

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

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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)<sup>1</sup>—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 neuro-protective, 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.<sup>2</sup>

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,<sup>3</sup> which routinely included parents in the observations to increase their knowledge and understanding of their baby's cues, which affect their



Joint observation with a mother

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.

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,<sup>4</sup> 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



Reflective session with parents

postmenstrual age). One hundred percent of families followed up with the interdisciplinary consultation.

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 IFDC is more important than the physical environment. IFDC can be successfully implemented, even in crowded NICUs with older facilities, if the clinical team is committed and willing to invest in creative solutions.<sup>5</sup>

Strong evidence shows that outcomes improve for infants

and families when families are involved in their hospitalized infant's care.<sup>4</sup> 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.<sup>2,5</sup>

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<sup>6</sup> 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.*

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

**W**e 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.

