinated, functional manner, but the cortex is not yet involved! Instead, it is an alternate, so-called "reflexive" pathway from the eyes and optic nerve directly to the midbrain visual structures, such as the superior colliculus, and directly back to the eye muscles that make the movements. So babies can visually track, fixate, and soon establish and maintain preferential eye contact with parents – but this is accomplished without cortical participation. And remember: we ascribe cognition to the cortex. Thus, gaze in infants does not 'mean' the same thing as it does in adults because infants lack the critical "cortical outflow". This, I must note, is a part of the message contained in the important publication by Blumberg and Adolph[16] that was discussed in a previous issue of the Developmental Observer.[17]

These concerns have important implications for the diagnosis of delirium in the NICU. Gaze by infants can be used appropriately and rigorously for perceptual tests such as detection, discrimination, recognition, or acuity. In contrast, delirium is defined primarily in terms of cognitive function and dysfunction. If we adhere to the established, conventional standard that the late-developing cerebral cortex is the neural seat of cognitive processes, then it is not appropriate to use measures of gaze as an index of cognition in infants, and certainly not for the preterm babies that populate the NICU! In fact, delirium, as it is currently defined, is not an accessible condition, not with the normal scientific standards that are appropriate for applying interventions based on cognitive symptoms!

What should be done? My view—as an initial contribution to a needed dialogue—is that it is vital to have tools to recognize dysfunction in newborns and infants, but the tools, the interventions, and the measures of treatment outcome must be valid, precise, and accurate. Cognitive measures for adults and infants are not comparable. For babies at preterm and corrected infant ages, observational metrics based on Synactive Theory, i.e., autonomic, state, behavior, coupled with systematic evaluations that incorporate normal and necessary procedures, during routine bedside care, examinations, bathing, feeds, and Kangaroo care for example – are sources of valuable

data. In other words, NIDCAP observations[18] (or similar tools from other, related forms of developmental care) offer valid and valuable data for assessments. It is inappropriate, I would argue, to apply to infants batteries of highly interpretive and neurologically counter-indicated methods derived from and developed for adult patients. Words such "disorganized" are more precise and accurate than "delirious", especially when organization/disorganization are described and scored rigorously. Methods such as NIDCAP observations are available, accurate, and preferable.

References

1. American Psychiatric Association. (2013) *Diagnostic and statistical manual of mental disorders, 5th edn* (DSM-5), American Psychiatric Association Publishing
2. Liviskie, C. & McPherson, C. (2021) Delirium in the NICU: Risk or Reality? *Neonatal Network*, 40(2) http://dx.doi.org/10.1891/0730-0832/11-T-727
3. Bergeron N, Dubois MJ, Dumont M, Dial S, Skrobik Y. (2001) Intensive Care Delirium Screening Checklist: evaluation of a new screening tool. *Intensive Care Med*. May;27(5):859-64. doi: 10.1007/s001340100909. PMID: 11430542..
4. Inouye, S. K., Leo-Summers, L., Zhang, Y., Bogardus, S. T., Leslie, D. L., & Agostini, J. V. (2005). A chart-based method for identification of delirium: Validation compared with inter- viewer ratings using the confusion assessment method: chart Identification of Delirium. *Journal of the American Geriatrics Society*, 53(2), 312–318. https://doi.org/10.1111/j.1532-5415. 2005.53120.
5. Maldonado JR. (2008) Pathoetiological model of delirium: a comprehensive understanding of the neurobiology of delirium and an evidence-based approach to prevention and treatment. *Crit Care Clin*. Oct;24(4):789-856, ix. doi: 10.1016/j.ccc.2008.06.004. PMID: 18929943.
6. Ely EW, Inouye SK, Bernard GR, Gordon S, Francis J, May L, Truman B, Speroff T, Gautam S, Margolin R, Hart RP, Dittus R. (2001) Delirium in mechanically ventilated patients: validity and reliability of the confusion assessment method for the intensive care unit (CAM-ICU). *JAMA*. Dec 5;286(21):2703-10. doi: 10.1001/jama.286.21.2703. PMID: 11730446.
7. Mart MF, Pun BT, Pandharipande P, Jackson JC, Ely EW. (2021) ICU Survivorship-The Relationship of Delirium, Sedation, Dementia, and Acquired Weakness. *Crit Care Med*. Aug 1;49(8):1227-1240. doi: 10.1097/CCM.0000000000005125. PMID: 34115639; PMCID: PMC8282752.
8. Wilson, J.E., et al., Ely, E.W. (2020) Delirium, *Nature Reviews/ Disease Primers*, 6:90, https://doi.org/10.1038/ s41572-020-00223-4
9. Adams, S.J. & Sprecher, A. (2022) Delirium in the neonate, *Clinical Perinatology*, 49: 1-14. https://doi.org/10.1016/j.clp.2021.11.001
10. Wilson, J.E., et al., Ely, E.W. (2020) Delirium, *Nature Reviews/ Disease Primers*, 6:90, https://doi.org/10.1038/ s41572-020-00223-4
11. Edwards LE, Hutchison LB, Hornik CD, Smith PB, Cotten CM, Bidegain M. A case of infant delirium in the neonatal intensive care unit. (2017) *J Neonatal Perinatal Med*. 10(1):119-123. https://doi.org/10.3233/NPM-1637
12. Groves A, Traube C, Silver G. (2016) Detection and management of delirium in the neonatal unit: a case series. *Pediatrics*.137(3):e20153369. https://doi.org/10.1542/peds.2015-3369
13. Holberg, M.Y., Larsen, M.H. Mariussen, K.L. & Kyna, N.M. (2021) Delirium in children under two years of age admitted to intensive care units – a systematic review. *Sykepeien Forskning*, 16 (85808) (e85808) DOI: 10.4220/Sykepleienf.2021.85808en
14. Silver, G., Kearney, J., Traube, C., & Hertzig, M. (2015) Delirium screening anchored in child development: The Cornell Assessment for Pediatric Delirium, *Palliative and Supportive Care*, 13(4): 1005-1011. doi:10.1017/S1478951514000947
15. Porter S, Holly C, Echevarria M. (2016) Infants with Delirium: A Primer on Prevention, Recognition, and Management. *Pediatr Nurs*. Sep-Oct;42(5):223-9. PMID: 29406640..
16. Blumberg, M.S. & Adolph, K.E. (2023) Protracted development of motor cortex constrains rich interpretations of infant cognition. *Trends in Cognitive Science*, 2023. 27(3): 233-245. doi.org/10.1016/j.tics.2022.12.014.
17. Alberts, J.R. (2024) Reflecting on motor cortex and its place in developmental care. *Developmental observer,* 17(3): 20-22. DOI: 10.14434/do.v17i3.39755
18. Als H. (1986) A synactive model of neonatal behavioral organization: Framework for the assessment of neurobehavioral development in the premature infant and for the support of infants and parents in the neonatal intensive care environment. *Physical & Occupational Therapy in Pediatrics*. 6(3-4): 3-53.

Reviewers for the Developmental Observer

Are you interested in gaining experience as a reviewer? Do you have experience with publications? We are seeking expressions of interest from a range of members of the NFI. Please send an email and a brief copy of your CV to: Kaye Spence, Senior Editor at *kayenfi@gmail.com*

Developmental **Observer**

The official publication of the NIDCAP Federation International published on-line three times a year.

Contributions

We would like to thank all of our corporate and individual donors for their generous support of the NFI and its continuing work.

Developmental Observer current and past issues from: ***https://scholarworks.iu.edu/journals/***

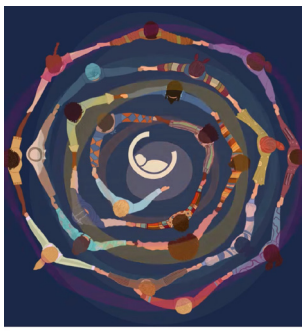
nidcap® FEDERATION INTERNATIONAL voice of the newborn

Articles are welcome for peer review and may be submitted via the ScholarWorks site or sent directly to the Senior Editor. The submission guidelines are available on the ScholarWorks site.

ISSN: 2689-2650 (online)

All published items have a unique document identifier (DOI)

Congratulations to Silke Mader and her team on their fantastic achievement on becoming a Global Organization.



The Global Foundation for the Care of Newborn Infants (GFCNI) is a **leading global organization** and network dedicated to **improving the care and outcomes for preterm and sick newborns and their families** in each region of the world. Drawing on nearly two decades of advocacy, research, and collaboration, GFCNI unites patients and their families, healthcare professionals, and global partners to **advance neonatal and maternal health worldwide**.

Through **innovative projects, evidence-based guidelines, and a strong focus on family-centered care**, GFCNI drives progress at local, national, and international levels. Their work is underpinned by partnerships with parent organizations, universities, medical societies, hospitals, and select industry partners, ensuring that every initiative reflects both **expert insight and lived experience**.

NIDCAP Care in the Moment

A mother's presence

Mission

To improve 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.

Vision

A global society in which all hospitalized infants and their families receive care in the evidenced-based NIDCAP* model.
*The Newborn Individualized Developmental Care and Assessment Program (NIDCAP) Model:

- Infants are considered individuals, persons, collaborators in care, supported and nurtured by their parents, enhancing their healthy overall development, well-being, 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 environments and culture support and nurture infant and family relationships, and promote 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.

Adopted by the NFI Board, May, 2025

The 36th Annual NIDCAP Trainers Meeting

NIDCAP: Early Interaction Within a Nurturing Environment

September 16-18, 2025
Comwell Portside Hotel
Copenhagen, Denmark

Hosted by the four NIDCAP Training Centers of Denmark and Sweden

(By invitation only)

Annual NFI Membership Meeting

Tuesday, September 16, 2025
2:45 PM CEST

Comwell Portside Hotel
Copenhagen, Denmark

(Members may also attend via Zoom)

nidcap® FEDERATION INTERNATIONAL voice of the newborn

REGISTER TODAY

Open One-Day Conference

NIDCAP: Early Interaction Within a Nurturing Environment

OPEN ONE-DAY CONFERENCE

September 18, 08:00-18:00 CEST

Comwell Copenhagen Portside
Copenhagen, Denmark
Hybrid Meeting

SPEAKERS

Dorothy Vittner
Linnéa Christenson
Juzer Tyebkhan
Ulrika Ådén
Gustaf Gredebäck
Monica Hedenbro
Sari Alqvist-Björkroth
Katrin Mehler
Siri Lilliesköld
Charlotte Sahlén Helmer
Erika Baraldi
Bjorn Westrup
Deborah Buehler

The NFI is proud to present the Swedish/Danish Conference on Ultra-Early Intervention on the last day of the *36th Annual NIDCAP Trainers Meeting*.

The purpose of the meeting is to equip the learner with the knowledge to provide high level and evidence-based, developmentally supportive care to hospitalized infants and their families.

Visit our conference page for details:
nidcap.org/18sep2025

Skåne · Karolinska University Hospital · Region H · Rigshospitalet · Aarhus University Hospital

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 Training Center
University of Illinois Medical Center at Chicago
Chicago, Illinois, USA
Co-Directors: Doreen Norris-Stojak MS, BSN, RN, NEA-BC and Jean Powlesland, RNC, MS
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
Contact: Linda Lacina, MSN
email: *lydialacina@me.com*

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

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*

NIDCAP 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: Lutz Nietsch, MD
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
Co-Director and Contact: Stina Klemming, MD
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*

www.nidcap.org