

“To be able to carry a child is a gift, giving birth in Sweden is a privilege, to be cared for according to NIDCAP is beyond everything.”

—Magdalena Persson Pettersen
and André Persson

“**Connection is essential.**”
— Jacques Sizun MD

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FAMILY VOICES

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Magdalena Persson Pettersen and André Persson | Column Editor – Debra Paul, OTR/L

NIDCAP from a Parent’s Perspective

It was August 15th. Magdalena’s water breaks and we travel at a high speed to the hospital. Early in the pregnancy we had been told Magdalena could not sit, only lie down. We are keeping positive thoughts. The baby is healthy and is strong. Should we call before leaving for the hospital? Remember the Vitamin K injection. We can do this! In a chaos of thoughts, words, and exhortations between the contractions, we try to be brave and remind ourselves that “nothing has happened before it happens”.

After a troublesome pregnancy, we are finally here. The day when our boy decided to see the light of day. We arrive to the hospital. Like flies around a piece of sugar, the hospital staff flocks around us and do their utmost to stop the contractions and skillfully manage to give us a break of a few hours. An obstetrician rushes into

the room to announce that a research study on immediate skin to skin contact directly after birth is being conducted at the hospital and that we match the study group, as we are now expecting the preterm birth of our son. She gathers herself as if she understood very well that this was not really a good time for us to receive a lot of new information. But because she says so, we are attracted to next steps. We consider the pros and cons and decide to take our chance on the practice explained to us. The doctor responsible for the study is called to the hospital and a meticulous presentation about the study and its risks versus benefits is pointed out for us. There are no risks in our heads. Just a win. Now the problem remaining is that the chance to hold our boy right from the start is decided in the toss of a coin.

(continued on p. 2)

There is nothing natural about being separated from your child.

The doctor's obvious joy cannot be missed when she informs us about the outcome of the draw. We will get to hold our son from the very first second. We will not leave him.

A large weight falls from our shoulders and from this moment on, we are convinced that everything will go well.

The midwife looks in on us in the middle of the night just to see how we are. There were no contractions, and everything was calm, and we agree on a quick check just to be sure. The eyes of the midwife are wide-open as she throws herself at lamp buttons and the alarm buttons and loudly and joyfully shouts "we are giving birth here!" In an instant, the room is filled with medical staff and machines. The birth comes in what we think can be called rocket speed. Benjamin arrives into the world after nine minutes and lays on his mother's chest. He is a small wonder and is checked and connected to devices. He gets help to breathe. The focus and seriousness in the eyes of healthcare professionals is unwavering. We observe them all in detail. Their facial expressions and behavior reassure us. Dazed and dizzy, we rest in their safe hands. We look at our beautiful baby boy and feel proud and calm.

After two hours we are transported to the neonatal ward. We are all good. Our son is with us and still on his mother's chest and is healthy and strong. He just needs a little help to get on track, grow and develop. Just as the doctor informed us about many weeks earlier when we were getting ourselves ready for childbirth in week 25.

Anyone can have children. But it takes something special to become a parent.

The IPISTOS (Immediate parent-infant skin-to-skin) study that we were included in emphasized that skin-to-skin care should be carried out for at least six hours to provide positive effects. We were both convinced that our little boy needed us 24/7 and divided the day into eight-hour shifts to be able to give the best care for him. We took turns having our little one on our chest, skin to skin. The days went by, and seven days passed before Benjamin was put in his bed.

With a firm and secure hand from the healthcare team we were surrounded by, we were guided through newborn care and parenthood. We learned how important it is to speak in a lowered voice; how to provide positive touch and not to "stroke" Benjamin on his skin; how to protect him against bright light; how to support him with soft hands, arms and our bodies; how to provide safety and calm; how to feed and comfort him; how to wash him, care for him, and when that time came, how to arrange his bed for best support. When placing Benjamin in his own bed for the first time at seven days of age, we got to learn about the importance of providing a blanket with our scent for Benjamin to feel our presence. All this was given to us allowing time for us to adjust and become



Immediate skin-to-skin with Magdalena after Benjamin's birth

comfortable caring for Benjamin. We got the best for our son and with that we were shaped into secure and calm parents who could focus on providing love and care to our son.

It was unclear whether Benjamin could be breastfed due to a previous operation. But after a few days with Benjamin on our chest, we were asked to try breastfeeding. It was a fantastic feeling when Benjamin was put to Magdalena's breast and with the help of a small "taste portion" (breast milk in a syringe) and with enormous willpower, Benjamin took the breast for the first time. He who was so small. How could he know? How could he cope? By alternating tube feeding and breastfeeding, he got his meals.

Can you stay in the hospital forever?

The days and nights passed, and we were moved into a family room. The breathing alarm went awry the first night and we were scared for the first time. When we lived in the intensive care unit, the staff kept an eye on the screens, and we kept an eye on Benjamin. Now it was just us. Were we supposed to keep an eye on him while sleeping? We do not know if it was

"If there is a time in life when you have to try your luck, it must be when having a chance for "special treatment" to get the best opportunity to protect your child."

*—Magdalena,
Benjamin's mother*

exhaustion or a feeling of safety that made it possible for us to sleep, but the night passed, and we heard neither beeping nor howling except those from our own alarm clock that rang at Benjamin's feeding time.

At rounds the next day it was announced that we would have the opportunity to go home any day. Benjamin was strong and healthy. But how could we leave the NICU? It was evident that the doctor was used to parents' concerns, and she reassured us and conveyed security. She reminded us of everything we had learned and that we were well prepared for taking Benjamin home. We also got relevant CPR and first aid training and before discharge and had a mandatory conversation with a counselor.

On August 31, after thorough checks, Benjamin was transferred to neonatal home care. We carefully positioned him in the car seat, carried him out of the NICU and lifted him into the car. The same car that almost one year earlier, we had to leave empty-handed after a previous pregnancy. Memories hit us and fear was a fact. We took a few deep breaths, looked at our son and brought out all the strength we had built up over the last few weeks and off we went! The feelings we experienced at that moment cannot be described in words. We were full of fear and were crying and laughing at the same time. Benjamin was here with us, and he was fine. He curled up in his car seat with his pacifier blanket next to him. He was newly fed, calm, and relaxed, was breathing well and had a nice complexion - everything that is important. Let's go home! Home to us - the three of us!

In the home care unit, we had a primary care nurse and she visited us twice a week to check Benjamin's weight and food intake. She patiently answered millions of questions from us. Benjamin grew as expected and made giant steps in his development. After only a few days in home care, Benjamin chose to eat full meals with a bottle and even cuddled at the breast afterwards. On September 11, Benjamin's feeding tube came out with a sneeze. He was probably as fed up with the tube as we were. We agreed that food should be enjoyed through the mouth and the tube was history.

When we were discharged from the hospital and the NICU - what an indescribable feeling! At last, we were just like an ordinary family dealing with vomit, diapers, and visits to the health center. One thing that we continued to do, however was to enjoy our little boy skin to skin as soon as opportunities arose.

Gratitude and sadness.

We are so grateful for getting the opportunity to be with our son from the very start... to be able to be close to him all the time, never to be separated, and to hold him skin-to-skin. We also look back at all the help we got to become the best parents for our boy. Only the stars know what life would be like if we did not end up right there and then in this country, at this hospital, and in the skin-to-skin study!

Now, two years after Benjamin's birth, we understand that we had a journey in newborn care that is not offered to

everyone. This makes us so sad. Never had we thought about what newborn care could look like and does look like for many premature babies. We have been asked if we were afraid or worried about having a prematurely born child. Our only fear now, when we know that other possibilities exist, is that someone, somewhere will have to be cared for according to "routine" care in an extremely old-fashioned way and will have to be separated from their little one.

Being able to care for your child skin to skin, when there is a medical possibility, feels like such an obvious thing. To be able to care for your child skin to skin after a turbulent time where the odds have swayed is indescribable. A small child needs his parents, a tiny child needs them even more.

And if a parent's love and closeness is not paramount in a child's wellbeing, then what is?

Thank you everyone at The Astrid Lindgren's Children's Hospital and everyone fighting for newborn and small babies and their parents to be able to be together always!

"Give the children love and even more love and the common sense will come by itself."

—Astrid Lindgren



Benjamin was 2 years, 2 months corrected age in December! He lives with his proud parents, Magdalena and André in Stockholm, Sweden



This issue of the *Developmental Observer* launches the move from a newsletter to the official publication of the NIDCAP Federation International. We have a fresh look and have introduced some new ideas as we increase to three issues each year – February, June and October. With this expansion we would like to receive stories

and articles from the membership. You can submit in any language, or work with the editorial team if English is not your first language.

We are challenged each year to meet virtually, yet the content of the NIDCAP Trainers Meeting goes from strength to strength. In this issue we see a global contribution from Japan, Italy, Israel, Canada, Sweden, India, USA, Ireland, and France. These perspectives, research and practices all support the NIDCAP approach to care of the Newborn and their families. The abstracts contribute to the body of evidence for NIDCAP, and we have included the Journal Club summaries for the first time.

Magdalena Persson Pettersen and André Persson from Sweden share their beautiful story of Benjamin's start in life with couplet care and all the benefits of this sensitive approach in avoiding separation. We hear about Trauma Informed Care and the road to self-discovery from Kristy Fuller and her team. Our regular features take us to Ireland to learn about developmental care and Jeff Alberts challenges us from the Science Desk.

It is always a pleasure to hear about the fantastic achievements from the membership and this issue we congratulate Pierre Kuhn on his award. We also have a sad farewell to John Buehler who was a strong supporter of the NFI over the years.

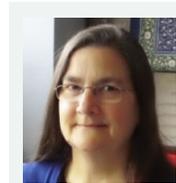
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Editorial Board



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



gretchen Lawhon, PhD, is the Clinical Nurse Scientist with Newborn special care associates, at Abington Jefferson Health and a NIDCAP Master Trainer. gretchen has reviewed articles for peer reviewed journals. gretchen has extensive experience as a clinical nurse scientist and has authored numerous articles in her areas of expertise.



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



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



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



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



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



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

Member Achievements

Congratulations to Professor Pierre Kuhn

During the Journées Francophones de Recherche en Néonatalogie SFN-JFRN congress 2021, the Scientific Council of the French Society of Neonatology awarded the Apgar Prize of the Neonatologist of the Year to Professor Pierre Kuhn of the CHU of Strasbourg. Professor Pierre Kuhn, through his research on the sensibility of the premature newborn, his participation in the development of the European Standards (EFCNI), and the coordination of GREEN (Groupe de Réflexion et d'Évaluation de l'Environnement des Nouveau-nés), is a tireless advocate of the values and practices inspired by NIDCAP which has been practiced at the University Hospital of Strasbourg for many years.

Many congratulations to Pierre Kuhn, MD and his team.



Professor Pierre Kuhn

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Predictive Relations between Pre-discharge APIB Scores and Postterm General Movement (GM) Assessment in Very Low Birth Weight Infants

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Background

Non-invasive assessments of at-risk infants are important tools for recognizing individual needs for support and intervention, as well as the prediction of such needs. The APIB (Assessment of Preterm Infant's Behavior) is a sensitive technique for assessing prematurely born infants at early ages¹ and, similarly, the GMs (General Movements) assessment at two – four months corrected age is used to predict developmental disorder.² APIB is based on the Synactive Theory and the NBAS (Neonatal Behavioral Assessment Scale).³ It is a neurobehavioral battery that yields a panel of multicomponent “packages” reflecting the status of various physiological and regulatory systems in preterm infants. The GM's greatest predictive value is around three months postterm (in the “fidgety” GM stage). The GM evaluation of Hadders-Algra yields a Gestalt evaluation of movement complexity and variation, ranking infants as manifesting normal-optimal GMs (NO), normal-suboptimal GMs (NS), mildly abnormal GMs (MA), or definitely abnormal GMs (DA).

Aims

The aim of this study was to test whether there are systematic relations between APIB system scores before discharge and those of the GMs assessment around three months corrected age. If there are reliable associations between the two measuring tools, the extra predictive powers may prove valuable to early detection of individual needs and to help guide intervention, remediation, and enhance developmental care.

Subjects and Method

Among the very low birth weight (VLBW) infants admitted to our NICU/GCU from June 2019 to January 2021, 24 cases (10 boys, 14 girls, average birth weeks 29.7 ± 3.2 weeks, average birth weight 1143.3 ± 248.6 g) were selected. They were the cases in which APIB could be performed before discharge, and GM assessment performed around three months corrected age. Excluded from the sample were infants with neurological abnormalities such as hypoxic-ischemic encephalopathy (HIE) and periventricular leukomalacia (PVL). We used the mode of the post package status score of the APIB system scores and summary score derived before discharge (mean

39.3 ± 1.4 weeks). We conducted the GM assessments around three months corrected age (average 3.1 ± 0.6 months); the classification of Hadders-Algra was used to evaluate in stages with NO as 4, NS as 3, MA as 2, and DA as 1. Then, we examined quantitatively the relations between APIB's post package status score and summary score, and GM assessments. The APIB procedure and scoring was performed by an APIB Professional; the GM assessments were conducted by three physiotherapists with GM training. Statistical examination was carried out using Spearman's rank correlation coefficient (rs), and the risk factor $p < 0.05$ was statistically significant.

Results

There were statistically significant correlations between the APIB's physiology and regulatory systems post package status scores and GM assessments (physiology system: $rs = -0.46$, $p < 0.05$; regulatory system: $rs = -0.44$, $p < 0.05$). In contrast to these findings, no significant relations were found with the scores of motor system, state system, attention/interaction system, and examiner facilitation. Also significant was the relation of the APIB summary score and the GMs assessment ($rs = 0.47$, $p < 0.05$).

Conclusions

We found that APIB scores of the physiology and regulatory systems status in VLBW infants in the NICU/GCU predicted their General Movements GM scores at about three months corrected age, during the so-called fidgety period. Not only does the finding suggest the possibility of enhanced prognosis of developmental disorder, but it helps point to specific developmental systems that can be targeted for intervention. Furthermore, these findings also suggest that the physiology system and regulatory system in the neonatal period may affect the subsequent development. Nevertheless, the GMs assessment may be influenced by state.² Thus, we may examine whether stable autonomic function, high self-regulation, and good wakefulness may help explain the pattern of the results. In the future, measures of variability in different infant populations could help clarify such interpretations. Regardless, the present findings elevate the efficacy of a synactive-based method to link to another diagnostic tool for increased predictive power of the need for developmental support.

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NIDCAP Rounds: Reaching More Babies and Families

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Aims

The purpose of this project was to institute developmental care rounds in our NICU. The premise for the project arose when, upon completion of training to become a NIDCAP Professional, this writer posed the question, "Now that we've completed training, how do we reach more babies in our limited time? What does it look like in practice?" The aim was to work together with families to learn how to interpret their babies' communication, to support their babies' positions, touch them, talk to them, and hold them in a way that they are able to attend, respond, and interact socially.

Methods

The ENTCC (Edmonton NIDCAP Training Centre Canada) and rehabilitation therapists at the Stollery Children's Hospital teamed up to develop a plan for instituting NIDCAP Rounds. These were set to occur for two hours every two weeks from October 6, 2020 to the present, excluding holidays. NIDCAP certified participants would include a speech language pathologist (SLP), occupational therapist (OT), and another NIDCAP certified member (nurse, neonatal nurse practitioner, or neonatologist) when available. Eligibility for family participants included those who were:

- a) available for rounds
- b) and interested in working with the team to learn more about their babies, how to connect with them, and how to support their development and
- c) and expected to require a long stay in the NICU

Input was elicited from head nurses and other NICU team members to select families to approach for NIDCAP rounds. The plan was to visit with three families each round. At the start of each round, one team member would introduce NIDCAP and the premise of rounds, providing a handout to families for reference. Families were encouraged to describe their babies, what they showed them in their behaviour, their strengths, current challenges, concerns, and where they'd like support. The team would perform a joint short, guided observation, bring parent and baby together, and coach parents in providing supports. Team members would then work with families to devise specific developmental care goals for their babies. The goals were recorded in the patient's chart and reviewed with bedside staff.

Results/Findings

NIDCAP Rounds were conducted 15 times in nine months with 25 families participating. Seven families participated in two sessions and 18 in one session. NIDCAP Rounds were attended by SLP (14 times), OT (14 times), neonatologist (4 times), and neonatal nurse practitioner (one time).

Developmental care goals addressed included:

- hold baby skin-to-skin (4)
- support baby to come to alertness by speaking/singing in parents' first language (8)
- support baby to fall asleep by hand swaddling and protect sleep by keeping noise, lights, and activity low (5)
- provide positioning supports to help baby maintain a comfortable flexed position in bed (4)
- nuzzle at a pumped breast whenever alert and rooting (3)
- implement supportive feeding strategies (swaddle, elevated side-lying position, gentle burping, pacing, hold upright during tube feeds) in order to support positive oral experiences (8)
- schedule interventions when parents available to provide support (3)
- gradually reduce rolls and start day/night routine in preparation for transition home (9)

Relevance to NIDCAP

This project addresses the NIDCAP Nursery Program categories of the nursery environment and care of the infant, family, and professional healthcare team.

Conclusion

By implementing NIDCAP rounds, we were able to use a small time-commitment to meet with many families.

NIDCAP observations led to parents and staff partnering to define infants individualized developmental goals.

NIDCAP Trainers Meeting Feedback

"It was rewarding to see the work NIDCAP is achieving."

The APIB Examination in the NICU: Its Clinical Use

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Background

The *Assessment of Preterm Infants' Behavior* (APIB) is a structured, neurobehavioural examination that objectively measures neurobehavioural functioning. Preterm infants who have received NIDCAP care have improved neurobehavioural outcomes by APIB scores; these APIB measures correlate with developmental function at older ages.

Reliability in APIB administration and scoring is required for certification as a NIDCAP Trainer. The examination requires time, physical and emotional energy on the part of the examiner, who facilitates the infant into his / her most responsive, modulated state. Infant response patterns must be clinically relevant, although we do not know if APIB is used in this way.

Aims

I will present my experience of 'Clinical APIB' and the surprising benefits for babies, families, and staff, and for the NICU System. I hope to promote interactive discussion about clinical use of this informative instrument.

Relevance to NIDCAP

APIB helps us see infant neurobehaviour "in 3D", making the NIDCAP observation simpler, while revealing more detail. If more NIDCAP professionals/ NICU staff know the APIB, this will positively impact NIDCAP training and thus directly affect the Physical Environment and the Care of the Infant, Family and Staff.

Methods

APIB is structured in six sections ("packages"), some of which are directly applicable to the infant's everyday experience in the NICU. Replace with For example, Package 1 assesses responses to light and noise, during sleep. The clinical question is "How does this baby sleep, in this bedspace, within this NICU". Package 2 assesses responses to being unbundled and turned supine – which occurs repeatedly during diaper changes.

Package 6 evaluates social attention and interaction; directly relevant to feeding and interactions with parents.

APIB exams were done at different time points during infants' NICU stays. Some exams were video recorded, if parents consented. APIB exams were done at bedside, or in a quiet, dark room. Parents were invited and informed about the exam flow, time required and what to expect of their babies. At times, parents were invited to participate in Package 6 (social

interaction). Parents were provided narrative summaries with suggestions for caregiving, similar to a NIDCAP report.

Results

All babies demonstrated neurobehavioural strengths. Some were surprising: e.g., a severely asphyxiated, "completely unresponsive" infant oriented to mother's voice when guided to speak in synchrony with the baby's unique neurobehavioural thresholds. Other surprising strengths included habituation to light and noise, and the quality of sleep. Staff education was enhanced as a result.

APIB led to fewer investigations and interventions, and earlier discharge. For example, (A) Home oxygen for a late preterm infant who was having more frequent apnea and desaturations. APIB done with parents helped guide "in synchrony" caregiving and feeds; apnea resolved, and baby was discharged home, without oxygen, 2 days later. (B) Three preterm infants who had early post-hemorrhagic ventriculomegaly were felt to be appropriately responsive for age; neurosurgery was avoided (n = 1) or delayed (n = 2).

APIB allowed early detection of neurologic findings, e.g. asymmetry of movement and /or unusual patterns of tone not detected by others, leading to early intervention referral.

Conclusions

Clinical APIB revealed neurobehavioural strengths and challenges that had otherwise been missed. Clinical APIB led to changes in clinical care and use of NICU resources.

NIDCAP Trainers Meeting Feedback

"Congratulations to the organizing committee led by Fatima Clemente and Jean Powlesland."

Family Centered Music Therapy for Preterm Infants and Their Parents in the NICU: A Mixed-Method Study

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Background

Preterm infants experience noxious stress during their NICU hospitalization. Unbuffered stress may negatively influence their autonomic nervous system (ANS) maturation thus affecting neurobehavior and development.¹ Music therapy (MT) is an evidence-based intervention used in neonatal settings.² When coupled with skin-to-skin care (SSC) it may reduce stress responses in both preterm infants and their parents and enhance family-centered care.^{3,4} Few studies have investigated these interventions combined, and evidence of longer-term effects is missing.

Aim

To investigate the effects of combined, family-centered MT and SSC on preterm-infants' ANS stability and their parents' mental well-being.

Methods

An embedded mixed-methods design was used.⁵ A single-center, cluster-randomized trial with two parallel arms was conducted. Ten time-clusters of two months, each with five - eight participating families, were randomized to either combined MT+SSC or SSC alone. Sixty-eight families were offered two weekly sessions of the allocated condition in the NICU, and a follow up at home at three-months corrected age (CA). The primary outcome was stabilization of the ANS as defined by change in the high frequency component of heart rate variability during the second session. Secondary outcomes included additional HRV measures, attachment, and parental anxiety. Outcomes were analyzed on an intention-to-treat basis using linear mixed-effects models.

A qualitative exploration of parents' experiences regarding MT sessions was performed. Ten parents participated in semi-structured interviews at four-months CA. Data was analyzed using thematic analysis methodology within a reflexive hermeneutic approach.

The MT intervention was based on the "First sounds: Rhythm, Breath and Lullaby" model⁶, which focuses on the parent-infant dyad. Key elements include specific attention to infant's cues, parent, and environment, and to their reciprocal

interaction; rhythmic entrainment; use of parents' voice and musical heritage; and encapsulating the sounds of the intra-uterine environment. Guidelines for the intervention afforded high flexibility to address alternating parental or infants' needs, and to offer additional means for musical engagement.

Results/Finding

MT+SSC improved infants' ANS stability, as indicated by a greater increase in HF power (mean difference 5.19m2/Hz, SE=1.27, $p < 0.001$) (95% confidence interval 0.87 to 2.05), as compared to SSC alone. HF power is an indicator of a relaxed state in the ANS, representing improvement in autonomic regulation, which highly impacts preterm-infants' processes of recovery and maturation.⁷

Other HRV indices as well as parental anxiety showed a nonsignificant tendency favoring MT+SSC condition. Main themes derived from parents' interviews revealed that MT+SSC sessions were perceived as unique moments solely dedicated to connecting with their baby, and as such, essentially different from daily medical routines. Singing was experienced as means to provide "something deep from within themselves" and enhanced feelings of self-coping by overcoming personal difficulties. Parents reported that MT has promoted relaxation for both them and their baby, leading to feelings of intimacy and being-in-the moment. MT informed and motivated their use of music throughout the hospitalization period and was incorporated into their everyday lives.

Relevance to NIDCAP

This study relates to core components of the NIDCAP model, namely, modulation of stress in the NICU, promotion of infant's behavioral organization, and enhancement of early parent-infant bonding.⁸ Implementation of family centered MT during SSC might provide additional opportunities to enhance stability, intimacy, and bonding in the NICU.

Conclusions

Combined MT+SSC contributes to preterm-infants' ANS stability and stress reduction, laying an important foundation for neuro-behavioral and psycho-emotional development. Family-centered MT is highly attuned to parents' and infants' needs and may support the dyad to engage musically and enhance meaningful interactional moments during hospitalization. Studies evaluating longer-term effects of MT on preterm infants' development are warranted, as well as the investigation of longer therapeutic processes and their impact on parents' experiences.

(References on p. 27)

NIDCAP: A Psychoneuroendocrine Perspective

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Aims

This presentation outlines the pathways through which NIDCAP promotes hypothalamic control of cognitive development by attenuating inevitable NICU stress, thus regulating over-arousal, flaccidity, and shutdown.

Methods

By integrating past decade's research on the hypothalamus and preterm infants.

Results

HPA - Three hormones regulated by the HPA, Melatonin, Cortisol and Oxytocin, are implicated in the preterm infant's NICU experience: Melatonin as regulator of circadian rhythm maturation and in turn influencer of cognitive development¹ (Bayley Scales); Cortisol as regulator of stress modulation, and Oxytocin as mediator of parent infant affectionate relationship and bonding. Moreover, preterm newborns lack the capacity to generate a full adrenocortical response to stress or illness, which conversely, later in development turns into a disproportionate increase in glucocorticoid action and over-arousal states.

HPT - Congenital hypothyroidism is frequently associated with the development of intellectual disability. Often it is involved in the association of lower gestational age at birth and impaired cognitive and self-regulation functioning later on.² In addition, inadequate HPA stress regulation in preterm infants further compromises their HPT function through HPA-HPT cross-connectivity.

HPG - Fluctuations of progesterone and estrogen levels are relevant for females' optimal HPA reactivity. In males, early programming of testosterone levels affects HPA and testosterone reprogramming during puberty and is necessary for adaptive HPA reactivity in adulthood.³

Thus, all three axes of the hypothalamus and their 'cross-talk' are relevant, either by direct or by secondary impact,³ to the understanding of prematurity and its resulting compromised cognitive and self-regulation development. The variability documented in the methylation of the genes of these metabolic neurochemicals' receptors, OXTR, NR3C1 and Nrf2,

may suggest that hypothalamic regulation works in concert with the epigenetic effects to bring about an optimal range of receptor availability if supported by optimal environmental inputs. Reduction of stress may bring about compensatory transcription processes in the hypothalamic pathways. Thus, ameliorative alterations of the epigenome are possible with balanced environmental inputs.^{4,5}

Relevance to NIDCAP

By affecting stress reactivity and the HPA, NIDCAP methods appear to affect the function of the hypothalamic axes, which show association and causality pathways with cognitive and self-regulation functions. It is postulated that feedback mechanisms and correction signals of hypothalamus-based homeostatic modulating functions account for the stress reduction brought about by very early NIDCAP intervention.

Conclusion

The balancing effects of NIDCAP are fed back to the hypothalamus for correction of the signaling to prefrontal cortex, the seat of executive functions. Given their bi-directional pathways, in turn the neuro-hormone and neuropeptide production levels adjust accordingly.

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NIDCAP Trainers Meeting Feedback

"We would like to see more clinical practice sessions, open discussion around APIB and small discussion groups."

NICU “graduates” Follow-up: Goals Achieved and Future Perspectives of a NIDCAP Team

DOI: 10.14434/do.v15i1.33778

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*Trainee at the Bologna School of Cognitive Psychotherapy

Background

Preterm infants require individualized care and family support after NICU discharge, both to close the gap from discharge to first follow-up appointment, and to support neurodevelopment throughout the first 1000 days from conception. *EFCNI's Standards of Care* emphasize the need of a multidisciplinary follow-up (FU) program for premature infants after NICU discharge. A fundamental component of good nurturing care is supporting parents to be co-regulators in their child's neurodevelopment. Parents of premature infants are at high risk of short- and long-term mental health difficulties, partly due to an abrupt change in the caregiving environment after discharge - from a highly supportive environment in the NICU to a relatively isolated home environment - especially during the COVID-19 pandemic.

Aim

To describe a new modality used in our preterm infants FU program, which incorporates NIDCAP-based principles of care.

Methods

Since 2015, our FU program has been reorganized as follows: application of the NIDCAP approach, combined with structured neurobehavioral evaluations (which includes naturalistic observations of parent-infant interaction and the Hammer-smith Infant Neurological Examination (HINE)) and a NIDCAP observation report for the family in which the infant's strengths, achievement of neurodevelopmental milestones, future challenges, and key recommendations are emphasized. This reorganization was possible because the FU team included NIDCAP professionals and trainees. The FU evaluation also includes two psychologists to support the families and to administer psychometric tests to infants. The FU is scheduled at 3, 6, 12, 24 and 36 months of corrected age (CA). Bayley Scale of Infant Development III ed. (BSID) is administered at 12, 24 and 36 months CA.

Results

Since 2015, 173 ELBW-VLBW attended the FU program. Prevalence of cerebral palsy was 5.2%, according to Gross Motor Function Scale (9/173), lower than previously reported for a comparable population in literature (10-15%). BSID data were

collected from 171, 127, and 80 infants at 12, 26 and 36 months CA, respectively. Poorer outcomes were correlated with lower gestational ages (GA). Cognitive scores ≤ 75 were detected in about 5% of cases (9/171 at 12 months CA, 6/127 at 24 months CA, 4/80 at 36 months CA).

Single infant's neurodevelopmental trajectories showed an improvement of BSID motor scores through the years even at lower GAs. However, up to 25% of infants showed low performance scores at 24 and 36 months CA in the expressive domain of BSID language scale.

During the same period, our NICU transitioned from standard care to NIDCAP-based care and a NIDCAP Training Centre opened in 2020.

Relevance to NIDCAP

Developmental care is to be continued long after NICU discharge, in order to support parents in providing appropriate developmental experiences to their infants. A NIDCAP-trained team in the FU program afforded the continuation of individualized family centered care for parents and infants long after discharge.

Conclusion

Improvement in single infants neurodevelopmental motor trajectories, low prevalence of poor cognitive outcome and cerebral palsy (CP) were observed during a FU that included the principles of the NIDCAP care for infants and families also after discharge from NICU.

To enhance individualization and multidisciplinary support in the follow-up program, future steps in our Unit will be the introduction of videotaped naturalistic observations, APiB assessments and measurement of parents' perceived experience.

Investigation of the role of the application of the NIDCAP approach during the follow-up period deserves future studies.

NIDCAP Trainers Meeting Feedback

“We are challenged to integrate research findings into NIDCAP work.”

NIDCAP Partners with Industrial Design: Training for Success

DOI: 10.14434/do.v15i1.33779

Tybekhan JM^{1,2,3}, Van der Leek C⁴, Gustin B⁴, Salamon K⁴, von Hauff P⁵

¹ Stollery Children's Hospital

² Dept of Pediatrics, University of Alberta

³ Edmonton NIDCAP Training Centre Canada (ENTCC)

⁴ Dept of Industrial Design, University of Alberta

⁵ Academic Technology, Faculty of Medicine and Dentistry, University of Alberta. (All located in Edmonton, Canada)

Background

The NFI's Strategic Plan (2017) includes "Strengthening NIDCAP training processes" and "Expanding NIDCAP education and training resources".¹ NFI members discussed 'Training Materials and Pathways' at the NIDCAP Trainers Meeting 2019.² However, constraints of time, people-power and resources mean that a logical starting point for the development of enhanced Training Materials has not yet been defined.

Coincidentally, the Edmonton NICU has been exploring the creation of an online educational platform with the Departments of Academic Technology (AT) and Industrial Design (ID) at the University of Alberta (U of A). This platform could host specialized training programs offered in Edmonton – one of these being NIDCAP.³

AT and ID at U of A have previously developed educational material for use in clinical settings, e.g. neonatal resuscitation,⁴ electronic portfolios.⁵ Some of this work is distinctly family-focused, e.g. 3-D models of the heart to help families and learners understand the anatomy of congenital cardiac anomalies.⁶ Learning about this work led to the first meeting of our study team. AT faculty and ID students quickly grasped the essence of NIDCAP and three students devoted their final practicum to this project.

Aims/Purpose

ID brings an interdisciplinary approach to improve the quality of experience and to overcome challenges, using profession-specific analytical methods. The aim was to use the ID perspective to create a model to serve NIDCAP in a contemporary, globalised context. For this first phase of our collaborative project, ID students focused on the educational pathway of NIDCAP Training, i.e. preliminary readings, didactic lecture, individual training, Advanced Practicum of NIDCAP training, and certification.

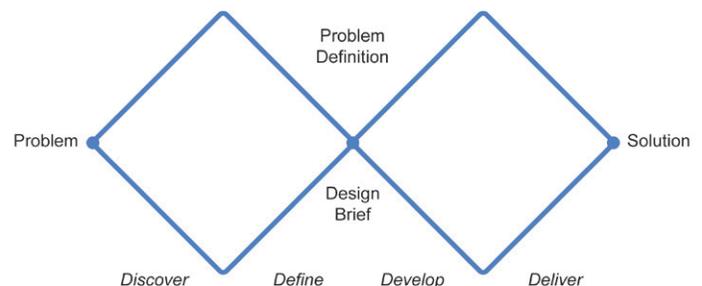
Relevance to NIDCAP

NIDCAP is a training program. Augmenting the success of this training will directly impact clinical care and improve the outcomes of hospitalised newborn infants. This project directly addresses some of the NFI's Strategic Goals.¹

Methods

Primary research methods included interviews, and the use of convergent and divergent design thinking, using a 'Double Diamond' diagram (Figure 1). The Double Diamond is a common design model used to showcase different thinking skills throughout a design process. ID students visited the Edmonton NIDCAP Training Centre Canada (ENTCC) to gain an understanding of the NIDCAP Training framework, and the intricate relationship of Trainer and Trainee. They toured the NICU to see 'NIDCAP in Action'. Further insights were obtained through interviews with members of ENTCC and the Edmonton NICU Program. The ID approach of interviews and design-based methodology enabled critical analysis and distillation of the multilayered steps of NIDCAP Training. Creating a series of Spider Diagrams enabled the delineation of areas of intervention and existing relationships within the NIDCAP Training pathway, (Figure 2). This led to a practical, defined starting point for a small change that could have great impact.

FIGURE 1 – A Design Process: Convergent and Divergent Thinking Diamond



Results/Findings

The study team agreed early in the process that a functional, on-line learning platform could not be created without this preliminary work. ID methodology led to a practical first step towards enhanced NIDCAP Training: "How can the NIDCAP Observation Sheet be made easier to learn?" The sequential stages that led to this result will be explained during the presentation. The goal was not to change the existing Observation Sheet; making this easier for trainees would be similar to practice exercises for learning the use of a computer keyboard.

Conclusions

ID methodology applied to the NIDCAP Training Pathway found that the NIDCAP Observation Sheet is a logical first

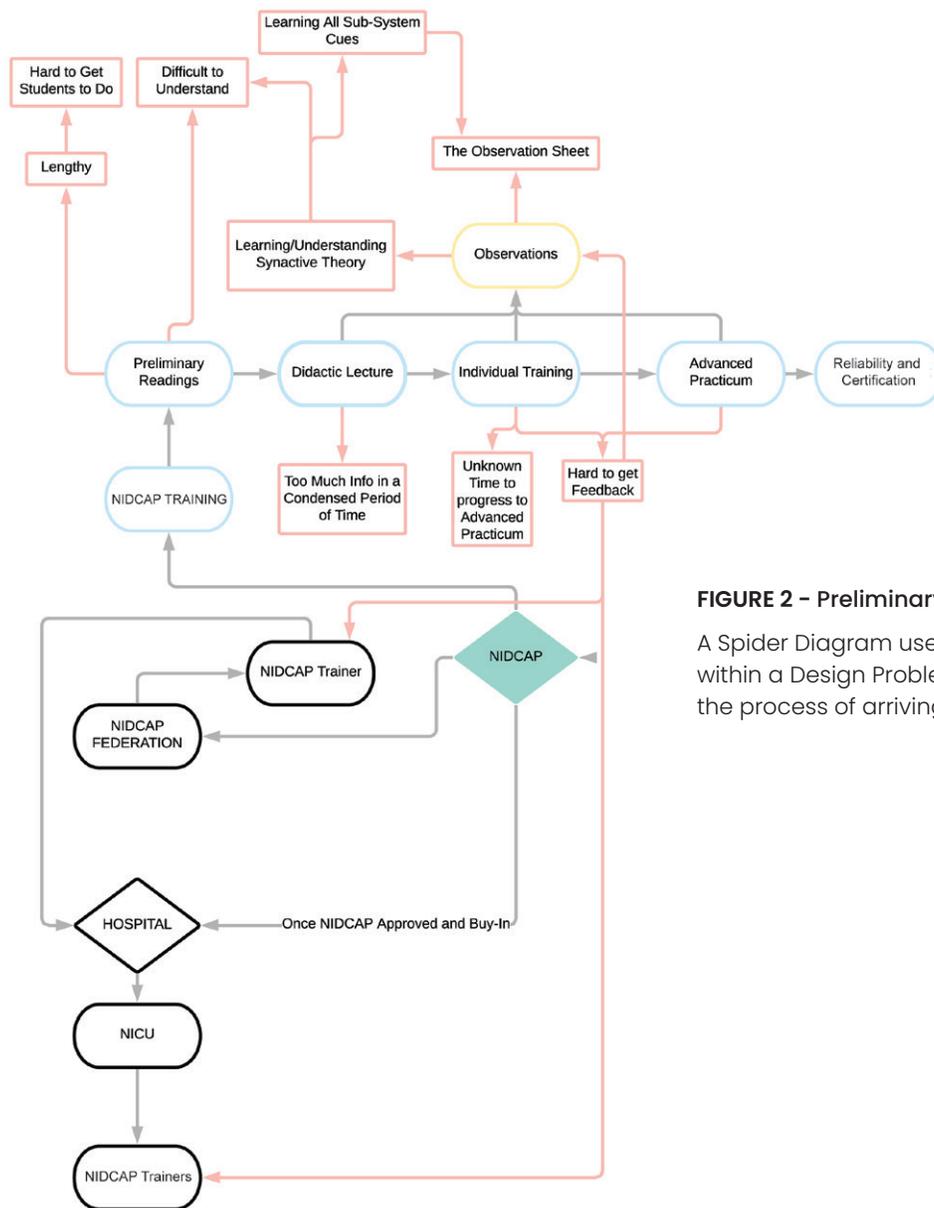


FIGURE 2 - Preliminary Prototype

A Spider Diagram used to Illustrate Multiple Relationships within a Design Problem. This diagram illustrates a step along the process of arriving at our proposed design solution.

point for adaptation. This conclusion could provide focus for the NFI's Next Steps related to Training Materials and Pathways. Further work should explore such adaptation(s), with respect to the educational experience and success of training. Collaboration with AT, ID and other professions could help accomplish NFI Strategic Goals.

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Journal Club Presentation:

Is Medical Education Ready for Generation Z?

Chabba R, Tyebkhan J

*Edmonton NIDCAP Training Centre Canada (ENTCC)*Citation: Eckleberry-Hunt J, Lick D, Hunt R. Is medical education ready for generation Z. *J Grad Med Educ.* 2018;10(4):378-381

The article begins by pointing out how medical education should plan to make adaptations based on how different Generation Z is from other generations.

Generation Z are those born between 1995 and 2012. They are the only generation that has always had access to the internet and social networking, and hence have a hard time disengaging from technology. They are hardworking and independent in their learning but also prefer close mentoring relationships. Having always had access to technology and the internet, they want to know what they need to know in the moment and prefer not to spend long hours listening to lectures. Rather than the traditional approach to medical education, these students will both need and expect a customized experience.

Generation Z is known to have a shorter attention span compared to other generations, and expect material presented to them to be engaging. Since retrieving information has always been so easy for this generation, they lack the skills to be able to evaluate information and will need help to do so.

The authors suggest education of Generation Z should include modern technology, and creative modalities such as podcasts and simulations. This generation also expects quick and personal feedback. Active learning methods including reflection and discussion will be more useful with this generation versus traditional lectures.

The authors conclude by reminding us that the goal should always be to ensure quality patient care as we consider making these changes, although historically, medical education has been hesitant to make reforms.

Relevance for NIDCAP

- The youngest parents and new staff coming into the NICU are Generation Z and will want to receive information as described by this article.
- The NIDCAP model involves observation and sharing that observation in a detailed narrative report to both staff and patients. Based on the findings of this article, both staff and patients may not engage with this material thus suggesting there is an immediate need for change.
- The new generation of NIDCAP trainees are likely to prefer more creative ways of sharing their observations. We suggest that these creative ways are embraced by the NFI.

Journal Club Presentation:

Early Parenting Intervention – Biobehavioral Outcomes in Infants with Neurodevelopmental Disabilities (EPI-BOND): Study Protocol for an Italian Multicenter Randomized Controlled Trial

Thergaonkar N.

*Aaroha Centre for Psychological Services, Mumbai, India*Citation: Montirosso R, Rosa E, Giorda R Early Intervention Study Group, et al Early Parenting Intervention – Biobehavioral Outcomes in infants with Neurodevelopmental Disabilities (EPI-BOND): study protocol for an Italian multicenter randomised controlled trial *BMJ Open* 2020;10:e035249. doi: 10.1136/bmjopen-2019-035249**Overview**

Infants with neurodevelopmental disability are at risk for altered behavioral and socio-emotional patterns. The present longitudinal, multi-center interventional clinical trial aims at assessing the effectiveness of an early parenting intervention based on video-feedback technique (VFI) to support maternal responsiveness (parental sensitivity) and the socio-emotional

development of infants with developmental disabilities using a multi-layer approach to outcomes assessment (behavioral, neuroendocrine and epigenetic outcomes).

The study plans an estimated enrollment of 180 participants, randomized into parallel assignment intervention model with double masking participant, outcome assessors. The study start date was September 2019 and estimated completion date was December 2021.

Study design

Inclusion criteria

- Infants: Age range 3-18 months with mild- moderate psychomotor delay

- Mothers: Age > 18 years, living with the father of the infant and mastery of Italian language

Exclusion criteria

- Infants: Presence of severe sensory deficits and genetic syndrome with known functional implications for epigenetic regulation of target genes
- Mothers: Documented mental disorder and documented disability

Methodology

- The intervention group will include dyads of mothers and their infant with developmental disability who are exposed to the VFI focused on different domains of mother-infant quality of interaction (number of sessions: 6)
- The control group will have dyads of mothers and their infant with developmental disability who will receive phone calls focused on obtaining descriptions of different domains of infant behavioural development instead of the VFI, (number of sessions: 6).

Primary outcome measure:

- The study will have four assessment sessions: T0- baseline, T1- Post intervention, T2- Short-term follow-up (3 months) and T3- long-term follow-up (6 months).
- Improvement of infants' behavioural and socio-emotional regulation will be measured by GRS coding system, based on infant behavioural regulation as well as Face-to-Face Still Face (FFSF) double exposure paradigm from a 10 minute unstructured mother- infant interaction with standard set of toys.
- Developmentally supportive parental behaviour (maternal sensitivity) will be assessed by the PICCOLO coding system

as well as Face-to-Face Still Face (FFSF) double exposure paradigm from a 10 minute unstructured mother-infant interaction with a standard set of toys.

- Salivary samples of mother and infant for cortisol and oxytocin will be collected at each assessment session (additional samples for infants will be taken at 15 (reactivity) and 30 (recovery) minutes after the FFSF procedure.
- Change in hormones and capital Salivary oxytocin concentrations will be assessed for differences between and within group by generalized linear model.
- The hypothalamic-pituitary -adrenal (HPA) axis stress regulation will be assessed in terms of direction and magnitude.
- DNA methylation of target genes will be assessed at specific CpG sites by separate saliva samples of infants for epigenetic analysis at the end of the FFSF procedure.

Feasibility outcome measures

- Feasibility of the interventions will be assessed by 'acceptance of the intervention' and 'maternal experience' with VFI rating scales from mothers, at T1.

Relevance for NIDCAP

- Brings new evidence to promote early intervention for mothers of infants with developmental disabilities.
- Provides a common early intervention program to optimize healthcare costs.
- Introduces an innovative approach to early parenting intervention for families of infants with developmental disabilities by studying the epigenetic variations.

Journal Club Presentation:

DOI: 10.14434/do.v15i1.33784

Thematic Brief: Nurturing Care for Every Newborn

Westrup B.

Co-Director Karolinska NIDCAP Training & Research Center.

Dept of Neonatology; Astrid Lindgren's Children's Hospital Karolinska University Hospital

Dept Women's & Children's Health, Karolinska Institute

Citation: World Health Organization, United Nations Children's Fund, World Bank Group. Nurturing care for every newborn (in progress). Geneva: World Health Organization; 2021.

Summary

The first hours, days and weeks after birth are a precious time for a newborn's survival, health and development. Knowledge

and tools are available to provide every newborn with nurturing care that involves parents and other caregivers directly. To create the enabling environment for providing such care, there is a need to invest in policies, health systems and community awareness. As more newborns survive, we now need to make sure that they also thrive. This is especially important for those at greatest risk: small and sick babies who are more likely to die or suffer more illness. This Thematic Brief summarizes why nurturing care is essential for every newborn. Nurturing care comprises five interrelated and indivisible components: good health, adequate nutrition, safety and security, responsive

caregiving and opportunities for early learning. Nurturing care happens when we maximize every interaction with a child. Every moment, small or large, structured or unstructured, is an opportunity to ensure children are healthy, receive nutritious food, are safe and learning about themselves, others and their world. What we do matters, but how we do it matters more. Nurturing care protects children from the worst effects of adversity and produces lifelong and intergenerational benefits for health, productivity and social cohesion.

Comment

Nurturing care for early childhood development <https://www.who.int/activities/addressing-nurturing-care-for-early-childhood-development> is a very important work developed in collaboration by World Health Organization, United Nations Children's Fund, World Bank Group – all organizations of

course with very high credibility and impact. This is their thematic brief of nurturing care of the newborn planned to be published in July 2021.

Relevance for NIDCAP/NFI

Many of us in the NFI have substantially contributed to this important document through the work with the EFCNI standards of IFCDC (Infant- and Family Centered Developmental Care) or directly by submitting narratives and pictures from clinical practice of NFI affiliated NICUs. This document could play a very important role in enhancing the dissemination of the key values and recommendations of NFI globally in low- and middle- but also high-income countries.

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Endorsed by the NFI as foundations of NIDCAP education.

CALLING ALL MEMBERS OF THE NFI

We would like to include more stories, poetry or reflections from the NFI membership.

If you have a story to tell, a reflection about your NIDCAP experience or some poetry you have written inspired by NIDCAP then please send to the Editor.

developmentalobserver@nidcap.org



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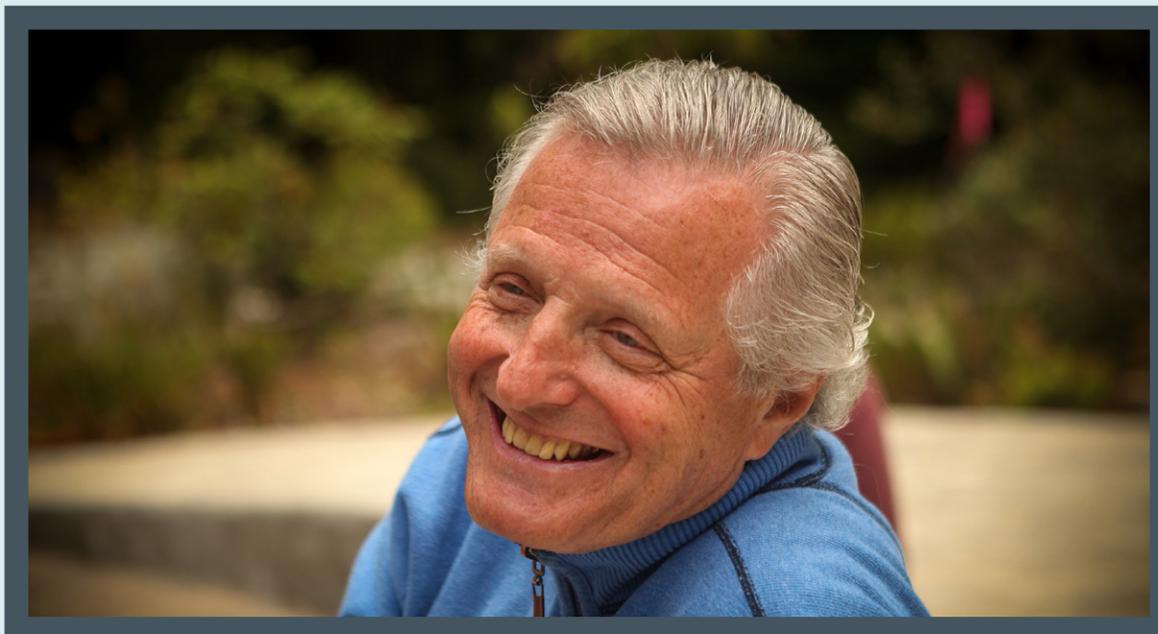


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John Eugene Buehler, Jr., 1947–2021



In July of 2021, the NIDCAP Federation International (NFI) lost a friend, a true champion of our mission, and a generous benefactor, John Eugene Buehler, Jr. Through the Buehler Family Foundation, John and his wife Deborah, supported the NFI on a very personal level for 20 years. John's support of his wife's work with premature infants grew quickly into a profound understanding and true appreciation of the NFI's importance to the international community of intensive care professionals and the infants and families in their care.

Giving was an integral part of John's personality and his life choices, and as the NFI became a part of the fabric of the Buehler life, support of its mission became a philanthropic priority for them. John was a pillar of strength behind Deborah's efforts to advance the organization and in particular to design the face of the NFI and advance its reach in the world. John's generosity touched many aspects of the organization and is most recently and notably apparent in our new website, launched on the 20th anniversary of the NFI's founding.

The new website was achieved with the sole financial support of the Buehler family – a gift that lives to further the reach of NIDCAP and will do so for many years to come.

John was a caring, bright presence in the world, a compassionately-minded individual from whom the NFI's well-being has been nurtured and sustained, and for which the NFI is fortunate and grateful. For John Buehler, the NIDCAP Federation International truly was a labor of love.

Please learn more about his presence in the world through his obituary on the following page.

We thank John and Deborah, and their children, Josh, Kate and Ian for their generous contributions to the NIDCAP Federation International and we extend our heartfelt condolences to them for their loss.

As you read the *Developmental Observer*, be reminded of John, who was a contributing force behind the naming of the *Developmental Observer*. John's legacy of support lives on in many ways, and the NFI and its members are forever thankful.

Gloria McNulty and Sandra Kosta

DOI: 10.14434/do.v15i1.33790

Obituary as published by The Boston Globe, August 13-15, 2021

John Eugene Buehler, Jr., known as Gene to his family and college friends, died in Marin County, California on July 25, 2021. He was born in Syracuse, New York on December 3, 1947, the only child of John Eugene Buehler, Sr. and Jane Mary Agnes Roe Buehler. He is survived by his beloved wife of 32 years, Deborah Moir Buehler of Mill Valley, California, his three children Joshua D. Buehler, Kate R. Buehler and Ian P. Buehler, and his parents-in-law Joan P. Moir and Virgil P. Moir III.

After graduating from Christian Brothers Academy in Syracuse, John attended Boston College as a freshman in September 1965 and graduated in June of 1969. Soon thereafter, he served in the US Navy as an Electronics Technician, traveling the world and serving valiantly during the Vietnam Conflict, while earning the National Defense Service Medal, Vietnam Service Medal, and Vietnam Campaign Medal. John returned to Boston, his adopted home. He earned his JD at Suffolk Law School while serving as an editor on the Law Review. He later did graduate work at The Georgetown Law Center. After a stint serving as a clerk for the Rhode Island Supreme Court, he became an associate at Bingham, Dana & Gould LLP, working in the Investment Securities Department. He then took a position as Associate Counsel in the Investment Law Division at the John Hancock Mutual Life Insurance Company. In 1987, John moved on to become the General Counsel and Chief Business Development Officer at Energy Investors Fund Group in Boston, a private equity firm dedicated exclusively to the independent power and electric utility industry (the first of its kind). He became a Co-Managing Partner. John's vision and leadership spearheaded the remarkable growth of the company, establishing it as a leader in the industry.

John always remembered his roots and the core values that his parents and his beloved Granny Roe instilled in him. John was exceptionally honored by his Boston College affiliation and the friendships he made there. He was enormously proud of serving as a two-term member of the Boston College Board of Trustees. His business experience and love of his alma mater made him a valuable and guiding member of the university's governing body. In addition, he was an extraordinarily generous benefactor to the school he so dearly loved. He and Deborah

endowed The Buehler Sesquicentennial Assistant Professorship for educator scientists at BC's Lynch School of Education, supported BC's Veterans Memorial in honor of alumni who lost their lives serving in the military during wartime, and funded the John E. Buehler, Jr. Family Athletic Scholarship Fund for starting pitchers on his beloved BC baseball team in honor of his parents.

Many of his lifelong friends dated back to early days spent living in Fenwick Hall at BC. If "Friendship is like the Medicine of Life", the friendships that John had are a testament to that observation. John truly cherished the people in his life. His generous and engaging style of entertaining was legendary. He particularly loved The Sea Ranch in California where he was always happy hosting gatherings with family and friends alike, making everyone feel welcome. He was a BC football season ticket holder for four decades and he was proud to commandeer a loyal cadre of classmates, family and friends in their devoted attendance at games at Alumni Stadium and beyond.

John's journey was characterized by professional achievements, lifelong friendships, and most especially, by his love and devotion to his adoring family. He was exceedingly proud of the accomplishments of his wife Deborah and his spirited and talented children. John championed each member of his family in every way. He supported Deborah's work with the NIDCAP Federation International, the nonprofit organization for premature and ill newborns and infants and their families in hospitals. John was an enthusiastic supporter of Josh's career as fine dining chef, Kate's passion for early elementary school teaching, and Ian's dedication to BC business schooling and soccer playing. It was typical for John to balance organizing his demanding professional travels around his attendance at school, sports, restaurants, cultural and family events whether they were in California, Massachusetts or somewhere in between. No occasion or conversation with John would be complete without his inviting others to share in the love and pride he had for his family.

John was effervescent, charismatic, yet humble. He had the unique ability to make everyone in his presence feel happy and welcome. He is greatly missed by everyone who knew and loved him.

Trauma Informed Developmentally Supportive Care

Kristy Fuller, OTR/L, CNT, CLC; Tara DeWolfe, DPT, CNT, CLC; Mary Coughlin BSN, RN, MS, NNP, RNC-E
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Introduction

Trauma informed developmentally supportive care creates a culture of care that focuses on the human experience. The concept of trauma informed care was co-opted from the field of behavioral and mental health in 2013 for application in the newborn intensive care unit (NICU). In essence, the concept realizes the pervasiveness of trauma in everyday life, recognizes signs and symptoms of trauma, responds to trauma through the adoption of evidence-informed best practices, and resists re-traumatization. Research across a wide range of scientific fields as diverse as neuroscience, molecular biology, epigenetics, developmental psychology, and psychoneuroimmunology verify intensive care hospitalization as a traumatic life event for babies, families, and clinicians.^{1,2} This experience is associated with significant morbidity and mortality across physiological, psychological, socioemotional, and spiritual domains.¹⁻⁶ Most recently, the American Academy of Pediatrics (AAP) has issued a policy statement summarizing the urgency and requisite steps necessary to facilitate the integration of trauma informed principles into all pediatric points of care.³ *“Trauma-informed care (TIC) in child health care operationalizes the biological evidence of toxic stress with the insights of attachment and resilience to enhance healthcare delivery to mitigate the effects of trauma.”*³

What is trauma?

According to the Substance Abuse and Mental Health Services Administration, trauma results from an event, a series of events, or a set of circumstances that is experienced by an individual as physically and/or emotionally harmful or life-threatening and has lasting adverse effects on the individual’s functioning as well as their mental, physical, social, emotional, and/or spiritual well-being.⁷ Within the context of the NICU, infants experience trauma in big and small ways; from life-threatening illness to the day-to-day experiences of parental separation, fragmented sleep, a disruptive environment, painful experiences, stressful eating encounters, limited mobility, prolonged time in bed, and so much more. Maternal separation is the most significant trauma experienced by all newborn mammals and preterm and/or critically ill newborns are no exception to this reality. Morgan et al. discovered that separation of mother and baby at two days of age for one hour results in a 176% increase in autonomic activity and an 86% reduction in quiet sleep with sleep cycling almost abolished during the separation period.⁸ In the NICU, the experience of maternal separation becomes the foundation for cumulative toxic stress exposures that include unmanaged or underman-

aged stress and pain, sleep fragmentation, susceptibility to inappropriate sensory stimuli from the physical and social environments, postural malalignment, and hazardous rituals and routines that do not honor the personhood of the baby.⁹ The trauma experienced in this setting, however, is not limited to the baby but encompasses the family’s experience as well as the experience of the clinician who bears witness to the lived trauma of both baby and family.

Why is trauma informed developmental care important?

Adversity during childhood impacts the developmental trajectory of health and wellness across the lifespan.² Individuals who survive childhood adversity are at greater risk for cardiovascular disease, metabolic syndromes, generalized anxiety disorders, depression, and other forms of psychopathology as well as central sensitizing syndromes that encompass fibromyalgia, migraines, and irritable bowel syndrome to name a few.¹⁰ In a cohort study of more than six million individuals with a birth history of varying degrees of prematurity there is a clear association of increased risk for premature adult death associated with non-communicable diseases; however, the most common cause of premature death in individuals born premature is accidents and suicide.¹¹

In addition to the trauma endured by the hospitalized baby, the family experience of NICU hospitalization has been described as a traumatic event that shatters hopes, dreams, and expectations for parenthood. Roque et al. report the significant impact the NICU experience has on the emotional and mental health of parents.¹² Outcomes include an increased risk of depression, anxiety, and post-traumatic stress disorder for both mothers and fathers because of their baby’s NICU hospitalization.¹² Finally, research highlights the effect of bearing witness to tragedy and trauma on clinicians’ physical, emotional, and spiritual health. Bearing witness is a “human-to-human way of being-relating” to the truth of another’s experience.¹³ However, when clinicians are not aware of the dynamic nature of trauma and trauma exposure it may limit their ability to interact in meaningful and safe ways with patients and families while also disrupting their personal wholeness.¹⁴

Why a trauma informed approach to care?

Trauma informed developmental care invites individuals to move past procedure-driven routines, rituals, and practices; to shift from a dualistic perspective on healthcare to a wholistic perspective. A trauma informed approach enables clinicians to not only understand the biological implications of trauma,



Endorsed by the NIDCAP Federation International, the National Association of Neonatal Nurses, the Council of International Neonatal Nurses and the National Association of Perinatal Social Workers, the program combines online and virtual/live education to support clinicians in developing competence across the eight attributes of the *Trauma Informed Professional*. (Learn more: <https://www.caringessentials.net/>).

but to then take the necessary actions to buffer the trauma experience. Policies, protocols, and practices don't transform an experience, people do. Exploring trauma informed care begins with getting in touch with one's own story. It is through personal self-discovery that one can connect authentically with others and begin the paradigm shift.

"In the process of creating transformation we ourselves are transformed" - Mary Coughlin

How to create transformation?

Personal transformation is the key to cultural transformation. In the words of Carl Jung, *"Your vision will become clear only when you can look into your own heart. Who looks outside, dreams, who looks inside, awakens"*. (Carl Jung, Letters Vol 1 – 1906-1950, p33, Princeton University Press, 1973). Becoming a Trauma Informed Professional (TIP) is a journey of self-discovery and personal growth that awakens the individual to their potentiality as a leader for change and a healer of hurts that too often go unnoticed in the highly technological world of newborn intensive care. Eight attributes of the *Trauma Informed Professional* have been established by an international, interdisciplinary faculty board of neonatal experts. These attributes are:

- **Knowledgeable:** Understanding core knowledge regarding the science underpinning early life adversity and the biologic sequelae.
- **Healing intention:** Fostering intention and presence, a cornerstone of trauma informed care, and based upon unitary caring science theory.
- **Personal wholeness:** Developing habits to support physical, psychological, social, spiritual, and existential well-being.
- **Courage:** Taking courageous action to effect change, increase self-actualization, and reduce moral distress by respectfully challenging the status quo.
- **Advocacy:** Showing up for self and others by demonstrating respectful influence and inspiring excellence.
- **Role model and mentor:** Integrating the qualities of humility and empathy as a role model and mentor to inspire others to greater success.
- **Scholarly:** Pursuing scholarship to consider all ways of sharing information.
- **Leader for change:** Cultivating a respectful approach to leadership as a *Trauma Informed Professional* is transformational.

Collaborative Caring

The aligned missions of Caring Essentials Collaborative and the NIDCAP Federation International have led to collaborative teamwork aimed at transforming the experience of care for babies, families, and clinicians in the NICU and beyond. The complementary nature of NIDCAP Certification and the Trauma Informed Professional Certificate Program serves to advance the competencies of the bedside clinician empowering these individuals to become confident leaders for change. NIDCAP observers bear witness to the tiniest expressions of suffering, beyond what others can see. This depth of awareness takes a toll on the observer. Becoming a trauma informed NIDCAP professional mitigates this impact on self and others. Integrating trauma informed developmentally supportive care in the NICU and beyond changes not only individual lives but society at large. Together, we can design the future of truly compassionate healthcare.

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TRAUMA INFORMED PROFESSIONAL

A continuous journey of self-discovery and growth moving towards excellence



NIDCAP Care in the Moment

Co-regulation during care giving tasks

The Importance of Doing Dual Diligence

Jeffrey R. Alberts, PhD

Indiana University, NFI Science Committee, Associate Editor for Science

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Target Article: Maryam Fatollahzade, Soroor Parvizy, Mandana Kashaki, Hamid Haghani & Mona Alinejad-Naeini (2020) The effect of gentle human touch during endotracheal suctioning on procedural pain response in preterm infant admitted to neonatal intensive care units: a randomized controlled crossover study, *The Journal of Maternal-Fetal & Neonatal Medicine*.

Little is ordinary about an ordinary day in a NICU. Without a break, 24/7, technological and biomedical wizardry is combined with expert applications of other, “low-tech” tools and “no-tech” methods. Together, it works: Babies born as early as 23- or 24-weeks survive and thrive. Miraculous outcome is almost ordinary. How do these miracles happen?

Let’s start with one element in the miracle-making formula: The element is human touch. No technology needed. Our target article, a recent study by Fatollahzade¹ was designed to ask whether an intervention termed Gentle Human Touch (GHT) would reduce pain during the suctioning procedure commonly needed to keep open the airways of premature infants equipped with an endotracheal tube.

34 preterm infants (born at 27-34wks) comprised the study population. Cleverly, this research team utilized the on-going care regime as a testbed, knowing that the suctioning procedure, vital to breathing support of the intubated neonate is potentially painful. Their “crossover” design refers to an efficient and statistically powerful approach in which each baby is tested with and without the experimental intervention. Order was counterbalanced, meaning half the babies received the GHT intervention during suctioning on the first trial and routine treatment (no intervention) during the next need-based suctioning. The other babies also experienced both conditions, but in the reverse order.

The GHT intervention was administered to infants positioned prone in a gently flexed posture. The researcher cupped one hand around the infant’s head while cupping the other hand around the infant’s bottom. GHT was provided for the duration of the suctioning procedure. Using the Premature Infant Pain Profile (PIPP) protocol, a 15-sec-long pre-suction baseline assessment was made, followed by a 30-sec-long post-suctioning assessment. The PIPP yields a numerical score of infant pain in three ranges (mild to severe). It is considered well-validated and is used widely in research.²

The results were impressive. With standard care, 85% of the infants showed moderate pain responses to the suctioning procedure. GHT reduced the occurrence of moderate pain responses to 65%. Severe pain responses were manifested in about 9% of the control trials and GHT reduced these to about 3%. Such results are a first step toward adding Gentle Human Touch to the list of non-pharmacological methods of pain management in the NICU. Many of us are aware of the powers of skin-to-skin contact (Kangaroo Maternal Care^{3,4}) as well as the efficacy of holding⁵, facilitated tucking,⁶⁻⁸ nursing,⁹ non-nutritive sucking,¹⁰ and oral sucrose,^{11,12} each a method for pain mitigation, and more. Our target article is a new contribution. It builds on past knowledge of GHT and touch; it newly addresses the procedural pain of suctioning; and it expands the range of PIPP for

assessment. There is more to learn about the scope, the magnitude, and unexplored outcomes of using GHT.

Though preliminary in several ways, Fatollahzade et al.¹ is an elegant study, particularly when viewed in the light of basic biomedical ethics. Importantly, they noted that GHT is safe. It did no harm. By explicitly registering that no harm to the baby came from the procedure, they formally recognized a vital dimension of their method. In other words, they addressed the familiar dictum, *Primum non nocere*, or ‘First, do no harm’.

But, it is not enough to deem something as ethically-sound because risk is minimal. There is an ethical imperative to examine whether procedure actually “does good”?¹³ In fact, Fatollahzade and her colleagues reported that GHT reduced pain responses. Gentle Human Touch during suctioning provided actual, active benefit.

Stay with me now: “Not to harm”, in the language of ethics is *non-maleficence* [mə-‘le-fə-sən(t)s]. The principle of non-maleficence is alive and well throughout medical ethics. After all, *Primum non nocere*. Infants cared for in the NICU deserve pledges of non-maleficence. All our patients do. But, again, it is not enough simply to avoid doing harm. In addition, ethical practices demand that we promote and do good. “To do good” in the language of ethics is *beneficence* [bə-‘ne-fə-sən(t)s]. A beautiful word for a beautiful principle.

Whereas non-maleficence is mainly a prohibition against harm, beneficence has at least three forms, each of which we should examine as part of our awareness of doing good. As such, beneficence includes (a.) doing good, (b.) preventing harm, and (c.) removing harm.

In the NICU we can say the coin of the realm is ethical treatment of each baby. There are two sides to this coin: non-maleficence and beneficence. As two sides of the same coin, they are inseparable. So, as we hold this coin in our hand, we must continually turn it and examine each side. Such diligence is due to both sides. For this reason, I favor the label of *dual diligence*, stipulating the obligation to honor both principles – beneficence and non-maleficence.

Illustrative examples of non-maleficence without beneficence abound. Look no further than the previous issue of the *Developmental Observer*!¹⁴ Dr. Ita Litmanovitz, a neonatologist and NIDCAP Trainer, contributed a thoughtful and expert Commentary to the Science Desk column. Ita examined a technological *tour de force* report,¹⁵ in which extremely prematurely born neonates were monitored for their first 72 hours with a combination of cerebral regional oxygen saturation (CrSO₂) via Near Infrared Spectroscopy (NIRS), amplitude-integrated EEG (aEEG), functional echocardiography (ECHO), further supported by head ultrasounds. The authors concluded that such multimodal monitoring “is feasible, safe, and well tolerated by extremely prematurely born infants in the first 72 h after birth”. True, yes, but remember dual diligence!

Dr. Litmanovitz’s commentary guides us through a set of critical considerations of the ocean of data that were collected -- without harming the newborns’ skin or increasing adverse events. Despite the investigators’ rationale, the multimodal mea-

sures did not prevent IVH or reduce adverse outcomes. More serious, however, was that to make these measurements, there was an obligatory, 72-hr separation of infant and mother!

It is well-documented that such separations can have both immediate and long-term negative effects both on the baby and mother. Dr. Litmanovitz cited of the costs of losing early postnatal mother-infant contact, while seeking some still-elusive benefits of predicting a hemorrhagic event. Awareness and attendance to dual diligence – recognizing and documenting both non-maleficence and beneficence can provide the clarity we need to realize ethical care.

Dual diligence is not only fully compatible with NIDCAP practice, it is embedded within it.

In caregiving, in formulating treatment protocols, and in evaluating research, it is imperative for us to examine both avoiding harm and doing good. Doing dual diligence is a foundation of ethically-guided practice.

NICU miracles of successful development arise from a combination of high-tech, low-tech and no-tech. We do not know how they combine into success, but we do know that they are all involved, and I bet that it is not via simple addition of separate factors. Each modality supports the other. High-tech medical wizardry is crucial. So is parental love and human touch.

Remember always that an *ordinary* day in a NICU is made of the extra-ordinary. *Ordinarie* in Old French, for *rule* or *ordinance*, as in rules that prescribe forms of action, gave us the English word *ordinary*. Think of the protocols you follow that make an ordinary day. In this way, everything you do makes miracles almost ordinary. Look for and see the duality of non-maleficence and beneficence present in a simple protocol. In developmental care, they are the core of the miraculous.

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Reflections on the Virtual 32nd NIDCAP Trainers Meeting 20 – 22 October 2021

Attendance at a NIDCAP Trainers Meeting provides us with the opportunity to hear new ideas and learn from our colleagues. Below we have three unique perspectives of the meeting from Members of the NFI.

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Jacques Sizun, MD

*Centre Hospitalier Universitaire de Toulouse | CHU Toulouse
Service de Néonatalogie*

During the 32nd Annual NIDCAP trainers Meeting, Sari Goldstein Ferber, PhD, from Bar Ilan University, Israel, presented an interesting reflection on the potential impact of NIDCAP on the homeostatic regulation of hypothalamic (HPA) axes. She presented three axes that are regulated by melatonin, cortisol and oxytocin. They play important roles in the maturation of circadian rhythms, the modulation of stress, and the relationship and bonding. The behavioral observations using the Synactive Theory framework are focused on the management of the wake/sleep states, and on the permanent balance (and imbalance) of the stress-induced behaviors. The baby's strategies for self-regulation and the co-regulation by parents are important to manage stress behaviors. Recommendations are always oriented toward attachment and bonding support.

This presentation could have three impacts:

- The first impact is on my own vision of the newborn, their development and care. It is very important not to stay in our "ivory tower", being too comfortable and secure can isolate us from the outside world. Confronting our own theoretical models with advances in science and medicine is an exercise that is sometimes intellectually difficult but very nurturing.
- The second impact concerns our healthcare professional colleagues who may not be convinced by our approach to care. The psychoneuroendocrine perspective can be a gateway to NIDCAP for them, as it has been observed for other fields of newborn care such as: pain (close link between developmental care practices and non-pharmacological treatments); palliative care (same philosophy of holistic, individualized, family-centered care); and/or breastfeeding support.
- The third impact could be for research. Using tools from other fields of clinical research to explore the impact of NIDCAP appears exciting.

Conclusion: Connection is essential!

Jim Helm, PhD

Director Emeritus, Carolina NIDCAP Training Center

When I attend a conference, and in particular, the NIDCAP Trainers Meeting, I hope to be re-energized around the mission and goals of the NIDCAP approach and... to see old friends who have shared goals; to learn about new ideas, research and applications; and to be inspired. This day did not disappoint me, rather it brought energy, reflection and the hard-to-come-by inspiration.

The Pearls of Wisdom segments of the meeting have members sharing personal experiences that have helped shape their caring and offer participants a unique opportunity to join a colleague's personal perspective. Andrea Nykipilo, RN and Gretchen Lawhon, PhD, RN, FAAN provided a wonderful start to the day with thoughts on how the NIDCAP approach has opened one to be in the moment and how learning imparts a sense of duty to teach others. Perfect for NIDCAP work.

Dr Als' keynote address built from that setting-of-the-stage as she embraced the meeting's theme – Always Together – and examined it from within the uncertainties and cautiousness of the pandemic. Discussing the critical importance of "being together" during critical times, whether during a pandemic or negotiating the challenges of being admitted to an NICU. No matter, human togetherness is supportive, facilitates growth, development and healing and especially for the fragile infants and traumatized families of the NICU.

The NFI Membership Meeting, presided over by Deborah Buehler, PhD, President of the NFI Board of Directors also had such a positive vibe as examples of the many pockets of growth were provided where the NIDCAP approach is understood, valued, and promoted. NFI members need to find and read the committee reports. In our daily lives we can easily lose the "big picture" of growth around the world. This meeting helps us reconnect.

Clinical Practice and Abstract presentations showed strong examples of affecting change in systematic ways be it a specific care practice (Four-handed care: L. Eitan) or a unit culture shift as we saw in the beautiful photo presentation from Sweden (Continuous skin-to-skin contact: S Klemming). The

NIDCAP TRAINERS MEETING 2021



Some of the 124 attendees from 23 countries present for the Virtual NIDCAP Trainers Meeting.

abstracts featured efforts to support families in their challenge to parent in the NICU and as NICU supports are removed, through the transition to home.

The Journal Club, a fairly new component of meetings that has taken hold, brings us new ideas. This segment gave us two articles to share and discuss. Generation Z, as with each new family, will challenge us to accept families, individuals, as they are, and adapt. The bio-ecology of behavior and behavior change offers new insights as to how we understand change and perhaps a way to measure differences in change.

A day full of thoughtful perspectives on change. May they inspire and challenge our next year as we work together.

Mandy Daly

NFI Board Member, Founder of the Irish Neonatal Health Alliance

Preterm birth flips the paradigm of parenthood on its axis and robs families of their hopes, dreams and expectations. A preterm birth is often preceded by a rocky and tumultuous pregnancy journey and can culminate in an emergency birth situation that is fraught with urgency, fear and uncertainty. A

full-term healthy pregnancy, a natural birth, those precious first moments when Mum meets baby, babies first outside of the womb sensory experience skin to skin with Mum, hearing her voice and smelling her scent are replaced by clinical handling by strangers, pain as airways are cleared and lines inserted, and fear and confusion.

When a newborn requires care in the Neonatal Unit families are forced to re-evaluate their anticipated parenting role and as if being separated from one's baby at birth is not traumatic enough, families are burdened further by having to learn the language of the neonatal unit, shelve their own need to recover physically and emotionally from the traumas of the pregnancy and delivery and find a way to parent their sick and vulnerable infant in an environment that excels at erecting barriers.

Research has demonstrated that the relationship that a baby has with their parent or primary carer, has an enormous impact on their future mental, physical, social, and emotional health. The neonatal period is critical to the development of the parent-child relationship. In fact, the strength of this relationship is the main predictor of how well a child will do both in school and in life. It is not founded on the quality of the care

or parental love, but on the non-verbal emotional communication that a parent develops with their child, known as the attachment bond.

Experience shapes the brain and having an infant in the neonatal unit has the potential to erode the fundamental and foundational natural connections; the consequences of which, if unaddressed can be detrimental for the infant and the family unit. Families are the cornerstone upon which newborn care must be developed and delivered. It is imperative that newborn care practices embody the essence of connecting families and strive to repair the fractured connections at every juncture. The NIDCAP approach to care acknowledges the important role that families play in their baby's development, it recognizes the infant's need for positive familial and sensory experiences to support his/her developing competencies and it facilitates connections at every step of the journey by protecting the developing infant brain and the evolving infant parent relationship.

The COVID-19 global pandemic has brought unimaginable challenges for newborn healthcare systems and families, but never has it been more important to remain steadfast in keeping babies and their families together. On the first day of the NFI Trainers Meeting, Dr. Manuela Filippa's presentation about her unit's family-based intervention that focuses on the benefits of early vocal contact between parents and preterm infants, struck

a chord close to my heart. Having spent over three months in a neonatal unit with my daughter many years ago, at a time when parents were still considered "visitors" on the unit, and seeing 15 years of advocating for family and infant centered developmentally supportive care to be embedded at the heart of care pathways, wiped out over-night in many NICUs around the world by the pandemic, it was encouraging to see the positive results from initiatives such as Manuela's. We need to see more neonatal units adapt their practices to reflect positive research findings and researchers need to explore more opportunities that embed families at the heart of neonatal care.

"Always Together Makes All The Difference For All Involved"

—Dr. Heidelise Als, Founder of the
NIDCAP Federation International

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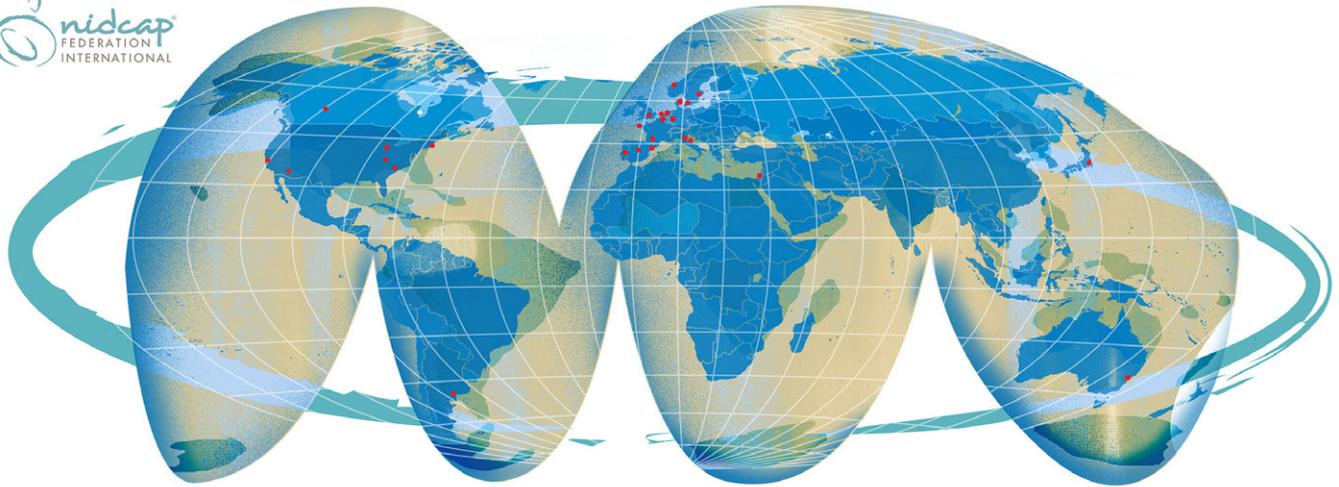
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(Continued from p. 11)

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We welcome four new Training Centers to the ever growing list

UZ Leuven NIDCAP Training Center

Leuven, Belgium

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Co-Director: Chris Vanhole, MD, PhD

NIDCAP Trainers: Bieke Bollen, PhD & Kelly Janssens, RN

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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 & Yoko Otake, RN

NIDCAP Trainer: Tomohisa Fujimoto, PT

NIDCAP Trainers in Training: Kanako Uchiumi, RN, MW, Noriko Moriguchi, MSN, RN, PHN, IBCLC & Yoko Otake, RN

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Lund-Malmö NIDCAP Training and Research Center, Sweden

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Trainer: Stina Klemming, MD

Trainer-in-training: Pernilla Stenman, RN

Nursing Director: Jessica Jubner, RN

Medical Director: Kristbjörg Sveinsdottir, MD

Psychologist: Johanna Månsson, PsyD, PhD, NBO-professional

Board members: Emelie Oscarsson, Christina Schilow Sandell, Kristina Albrecht



Together, the two hospitals, Lund and Malmö, serve a region of 15500 births every year and care for 1050 infants (6.8% of infants born) in their two NICUs. Lund-Malmö NIDCAP Training and Research Center has been open and active since October 1st, 2021 and will have its formal inauguration during the 2022 Conference on Ultra-Early Intervention, March 24th - in Lund and online in a hybrid format.

Sant Joan de Déu Barcelona NIDCAP Trainer Center

Barcelona, Spain

Director: Ana Riverola, MD

NIDCAP Trainer: Ana Riverola, MD

Medical Director: Martín Iriondo Sanz, MD, Chief of Neonatal Service

Nursing Director: María José Troyano Martos, RN, NIDCAP Professional

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Mission

The NFI promotes the advancement of the philosophy and science of NIDCAP care and assures the quality of NIDCAP education, training, mentoring and certification for professionals, and hospital systems.

Adopted by the NFI Board, July 1, 2019

Vision

The NFI envisions a global society in which all hospitalized newborns and their families receive care in the evidence-based NIDCAP model. NIDCAP supports development, enhances strengths and minimizes stress for infants, family and staff who care for them. It is individualized and uses a relationship-based, family-integrated approach that yields measurable outcomes.

Adopted by the NFI Board, October 20, 2017

Global Perspective on Developmental Care – Ireland

Susan Vaughan¹ and Mary O'Connor²

¹Cork University Maternity hospital; ²Coombe Women & Infants' University Hospital, Dublin.



Ireland is an island country in north-western Europe, comprising the Republic of Ireland, and Northern Ireland which is part of the United Kingdom. The population of the Republic of Ireland is approximately five million. The publicly funded healthcare system in Ireland provides healthcare and personal social services. The hospital structure is organised into seven groups, four of whom have tertiary centres. The nineteen neonatal units are classified according to their number of births into local, regional and tertiary neonatal units. There are 11 local units, four regional units and four tertiary units. There are 300 neonatal cots in total: 193 special care, 52 high dependency care and 55 intensive care. Three of the four tertiary Level 3 Neonatal Units are situated in Dublin city and one in Cork city: Cork University Maternity hospital.

A new model of care for neonatal services in Ireland was launched in 2015. The recommendations set out in this model were benchmarked against international standards and have been informed by neonatologists, paediatricians, neonatal nurses and health and social care professionals (HSCPs) involved in providing care to newborn babies. There was also consultation with the key stakeholders: parents whose babies had received care in a neonatal unit, through our partners the Irish Neonatal Health Alliance and the Irish Premature Babies Association. The views of all groups were considered in the development of the new model, with the overall aim of designing systems that will provide quality evidence-based care to every baby. The report stated that, "It is a goal in NICUs to provide family-centred care, aided by programmes such as the Newborn Individualized

Developmental Care and Assessment Programme (NIDCAP) which aims to provide individual holistic care to infants in an environment that can be potentially toxic to the developing brain". Currently, limited numbers of nurses have been NIDCAP trained. A CNS role specialising in family-centred care and NIDCAP will be established, initially in the tertiary units with future expansion to other units. Developmental care is the name that encapsulates NIDCAP, FINE and FiCare in Ireland. Some units are adapting aspects of FiCare while others are working with the FINE programme.

Cork University Maternity hospital (CUMH) was opened in 2007, formed by the amalgamation of services of three maternity hospitals in Cork city. CUMH is one of the busiest units in the country with 7,500 births yearly with 1 in 10 babies admitted to the Neonatal Unit (NNU). CUMH, forms part of the Health Service Executive South/South West hospital groups, the Neonatal Unit at CUMH is a referral centre for extreme preterm and ill babies from counties Kerry, Tipperary, Waterford and Limerick Maternity units. The NNU in CUMH is a 50 bed unit, made up of 18 intensive care beds and 32 special care/immediate care beds. Newborns from 23 weeks gestation to term are looked after in the unit, from admission to discharge. It is also the regional centre for newborns needing therapeutic cooling.



Developmental care was first introduced into Cork by Inga Warren with lectures to staff in 1990 but it wasn't until 2007 that Professor Anthony Ryan (neonatologist) and Lucille Bradfield (neonatal nurse manager) secured funding for formal NIDCAP training to begin. In 2009, two neonatal nurse/midwives, Susan Vaughan and Ann Flynn were certified under the guidance and training of Dr. Nikk Conneman and Monique Oude Reimer. In 2011/2012 three more nurses, Ann Buckley, Kathleen O' Riordan and Mary Cullinane and Annmarie Cronin, NNU physiotherapist, became NIDCAP professionals. In CUMH, a multidisciplinary group was set up including past parents of the unit, social work, OT, SLT, medical and nursing staff and the NIDCAP Professionals to develop a more family-centered unit and to promote developmental care. We are striving as a unit to become not just family centred but family integrated. Some of our recommendations and changes to the unit are: welcome booklets for parents, in-service study days for all staff members in the unit, ownership to the promotion of developmental supportive environment and care to all staff, a read-a-thon to encourage parents to read and speak to their babies now and in the future. We developed Kangaroo/skin to skin care protocols, guidelines and education days and were very proud that KC was such a normal and highly valued part of our care of newborns that it was not stopped or time limited to mothers during the recent pandemic. The NIDCAP group in CUMH is responsible for the education sessions in Developmental Care in the Higher Diploma Neonatology Nursing at University College Cork (UCC), new medical doctors to the NNU, and student nurses and midwives within CUMH. We have celebrated World Prematurity Day on November 17th for the last 10 years, combined with a coffee morning for all past patients and their parents. We are very lucky to have the presence and support of Mandy Daly and the Neonatal Health Alliance at the coffee morning and throughout the year. CUMH is also a research hospital and is linked to INFANT, Irish Centre for Maternal and Child Health Research. The NIDCAP team are currently involved in research projects within the unit. There are plans to develop nurse specialists roles in Developmental Care within the unit.

The Coombe hospital in Dublin was founded in 1826 due to extensive maternal and infant mortality in the environs and relocated in 1967 to the current site. The hospital, one of the three stand-alone maternity hospitals in the Irish setting has undergone several revisions of title and is presently known as the Coombe Women & Infants' University Hospital (CWIUH). After much discussion on location, it will be the maternity hospital that will be co-located with St James's Hospital and the National Children's Hospital which is currently under con-



struction. We work closely with our Level one partner within the Dublin Midlands Hospital Group. Our neonatal centre has a forty-cot capacity, 14 intensive care, 10 high dependency care and 16 special care cots. We are one of the three Dublin hospitals that facilitate the National Neonatal Transport programme on a three-week rotation. We are also the national cardiac referral centre including referrals from Northern Ireland for delivery and stabilisation before transferring to the Children's Heart Centre. At local level we have introduced several family centred developmental care initiatives, which include increasing parental presence, encouraging their presence on ward rounds, and increased participation in their baby's care. There is very positive feedback from the read-a-thon. We have reinvigorated our parents support group, 'Parents' Time Out' (PTO), facilitated by an interdisciplinary team including psychologist, neonatal nursing, and allied health professionals again with positive feedback. COVID-19 really interfered with our philosophy as infection control measures took precedent during the pandemic, yet we collaborated with parents and while we restricted both parents being present together, we did not restrict/limit their time with their baby. We introduced face-time for baby and families which was a great success.

Continued professional development is central to our ethos in CWIUH and we facilitate family centred developmental education sessions for the Foundation Levels I and II in Neonatal Nursing which is affiliated to Trinity Collage Dublin, Postgraduate Diploma in Neonatal Intensive Care Nursing which is affiliated with the Royal College of Surgeons (Ireland) and both Foundation and Postgraduate Diploma level in Paediatric Intensive Care Nursing affiliated to University College Dublin.

CWIUH is the Irish FINE hub and we work closely with Inga Warren, who facilitated NIDCAP training in our unit. Presently we have one NIDCAP Professional, however formal NIDCAP observations and write-ups are not performed at the moment. This will change once we appoint the Clinical Nurse Specialist in Family Centred Developmental Care. Our second NIDCAP Professional immigrated to the Middle East. Our close association with Inga Warren continues in facilitating all FINE programmes and we have collaborated with the team from CUMH for FINE level I. We have coordinated FINE Level I on an annual basis since 2014, serving neonatal, paediatric nurses and allied health professionals and have worked with Inga in facilitating FINE level I online, our first in the autumn. Since 2018 FINE Level I became mandatory for all nursing staff in our unit, health care assistants and our allied health colleagues also participate. Five neonatal nurses and a physiotherapist have completed FINE Level II.

It is clear that there is still considerable development needed in family centred developmental care in Ireland, a challenge that we are rising to meet.

NIDCAP Training Centers – Facebook Pages

During the past six months, despite the adversity facing the NIDCAP Training Centers and NIDCAP Professionals worldwide, many positive achievements have taken place. This series of snapshots from the various Training Centers enable us to all celebrate and acknowledge each other's achievements.

NIDCAP Federation International
27 November at 04:15 · 🌐

NFI's 20th Anniversary Fundraiser
Fundraiser for Nidcap Federation Intl Inc by NIDCAP Federation International

\$338 of \$28,204 raised

Fatima Clemente is with **Graciela Basso** and 13 others.
17 November at 19:54 · 🌐

Another meeting of mentoring and reflection of NIDCAP professionals this time also with participation of professionals who completed FINE2! About 35 participants from Portugal 🇵🇹, Spain 🇪🇸, Italy 🇮🇹, Argentina 🇲🇪 and Israel 🇮🇱!
Improvement of care centered on the development of the baby and his family!
[#federationinternationalnidcap](#)
[#alapediatrica](#)
[#neonatologiasaojoao](#)
[#WPD2021...](#) See more

🔗 See original · Rate this translation

Como profesional NIDCAP, ¿cómo acompañarías a estos padres y a los profesionales?

24 h 48 h 12 d

Nacimiento

The Australasian Nidcap Training Centre
17 November at 20:26 · 🌐

An exceptionally big thank you to [CommBank Stadium](#) and [Stadium Australia](#) for lighting it purple for [#worldprematurityday](#) we are so grateful for your support!
[#graceNICU](#) [#NIDCAPAustralia](#) [#lightitpurple](#)

CommBank Stadium
10 m · 🌐

Shining a light on [#WorldPrematurityDay2021](#) 🍆

We're dressed in purple tonight to help raise awareness of the incidence of premature birth and it's impact on newborns, families and the community.
[#LightItPurple](#)

Stadium Australia
9 m · 🌐

[#WorldPrematurityDay2021](#) and 'Lighting It Purple' reminds the community of our important role in caring for and supporting the future generations of Australia.

Purple is the symbolic colour of WPD representing sensitivity and individuality 🍆

Karolinska Nidcap Training and Research Center
30 April 2020 · 🌐

Olga Bebenek, congratulations to achieving NIDCAP professional reliability! Karolinska NIDCAP Training and Research Center proudly present our new NIDCAP Specialist, Olga Bebenek ❤️

It has been an honor to be your guide on this journey, with wonderful support from Senior NIDCAP master trainer Agneta Kleberg. Grattis Olga 🍷

Sophia Nidcap Training Centrum
17 November at 08:52 · 🌐

Together with the nidcap centre from Australia, developed a beautiful e-learning as a basic education for development-oriented care .
To be continued!!!
🌐 · See original · Rate this translation

Nidcap France
4 November at 00:43 · 🌐

The word of order for World Prematurity Day: "Zero separation: act now!" "

🌐 · See original · Rate this translation

Brussels Nidcap Training Center
26 November at 06:11 · 🌐

20 years of the NIDCAP program at CHU de Brest!
🌐 · See original · Rate this translation

CHRU Brest
24 November 2018 · 🌐
#InfossantéCHRU

The NFI [NIDCAP Blog](#) offers observations from many different perspectives on NIDCAP and its implementation, such as NIDCAP and APiB training, Nursery Certification, the science behind the approach, the family experience with NIDCAP, the NFI, and much more. We encourage you to visit the NIDCAP Blog and to leave comments for our bloggers and our NIDCAP community in general. If interested in becoming a guest blogger please contact Sandra Kosta at sandra.kosta@nidcap.org.

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