

Developmental Observer

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A philosophy....can help us choose the best approach from an ethical point of view, such as the philosophy of person/ family-centered care

—Jacques Sizun

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Translating Data on Brain Development Into Practice

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A summary of the presentation given at the 33rd Annual NIDCAP Trainers Meeting in Bad Bol, Germany 2022

ne of the goals of the neonatal teams is to support and protect the developing brain in the Newborn Intensive Care Unit (NICU), as the baby only has 'one brain for life'.1 Medical treatments, such as antenatal steroids and magnesium sulfate, have been shown to be effective in preventing brain damage in preterm infants. In parallel, environmental and behavioral strategies have been proposed under the generic term of 'developmental care' or 'brain care'. Developmental care is an emerging science and needs to be as evidence-based as possible so that healthcare providers are in a position to choose the best strategies for care, and in order for healthcare teams to be trained effectively, and parents and

families to be provided with the best and most comprehensive information available.

Brain plasticity is 'the ability of the nervous system to change its activity in response to intrinsic or extrinsic stimuli by reorganizing its structure, functions, or connections.' Brain plasticity is an opportunity for the newborn, as it offers a chance for rehabilitation after brain damage. Brain plasticity is also a challenge: an early hostile environment could alter the steps of brain development, such as synaptogenesis. In case of prematurity, synaptogenesis occurs while infants are hospitalized in the newborn intensive care unit.

This article focusses on the effects, as described in recent systematic reviews,

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of some approaches aimed at preventing the negative impact of frequent stressors on brain development in the NICU. The stressors are sleep deprivation, pain, mother-child separation, and sensory dysstimulation.

Stressors in the NICU

Sleep deprivation

Animal studies, mostly conducted on rodents, have provided useful insights with regard to sleep deprivation.3 These studies have shown that sleep deprivation may result in: oxidative stress, neuroinflammation via chronic microglial activation, and the accumulation of the abnormal proteins p-Tau and amyloid- β in the cerebral cortex. These studies have also shown a neurogenesis decline via complement activation, which alters the balance of Fragile X-Mental Retardation Protein expression.3 In addition, the impact of chronic sleep deprivation on behavioral development has been demonstrated. Sare et al⁴ found short- and long-term changes in behaviors of sleep-deprived mice, measured by activity in an open field arena. Males demonstrated decreased sociability and increased repetitive behaviors. This data from preclinical studies show that sleep deprivation in the neonatal period has long-lasting behavioral changes, possibly modulated by gender.

Pain

A meta-analysis by Steinbauer et al⁵ concluded that neonatal pain has a large effect on neuronal cell death in rodents. The higher number of neonatal pain events was significantly asso-

ciated with increased neuronal cell death, increased anxiety, and depressant-like behavior. Boggini et al⁶ summarized the impact of pain on preterm infants' brain development demonstrated by MRI studies. A volume reduction of white and gray matter structures at neonatal and school ages is associated with early postnatal pain exposure. However, there is a possible bias, as the most severe clinical conditions are associated with higher exposure to painful procedures.

Mother-child separation

Maternal separation, an early stressful experience, can negatively impact the newborn's nociceptive system development and pain responses at different levels⁷ (Table 1). Epigenetic mechanisms are implicated in the long-term effects of this early life stress that could also impact the next generation.

Sensory Stimuli

During prenatal development in mammals, the sensory systems do not become functional at the same time, but rather in a specific and invariant sequence: first tactile, then vestibular > chemical > auditory > visual.⁸ This differential timing of sensory system onset could benefit the earlier developing sensory systems as it allows them to develop without competition or interference from later developing sensory systems. In the case of preterm birth, the sensory stimuli are numerous, intense, simultaneous, chaotic, and physically different from those observed in utero.⁹ This could negatively impact synaptogen-

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Editorial

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The influence of NIDCAP is steadily increasing, as evident from the comprehensive body of work it encompasses. In this edition, Jacques Sizun presents compelling proof of NIDCAP's efficacy by examining current research and practical applications. Notably, there has been a surge in

publications citing NIDCAP's principles across multiple languages, underpinning its growing global recognition.

The path of our global outreach remains unwavering. The NIDCAP Federation International, driven by dedicated members, continues to propel the frontiers of this approach. Through leadership, we are privileged to embark on journeys of discovery with our valued members. An insightful introduction to Monique Oude Reimer-van Kilsdonk hailing from the Netherlands, offers a glimpse of our diverse membership.

Joy Browne enriches our understanding of APIB through a survey of our members, providing valuable insights that deepen our appreciation of its implementation.

A pivotal facet of the NFI is our community of family members. Nina Nikolova's poignant account from Bulgaria exemplifies how adversity can be the catalyst for assisting fellow families.

I invite the members and readers of the Developmental Observer to share their journeys with developmental care. We warmly welcome your reflections on training, practice, interesting case studies, and the invaluable lessons drawn from personal experiences. Your contributions stand to strengthen the Developmental Observer and the information to move developmental care forward.

Kaye Spence AM FACNN

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Table 1: Overview of maternal separation on the nociceptive system [adapted from Melchior et al.⁷]

Gastro-intestinal tract	Dorsal root ganglion	Spinal cord	Higher brain centers
- Increased permeability of the mucosal layer	- Increased excitability of afferent neurons	- Increased activity of superficial and deeper layers	- Differential activation of the pain matrix
- Inflammation - Change in microbiota composition	Increased expression of Nav 1.8Decreased expression of Kv1.2	- Changes in neurotrophic factors expression	Alteration of descending controls of painCentral inflammation

esis. According to Bourgeois, 'experimental models provide an additional example showing that a perturbation at an early neurodevelopmental stage may have a late and long-lasting effect of disorganization despite an apparently normal intermediate period.'10

The research data shows evidence for the importance of prevention of pain, stress, mother-child separation and inappropriate stimulation in the NICU. What is the evidence for the strategies that reduce these stressors?

Strategies for Reducing Stress

Sleep support strategies

A systematic review found that swaddled preterm newborns arouse less and sleep longer. 11 Swaddling stimulates sleep continuity, as shown under laboratory conditions and in descriptive studies. The effect is most consistent in periods of Quiet Sleep (QS), but not always consistent during Rapid Eye Movement (REM) sleep.

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Editorial Board



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A Cochrane Review of non-nutritive sucking (NNS) found four studies reported on behavioral states with different methods of reporting states. ¹² Two studies reported no effect, one study reported the most frequent transition was from QS to drowsy for the NNS group, and one study reported that sleep states were more frequent in the NNS group.

The impact of skin-to-skin on sleep in neonates has been clearly demonstrated. According to a review from the American Academy of Pediatrics, skin-to-skin increases frontal brain activity during both quiet and active sleep, supports a more mature sleep organization, with increased total and quiet sleep, decreased REM sleep and arousals from sleep, and improves sleep cycling. Therefore, the best strategy to protect sleep is to encourage parents to be present in the NICU and to provide extensive skin-to-skin for their infant.

In a study of infants receiving regular care versus developmental care practices (covering the incubator, decreasing environmental noise, using supportive bedding, and promoting state transition by hand swaddling, non-nutritive sucking, or grasping), sleep time was increased both in AS and QS states.¹⁴

In a systematic review of randomized control studies on the effects of music therapy on premature infants, ¹⁵ recorded music interventions were not associated with a significant effect on behavioral states. Live music interventions were shown to improve sleep in three out of four studies, however, behavioral states were defined with different non-validated tools. Due to the heterogeneity of type and duration of interventions, gestational age of the subjects, and outcome measures, there was not enough evidence to recommend music therapy.

Pain control strategies

Numerous clinical trials and meta-analyses have demonstrated the efficacy of non-pharmacological interventions on the behavioral expression of pain in newborns: swaddling, flexed position, non-nutritive sucking, oral sucrose, breastfeeding or mother's milk, and skin-to-skin. Association and/or superiority of interventions are less studied. More trials studying the impact of these interventions on the cortical response and the effect of structured parent involvement are needed.

Maternal Separation Strategies

New World Health Organization (WHO) guidelines advise that kangaroo mother care should start immediately after preterm birth without an initial period in an incubator.¹⁷ These recommendations are based on recent trials demonstrating the positive impact of very early skin-to-skin on survival or cardiorespiratory stabilization.^{18,19}

Mother-newborn couplet care is considered the best strategy to support the zero-separation concept. However, the current evidence is scarce.²⁰ The Stockholm Neonatal Family Centered Care Study demonstrated a 5.3-day reduction in total length of stay and a reduced risk of moderate-to-severe bronchopulmonary dysplasia in the Couplet-care group.²¹

Believing that all these interventions could be integrated with an evidence-based global approach, Roué et al collaborators identified eight principles that do not need more research before routine use.²² These include free 24-hour parental access, pain management, environmental influences, support of skin-to-skin, and sleep protection.

Science, Philosophy, and Human Rights

While the scientific evidence is strong, science alone cannot guide all aspects of care for hospitalized newborns. A philosophy - 'a theory that acts as a guiding principle for behavior' - can also help us choose the best approaches from an ethical point of view, such as the philosophy of person/family-centered care. In this case, scientific evidence is not then necessary. Instead, the ethical reflection, both individually and as a group, can inspire and enrich the approach. Moreover, in a study concerning the participation of NICU parents in medical rounds, some parents argued that it was not a philosophical question, but just the expression of human rights, their 'right' to be present, and their 'right' to participate in the decisions concerning their baby.²³ Although science is an important factor in determining best practice, the respect of human rights is also very important.

Guidelines

In order to put the science and philosophy to practice it is necessary to have access to the data and for clear guidelines/ recommendations/standards to be formulated and followed. Many guidelines are easily accessible and can guide high quality care in the NICU.

Gap Between Research and Practice

Despite the existence of scientific evidence and easily accessible recommendations from national or international agencies and organizations, a significant gap exists between knowledge and practice. An example is a multisite survey across 13 NICUs in Paris about procedural pain in newborns. 24,25 One NICU used non-pharmacological interventions for painful procedures only 2.4% of the time, whereas another NICU used these strategies 81% of the time. They also measured the difference in pain control during the day and the night and found that the babies were more protected from pain during the day than at night. The only difference was parental presence. There is high evidence for the importance of parental presence, yet implementation is lacking. Why is there such a difference between these units given they all have access to the same research? Another study, the French EPIPAGE study²⁶ showed that there was little range in difference across units on medical interventions, but there was a large difference across units in the use of behavioral strategies. It was also shown that there was no significant difference between the cluster of infants who received intensive medical intervention and those who received more behavioral interventions. Although there is a high level of research on the benefits of

behavioral strategies there is great difference in the implementation of these strategies which has an effect on the comfort and care of the baby and ultimately on the baby's outcome.

NIDCAP Training and implementation of brain-care practices

The French EPIPAGE study gives us information on the implementation of medical and nursing practices such as skin-to-skin, breastfeeding support, and pain control, and the association with professional education and training. ^{26,27} The authors observed large unit-level variations not explained by differences in infants' characteristics across units, but possibly explained by neurodevelopmental care policies and training. The NIDCAP training compared with no training was significantly associated with early kangaroo-mother-care (KMC) initiation: [OR, 3.5; 95% CI, 1.8–7.0] and sufficient perceived maternal information on infants' pain [aOR (95% CI) 2.6 (1.7–4.1)]. ^{26,27} There has been much evidence on the effectiveness of NIDCAP on the infants' outcome, but this was one of the first studies to show the influence of NIDCAP training on evidence based care practices.

How can we explain this? Dominique Haumont identified ten points where NIDCAP impacts early developmental care, including assessment of pain, kangaroo care, and sleep organization. The tenth point identified NIDCAP training as a tool for change. NIDCAP is not a prescribed protocol, instead NIDCAP implementation is said to be 'process-guided': a continuous process requiring flexible procedures and not procedurally-based attitudes. NIDCAP is also 'relationship-based' as it provides a new way of thinking about our relationships with the babies, the parents, and our colleagues. The third aspect is 'system-oriented' thinking as a change in any part of the system has an effect on the whole system.²⁹

Conclusion

- Research highlights the vulnerability of the developing brain in hospitalized newborns.
- Developmental care practices are evidence-based.
- A research-practice gap exists.
- NIDCAP could bridge this gap.

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Assessment of Preterm Infants' Behavior: Insights from the Field and Projections for the Future

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With appreciation and reflections of my journey in APIB training and practice with Dr. Elsa Sell, my APIB Trainer so long ago. Elsa was an early neonatology game changer, custom breaker, and consistent advocate of the NIDCAP work. She braved the medical system to learn and teach the APIB approach even before there was NIDCAP. Here's to you, Elsa!

In the NIDCAP world, there is no achievement more rewarding than that of becoming an APIB (Assessment of Preterm Infants' Behavior) Professional and Trainer. The APIB, ^{1,2} has a reputation for a detailed, challenging-to-learn yet unparalleled assessment, providing insight into the baby's capabilities and voice.³ Its approach and systematic elicitation of a baby's responses to increasingly complex questions reveal optimal individualized information about their competencies. The APIB provides a feeling of delight when it tells us about babies' experiences. Parents marvel at the insights elicited by the administration of the APIB and what we professionals bring from the exam that helps them "see" their baby. Learning and applying findings from administering the APIB can be rewarding to the examiner, other professionals, and parents.

Only a few APIB Trainers are available to provide support and insights into the exam. Aside from NIDCAP Trainers, for whom reliability in the APIB is a required step, or researchers, who must be reliable to conduct studies, few individuals are considered "APIB Professionals".

The experiences of those APIB Professionals who have either been through the process or are in the process of learning the exam can provide insights into how the training was valued, how they are using the APIB, and what recommendations for changes in training and implementation they offer. A survey was developed and sent to a variety of professionals and trainees to request their expertise and recommendations for consideration of changes and next steps for the APIB. The survey was created to know how learning the APIB has influenced the activities in which APIB Professionals engage.

Methods

Survey Development

The "APIB Practice and Training Survey" was developed in consultation with four current APIB Trainers.

The following categories were identified to determine how the APIB is currently being used: the impact on clinical work; the impact on working with babies and families; the benefit to NIDCAP training; the use in research; and, the use in supporting other professionals. Further categories included: the requirement to become a NIDCAP Trainer; the impact on



training approaches; and, recommendations for APIB training for other professionals. Further details about the content of the survey can be accessed through the author.

Data Collection

Each APIB Trainer provided a Survey Monkey link for the survey to those whom they had previously trained or those currently in training. Thus, the survey was a convenient sample to elicit the views of those with a vested interest in the APIB and who were willing to share their insights. Direct responses to the questions were followed by a request for comments to each of the question offered.

Data Analysis

Results were analyzed using descriptive statistics and qualitative descriptions with representative quotes from the respondents included. The results provided valuable information regarding training, clinical application to the NIDCAP work, and recommendations for the future of APIB work.

Findings

Description of participants

Fifteen globally represented APIB Professionals and APIB Professionals-in-Training responded to the APIB survey. Most of the respondents were APIB Professionals who were trained between six years and "over 20" years ago. Although data were collected anonymously, based on those who were interested in receiving the results, respondents were from Canada, Europe, Australia, Japan, and the United States. For 70% of APIB Professionals, they reported it took between one and five years to become reliable.

Clinical application to use of the APIB

After APIB reliability, over 50% described not using the APIB clinically but 25% use it "a great deal." Overall, responses indicated that regardless of administering the APIB and scoring it, the knowledge and insights from learning APIB were valuable. The APIB is used both in the hospital before the APIB discharge and in outpatient follow-up settings. Modifications are frequent, including using it as a part of the neurological exam, at the baby's bedside, in discharge guidelines, using parts of the exam as appropriate and not scoring the exam.

Clinical application to work with babies

Respondents indicated that it was easier to identify the baby's strengths and challenges, organization, and disorganization that informed their daily assessments and interventions. Several commented on how it solidified their understanding of states and co-regulation and helped them understand the Synactive Theory better. Learning the APIB also helped them see the details and intricacies that were not readily apparent in observations.

All babies, even those who have severe brain injury, show neurobehavioral strengths. These strengths only become apparent if one goes at the babies' pace, and provides facilitation, and 'trust the baby'.

Clinical application to working with families

The themes of how to work with babies and families centered on how the APIB helps guide parents to understand the communication of their baby and how to bring out the best in their baby. It gives rise to how to communicate with the parents about how to optimally support their baby. Learning the APIB also promoted the value of supporting families which leads to greater competence and thus better outcomes for the baby.

[Learning the APIB helps me] to support them to facilitate for the baby to be attentive and by this for them to reach those important moments of interaction.

And

I can guide the family to make it easier for them to interact with the baby.



Impact on NIDCAP training

Over 70% of the respondents say that learning the APIB has enhanced the training they provide to others.

Overall themes included that the APIB helped to solidify their NIDCAP observations and integration of the subsystems. It also provided a sound foundation for training, feeling more secure about observations, and confidence in making recommendations for care.

(With NIDCAP) I learned about the strengths and weaknesses of babies only through observation, but with APIB, I think I was able to gain a deeper understanding of the strengths and weaknesses of babies by actually touching them.

Using the APIB in research

Of those who have used the APIB in research, 65% are not currently using the APIB, but over 30% either have used, plan to use, or are using the APIB in research.

Respondents commented on how unlikely it is that they do research using the APIB due to lack of funding, that the APIB is not well known in research communities, and that doctoral work is limited due to the time to learn and intensity of the training.

Use of the APIB in supporting other professionals or students

About half of the respondents use the APIB in training or supporting other professionals. The use of the APIB in training nurses, therapists, residents, developmental specialists, therapists, neonatologists, and others is ongoing for many of the respondents. However, the actual exam or scoring is not typically done as much as using the knowledge gained through APIB training.

I demonstrate the APIB evaluation. This opens the student's mind to the amazing insight that can be gained with appreciating each infant's emerging strength and competence as well as vulnerability.



Ghent Training Group learning the APIB: Eveline Van Dyk, Angeline Parez, Anneleis Keymeulin, Julie Verfaillie

Recommendations regarding the training process

A question that often comes up for those who have been trained in the APIB is the utility of the training approach. Because becoming reliable in the APIB is currently a requirement to be a NIDCAP Trainer, we asked if they would learn the APIB if it were not required.

About half of the respondents reported that they would be likely or very likely to learn it and half said they would be unlikely or very unlikely to learn it. Respondents reported that they were unlikely to learn the APIB due to the cost and time investment of training without understanding the benefit of learning the APIB. They also mentioned training challenges of coordination with the limited number of APIB Trainers, especially if a Master Trainer was also involved. Some concerns were raised about the lack of normed scores that support its use after reliability was achieved.

I also don't think that there is enough understanding amongst our NIDCAP colleagues [who have not done APIB] about why it is necessary to know APIB to be a NIDCAP Trainer.

Recommendations for changes in the training approach

The majority of respondents recommended support for APIB training. Specifically, themes included the development of updated materials and access through virtual distribution. Many recommended the use of videos as well as frequent access to trainers through virtual assistance between face-to-face visits. Some recommended the use of adult learning principles, breaking down sections for which to become reliable, and "workshops" to encourage frequent discussions about learning the APIB.

Recommendations to lower the reliability expectations for clinical and training purposes were made.

I see the challenge of teaching and learning APIB as the length of time between sessions with the trainer. In between there may be quite a bit of virtual work that can be accomplished. I think training videos for the APIB would be great as an adjunct to the in-person Trainer and trainee sessions and would speed up the process to certification.

Respondents commented on whether they would recommend learning the APIB to others if it is not a requirement to become a trainer

About 40% would recommend learning it to others and 30% would not.

Themes referred to role designation and the utility of those roles, and that it is an insightful, useful instrument for professionals in the NICU. However, themes again included that the APIB is not as practical as other instruments, it is not recognized as qualifying babies for services, trainers may not be available, the manual needs revision and it takes too much time to learn.

It is a VERY useful clinical tool for those who work in the clinical NICU. It would be very helpful for neonatal clinicians to SEE how challenging it is for very preterm infants to do "ordinary baby things" when they are around term age.... usually if the baby can feed/be "fed" then they are passed off as "neurologically normal" by the untrained clinician.

However:

Unless they want it for personal development, or to use it post discharge, but in the U.S., it is not an exam that is recognized to qualify infants for services. And often as a baby becomes stable enough to do the APIB, they are discharged! I think if you are already NIDCAP certified, then use the NIDCAP throughout the hospitalization, unless you have a large population of older babies who are stable enough.

Overall comments about the APIB, the training process, and the use of the APIB

The APIB is a useful if not essential instrument to understand the experiences of the baby and using it along with other approaches might be beneficial. Training is seen by respondents to be an absolute asset to working in a NICU. However, training approaches and reliability levels could be improved. Some recommendations were made for a shorter scoring process, and, throughout training, peer support is essential.

I am curious as to how many Trainers actively use the APIB, and how often. I wonder if we could reconsider this requirement and maybe create an abbreviated version focusing on the systems scores or have Trainers learn to administer and score the APIB but not require reliability but some other measure of competency.

Summary and recommendations for the way forward for the APIB

The responses to this informal survey indicate commitment and in-depth thinking about learning and implementing the APIB. The small number of APIB Professionals and APIB Professionals-in-Training included in the survey likely does not represent the entire population of people trained in the APIB. Their comments, however, provide much food for thought for not only the current application of the APIB for babies and families but also for professional researchers and systems thinking.

Overall, the respondents recommend training in the APIB as it is a powerful instrument for understanding the baby's experience and for helping others appreciate the intricacies of the baby's behavior. To strengthen the process of learning this instrument and its clinical application and use, a number of recommendations were made. Respondents strongly advocated for revisions to the APIB materials and for making training more available and accessible by using video instruc-

tion, electronic materials, and periodic APIB workshops. With these changes, expectations for advancement in the NIDCAP hierarchy will allow for wider dissemination of the APIB and NIDCAP work, acceptance into wider clinical use, and applicability for research.

The APIB is the most powerful tool I know. It would enhance any clinicians understanding of human behavior. For medical clinicians, the APIB would help them come from a model of emerging competence versus the classical deficit model in medical training.

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NIDCAP Founder, Past President 2001-2012 Senior NIDCAP Master Trainer Senior APIB Master Trainer Director, National NIDCAP Training Center, 1982-2022

Column Editor: Debra Paul OTR

Most families are not prepared for the possibility of a premature delivery, and the experience of having a premature or fragile infant can be overwhelming. Providing information regarding prematurity prior to a baby's delivery and during a baby's course in the neonatal intensive care unit and through discharge to home is imperative, yet these resources are not always readily available and is in some countries, are very limited if available at all.

In this mother's story, we hear firsthand what it was like for her and her husband when their baby girls were delivered and how the lack of information about prematurity and resources for parents, as well as, their personal loss spurred her to take action and advocate for change.

My Personal Loss Provoked Me To Fight

Nina Nikolova, Bulgaria

t was an amazing summer back in 2008 as we were on vacation with friends. After several Intracytoplasmic Sperm Injection (ICSI) procedures, I was pregnant with twins. We were expecting two little girls. I remember the first kicks and the butterflies in my belly. In week 21 of my pregnancy, my doctor saw a problem. There was a small amount of amniotic liquid, and he told me to go home and get a lot of bed rest. After a while, I started bleeding and went to the hospital. I was in shock with nightmarish fears. Everything had changed within a few hours. My water broke and I feared this was the beginning of the end. My husband spent the night with me trying to comfort me. Later he told me that he was going outside so that he could cry alone. I was not able to see the sadness in his eyes.

I was in much pain and was laboring for 22 hours and then gave birth to two baby girls. I was only 24 weeks pregnant. One of my babies was 730 grams and the other 680 grams. After birth, the babies were taken away immediately, and I was not able to see them. At that time this was the practice in Bulgaria. I went back to my room and fell asleep. I was so excited yet angry. I remember that the first thing I wanted when I woke up was to go home and start a new life. However, none of this has happened.

Feelings of shock and disbelief

I was called into the NICU to see my babies. In the beginning, I was crying and in denial about having my babies. I was sure both had died. And then I saw the most perfect and beautiful babies in the incubator lying next to each other wearing white and pink caps. There were so many cables and wires, and I will always remember the terrible noise in the ward.

After two days, my smallest baby died. She was too fragile and had no chance of survival. She never received a name or a birth certificate. She was considered biological rubbish and was taken away and discarded.

After 7 days, according to Bulgarian law, we gave a name to our only live child - Alexandra. She spent five months in the NICU, and it was a huge fight for her. Alexandra was in a pri-

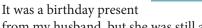
going to see her every day. At that time, I was not allowed to breastfeed. After I gave birth, the doctor gave me pills to stop my milk. They believed there was no chance for my baby to survive! I was not allowed to do kangaroo care and was only allowed a few minutes

next to the incubator.

months after her birth.

I hugged Alexandra for the first time four

vate hospital, and I was



from my husband, but she was still attached to the breathing machine.

It was a long treatment without success and we arranged for Alexandra to be transferred to another hospital in Israel. We paid a huge amount of money to hire an air ambulance because there were none in Bulgaria and there are still none today in 2023. The ambulance came and the doctors realized she was in terrible condition and was intubated and would not transfer her in this condition. We were returned to the hospital after five hours. Alexandra was getting worse day by day and three days after this situation, we were called to say goodbye to her. It was the worst moment in my life. I went to Alexandra's room for the last time and approached the incubator. Her oxygen saturation was between 80 and 40. She was ready to go. My husband stayed until dawn. I was there, talking to her, touching her but her skin was cold. I knew it was over. I said to her - "My dear Alexandra, now you can go. We will love you forever". I waited for the scariest phone call which came at 4 PM. Alexandra was gone. My whole world broke. I



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Family photo taken in 2021. Martin and Joana are 11 years old

was terrified and cried for days. Alexandra was buried next to my grandmother. There is nothing worse than to bury a child before yourself.

Next story - Hope

In 2010, I was pregnant again with twins – a boy and a girl. I was happy and at the same time terrified. I spent seven months on bed rest and medication, praying every day for a miracle to happen.

On the 9th of September in 2008, my first set of twins were delivered, and my first baby died on the 11th of September. My second set of twins were born on the 11th of September 2010 at 29 weeks gestation. They were tiny little miracles. Joana weighed 930 grams and Martin 1170 grams. This time I was able to breastfeed, hug, and touch them every day. They spent three months in the hospital and came home healthy and were amazing little beings.

The experience of having a baby born prematurely is difficult, sad, challenging, and amazing all at the same time. To be a parent of a premature baby is a thorny path that we must walk. I am more than happy and thankful today with my 12-year-old twins, and at the same time, I keep my love for my two little angels in my heart.

A way forward-Imagining and realizing big possibilities

In 2012, I and two other mothers (together we had five premature babies), decided to establish the first and only Bulgarian foundation for premature children – "Our Premature Children Foundation". We are strong and we have changed so much in Bulgaria including providing information about prematurity and how to support babies and families in the NICU. Our

foundation gives hope, and help to families, healthcare professionals, and babies. Now there are family rooms in hospitals, we have created a resource booklet for parents, and we speak the same language with the doctors and healthcare professionals.

Our Premature Children Foundation is the first non-governmental organization founded in support of Bulgarian premature children and their families. Our mission is to make a difference for those babies and make sure they have the best possible chance of survival and of reaching their full potential.

What we do

- Raise awareness about preterm birth and possible complications.
- Partner with the government in terms of improving the situation of mothers and newborn babies in Bulgaria as well as initiating constructive dialog with political leaders.
- Establish a network of experts, international and private sector organizations, officials, celebrities, media, business partners, and parents united by the idea of ensuring the best start in life for all premature and sick babies.
- Provide easy-to-understand information and make sure that all families have access to it so that we help them better understand the situation that they are dealing with.
- Facilitate medical and psychological support for affected families.
- Support families through our website, social media, publications, and events.
- Local support groups with volunteers and psychologists.
- Online consultation with psychologists.

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Revealing Form and Function with Brain Imaging

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orm and Function. The phrase appears often in English, sometimes modified to specify that "form follows function". This rubric is attributed to Louis Sullivan, a renowned architect of the late 19th century (the "father of the sky scraper"), especially famous as a mentor to Frank Lloyd Wright, who professed the same rule. Other industrial specialties, such as automobile and home product design, software formulations, robotics, evolutionary biology, paleontology, and more, tout the same. In such diverse areas and more, there is recognition of the intimate relations, at times the oneness, of form (structure) and function.

Here we turn our attention to the brain, specifically to the early developing brain. Most of us understand the immaturity of the newborn human brain and the extra fragility and vulnerability of the incompletely-formed brain of prematurely born infants. The early-stage brain is often considered to be a major symbol, if not the actual target, of NIDCAP practice. Understandably, many consider developmental care as "brain care" in which early brain growth and development is both protected and actively supported by providing physical, behavioral, and emotional contexts that channel healthy brain maturation. This is a kind of mantra in the world of developmental care, including among NIDCAP practitioners.

It's one thing to profess the special relation of developmental care on brain development. It is another thing to see it. But how can we look into a baby's brain and see structural health and proper functional capabilities or the opposite? How do we see into the brain and its development? Remarkably, there are now numerous ways "to image" the brain. In this article we offer a friendly guide to a popular imaging technology, magnetic resonance imaging (MRI), and two of its most popular modalities: structural MRI and functional MRI (also known as fMRI). We do this to take you a little deeper into the technical side of these methods. As we describe how they work, it will clarify what they tell us. Understanding this should deepen your appreciation of the relations among science, engineering, and many important practices in contemporary health care - including those in the Newborn Intensive Care Unit.

Structural and functional MRI are captured from the same device - the giant tube in which a patient is positioned, where high tech hardware cranks, rumbles, and whirs. As you will note, the same electromagnetic processes are employed. Yet structural MRI displays form, while fMRI displays function. Despite the intimate interdependence of form and function, these two kinds of imaging are different in process and in use.

First, let's consider the structural MRI as it is applied to brain imaging. MRI technology acts on and takes measures from some of the smallest imaginable elements in the brain – the nucleus of individual hydrogen atoms, most of which are part of the water in and around all brain cells. The nucleus of a hydrogen atom is a

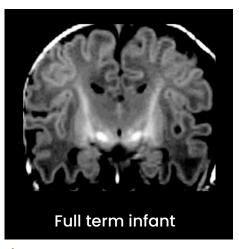


Figure 1. A coronal view with structural MRI of a full term infant

single proton, and the hydrogen proton nucleus spins on its magnetic axis (imagine our planet Earth spinning on its axis). When a brain is exposed to a strong magnetic field of an MRI scanner, the protons' axes shift from random orientations to lining up in a common orientation. While temporarily arranged in the same orientation, these charged axes create a directional magnetic vector. The scanner then adds radio waves that sweep over the magnetic vector, deflecting it and causing it to resonate. The dynamics of this nuclear magnetic resonance can be read as radio frequency (RF) pulses, and these are the signals that are captured, quantified, and spatially organized by computer wizardry into detailed gray scale images.

With awesome precision, the strength of the magnetic field can be manipulated, and with each change in energy, the axes of nuclei at different depths are altered and measured. This produces images of successive "slices" across the brain, at any angle or depth! We can see form revealed, often in exquisite detail. Figure 1 is an example. MRI can be similarly applied all over the body and has revolutionized many kinds of medical diagnoses and analyses. Again, structural MRI reveals form. No physiology, no function is exposed.

Now we turn to fMRI for brain imaging. Function is "up front" in fMRI thanks to the use of the magnetic properties of hemoglobin, depending on whether it is bound to oxygen molecules or not. When hemoglobin is bound to oxygen, it is repelled by magnetic fields (diagmagnetic) and when hemoglobin is unbound to oxygen, deoxyhemoglobin is attracted to magnetic fields (paramagnetic).

Increased neuronal firing in a particular area of the brain as part of its involvement in some sensory, motor, cognitive or physiological activity brings a concomitant increase in energy demand in the activated region. Oxygen is an essential part of the biochemical pathways of such metabolic activity. The arteries and minute capillary branches that perfuse the networks of the activated neurons will respond to increases of local cellular activity by dilating. Such dilation increases local blood flow to the active areas, thereby meeting the larger demands for oxygen and glucose.

As with the structural MRIs described earlier, the effects of RF waves on the magnetic fields become the signal detected by the fMRI. A special measure is used, called the Blood-Oxygenation Level Dependent response (or BOLD). The BOLD signal is a change (increase or decrease) in the proportion of oxyhemoglobin relative to deoxyhemoglobin. The contrast between the oxygenation from its prior baseline is the signal. In other words, this

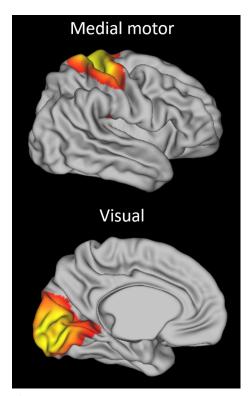


Figure 2. Functional maps for a group of term neonates as measured by fMRI

method does not directly reference neuronal activity, nor does it measure the oxygen itself. Rather, the BOLD signal identifies areas where there are relative changes in oxygenated hemoglobin presumed to correspond to the immediate metabolic needs of the neurons. Sophisticated analyses of these signals can achieve remarkable spatial resolution, mapping active areas about 1mm in size. These are displayed as maps of contrasting increases or decreases in regional activities, shown as graded changes in terms of color-coded nodes on a brain image. Dynamic brain function can thus be spatially portrayed by area, by network, or by structure. Figure 2 shows contrasting activities measured on the motor cortex and another image showing contrasting activities in a deeper, visual region.

We have merely scratched the surface of the creative combination of physics, chemistry, cell physiology, and systems neuroscience that has yielded a variety of imaging modalities. Beyond the technical tour de force represented in the use of magnetic resonance imaging is a panorama of applications. Because disease conditions usually include an increase in water content, MRI is suited for localizing some diseases. Brain function depends on brain structures large and small. MRI-based methods are used globally across the brain and microscopically on increasingly smaller scales of function.

Clinically, brain imaging is used to recognize early conditions of damage or malformation to predict outcomes and, significantly, to identify when and where therapeutic interventions can be applied. Brain imaging has revolutionized basic research as well. The tens of thousands of research papers describing insights gleaned from seeing brain structures within a living body as well as mapping dynamic functions have shaped entire new areas of neuroscience.

We hope to contribute at least one more *Developmental Observer* column on brain imaging, next focusing on applications suitable for newborns, including those born prematurely, for these babies present special challenges – and invite extra benefits from the knowledge gained on seeing the processes of brain development in the context of NIDCAP practice.

Unlike previous columns from the Science Desk, this one is not a commentary on a target article, but is an essay that in some ways, one side of a conversation. As such, we invite responses or questions. If this brief introduction to brain imaging inspires questions or comments, please contact us. We will gladly incorporate your input into a future essay – or simply answer your email.

Contact us at: silferra@iu.edu or alberts@indiana.edu.

NIDCAP Leader Profile

Monique Oude Reimer-van Kilsdonk

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am Monique Oude Reimer-van Kilsdonk and I live in the Netherlands in a town called Barendrecht. This small place is located 12 km from Rotterdam where I work. Usually, I cycle to work but when it rains, which I really hate, or snows, I take the train and metro and very occasionally the car. Parking in Rotterdam is very expensive, making the car my least favorite option. For almost 30 years I have worked at the Sophia Erasmus MC Sophia Children's Hospital in the Neonatology Department. Previously I was a Neonatal Intensive Care nurse and since 2004 I have worked for NIDCAP as Patient Care Advisor and NIDCAP Trainer. I like to travel, which is an excellent combination with being a NIDCAP Trainer. I like to read and walk, especially on long-distance trails. I used to bake birthday and wedding cakes as a hobby, yet this is a very time-consuming hobby and I no longer have time for it due to my workload. I will pick it up again when I retire.

My NIDCAP Journey

It was sometime in 1998 that I first heard about NIDCAP. The department was conducting a study on developmental care and looking at interventions for prematurely born babies. The research showed that NIDCAP would be the best fit for our department and our patient population. Staff could apply for NIDCAP training. Three people were given the opportunity to do the NIDCAP training. After a lot of thought and discussion which I found daunting, I was accepted much to my delight. Although I have experienced ups and downs in recent years, I have never regretted this choice.

In 2000, I started NIDCAP training under the guidance of NIDCAP Master Trainer Agneta Kleberg. I had no idea what to expect and was anxious that everything had to be done in English. My English was not very good at the time, and I found it challenging! Fortunately, I was able to start with two other colleagues. We were very much in support of each other and we could always turn to our NIDCAP Trainer. Her humanity, but certainly also her extensive knowledge, really helped me to complete the NIDCAP training and she is still a role model to me. After my NIDCAP certification, outside of my hours as a nurse, I was able to perform NIDCAP observations on the unit one day a week.

NIDCAP Trainer Dr. Nikk Conneman joined our department in 2004 which gave us the opportunity to open a NIDCAP Training Center, the Sophia NIDCAP Training Centre, Rotterdam. Soon I was able to spend more hours on NIDCAP observations, implementation, and supporting babies and their parents. After a few years, my workdays changed to one day a week as a neonatology nurse and four days a week for NIDCAP. Because keeping track of the technical aspects of



such an intensive department requires a lot, I decided at some point to dedicate myself completely to NIDCAP. First my title was NIDCAP Consultant and now this position has changed to 'Advisor Patient Care Development-Oriented Care'.

The work as a NIDCAP professional is much more than doing observations. We also plan care for the babies and guide parents and colleagues. In 2017, I took the step to become a NIDCAP Trainer under the guidance of Dr. Agneta Kleberg and Dr. Joy Browne. I felt privileged to be trained by these two remarkable women, increasing my knowledge and skills through their guidance and feedback. For the APIB part of the training, I collaborated with the professionals in Toulouse, France, and look back on that time with great pleasure. I have been a Senior NIDCAP Trainer now for two years. A step that Dr. Heidelise Als assigned to me just before she died.

My Passion

My passion has fluctuated in recent years. Seeing parents grow their parenthood has always encouraged me to persevere. I think it's fantastic to guide parents in this process, not only to see how they slowly recognize their infant's behavior and how they react to it, but also how empowered they become at times when they feel that caring for their infant is not the very best without developmental care. In recent years, we have started treating younger and younger newborns. Seeing the strengths these newborns can show us, no matter how small, makes me proud. It really touches me to see that hand that still manages to go towards the mouth and that cautious attempt to open an eye.

In recent years, the passion for providing education has been added to my role. It is quite rewarding to see the wonder on the face of a student when they see and hear why we do NIDCAP and their responsibility for it, fueling their passion to eventually work unconditionally for that infant and that parent. Of course, there have been times in the last 20 years when I've thought 'I'm quitting'. Frustration, overload, misunderstanding, and not feeling heard were all feelings that occasionally I felt, yet there was always something that helped me through. With my colleague, Nikk Conneman, it was possible to regularly evaluate and reflect. I can also contact my NIDCAP colleagues, and vice versa. It helps to know that others also encounter such feelings. After discussion, you can usually get back to it. Occasionally I have chosen to contact my master trainer.

NIDCAP Future

When I look at the Netherlands, I think NIDCAP will slowly expand. We provide a lot of foundational education and I've noticed that interest arises from there. It's slow, but I'm fine with that. We are a small country and besides the fact that it is important we have NIDCAP specialized care providers, I also think it is important that the foundation is good. We are working towards individualized developmentally oriented care becoming a permanent part of the nursing and medical training courses. Globally, I also see promising growth of NIDCAP in Europe, which comes from more foundational education. I personally think the future lies in having foundational developmentally oriented care in both nursing training and in the training for doctors. Which educational program it will be is, I think, less important, so long as it is based on the Synactive Theory of Development by Heidelise Als and perhaps endorsed by the NFI. A team could be put together to really look at the content. From that foundational education, some students could go on to more specialization, like NIDCAP training.

My Success

What is success? I am proud that I have been able to create my own position, and work in an environment where individualized developmental care is included in the vision of the department and generally supported by the management team. I see parents spending more and more time in the department and we still successfully implement in small steps. I am proud of my colleagues who, despite the busy times in the department and staff shortages, continue to do everything they can to spread the word about NIDCAP and guide newborns, parents, and colleagues. I can always count on them when, due to circumstances, I must take a step back. They have taught me that delegating and trusting each other can only improve cooperation. I'm proud of that!

My Advice

The advice I would give someone who is just starting their NIDCAP training is REFLECT! Make sure there is someone in your area that you can turn to. That doesn't always have to be an official meeting, but just being able to talk and reflect can be very helpful – and be patient. There comes a time in your education when you 'see the light' and then really experience why you do it all.

A wish of mine would be to have reflective processing groups worldwide. A small group where you can exchange your experiences with each other occasionally. Groups for master trainers, trainers, professionals, and students. We face the same strengths worldwide, but certainly also the same challenges. Sharing and learning from each other seems to me to be of enormous value.



Mission

The NFI improves the future of all infants in hospitals and their families with individualized, developmental, family-centered, research-based NIDCAP care.

Adopted by the NFI Board, June 29, 2022

Vision

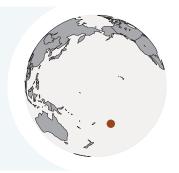
The NFI envisions a global society in which all hospitalized newborns and their families receive care in the evidence-based NIDCAP model. NIDCAP supports development, enhances strengths and minimizes stress for infants, family and staff who care for them. It is individualized and uses a relationship-based,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

Adopted by the NFI Board, October 20, 2017

Global Perspective on Developmental Care

French Polynesia

Jacques Sizun. French NIDCAP Center, Toulouse, France



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rench Polynesia is an 'overseas collectivity', part of the French Republic, located in the South Pacific Ocean, 8000km from Australia and Chile and 4000km from Hawaii. It comprises 118 islands of which 76 are inhabited. These islands, with their heavenly landscape, extend over a maritime surface equivalent to Europe. It has approximately 280,000 inhabitants, with a majority of Polynesians 'maohi' (65%) and metis/mixed 'demis' (16%), a minority of Caucasians 'popâa' (12%) or Asians (5%), mostly from Chinese origin. This population is young: 36% under 20 years old. The Polynesian language (Maori) remains widely used in daily life. The artistic heritage is rich in particular songs, dances, and the very old art of tattooing.

Culturally the child exists from procreation and not only from birth. There is a close continuity between the mother and the child: only one body. Massage, breastfeeding, skin to skin are major elements of traditional Polynesian care, the expression of bodies and emotions. The nuclear family is a recent concept. Traditionally, the child is cared for at the beginning by the mother and then by the clan. The child can be designated "faamu" and then change his/her caregiver, on the decision of the grandmother or the group, in the event of failure of the mother, or traditionally to support grandparents. The child can also be given to a sister, a cousin, or a loved family member because this woman has no child. However, the infant must remain in contact with his original family. This tradition has been disrupted by European adoption of international children causing a break with the biological parents and a change of family name, creating loyalty issues for the developing child.

The French Polynesia Hospital (CHPF) is a modern hospital that opened in 2010. The neonatology department includes 24 intensive care beds and six neonatal beds within the maternity unit. It is the only level three neonatal center in Polynesia. It stays in a relationship with the maternity units or perinatal centers in Papeete, the capital, or in other archipelagos (Society and the Marquesas Islands), some over 1400km from the CHPF.

The French Polynesia Hospital

The neonatal care team includes six neonatologists, a nurse manager, 30 nurses and 19 assistant nurses, a psychologist, a therapist, a breastfeeding consultant, and a milk-bank manager. The NICU



cares for preterm and full-term newborns and their families. Newborns who require urgent neonatal surgery are transferred to Auckland NICU (New Zealand) or Paris (France). The entire population has health insurance.

The former medical directors, Dr. Micheline Papouin and Phippe Kuo († 2019) were the initiators of the implementation of family-centered developmental care in the unit. The training began in 2004 with the support of the Brest NIDCAP Training Center (Dr. Nathalie Ratynski, Pr. Jacques Sizun). That year, all medical and nursing staff benefited from a short training (two days), 'Introduction to developmental care' focused on brain development, the importance of the early environment, the crucial role of parents, and system change. This training was renewed in 2005 and 2012.



Developmental care training group in 2018

In 2019, Dr. Ratynski started FINE 2 training, mainly via video conference and email exchange due to the COVID pandemic. Three neonatologists and three nurses have thus become FINE 2 certified.

One of the challenges in maintaining an optimal quality of developmental care is the high turnover of the nursing team. This underlines the need to train professionals very regularly. The current project is to train a trainer (Temara Mariteragi) to achieve certification both in NIDCAP and Baby Friendly Hospital Initiative.

Developmental Observer

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Selected Publications 2023

Kaye Spence and Maria Maestro Lopez. Editorial Team.

The following is a selection of the 90 publications yielded from a search of Pub Med and Google Scholar using the keyword – NIDCAP in all languages.

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- da Silva Medeiros N, Teixeira C, Silva M, de Oliveira L, do Amaral Rocha J, Contim D. Developmental care for preterm newborns: Scoping review. [Cuidado desenvolvimental para recém-nascidos pré-termos: revisão de escopo] Revista de Enfermagem do Centro-Oeste Mineiro. 2023, 13. DOI: 10.19175/recom. v13i0.4763.
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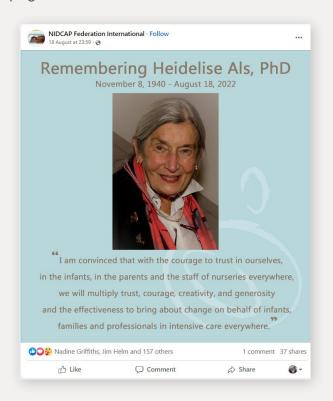
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NIDCAP Training Centers – Facebook Pages

NIDCAP Training Centers continue to provide useful and informative information on their Facebook pages. In this issue, we cover the broad range of educational activities promoted through these pages which continue to increase the information available on NIDCAP and developmental care.















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