

Developmental Observer

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Every single caregiver must enable parents to be parents not only cognitively within the framework of the rules but also intuitively.

—Frieder and Elena Pfeiffer

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FAMILY VOICES

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By Frieder and Elena Pfeiffer

A small newborn, a whole person

ur son Mattis was born in Tübingen, Germany, almost five years ago. Way too early at week 24. A small, tiny human being of 550 grams, but a whole person at the same time. It took us a while to understand that. When Frieder was allowed to visit him a few hours after he was born, he returned to Elena inspired. "He is so beautiful. It's a long way. But everything will be all right."

The third verse of the German lullaby "Der Mond ist aufgegangen" became Mattis' baptismal motto. Its truthfulness still touches us today:

Behold the moon - and wonder why half of her stands yonder, yet she is round and fair.

On the 1st of July 2018, our lives changed from one day to the next in a different way for each of us. Giving birth so prematurely was the negative culmination of very worrying weeks with a lot of problems leading up to the delivery. The pregnancy had not lasted. From Elena's point of view, being born extremely premature posed the greatest possible danger to her son's life. At first, she was just terrified. For Frieder, former worries turned into the chance to take an active role in Mattis' development, providing some relief to Elena in a way. Frieder was optimistic. Our feelings about our son's early birth were different. However, we both felt confused, overwhelmed, and inexperienced.

A multitude of emotions

We were overwhelmed by our emotions. A new kind of fear, a new level of loss of control, a state of constant alertness, and, on top of that, the search for understanding from the medical staff, "are we right in the way we feel?" And, more importantly, the question of positioning oneself: Too

Family Voices, continued from p. 1

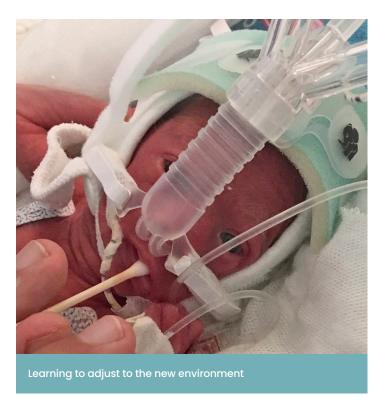
little optimism takes away hope and instead may paralyze you. Too much optimism makes you vulnerable and afraid of too much hope and, consequently, too big a fall.

Access to our child was difficult early on. There were so many medical procedures and hospital protocols around Mattis. So, we had to act counterintuitively. In addition, we naturally lacked medical understanding. Added to this was the challenge of self-organization and logistics (e.g., pumping, visiting times) and of course the constant goodbyes. Sometimes these were a relief, but more often they were dreadful. We also found it difficult to realize that touch, which is so important to us, can lead to breathing cessations. This situation was one example of so many dilemmas we found ourselves in. Therefore, it takes time to adjust to the situation and to actively take action. Especially if you already have experience as a parent of a first child. You feel - positively or negatively - the constant dependence on the nurses and doctors.

Another level of sensitivity

For us as parents, it was helpful when the staff showed a psychological understanding of what we were experiencing.

(continued on p. 3)



Editorial

P P T T

amilies are a great source of inspiration, and their approach enables professionals to adapt and use knowledge in different ways. Frieder and Elena Pfeiffer whom we met at the NIDCAP Trainers meeting in Germany last year write a beautiful story of their journey through the NICU with Mattis and illustrate how the NIDCAP approach

made a difference to their journey. There is a lot to consider as you read their story. Kylie Pussell from Miracle Babies in Australia tells us her story and how attending the International Kangaroo Mother Care conference in Madrid helped her champion the implementation of kangaroo care.

As NIDCAP and APIB training continues to spread we are challenged to see how we can continue to improve the training and the process. In this issue, Roman Chabba and Juzer Tyebkhan, a leader within the NFI ask if NIDCAP is ready for Gen Z. Working with different generations can give us insight into how others see the world, and by listening to younger generations we can learn how to make changes.

In this issue, we introduce a new feature – An Ethical Lens. Jeffery Alberts and David Smith give insightful commentary on an article on moral distress in the NICU. We hope to make this a regular feature raising awareness of the many ethical issues facing parents and healthcare professionals.

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The NIDCAP Training Centers continue to inspire us in their work. Natascia Bertoncelli gives us insight into the development and work of the Italian Modena NIDCAP Training Center. I am happy to receive updates from any of the NIDCAP Trainers Centres as this column continues to celebrate the work of NIDCAP and APIB.

I would like to hear from the readership and membership on what features you would like to see in the Developmental Observer. Of course, I would love to receive submissions on your NIDCAP work so we can continue to share the joy of working with newborns and their families.

Kaye Spence AM

Senior Editor – Developmental Observer Adjunct Associate Professor / Clinical Nurse Consultant Australasian NIDCAP Training Centre / Sydney Children's Hospitals Network / Western Sydney University / Australia

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We were especially helped by the nursing staff who understood that, with us, a soft approach was necessary. The nurses were empathetic, spoke an understanding language, and wanted to build an individual connection with parents. Not necessarily only through medical competence, but as engaging, compassionate people.

Many nurses and doctors showed this level of sensitivity and helped us a lot, especially when NIDCAP came into play. The NIDCAP Professional helped us to understand the medical framework and its effectiveness on the infant and additionally understood our personal framework as parents and individuals.

The NIDCAP Professional as a mentor

Parents need to be intrinsically motivated and accept that NIDCAP Professionals have a special role as mentors - in a way that parents who already have an older child are not used to. From our point of view, parents should therefore be psychologically met at their level and supported in different ways. For NIDCAPers this means that they have to establish their standing with their various stakeholders, find access and let parents have a say in what their baby tries to communicate to

the world, and how it "ticks".

NIDCAP as a gamechanger

After about a week of the greatest emotional challenges and of feeling overwhelmed more often than not, we became aware of NIDCAP for the first time. With NIDCAP came the change from having different observers of Mattis to having only one person observing him who stayed by our side for the rest of our time in the NICU. A reference observer, so to speak. This was incredibly helpful and comforting to us. The NIDCAP Professional was a knowledgeable observer who followed Mattis and knew him well, and we accepted her as a mentor for us. We gained confidence through this NIDCAP Professional, who gave us security, structure, and trust in the process.

This NIDCAP Professional got to know us and was able to relate to both of us in different ways. For Frieder, she served mostly as an observer providing structure and chronicling important insights and events that revolved around Mattis and his environment. With Elena, she was a sensitive interlocutor who helped Elena find her own intuition after the traumatic experience of becoming a mother. It helped to observe her

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



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





Mattis as a healthy five year old

and Mattis together and helped Elena learn to feel and realize her self-efficacy as a mother. In doing so, this helped to slowly build up the self-confidence needed to stand up for our child's concerns, on the one hand, and the implementation of the NIDCAP Professional's recommendations on the other hand. This allowed us to function for Mattis in our own way, but also for both of us in the best way for all involved.

Problem Parents

This self-awareness was important because our own actions could also lead to us being perceived as 'problem parents' on the ward. For some caregivers - but explicitly not for all – Mattis, the "King of the jungle", who needed a lot of attention, got company from his "Jungle parents", who also demanded a lot of attention. Parents who had to put up with the fact that some of the jointly developed NIDCAP recommendations were not taken into account by everyone involved according to the guidelines.

Standing up for a child's needs at the expense of one's own reputation, sometimes became a test of strength.

360° Empowerment

Every single caregiver must enable parents to be parents not only cognitively within the framework of the rules but also intuitively. This means empowerment regarding the child and their surroundings. Besides the goal *that* the child survives, it is equally important *how* the child survives. Structured observation with its clear guidelines and support helps here.

It is important to give everyone involved a good feeling by taking care of the child's and the parent's needs. Then, they realize, *It is being taken care of*, but also, *I can do something*. This approach works wonders. Self-confident actions that follow structured assistance ensure further self-confidence and further bonding with the child. However, it is important to remember that each person must be approached differently.

The power of reading Mattis' behaviors

Together with NIDCAP, we noticed after one observation, Mattis was no longer hungry after cuddling. It seemed like he still needed something. Our impression was that he still wanted to suckle something. That he might even be nursed to sleep. As a result, contact was made with the breastfeeding counselor. A visit was then very quickly implemented with the breastfeeding counselor which was successful, and things moved forward very quickly. It was a very liberating experience for us. Because an observation was made, empathetic thought was given, and the right conclusions were drawn. Mattis' delicate medical situation made individual caregivers refrain from taking this step towards breastfeeding. This is where NIDCAPers supported reluctant caregivers with empowerment.

The child we have today is also the child we had in the NICU and the one we recognize today when we read through the structured NIDCAP observations again. Just as he didn't like position changes in the past, he still has a hard time with major changes today. This means that, in our opinion, an individualized, observational approach to the child from the beginning is incredibly important and a great opportunity for the child to be seen as a whole person.

Learning a new role and thinking like a lawyer

We had to learn a new role as parents in the NICU. To be an advocate for our child, we remember the quote from our self-selected caregiver "there is no other advocate for your child here but yourselves". Embedding and teaching this fact was crucial. It enables a momentum of self-efficacy as the most important driver of resilience in the NICU. At the same time, the excessive demand of being able to perform this task seems too great, especially in such a medical environment, which is sometimes very foreign to non-professionals. Having a NIDCAP Professional by our side in this mammoth task was probably the decisive factor for us to stand up for Mattis in the right places. We were not alone. In the NICU and in society, premature babies deserve a voice. For parents to support this, they must first find their own voice.

Without doubt and fear

After 88 days, Mattis came home, three weeks before the estimated date of birth. He is now a bright, cheerful boy who throws himself into life and is full of basic confidence. Mattis is developing better than we ever dared to wish. He loves cars and role plays, music, and running. He is proud of his new bicycle with gears. And he enjoys the big family that has been so sensationally supportive all this time. For his great-grandmother's 98th birthday recently, Mattis sang a song together with his sister. Loud and full of joy. Without doubts and fears. Just as he entered this earth almost five years ago. We first had to learn this feeling from him. But now we know it. Mattis is round and fair. A small newborn, a whole person.

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email: nfipresident@nidcap.org

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email: asudini@outlook.com

Charlotte Tscherning, MD, PhD

Division Chief of Neonatology
Oslo University Hospital, Norway
email: charlottecasper66@gmail.com

Juzer Tyebkhan, MBBS

NIDCAP Trainer
Director, Edmonton NIDCAP Training
Centre
email: juzer.tyebkhan@
albertahealthservices.ca

STAFF

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Director, NIDCAP Nursery Program NIDCAP Trainer email: nidcapnurserydirector@ nidcap.org

Sandra Kosta, BA

Executive Director of Administration and Finance

email: sandra.kosta@childrens.
harvard edu

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Heidelise Als, PhD 1940-2022

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

NIDCAP TRAINING CENTERS WORLDWIDE



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Italian Modena NIDCAP Training Centre

Natascia Bertoncelli, NIDCAP Trainer

The NICU of Modena has based its care on the family-centred principles for years thanks to Prof. Ferrari Fabrizio, who guided the NICU for over 40 years. He met Heidelise Als and Berry Brazelton in Boston; he worked with them, and he learned the importance of the individualized assessment and the behavioral observation of preterm and full-term infants to identify their strengths, vulnerabilities, and developmental goals and to individualize the NICU care to the infant's needs.

At the beginning of 2000, the NICU of Modena started its education and training in the NIDCAP method for nurses and medical staff to offer individualized care which meets the unique neurodevelopmental needs of infants and parents from admission to discharge. The physiotherapist (Natascia Bertoncelli) flew to London to start her NIDCAP training with Agneta Kleberg. In 2005, she became the first NIDCAP Professional in the unit, and in 2013 she became the first NIDCAP trainer in Italy thanks to the invaluable support and experience of Agneta Kleberg and Deborah Buehler. During those years, four more NICU professionals (two nurses, one doctor, and one psychologist) became NIDCAP certified in the NICU of Modena.

The Italian Modena NIDCAP Centre was established in 2013, directed by Prof. Ferrari Fabrizio, and is based at Azienda Ospedaliera Universitaria. We celebrated the opening of our centre together with professionals coming from many Italian NICUS and Heidelise Als, Björn Westrup, Dominique Haumont, Monique Oude-Reimer, Sandra Lescure, Joseph Perapoch, Inga Warren, and Silke Mader joined us as speakers.



Heidelise Als at the opening of the Italian Modena NIDCAP Training Centre (2013)

Now, the training centre medical director is Prof. Alberto Berardi, who is also the head of the Neonatal Intensive Care Unit (NICU), and the NIDCAP Trainer is Natascia Bertoncelli.

In 2016, we were honored to host over 100 participants for the Annual NIDCAP Trainers Meeting in Bologna whose organization wouldn't have been possible without the huge work of many people over the years.

NIDCAP progress in Modena continued with the training of additional NIDCAP Professionals. Over the last five years, some NIDCAP Professionals left, and others started training and joined the team. Now, our NIDCAP multidisciplinary team includes nine nurses, two doctors, a physiotherapist, and a psychologist. Our goal is to offer a unique educational model of family-centred care for preterm and full-term babies and their parents. Our NIDCAP training centre offers education and training to various NICUs in Italy: Genova, Florence, Siena, and Rome.





Modena NIDCAP team

The implementation of NIDCAP care in our NICU has not always been easy, especially in the last three years of the global lockdown. In addition, the request for NIDCAP education and training from the Italian NICUs decreased during the lockdown. Despite the restrictive policies, our NICU was successful in not separating infants from their mothers and fathers. Parents continued to have 24/7 access to their infant, but only one parent at a time could enter the NICU. Skin-to-skin contact was never interrupted during the lockdown period. Over the last few months, requests for NIDCAP education and training came from several NICUs in Italy. This is very encouraging, and it makes us feel fueled again for new educational experiences.

On a national level, we participated in the writing of a document on discharge from the NICU together with the Italian Study Group on Developmental Care, the Italian Society of Neonatology, and Vivere Onlus, the national association of parents of preterm infants. The document will soon be published on the website of the Italian Society of Neonatology and it will be available for all NICU professionals in Italy.

We celebrated World NIDCAP Day together with infants and parents in the NICU and Mani di Mamma Onlus handmade nice little hats for all the babies in the NICU.

In the last year, we collected data on parents' experience of infants admitted to our NICU in Modena. Parents' experiences were gathered through guided interviews of their perceptions in a NICU implementing NIDCAP care. We also investigated the safety of early skin-to-skin contact with infants and parents in our NICU. The findings were rewarding, and they were published in two different articles.^{1,2}

In 2023 we celebrate 10 years since the opening of our

center in Modena and we are honored to be part of the amazing and supportive community of the global NIDCAP community.

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Annual NFI Membership Meeting

Wednesday, October 25, 2023 2:30-4:00 PM CDT

Hyatt Lodge 2815 Jorie Boulevard Oak Brook, Illinois, USA

We welcome members to attend in-person or virtually



Educating, training, recruiting, and retaining the best: Is NIDCAP ready for Generation Z?

Roman Chabba, 1,2 B Sc and Juzer M Tyebkhan, 2 MBBS, FRCPC

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¹Medical Student Class of 2024, ²Dept of Pediatrics, University of Alberta, Edmonton, Canada. Stollery Children's Hospital, Division of Neonatology; Edmonton NIDCAP Training Centre Canada. Roman.chabba@ahs.ca, juzer.tyebkhan@ahs.ca

s happens with many things we came across an article by Eckleberry-Hunt et al¹ by chance, while searching the cyber-library for another topic. This article caught our attention because it reminded us of a recent NIDCAP observation during a training day. The observation was of a very preterm baby, who was six weeks old at the time. Her mother, Amina, was heavily involved in the care of baby Farah (names changed for confidentiality): over the 100+ days of Farah's NICU stay, Amina only missed one morning ward round. She gradually took on the active parenting role so that she was doing much of her baby's care well before discharge. The family was planning to move to another country and Amina proactively asked that a follow-up for Farah be arranged via the Neonatal Follow-Up program at their future city of residence.

Amina agreed to the NIDCAP training observation and graciously gave her permission for the observation to be videoed; clips of the video can be viewed in the Snapshots section of the NASCENT NIDCAP APIB Supplement created by the Edmonton NIDCAP Training centre canada website (www. nidcapedmonton.com).

The observation of Farah was done by a NIDCAP trainee and a NIDCAP Trainer (JMT), together with a video photographer (RC). A five-page NIDCAP report written in the structured format recommended for NIDCAP training was given to the mother. Some days later while talking to Amina, we discovered that although she had seemed very interested in her baby's behavioural communication, and in the recommendations that arose from our observation, she had not had time to look at the written report. This made us question why this mother - who was so involved in her baby's care and seemed so interested in the NIDCAP observation, did not read her baby's NIDCAP report. It also made us wonder about the value of the detailed narrative report if parents – especially parents who are with their baby in the NICU for much of the stay – will not read it. The article that then popped up about Generation Z,1 resonated with our experience and turned the NIDCAP Training Day into a novel educational opportunity to learn about this new generation of learners, 'Generation Z'.

How is Generation Z (Gen Z) different from other generations?

The generations and their distinguishing traits are summarised in the table below. A global survey of 20,000 Gen Z individuals conducted by Dell Technologies found that young people

around the world share similar values and expectations, such as their desire for work-life balance, their preference for experiential learning, and their reliance on technology. Therefore, it is likely that many of the traits of Gen Z are indeed universal, and not limited to Western cultures.² Note that the birth years of the generations vary slightly depending on the source and that there is overlap across adjacent generations for some of the traits. We acknowledge that these are generalisations and that there is much individual variation amongst those of any one generation. The literature indicates that there is validity in these generational trends and traits.³⁻⁶ Understanding these traits may help us understand the population and families we are interacting with and assist in tailoring our educational methods for the best academic and professional achievement. Adapting our educational methods may lead to increased engagement of parents in the active care of their infants, while in the NICU.

The dividing lines between the generations are based on world events, for example, World War II, migration across countries, increasing use of technology, such as television, computers, and the Internet, and the resultant changes in lifestyle that occur during the formative years of that age group. All of these have influenced how people interact, learn and work, and have thus shaped the expectations of that generation of students and professionals.

Generation Z Characteristics

Gen Z is the cohort born after 1995 and thus makes up a large majority of today's younger workforce. They are the most diverse generation in terms of race, gender, and sexual orientation. They are a hard-working cohort and independent learners and value close mentoring relationships. This is a result of having trusting relationships with their parents in which they received both positive and negative feedback; thus authoritative, didactic styles of learning or feedback do not resonate with Gen Z.³

Gen Z is the first generation to have NOT known a time without the internet and thus has a hard time disengaging from technology. This may seem unfocused to teachers and supervisors who are from the older generations, but this hyperconnectiveness enables Gen Z to effortlessly use computers, the internet, and social media to access information instantly. Despite the facility of Gen Z at locating information online, they may however not take the time to critically evaluate information, nor

Table 1: Generational Differences 3,6

Name	Birth Years	Work Ethic	Communication Style	Leadership / Feedback	Technology	Learning Style	Role Today
Silent Gen*/ Veterans	1928 - 1945	Hard- working, disciplined	Formal, by the rules	Authoritative	Tech# for leisure	Didactic, formal, rote memorization	Take pride in their legacy
Baby Boomers	1946 - 1964	Work Hard	Formal, need details	Authoritative	Some Tech#; want to master it	Formal, lectures, note taking, handouts	Creating a legacy
Gen* X	1965- 1980	Work Hard and Play Hard	Informal, flexible, keep it professional	Hierarchical	High Tech#; want to enjoy it	Top-down, formal, some e-learning	Leadership
Millennials	1981 -1994	Work Smart	Fast, efficient, social media	Coaching	All Tech#; need to use it	On demand, creative learning	Discover passions; step into leadership
Gen* Z	1995 -	Work Fluidly	Transparent, highly visual, latest social media	Networked	"What Tech#?"; Tech# is an extension of Self	Constant, mobile, real- time	Entering workforce

Legend: *Gen = Generation; # Tech = Technology

are they likely to read assigned readings.⁴ They are unlikely to visit libraries to look up articles in bound paper journals; in fact, many Gen Z students do not know of the archived collections of bound journals that were consulted by their teachers in their own student days.

The traditional approach to teaching in the NIDCAP model is based on didactic classroom lectures, with intermittent evaluation and feedback, which is a method that seems counter to the learning methods of Gen Z.

Gen Z prefers more individualised learning, with immediate answers to questions that arise, and more personalized, rapid feedback.³

Gen Z is considered to have a very short attention span, described by some as only eight seconds.⁴ It is questionable if this eight-second span of attention truly describes the attention of these young people when involved in an activity that has engaged their attention. We speculate that this attention span is simply a feature of how Gen Z surfs the Internet.

Gen Z's hyperconnectivity is challenging educational systems at all levels, not only in the health sciences.

Suggested interventions to NIDCAP Education and Training to engage Gen Z

The youngest generation of healthcare professionals and the youngest NICU parents will now be from Gen Z. How can we, as NIDCAP professionals engage our young professional colleagues to embark on NIDCAP training when the methods used

for NIDCAP training may not resonate with the preferences of Gen Z? How can NIDCAP Professionals best share the critically important, individualised neurobehavioural information about the infants in their nurseries, with both parents and staff, if neither are likely to read narrative-based reports?

The literature suggests that modifications to traditional methods of medical and nursing education are urgently required, otherwise, it will prove challenging to train, recruit and retain the best of the younger generation. Educational programs that switch to more active learning methods, encouraging more hands-on participation, with opportunities for discussion and reflection with peers and instructors may prove more effective. At many universities, lectures are now available online to students, who can listen/view them at their convenience, and some choose to do this at faster speeds to save time. Online educational lectures (together with other educational resources) are a strategic goal of the NFI and could help to attract our Gen Z colleagues towards NIDCAP training. It may be unrealistic to expect Gen Z to attend a full or even a half-day lecture, where the material is presented to them with little opportunity for interaction. Other possibilities to explore are learning experiences where the student leads the teaching activity¹ - perhaps online discussion groups could occur where trainees decide the topic and are guided by a trainer to direct the discussion.

Eckleberry-Hunt et al¹ suggest that Gen Z expects innovative and creative modalities such as podcasts, interactive tutorials, simulations, and internet-based educational games. Kahoot,

Socrative, and Jeopardy are teaching methods that can be tailored to Gen Z in that they are fun, promote critical thinking, and can be set up to provide more immediate feedback.⁵

NIDCAP and APIB (Assessment of Preterm Infants' Behavior) training are already based on individualised mentored education, with much one-on-one interaction and immediate feedback from the trainer on training days. This may be attractive to Gen Z'ers, as they expect quick, personalised feedback, although this (training day immediate feedback) will only happen once the learner has begun NIDCAP or APIB training. Thus, the preliminary steps (before a trainee embarks on formal NIDCAP or APIB training) must be more enticing to Gen Z.

If the attention span of Gen Z is truly very short, then tailoring the material to be responsive to their attention span needs may foster increased engagement. Gen Z is the future of NIDCAP and all professions and skills. Suggested ways to do this include 'Reverse Mentoring'¹ and methods where learners can receive help from mentors to appraise the relevance and validity of the information that they have so effortlessly found. It may also be advantageous for Gen Z trainees if the larger goal(s) of training are broken down into smaller but more obvious milestones of achievement,¹ rather than requiring a trainee to wait until the end of NIDCAP or APIB training to either receive certification or not.

The use of mobile technology such as individualised podcasts are ways by which information can be shared with Gen Z parents whose baby is in the NICU. These podcasts could be shared with other caregivers. Information relevant to the baby's developmental progress can only help the baby if families (and staff) have received and understood the key points of their baby's neurobehavioural observations. Perhaps this information must be provided in small chunks, using the technology or social media platforms to which Gen Z parents and staff are hyperconnected.

Recruiting from Gen Z to benefit NIDCAP

Given the research presented here, it may be beneficial for the NFI to recruit from the Gen Z age group, not only to develop the next generation of NIDCAP Professionals but also to learn from them how to engage their peers, and how the NFI can employ educational methods that will be effective for Gen Z. Perhaps each committee, subcommittee and working group of the NFI could recruit one new member from Gen Z to assist in the development of teaching tools that adapt to the learning methods of their age group.

Historically, medical education has been hesitant to make reforms. Some of this hesitation has been due to uncertainty about the impact of educational change on patient care. However, the literature reviewed indicates that we are at risk of losing the best of the young generation if we do not adapt our educational methods as quickly as other professions and occupations. To end, we quote from Eckleberry-Hunt et al. "The good news is that we have a little time to make changes. The bad news is that we only have a little time to make these changes". We look forward to attracting Gen Z toward NIDCAP training by engaging them in a learning process that optimizes their success.

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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



TAINERS MEE

NIDCAP: Supporting and Sustaining Systems Change

25, 26, 27*, October 2023

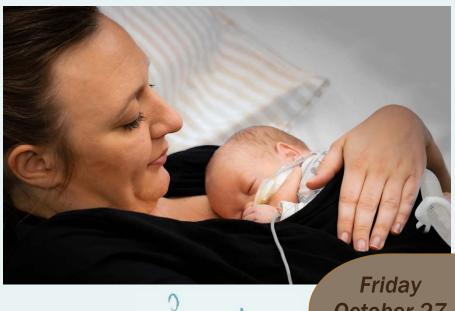
Hyatt Lodge, Oak Brook, Illinois, USA

Hybrid Meeting

Hosted by NIDCAP Federation International (Full meeting attendance is by invitation only)

*Friday, October 27, 2023

One Day Conference is open to all



INTERNATIONAL

October 27 2023

SAVE the DATE

Open One-Day Conference

NIDCAP:

Supporting and Sustaining Systems Change

OPEN ONE-DAY CONFERENCE

Friday, October 27, 8:00-5:30

SPEAKERS

Jeffrey Alberts, PhD
Joy Browne, PhD
Nikk Conneman, MD
Mandy Daly, ACII, DLDU
Saadieh Masri, RN
Debra Paul, OTR
Elizabeth Rogers, MD
Jacques Sizun, MD
Keira Sorrells

The last day of the 34th Annual NIDCAP Trainers Meeting will be an open one-day conference. The purpose of the conference is to equip the learner with the knowledge to provide high level and evidence-based, hospitalized infants and their families.

Visit our conference page for details:

nidcap.org/27oct2023

HYATT LODGE

2815 Jorie Boulevard Oak Brook, Illinois, USA **Hybrid Meeting** thelodge.hyatt.com



Global Perspective on Developmental Care

Inspiring Global Outcomes – Kangaroo Mother Care

Kylie Pussell, Co-Founder Miracle Babies Foundation, Australia



DOI: 10.14434/do.v16i2.36198

My Story

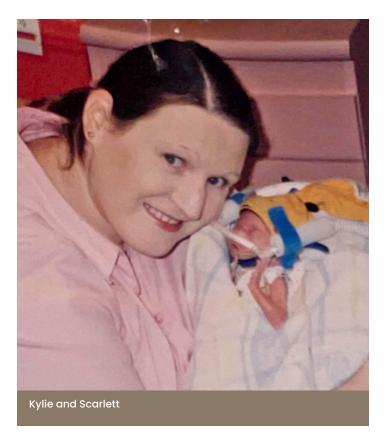
In 2004 I delivered twins at 25 weeks gestation, and this changed my life forever.

After years of struggling with fertility issues, miscarriages and then being diagnosed with cervical incompetence I delivered my first surviving daughter at 30 weeks, following 8 weeks in hospital on bed rest. Two years later after three weeks of bed rest in the hospital, I had an emergency cesarean section to deliver my twins at just 25 weeks gestation. In 2005 I was asked to attend a meeting with other parents to explore the establishment of a parent support network. I jumped at the idea as my second surviving daughter was home with us, but we were also dealing with the grief and loss of our son after two days of life. As hard as it was, I knew that we needed to make more positive changes for families experiencing such a life-changing experience. Even though I didn't see it at the time, my experience and courage to share my personal story could help so many other families. Resilience is something you reflect on afterward, not realizing at the time what it is. I just remember trying to breathe and having some type of normal function to care for my two daughters. Many years later I do believe that in some way I knew my experience could help other parents and sharing my heartbreak could change the future of care for babies and families.

As a result of my personal experience, I am the co-founder of Miracle Babies Foundation, Australia's leading organisation for parents that supports premature and sick babies and their families. Since 2017 I have been CEO, leading the organisation to deliver our vision of 'better, healthier outcomes for newborns and their families challenged by prematurity or sickness.'

An Invitation

In November 2022, I was invited to attend *The XIII International Kangaroo Mother Care Congress* in Madrid Spain as a parent representative. I always felt that we could do kangaroo care better in Australia. This important healthcare congress included two days of learning through workshops with other parent representatives and clinicians from across the globe. I was so impressed with the two days of conference presentations with such inspiring work being delivered saving lives right around the world.



Also, in November 2022, in line with World Prematurity Day, the World Health Organization (WHO) announced its advice for immediate skin-to-skin care for the survival of small and preterm babies. WHO advises immediate skin to skin care for survival of small and preterm babies

The guidelines advise that skin-to-skin contact with a parent – known as kangaroo mother care, should start immediately after birth, without an initial period of time in an incubator. This marks a significant change from earlier guidance and common clinical practice, reflecting the immense health benefits of ensuring caregivers and their preterm babies stay close, without being separated, after birth.

'Preterm babies can survive, thrive, and change the world – but each baby must be given that chance,' said Dr. Tedros Adhanom Ghebreyesus, WHO Director-General. 'These guidelines show that improving outcomes for these tiny babies are not always about providing the most high-tech solutions, but





Networking with International colleagues Dr Samia Rizwan from Pakistan, Kylie, Mandy Daly from Ireland and Dr Pierre Kuhn from France

rather ensuring access to essential healthcare that is centered around the needs of families.'

The XIII International Kangaroo Mother Care Congress was hosted by International Network in Kangaroo Mother Care (INK) and featured presentations from Colombia, Spain, the USA, Philippines, Canada, Norway, Sweden, South Africa, Vietnam, France, India, Ethiopia, Qatar, and Cameroon. A truly global forum.

The presentations were inspiring! There is so much good that can come from kangaroo mother care and immediate contact after birth that benefits both baby and mum, dad, and partner. That this human connection can save hundreds of thousands of babies' lives every year across the world, highlights the miracle of life and love.

I was touched by the open and emotional presentation of the EFCNI (European Foundation for the Care of Newborn Infants) Chair and Co-Founder, Silke Mader who emphasized the importance of parent involvement and the primary caregiving role for parents. She encouraged clinicians across the globe to partner with parents and parent groups to continue improving the care for babies and parents.

A presentation delivered by the World Health Organization noted that the current impact of kangaroo mother care globally was 5% coverage which resulted in the saving of 10,000 babies' lives a year. To add impact and scale up implementation research to a 60% coverage would result in the saving of 150,000 babies' lives per year and at the high end of the potential with 80% coverage, would prevent 400,000 babies

from losing their fight for life each year globally. This was really amazing to hear of such an impact of parents' love and touch on health outcomes for their babies.

The WHO also shared that 20 million, 15% of all births worldwide are babies born with low birth weight, 95% of these babies are from low- and middle-income countries and heartbreakingly account for 70-80% of neonatal deaths. https://www.who.int/publications/i/item/9241590351

Parents Involvement

The WHO guidelines bring home the importance of parents' involvement and touch immediately after birth and it is great to see so much research and improvement in zero separation for families from those at the INK Congress and beyond.

When my twins were born at 25 weeks in 2004 via emergency cesarean section, their resuscitation and stabilizing were the priority. On day two of life, my son Marcus passed away from his extreme prematurity and I never got the chance to kangaroo care with him. When Scarlet was eight days old, I was offered to hold her, it wasn't kangaroo care or skin to skin and it was only for a few moments. As Scarlet grew stronger, we did get to have kangaroo care with her, but it should have been earlier. Knowing what I now know about the benefits of kangaroo care and this life-saving connection, I want all parents to feel educated on kangaroo care and advocate for their baby to have this very special time and ask for zero separation at birth. More touch, love, and bonding in those early moments can really be lifesaving and improve outcomes for babies and families.



In Australia, we celebrate International Kangaroo Care Day on 15th May each year and host our annual Kangaroo-A-Thon with participating hospitals to raise awareness and education about kangaroo care. This day was established by Yamile Jackson, Founder of the Zaky Hand and mother to Zak, another passionate movement for Kangaroo Care.

Networking

We need to globally work together to share experiences and outcomes to increase education and access to kangaroo care. It can all play a part in improving parents' mental health and confidence and in some circumstances can save a life. In attending the IKMC conference in 2022, I was able to meet so many other clinicians and parents passionate about improving education, awareness, and saving lives. These networking connections are invaluable for all countries to learn from each other and help

all newborns have the best opportunities from birth.

I look forward to a NICU world where all babies and families are cared for together. Where parents feel like parents right from the start. And all babies no matter where they are born can have a better start to life.

In helping more babies and families have earlier access to kangaroo care and be more involved in their baby's neonatal journey as the primary caregivers, we can work toward zero separation, saving more lives and creating better, healthier outcomes.

To find out more about Kangaroo Mother Care and Skin to Skin contact please visit <u>Kangaroo Care Awareness</u> <u>Campaign - Miracle Babies</u>

Our Sponsor



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

The NFI thanks its current sponsor, Dr. Brown's Medical, for their continued support.

Developmental Observer

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SCIENCE DESK - THROUGH AN ETHICAL LENS

Moral Agents on the NICU Stage

DOI: 10.14434/DO.V16I2.36239

Jeffrey R. Alberts, PhD

Indiana University, USA, NFI Science Committee, Associate Editor for Science David H. Smith, PhD

Indiana University, Professor, Director Emeritus, Poynter Center for the Study of Ethics, USA

Target Article: Peter Barr (2022) Moral distress and burnout in NICU Nurses, Journal of Obstetric, Gynecologic, & Neonatal Nursing. 51, 461-449. https://doi.org/10.1016/j.jogn.2022.04.007

The target article (Barr, 2022) brings the reader to a theatre in which the NICU is on stage. There's a cast of characters, including neonatologists, surgeons, cardiologists, nurses, therapists, and parents. Despite their shared purpose — to provide care for the babies — collisions occur on this stage, within and between the different specialties and interests represented by each group.

Continuing with our theatre metaphor, Peter Barr's research aims the spotlight on the NICU nurses. They are the essential protagonists, whose central roles are played while providing continuous, 24/7 care to the babies and serving as the interface with parents. The nurses' role is crucially important and can be exceedingly difficult to play. Indeed, we learn that NICU nurses are the players most vulnerable to moral distress and burnout. Yes, this is a morality play!

If there were a script or a Playbill, morals and ethics would pervade the lines. Everyone in the cast is a moral being. Each brings a personal moral code to the shared stage. We would note that the stage is part of a larger theatre in which actors, numerous creative specialists, stagehands and administrators all perform according to standards traceable to ethical codes and moral foundations. With so many players and priorities, it is inevitable that some situations evoke different and conflicting -- but ethically based responses. Hence, moral dilemmas arise. When such dilemmas go unresolved, accumulate, and reoccur, moral distress can emerge. Like other forms of stress, it can become toxic. (Barr's definition focuses on institutional barriers to human action, but we recognize both institutional barriers and differences between individuals, are all morally driven.)

In addition to moral distress, burnout occurs. There are instruments to measure burnout. Barr used one with which he distinguished among three dimensions of burnout: Demoralization, Exhaustion, and Loss of Motive. Barr has been sleuthing around emotional, personal, and moral dimensions of the NICU.1,2,3 His studies in Australia and by others in Italy and the U.S. have documented moral distress and burnout in NICU nurses. Such effects are more prevalent and damaging to nurses than to other NICU professionals. Overall, we see the deep questions unfold: how does the provision of life-saving and loving care become harmful to a professional provider's physical and mental health? Here, the plot thickens, becoming both drama and a detective story.

Methodologically, Barr's (2022) work is "state-of-the-art". He collected survey data from a cohort of nurses in six, Level 3 and Level 4 NICUs in New South Wales, Australia. There were 142 respondents, representing 24% of those eligible to participate in a standardized and validated written survey called the pediatric Moral Distress Scale (MDS-R), along with another scaling instrument aptly named

the Burnout Measure (BM). In all, there were some 38 survey items, each answered with 5 – 7 "levels" or weightings. Thus, each respondent provided a large set of values. The combined mass was voluminous and complex. Barr then applied a series of computer-based analyses that addressed the statistical associations among the various survey elements.

Table 1 shows examples of events selected by Barr that could conflict with a nurse's morals or professionalism and lead to moral distress. Think of each descriptor as an item in one of the surveys. Then note the three dimensions of care: Futile, Compromised, and Untruthful Care. They were used as "factors" and appear as headings in Table 1. Each factor was tested for its association with each kind of event. You can understand a factor's meaning from the items beneath each one. Before the factor analysis is completed, each kind of event is examined in relation to each of the factors. The strength of these many associations are analyzed by calculating "regressions" which examine whether one variable changes systematically in relation to changes in another. When strong relations are found this way, it helps identify significant associations. This is a statistical method that can reduce a large and unwieldy set of numbers into a smaller set of "factors" which, can bring helpful order and clarification to an otherwise bewildering set of results.

In the Australian hospitals, about

one-third of the nurses witnessed forms of compromised care. Reports of futile care were fewer, from about 20% of respondents. Factor analysis revealed that moral distress from compromised care was more intense than from futile care and was associated with various forms of burnout, whereas futile care was associated with exhaustion. Untruthful care was reported much less frequently (5% of respondents) but it predicted burnout demoralization.

Using the methods of factor analysis, Barr quantified a spectrum of emotions and perceptions that were affected by NICU procedures and, in turn, could affect the efficacy of their work with babies, families, and colleagues. In the target article, Barr elevates the analyses over that in past work, revealing a "multi-dimensional" structure to each of the factors. This is partly the "art" of the "science". Barr (2022) is advancing the field. He sees practical value in improving our understanding of the causes of moral distress. Each step of improved understanding is a piece of evidence that can help identify precise changes can be enacted to reduce moral distress.

When ethicists analyze a situation or evaluate a phenomenon, they often apply specialized conceptual tools. These tools enable them to organize their perceptions, to see patterns embedded in complex systems and identify the components that might be at play. Sometimes the goal is to make interpretations, judgements, or draw conclusions. Other times, the outcome is to pose key questions but leave it to others to answer them.

Complex, interactive systems, such as a NICU, are often analyzed with the concept of "agency". All the players in a NICU are "agents", i.e., someone who can influence others and events, or be influenced by them. Nurses are arguably the major agents

Table 1: Events That Might Create Moral Distress in Nurses

Futile Care

- Initiate extensive life-saving intervention when it seems clear it will only prolong infant's death
- Follow parents' wishes to continue life support even though it is not in infant's best interest;
- Witness parents' receiving 'false hope' from doctors or nurses
- Help maintain hopelessly ill infant on ventilator because no one makes decision to turn it off

Compromised Care

- Witness poor care quality due to poor communication among team
- Work with inadequate levels (of competence or numbers) of staffing
- Witness repeated unsuccessful performance of painful procedures on babies
- · Assist a doctor who is providing incompetent care

Untruthful Care

- Parents not given sufficient information to ensure informed consent
- Follow parents' unwise choice of care due to fear of litigation
- · Avoid action when staff colleague fails to report a medical error
- Take no action about an ethical breach due to pressure not to report it

in the NICU, at least in the sense that they spend more time interacting with, and directly treating the babies. In addition, they are responsible for relating with and teaching the families. Yet, the nurses' agency is constrained by that of the parents and physicians. This may help bring into focus some sources of their moral dilemmas.

Barr eloquently noted that "NICUs are ethically complex settings staffed by nurses with different personal strengths and vulnerabilities" (p.447). Consistent with this, but more pointedly, is that *nurses are moral agents*. But there is a problem of balance within the constraints of their agency.

The NICU nurses' responsibilities are enormous in scope and importance. Their authority, however, is not proportionate to their responsibilities. This is apparent from the elements listed in Table 1.

There is urgent need to understand the phenomena of moral distress, burnout and agency. If nurses suffer moral distress and moral distress leads to burnout, then we must address human suffering that arises in the service of others. If such suffering can be removed, mitigated, or prevented – it would be both ethical and practical to do so. It should be done.

A NIDCAP perspective brought to the entirety of the issues raised by the

target article and this commentary would surely assert that the key elements include the family unit and the nurses. These agents must be brought to center stage. Similarly, through NIDCAP observations and reports, the critical relations in the dynamic agency between nurses and parents would be in the limelight. Physician-nurse relations and the crafting of responsibility-authority balance would be next

to explore. These extrapolations imply systems change which, handled with ethical care, can facilitate the healthy evolution of NICU culture and practices.

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NIDCAP Care in the Moment

A mother's supporting hand

News from the European Foundation for Care of Newborn Infants (ECFNI)

5th edition: Parent Organisations Summit 2023 | Kangaroo Mother Care | Born Too Soon (cleverreach.com)

In May 2023, EFCNI hosted the annual international meeting of parent and patient organisations with an eventful, successful, and inspiring Parent Organisations Summit (POS). Every year, EFCNI invites the international community of parents of preterm born infants to connect and network, exchange experiences, learn from one another, support each other, and, last but not least, make and maintain empowering friendships. With exciting presentations and hands-on workshops, this summit is always an opportunity to gain motivation and exchange ideas with like-minded people from all over the world.

A new EFCNI Parent and Patient Advisory Board were elected with representation from Australia, Bulgaria, Canada, Ghana, Greece, Ukraine, USA, Lithuania, Northern Ireland and Portugal.

<u>Please read the full May 2023 edition for an update on other key initiatives from this group.</u>



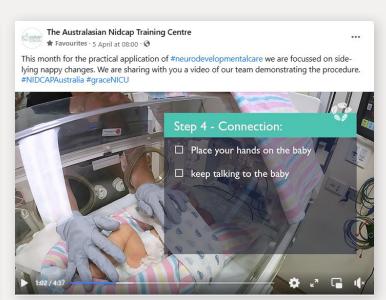
Congratulations to Dr Björn Westrup who received "The Stan and Mavis Graven's Award for Leadership in the Environment of Care for High-Risk Babies and Families" in 2022. Dr Björn Westrup with Dr Joy Browne and Dr Robert White, conveners of the Gravens Conference.

NIDCAP Training Centers - Facebook Pages

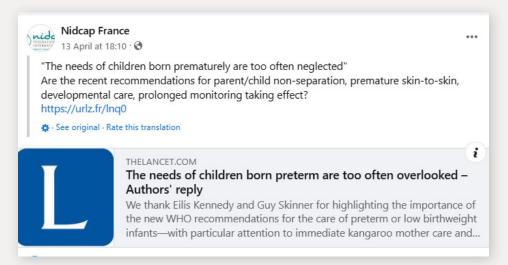
NIDCAP Training Centers continue to provide useful and informative information on their Facebook pages. In this issue, we cover the broad range of educational activities promoted through these pages which continue to increase the information available on NIDCAP and developmental care.



The NFI launches their NIDCAP Wisdoms designed to get each of us to benefit from what others have learned about NIDCAP.



The Australasian NIDCAP Training Centre has developed a series of practical videos and shared Side Lying Nappy (Diaper) Change with prompts.



NIDCAP France provided a link to an interesting article in the Lancet addressing the needs of premature infants.





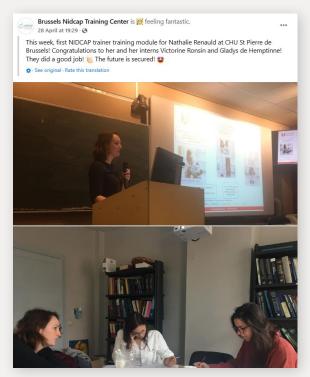




NIDCAP ON THE WEB



NIDCAP Portugal shared a great resource from EFCNI about unit design and layout.



Brussels NIDCAP Training Center provided an update about NIDCAP training through their new trainer and her interns.



NIDCAP Sweden celebrated their achievement of the successful Swedish Conference on Ultra-Early Interventions.









NIDCAP TRAINING CENTERS

AMERICAS

North America

CANADA

Edmonton NIDCAP Training Centre

Stollery Children's Hospital Royal Alexandra Site Edmonton, AB, Canada

Co-Directors: Andrea Nykipilo, RN and

Juzer Tyebkhan, MB

Contact: Juzer Tyebkhan, MB email: Juzer.Tyebkhan@ahs.ca

UNITED STATES

St. Joseph's Hospital NIDCAP Training Center

St. Joseph's Hospital and Medical Center Phoenix, Arizona, USA

Co-Directors: Bonni Moyer, MSPT Contact: Annette Villaverde

email: Annette. Villaverde@commonspirit.org

West Coast NIDCAP and APIB Training Center

University of California San Francisco San Francisco, California, USA

Director and Contact: Deborah Buehler, PhD

email: dmb@dmbuehler.com

Children's Hospital of University of Illinois (CHUI) NIDCAP Training Center

University of Illinois Medical Center at Chicago

Chicago, Illinois, USA

Criicago, IIII Iois, USA

Co-Directors: Doreen Norris-Stojak MS, BSN, RN, NEA-BC &

Jean Powlesland, RNC, MS

Contact: Jean Powlesland, RNC, MS **email:** *nidcapchicago@gmail.com*

National NIDCAP Training Center

Boston Children's Hospital Boston, Massachusetts, USA Director: Samantha Butler, PhD Contact: Sandra M. Kosta, BA

email: nidcap@childrens.harvard.edu

NIDCAP Cincinnati

Cincinnati Children's Hospital Medical Center

Cincinnati, Ohio, USA

Director: Michelle Shinkle, MSN, RN Contact: Linda Lacina, MSN email: lydialacina@me.com

South America

ARGENTINA

Centro Latinoamericano NIDCAP & APIB

Fernández Hospital

Fundación Dr. Miguel Margulies and Fundación Alumbrar, Buenos Aires, Argentina

Director and Contact: Graciela Basso, MD, PhD

email: basso.grace@gmail.com

OCEANIA

AUSTRALIA

Australasian NIDCAP Training Centre

The Sydney Children's Hospitals Network Westmead, Australia Co-Directors: Nadine Griffiths, MN and Hannah Dalrymple,

MRRS

Contact: Nadine Griffiths, NIDCAP trainer

email: SCHN-NIDCAPAustralia@health.nsw.gov.au

EUROPE -

AUSTRIA

Amadea NIDCAP Training Center Salzburg

University Clinic of the Paracelsus Medical University, Salzburg, Austria

Director: Elke Gruber, DGKS

Co-Director: Erna Hattinger-Jürgenssen, MD

Contact: Elke Gruber, DGKS email: elke.gruber@salk.at

BELGIUM

The Brussels NIDCAP Training Center

Saint-Pierre University Hospital Free University of Brussels

Brussels, Belgium

Director: Inge Van Herreweghe, MD Co-Director: Marie Tackoen, MD Contact: Delphine Druart, RN

email: delphine_druart@stpierre-bru.be

UZ Leuven NIDCAP Training Center

Leuven, Belgium

Director: Anne Debeer, MD, PhD **Co-Director:** Chris Vanhole, MD, PhD

Contact: An Carmen

email: nidcaptrainingcenter@uzleuven.be

DENMARK

Danish NIDCAP Training and Development Center

Aarhus University Hospital, Aarhus N, Denmark

Director: Tine Brink Henriksen Professor, MD, PhD

Co-Director: Tenna Gladbo Salmonsen, RN, MScN

Contact: Eva Jørgensen, RN

email: auh.nidcaptrainingcenter@rm.dk

FRANCE

French NIDCAP Center, Brest

Medical School, Université de Bretagne Occidentale and

University Hospital, Brest, France **Director:** Jean-Michel Roué, MD, PhD

Contact: Sylvie Minguy

email: sylvie.bleunven@chu-brest.fr

French NIDCAP Center, Toulouse

Hôpital des Enfant Toulouse, France

Director: Jacques Sizun, MD

Co-Director and Contact: Sandra Lescure, MD

email: lescure.s@chu-toulouse.fr

NIDCAP TRAINING CENTERS

GERMANY

NIDCAP Germany, Training Center Tübingen

Universitätsklinik für Kinder- und Jugendmedizin

Tübingen, Germany

Director: Christian Poets, MD, PhD Contact: Natalie Wetzel, RN

email: natalie.wetzel@med.uni-tuebingen.de

ITALY

Italian Modena NIDCAP Training Center

Modena University Hospital, Modena, Italy Director: Alberto Berardi, MD

Contact: Natascia Bertoncelli, PT email: natascia.bertoncelli@gmail.com

Rimini NIDCAP Training Center

AUSL Romagna, Infermi Hospital, Rimini, Italy Director and Contact: Gina Ancora, MD, PhD Co-Director: Natascia Simeone, RN

email: gina.ancora@ausIromagna.it

THE NETHERLANDS

Sophia NIDCAP and APIB Training Center

Erasmus MC-Sophia Children's Hospital Rotterdam, The Netherlands

Director: Nikk Conneman, MD

Co-Director and Contact: Monique Oude Reimer, RN

email: nidcap@erasmusmc.nl

NORWAY

NIDCAP Norway, Ålesund Training Center

Ålesund Hospital, Ålesund, Norway

Director: Lutz Nietsch, MD Contact: Unni Tomren, RN email: nidcap@helse-mr.no

PORTUGAL

São João NIDCAP Training Center

Pediatric Hospital at São João Hospital

Porto, Portugal

Director: Hercília Guimarães, MD, PhD

Co-Director and Contact: Fátima Clemente, MD

email: nidcapportugal@gmail.com

SPAIN

Barcelona NIDCAP Training Center: Vall d'Hebron and **Dr Josep Trueta Hospitals**

Hospital Universitari Vall d'Hebron, Barcelona, Spain Director and Contact: Josep Perapoch, MD, PhD email: jperapoch.girona.ics@gencat.cat

Hospital Universitario 12 de Octubre NIDCAP **Training Center**

Hospital Universitario 12 de Octubre, Madrid, Spain Director: Carmen Martinez de Pancorbo, MD

Contact: María López Maestro, MD email: nidcap.hdoc@salud.madrid.org

Sant Joan de Déu Barcelona NIDCAP Trainer Center

Sant Joan de Déu Hospital

Barcelona, Spain

Director and Contact: Ana Riverola, MD

email: ariverola@hsjdbcn.org

SWEDEN

Karolinska NIDCAP Training and Research Center

Astrid Lindgren Children's Hospital at Karolinska University

Hospital Stockholm, Sweden Director: Agnes Linnér, MD, PhD Co-Director: Siri Lilliesköld, RN, MS Contact: Ann-Sofie Ingman, RN, BSN email: nidcap.karolinska@sll.se

Lund-Malmö NIDCAP Training and Research Center

Skane University Hospital

Malmö, Sweden

Director: Elisabeth Olhager, MD

Co-Director and Contact: Stina Klemming, MD

email: nidcap.sus@skane.se

W UNITED KINGDOM

UK NIDCAP Centre

Department of Neonatology,

University College Hospital, London, UK Director: Giles Kendall, MBBS, FRCPCH, PhD

Contact: Beverley Hicks, OT email: beverleyann.hicks@nhs.net

MIDDLE EAST –

ISRAEL

Israel NIDCAP Training Center

Meir Medical Center

Kfar Saba, Israel

Co-Directors: Ita Litmanovitz, MD and

Dalia Silberstein, RN, PhD

Contact: Dalia Silberstein, RN, PhD email: daliasil1960@gmail.com

ASIA -

JAPAN

Japan National NIDCAP Training Center

Seirei Christopher University, Shizuoka, Japan

Director: Tomohisa Fujimoto, PT

Co-Directors: Kanako Uchiumi, RN, MW, Noriko Moriguchi,

MSN, RN, PHN, IBCLC and Yoko Otake, RN

Contact: Tomohisa Fujimoto, PT email: fusan.mail@gmail.com

