

Developmental Observer

The Official Publication of the NIDCAP® Federation International



Resilience is not an innate capacity. Rather it is a dynamic process that requires support and nurturance.

—Deborah Buehler

>>

INSIDE

The Inaugural Heidelise Als
Editorial2
Moment by Moment 6
Abstracts from the 2023
34 th Annual NIDCAP Trainers 19 Meeting Summary and Reflection
Behind the Scenes 22
Family Voices23
Global Perspective: China 26
NIDCAP on the Web28
NIDCAP Training Centers

10.14434/do.V17I1.37084

The Inaugural Heidelise Als Lecture The Synactive Theory, NIDCAP, and Resilience

Deborah Buehler, PhD

DOI: 10.14434/do.v17i1.37039

eidelise Als, PhD asked Can we integrate technological advance into our affective launched-ness as humans.¹ This idea of our humanness, our affective launch, and NIDCAP's opportunities to support healthy progressions is a critical one. And further, these developments seem interrelated to the notion of resilience.

What is resilience? The Merriam Webster dictionary definition reads: re-sil-ien-cy; an ability to recover from or adjust easily to adversity or change.² Resilience is considered a brain capacity. Neuropsychologist David Eagleman wrote: The human brain is a dynamic, information-seeking system... it alters its own circuitry to match the demands of the environment and the capabilities of the body.³ What are these environmental demands and body capabilities? Within our work, our NIDCAP framework recognizes the mismatch between the displaced fetus and

young infant and their hospital environment. As Heidelise often said, we are never not in an environment. She described human infants as having been promised three environments: (1) the mother's womb; (2) the mother's breast and body; and (3) the species social group. Since the intensive care environment is NOT one of these evolutionarily promised environments, what are the implications for development and unfolding relationships, for well-being, and, interrelatedly, resilience by being in this environment at such a time in their growth? Resilience is the capacity to withstand difficulties. To say that intensive care settings present "difficulties" is a tremendous understatement.

Difficulties may be experienced as stress. Stress may result from novel, unexpected, unprepared, or untoward experiences. For newborns and young

(continued on p.2)

infants, this may be a mismatch between capabilities and capacities and their environments. The Center on the Developing Child at Harvard University describes stress as *positive*, *tolerable*, or *toxic*. They write that stress *can have a cumulative toll on an individual's physical and mental health—for a lifetime. The more adverse experiences in childhood, the greater the likelihood of developmental delays and later health problems. We know what this looks like from our observational NIDCAP training. We observe autonomic, motoric, state, attentional, and regulatory stabilities, stresses, and strivings.*

Heidelise frequently quoted Winnicott's writing: Babies are liable to the most severe anxieties... if left for too long (hours or minutes) without familiar and human contact; they have experiences which can only be decribed as: Going to pieces; Falling forever; Dying, dying, dying; and Losing all vestige of hope for the renewal of contact.⁵

Resilience is not an innate quality. From the womb, fetuses are developing all sorts of competencies. When newborns are born prematurely, they may be described as "fighters" with strong drives to steady, survive and thrive. Yet, after attempts to steady and to thrive, they may have experiences of repeated overwhelming instability and they may give up. This is what is referred to in psychology as learned helplessness. If this situation persists it may result in failure to thrive outcomes.

Reilience develops and is affected by experience. The Model of Stress apples to individuals of all ages, including parents of infants in intensive care. Illness, sleep deprivation, anxiety, fears, struggles, all strain experiences of resilience and well-being and unfolding parenting confidence and competence. Professor Kristen Lee Costa wrote: sometimes we just don't have the skills we need for emotional regulation or stress tolerance. In general, our threshold for coping can vary a lot,

(continued on p.3)

Editorial

DOI 10.14434/do.v17i1.37037

A milestone in a shared journey



The echoes of the 34th Annual NIDCAP Trainers Meeting are still resonating, marking yet another milestone in our shared journey of promoting developmental care for hospitalized newborns. In this issue of the Developmental Observer, we are thrilled to bring you the essence of the

meeting, capturing the energy and insights that unfolded during this significant event.

One of the highlights was Deborah Buehler's Inaugural Heidelise Als Lecture, a powerful discourse on resilience that injects fresh inspiration into our NIDCAP endeavors. The echoes of her words continue to reverberate, reminding us of the profound impact our collective efforts can have on the lives of the infants we care for.

Our global community shone brightly as we heard about the groundbreaking work happening across continents. Abstract presentations from Australia, Belgium, Canada, Colombia, France, Germany, Iran, Israel, Qatar, and Spain showcased the diversity and richness of our shared commitment. We are confident that the innovative approaches highlighted in these presentations will serve as motivation for your work.

gretchen Lawhon, in her insightful summary of the meeting, emphasizes the paramount importance of family in our mission. She articulates how the family unit plays a pivotal role in the NIDCAP journey, underlining the interconnectedness of our work with the broader fabric of familial bonds.

Through the lens of Family Voices, Katie Reginato Cascamo shares a deeply personal account of her NIDCAP experience, demonstrating the transformative power of listening

and the profound impact it had on her premature son. Her narrative exemplifies the human dimension of our work and reinforces the enduring value of empathy in healthcare.

Venturing into the international landscape, we explore developmental care in China and Xiaojing Hu's dedicated efforts to integrate NIDCAP principles. The global imprint of NIDCAP is evident, resonating with our shared commitment to realizing the goals set by the NFI for NIDCAP care worldwide.

As the Developmental Observer embarks on its 17th volume, we are committed to bringing you innovative stories that captivate and inform. In our new "Behind the Scenes" feature, we introduce Rob Catalano, a hidden force behind the scenes since the inception of our publication. His story illuminates the collaborative efforts of the many committed individuals who contribute to each issue.

Your feedback is the lifeblood of our publication, and we eagerly anticipate hearing from you. Let us know which features resonate with you and share your ideas for new content.

Thank you for your unwavering commitment to the NIDCAP mission.

Kaye Spence AM FACNN

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

Erratum. Image on page 10 of Vol 16, Issue 3 should read - 'Joana'

according to a lot of variables. Even missing a night's sleep, or not being nourished, or cranking at work with a lot on your plate can press upon us and affect our resilience at a point in time. For Healthcare Professionals, those variables may include staffing shortages, experiences of burn-out, a pandemic and caring for vulnerable and ill infants and their families, including the demandingness of twelve-hour shifts. One can easily see how stressors compound, leading to exhaustion, anxiety and frustration which further lead to lessened feelings of effectiveness, well-being, and resilience.

One of the central tenets from our NIDCAP model is that when stresses are too great for an individual, support from the social environment may have steadying, balancing influences – at all ages. The same council from the Center on the Developing Child at Harvard University wrote: *The single most common finding is that children who end up doing well have had at least one stable and committed relationship with a supportive parent, caregiver, or other adult.*⁷ Stable, committed, supportive, nurturing relationships are at the core of NIDCAP philosophies and practices. This is the Affective Bond that Heidelise described.

To understand the nurturing influence of NIDCAP on functioning, we can look to the writings and research of our very own NFI scientists:

The field of neuroscience provides overwhelming evidence that the brain organizes itself based on its early experiences. Heidelise, Frank Duffy, MD, and Gloria McAnulty, PhD wrote: NIDCAP significantly improved neurodevelopment in terms of behavior, functional brain connectivity and brain structure and health.⁸

The study of epigenetics provides mounting evidence that infant environments can change the chemistry of their genes—both negatively and positively. Heidelise wrote: NIDCAP may work at the level of preventing such untoward epigenetic effects by supporting the infant's optimal genomic rather than distorted epigenomic blueprints.⁹

From the field of microbiology, Jeffrey Alberts, PhD introduced the idea of a shared Mother-Offspring Microbiome (or MOM) with extensive involvement of autonomic, motor, state, attention, and self-regulation functions. Alberts was *struck by the compatibility of gut-brain ideas with the distinctly integrative and bi-directional qualities of NIDCAP perspectives.*¹⁰

(continued on p.4)

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.



Deborαh Buehler, PhD, has a degree in developmental psychology and is 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

Within neurophysiology, oxytocin has been shown to play a role in human behaviors and social interactions. Dorothy Vittner wrote: Oxytocin may serve as a potential moderator for improving responsiveness and synchrony in parent-infant interactions.¹¹

The field of Functional Medicine studies the influences and interactions of nutrition, molecular biology, and epigenetics on health and disease with individualized approaches to promote well-being. NIDCAP Trainer, Deana DeMare Hally describes Functional Medicine as the focus of the epigenetic interplay between environmental influences and one's biological systems; which of course very much aligns with Synactive Theory.¹²

Brain, genes, gut, hormones, and their interactions - the evidence is mounting to support the necessity of caring for young infants in environments that closely align with their expectations and capabilities.

When NIDCAP is studied, it is done so as a whole caregiving approach rather than as ingredients to care. This is because the NIDCAP approach supports dynamic, evolving developmental progressions, relationships, interactions, and systems. The Synactive Model of Development and interrelatedly the Synactive Model of Developmental Care have been conceptualized as graphics. To appreciate the complexity of this care, you can overlay these two models on one another for considerations of individuals in the context of the intensive care setting.¹³

We know from the Synactive Model of Development (Figure 1) that individual/environment interactions are con-

tinuously occurring with active developmental strivings and that infants are integrally part of their social systems. We also know that development never stops, for any of us. Everyone is on their own developmental trajectory and is developing all the time. In our NIDCAP lectures, we make analogies about how our subsystems are taxed by learning new skills, such as driving a manual car or learning to downhill ski. In intensive care settings, families and healthcare professionals alike are experiencing new and perhaps difficult moments and situations. For the infants, their parents are their primary nurturers and advocates. Parents are learning and responding to their own experiences, which include parenting their infant in a hospital setting and all that that means. Parents are part of family systems, who are also made up of individuals on their own trajectories. Parents, and their family systems, are all in turn cared for by the infant intensive care healthcare professionals and staff. These hospital team members are also interacting with their physical and social environments and developing themselves. Healthcare professionals and staff care for infants and families are part of hospital, healthcare systems – which are all made up of individuals. All these individuals and their systems are all part of larger local and global communities.

Figure 2 is a purposefully dizzying graphic to show that stresses are being experienced at all levels by all individuals... positive, growth-promoting ones, and negative, damaging ones, as well as ones in between. It may be daunting to imagine how to support optimal experiences and outcomes for infants, parents, families, healthcare professionals, and hospital systems,

Figure 1

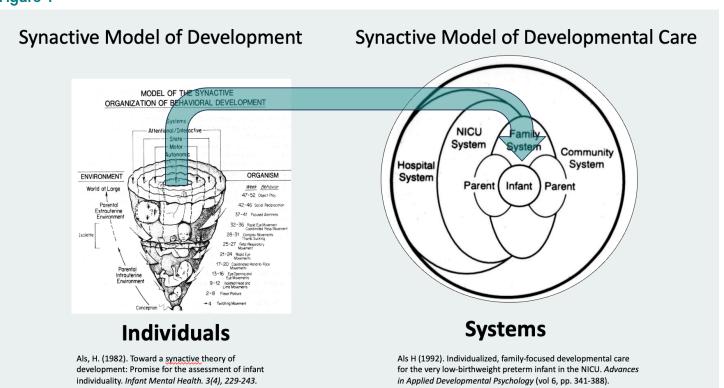
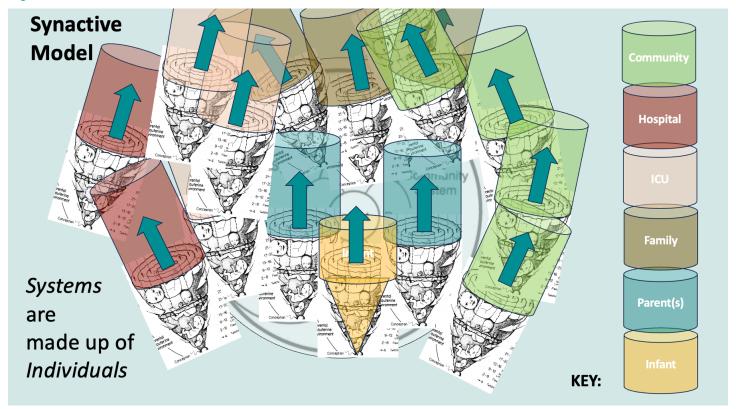


Figure 2



so we look to our NIDCAP framework to guide us under these circumstances.

The key to resilience and well-being in infants, families, healthcare professionals, and even whole systems is through embedding understandings and support for all those individuals with consistently well-integrated, infant-family-staff mutually regulating NIDCAP care. Supported, resilient professionals will support and guide families and parents who in turn will nurture their infant's emerging next steps and their own resiliencies. This is also multidirectional – balance and strength in an individual (infants through adults) support the balance and strength of others.

Inspirations from the field of Infant Mental Health support our NIDCAP care translations to create optimal healthcare environments. Joy Browne, PhD has written extensively and is an important resource on this topic. She wrote: *There is no more important place to establish a solid foundation for a baby's emerging infant mental health than in intensive care.* ¹⁴ She also described the importance of creating a solid foundation for parents and their roles as the parents of their vulnerable young infants.

Reflection and supportive relationships, integral components of Infant Mental Health approaches, have long been valued and well-integrated into our NIDCAP approach. Linda Gilkerson and Heidelise wrote: *Relationships are central to the goals and the implementation of developmentally supportive care. And they quoted Shanok to say (t)he inclusion of reflec-*

tive process as a component of developmentally supportive care helps the nursery become a place where strengths are emphasized while vulnerabilities are partnered.^{15,16}

Dr. Amit Sood stated *Resilience is the core strength you use to lift the load of life.*¹⁷ One of the most poignant examples of this message can be found in the story that Heidelise used to share in her introductory NIDCAP lectures about a young infant named Ronnie. Ronnie was a child who had chronic lung disease. His hospital stay lasted months and months. The triage room in the back of the NICU was converted into his private room with his family. Heidelise worked very closely with them. She maintained contact with Ronnie through at least 20 years of age. Ronnie's early childhood experience in the hospital, included receiving a tracheotomy and lung disease, yet none of these challenges diminished his delight and joy in his world - nor his mother's confidence in his care and in herself as his mother. That is the beauty of resilience and the power of NIDCAP care.

Resilience is not an innate capacity. Rather it is a dynamic process that requires support and nurturance. How do infants develop the tools for resilience? How do they go from "giving up" to the beginning of experiences of competence and stability? The guide for developing resilience comes from turning the lights down low, being tucked into flexion, hand swaddling, and holding, it comes from nurturance. The infant's parents are what is needed for these ongoing opportunities for the infant to experience relaxation and success. And parents need support and nurturance from the healthcare professional team,

who in turn, need to be nurtured themselves. NIDCAP care provides critical scaffolding for the development of resilience.

Heidelise's charge to all of us... was *Can we integrate that technological advance into our affective launch as humans?* This is an extraordinarily important challenge to strive to do. Because having greater resilience and well-being at all ages helps to navigate difficult challenges of life which in turn may lead to their mastery and ever-joyful lives.

References

- Als H. The Family in Synactive Perspective: Evolution, Biology and Psychology. NIDCAP Trainers Meeting, October 19, 2015. Phoenix Arizona USA.
- 2. Merriam-Webster Dictionary https://www.merriam-webster.com/dictionary/resiliency#
- Eagleman D. (2020). Livewired The inside story of the ever-changing brain. Vintage Books, New York. P. 7. https://eagleman.com/books/livewired/
- Center on the Developing Child Harvard University https://developingchild.harvard.edu/ science/key-concepts/toxic-stress
- Winnicott Donald W., 'Dependence in Child Care', in Lesley Caldwell, and Helen Taylor Robinson (eds), *The Collected Works of D. W. Winnicott: Volume 9, 1969 - 1971* (New York, 2016; online edn, Oxford Academic, 1 Dec. 2016), https://doi.org/10.1093/med:-psych/9780190271411.003.0047
- Costa K. http://Mentalfloss.com/article/80152/reliance-isn't-innate-heres-how-we-can-cultivate-it
- Supportive Relationships and Active Skill-building Strengthen the Foundations of Resilience (Working Paper 13) (2015) National Scientific Council on the Developing Child, Center on the Developing Child at Harvard University. https://developingchild.harvard.edu/wp-content/uploads/2015/05/The-Science-of-Resilience.pdf

- Als H, Duffy FH, McAnulty G, Butler SC, Lightbody L, Kosta S, Weisenfeld NI, Robertson R, Parad RB, Ringer SA, Blickman JG, Zurakowski D, Warfield SK. NIDCAP improves brain function and structure in preterm infants with severe intrauterine growth restriction. *J Perinatol.* 2012 Oct;32(10):797-803. doi: 10.1038/jp.2011.201. Epub 2012 Feb 2. PMID: 22301525; PMCID: PMC3461405.
- Als H. Lamarck, Darwin and the Science of NIDCAP: Epigenetics in the NICU. *Developmental Observer*, 2011, 4(2).
- 10. Alberts J. (personal communication) October 13, 2023
- Vittner D, McGrath J, Robinson J, Lawhon G, Cusson R, Eisenfeld L, Walsh S, Young E, Cong X. Increase in Oxytocin From Skin-to-Skin Contact Enhances Development of Parent-Infant Relationship. *Biol Res Nurs*. 2018 Jan;20(1):54-62. doi: 10.1177/1099800417735633. Epub 2017 Oct 11. PMID: 29017336
- 12. DeMare Hally D. (personal communication) October 18, 2023
- Als H. (1982). Toward a synactive theory of development: Promise for the assessment of infant individuality. *Infant Mental Health*. 3(4), 229-243.; Als H (1992). Individualized, family-focused developmental care for the very low-birthweight preterm infant in the NICU. Advances in Applied Developmental Psychology (vol 6, pp. 341-388).
- Browne J. From Infant Mental Health Focus (Principle 2) Standards in development. The Basics of Infant and Early Childhood Mental Health: A Briefing Paper | ZERO TO THREE.
- Gilkerson L, Als H. Role of Reflective Process in the implementation of developmentally supportive care in the newborn intensive care nursery. *Infants and Young Children*; 1995; 7(4): 20-28
- Shanok RS The Supervisory Relationship: Integrator, resource, and guide. In Fenichel E, ed. Learning Through Supervision and Mentorship: A Source Book. Arlington, Va: Zero to Three; 1992. p40. https://www.amazon.com/Learning-Supervision-Mentorship-Develop-ment-Toddlers/dp/0943657199
- Sood A. Stronger: The Science and Art of Stress Resilience Paperback December 13, 2018
 Gauri Sood (Editor) Publisher: Global Center for Resiliency and Wellbeing. https://www.amazon.com.au/Stronger-Science-Art-Stress-Resilience/dp/0999552511



States and State Transitions – Dilemmas for Dialogue

Burhani HA^{1,2,3}, El-Tawil A^{1,3}, Tyebkhan JM^{1,2,3}

¹Department of Pediatrics, University of Alberta; ²Division of Neonatology, Stollery Children's Hospital; ³Edmonton NIDCAP Training Centre Canada, Edmonton, AB, Canada DOI 10.14434/do.v17i1.37040

Aims

The state subsystem is difficult to understand as a NIDCAP Professional-in-Training. NIDCAP Professionals-in-Training are expected to reliably recognize the six Brazelton states¹, and the division of each state into the diffuse (A) or robust (B) subcategory.^{2,3}

The AA State is a unique feature of NIDCAP naturalistic observation, recognized as a respiratory pause greater than eight seconds and defined in the NIDCAP Training Manual as 'removal from the state continuum.' This definition seems to contradict Prechtl's definition of the state as a "discrete mode of neurological activity, during which a group of physiologic and behavioural characteristics that regularly recur together." This implies that the six states are discrete; whereas the AA State definition postulates a state continuum.

The complexity of states increases when referring to the APIB Manual, where States 1AA and 2AA are mentioned as "states in which severe diffuseness is embedded".⁵

The confusion about states, particularly the AA state, is a frequent topic of uncertainty at NIDCAP training days at our NIDCAP Training Centre. A lively discussion usually follows but without a conclusion. To gain a deeper understanding of, and to clarify uncertainties about infant state, a survey was sent to NIDCAP Trainers. Trainers were asked for their interpretation of the states seen on a short video, and for their understanding of states 1AA and 2AA.

Methods

A six-minute video from a training observation was sent to NIDCAP Trainers, with a Google distribution listserv survey. Trainers were asked to view the video, and then answer questions about states and transitions, and whether the two-minute intervals used in a NIDCAP observation accurately captured details of the infant's state profile. Trainers were also asked if the infant moved into State 2AA, and how they explained States 1AA and 2AA to NIDCAP Professionals-in-Training.

Results/Findings

Three responses have been received to date.

- A) The number of State Transitions identified during the video was either 7 or 15 (one respondent did not reply).
- B) Transitions between states: The number of respondents who identified any state(s) during each two-minute time interval is shown below. Multiple states could be chosen for each interval:

Table 1

State/ Time Interval	0 to 2 minutes	2 to 4 minutes	4 to 6 minutes
1A	-	_	-
2A	1	2	2
3A	2	2	2
4A			
5A	1		2
6A			
АА	1	2	

- C) All respondents felt that details of the state profile were not captured by simple recording in the table above.
- D) In response to "When baby stops breathing and becomes flaccid, is he moving into state AA or 2A?', two replied 'AA; one did not commit.
- E) In response to "How do you explain the states 1AA and 2AA to your trainees," the trainers were not sure; "Very good question, not sure myself!".

Limitations

Only three responses have been received to date. The link to the survey and video will remain live at https://forms.gle/fNNmEMSTPY258JEv5. Responses received between the submission of this abstract (30 June) and 31 August 2023 are presented.

The quality of the video (e.g. movement artifact) was challenging for some respondents.

Relevance to NIDCAP

Understanding states is critical for reliability as a NIDCAP Professional. Caregivers also ideally synchronise interactions to infants' states and need some appreciation of this concept. Our questions and the input from trainers highlight the complexity of 'State'. We hope to begin a dialogue with the NIDCAP community toward enhanced understanding of states, that will lead to improved care and outcomes for newborns in hospitals.

Conclusion

States and State Transitions are complex and confusing to

ABSTRACT - NIDCAP TRAINERS MEETING 2023

understand. The subtle features of states 2AA and 1AA may need to be clarified for NIDCAP Trainers.

References

- Brazelton TB and Cramer (1990) States of Consciousness. Pages 63-68 in The Earliest Relationship, Da Capo Press. https://doi.org/10.4324/9780429481512
- Als H. (2006) Manual for the naturalistic observation of newborn behavior. Newborn Individualized Developmental Care Assessment Program (NIDCAP). NIDCAP Federation International, 2015. https://nidcap.org/wp-content/uploads/2015/02/B.-Manual-Naturalistic-Observation-of-Newborn-Behavior-NewDesign-Feb15.pdf
- Als H (1999) Reading the premature infant. In: Goldson E, editor. Developmental interventions in the neonatal intensive care nursery. New York: Oxford University Press; p. 18-85.
- 4. Prechtl HFR (1974) The Behavioural States of the Newborn Infant. Brain Res 76:185 DOI: 10.1016/0006-8993(74)90454-5
- Als H, Lester BM, Tronick EZ, Brazelton TB. (1982) Manual for the Assessment of Preterm Infant's Behavior (APIB). In Theory in Research in Behavioral Pediatrics, Fitzgerald H, Lester B and Yogman M (eds). Vol 1, New York: Plenum Press. Pages 65-132. https://nidcap.org/wp-content/uploads/2014/12/APIB-Manual-with-HAEdits-1Feb2011-currently-used.pdf

Help Us Support Healing (HUSH): A Preliminary Assessment of Staff's Estimates of Acoustic Noise in their Level 4 NICU

Dela Cruz A, Cauan R

Sidra Medicine and Research Center, Doha, Qatar

DOI 10.14434/do.v17i1.37041

Aims

Maintaining a sensory environment appropriate for prematurely born infants is essential to NIDCAP practice. Reflecting such priorities, the American Academy of Pediatrics recommends baseline noise levels in a NICU at <45 decibels (dB) with allowable transient events <65 dB.

We assessed levels of acoustic noise within the incubators of an open-bay, Level 4 NICU resulting from identified sources of equipment and procedures. In parallel to these measures, we sought via a survey of NICU staff, to measure their understanding of the NICU acoustic emissions.

Methods

We assembled a Sensory Group consisting of 15 nurses from both the day and night shifts, who were trained to use the NIOSH Sound Level Meter Application (app) for iOS devices, which is free from the National Institute for Occupational Safety and Health. We then enrolled a diverse group of preterm babies (24 – 36 weeks GA) as HUSH subjects. The HUSH cohort was updated every week to record their status and screen for any changes in patient condition and hemodynamical instability.

Sensory Group members recorded the acoustic measurements with the NIOSH app during times designated for protected sleep or "quiet time". Recordings were made for one hour each time. The monitoring device was placed in the incubator, approximately 25-30 cm from its ears as a means of characterizing the acoustic environment experienced by the baby that is transduced into the incubator.

A survey was circulated among the NICU staff, mostly nurses, and 87 (> 73% of those invited to participate) completed the multiple-choice survey. They estimated noise levels associated with a variety of NICU events and procedures. Their responses were compared to the measured values collected by the Sensory Group.

Results

The average noise level within the incubators exceeded the recommended baseline maximum of 45 dB. Of the various sources of NICU noise exceeding recommended levels, alarms from the cardiac monitors were the loudest. In addition, common procedural events such as closing a port hole door produced transient sounds in excess of 100 dB, also exceeding recommendations.

Many respondents (one-third or more) to the survey correctly estimated several sound levels in decibel units. When the estimates made by the respondents deviated from the actual values, they often underestimated the noise levels experienced by the babies. Yet, only about 21% of the 87 respondents had an accurate idea of the acceptable maximum decibel level for NICU noise (40-45 dB). The respondents offered a variety of appropriate suggestions for limiting NICU noise.

Relevance to NIDCAP

Our findings identify sources of acoustic noise in an open bay NICU that regularly penetrate incubators and expose infants to dB levels deemed excessive by current medical standards and which are typically identified as reducible through NIDCAP practice.

Conclusions

There are numerous identifiable sources of baseline, ambient noise in the NICU, and several sources of transient sounds that vastly exceed acceptable levels. Many of these sounds can be reduced or eliminated by resetting equipment and making minor adjustments to procedures. Only a minority of NICU nurses in our sample were aware of the quantitative threshold of acceptable NICU noise, but they can be readily equipped to measure and understand it. The results of this preliminary study help clarify staff awareness of noise levels and sensitize us to other non-acoustic factors that affect babies. These exercises demonstrate the importance of research for improving practice.

Behavioural and Physiological Responses of Infants Post-Surgery During Nurse-Delivered Caregiving

Griffiths, N^{1,2}, Laing, S¹, Spence, K^{1,3}, Foureur, M⁴, Popat, H^{1,5}, James-Nunez, K¹, Sinclair, L²

DOI 10.14434/do.v17i1.37079

¹ Grace Centre for Newborn Intensive Care, The Sydney Children's Hospital Network (Westmead) NSW, Australia, ² University of Technology Sydney, NSW, Australia, ³ Western Sydney University, NSW, Australia, ⁴ University of Newcastle, NSW, Australia, ⁵ University of Sydney NSW, Australia

Aim

To evaluate the immediate physiological and behavioural responses of infants during routine nurse-delivered caregiving in the surgical neonatal intensive care unit (NICU)

Methods

A prospective observational study was conducted in a surgical NICU. Paired physiological and behavioural data were collected to evaluate surgical infant responses during routine nurse-delivered caregiving (diaper change). Continuous heart rate (HR) data were reviewed to explore variation in the mean HR pre-, during-, and post-nurse-delivered caregiving. Physiological stress was defined by the study team as a change in the HR of 10bpm or more. Videos of infant caregiving were captured by a web camera. Dedicated software combined audio-visual and physiological data. Two NIDCAP Certified Professionals independently scored the video recordings, using a study-specific behavioural observation tool consisting of 43 items: 6 measure infant state; 19 measure stress responses; 7 measure self-regulation; 11 measure caregiver-support. Videos comprised three epochs: epoch one and epoch three pre- and post-caregiving of 10 minutes each; epoch two nurse-delivered caregiving of variable timing. A tick was recorded when a behaviour, state or support was observed, and item scores were summed. Inter-rater reliability was calculated using the Intraclass Correlation Coefficient (ICC).

Results

Forty infants participated in the study, physiological data was analysed for 40 infants and behavioural data was scored for a sub-group of 10 infants. The sample had a mean gestational age of 36.9 weeks (SD 2.2) and participated in the study at a mean of five (SD 2.9) days postoperative. Twenty-two infants (55%) had gastrointestinal (GIT), ten (25%) cardiac, and eight (20%) respiratory/oesophageal surgery.

Physiological results

A total of 74,880 data points were reviewed. All groups showed significant changes in heart rate (HR) between pre-caregiving and during caregiving; Mean change (bpm) of 15.4 (SD 13.3) in GIT, 6.3 (SD 4.0) in cardiac, and 16.1 (SD 9.2) in respiratory/ oesophageal groups. Effects of caregiving were seen beyond the caregiving period across all groups with HRs not returning to the pre-caregiving baseline within 10 minutes of caregiving completion.

Behavioural results

Four-hundred and thirteen minutes of video data were analysed; epoch one - 106 minutes, epoch two – 207 minutes, epoch three – 100 minutes. The ICC's were good to excellent across all components of the behavioural assessment tool (Table 1).

The most frequently observed states, stress, and self-regulation behaviours during caregiving for the sub-groups are

Table 1: Intra-class correlations for scale components of the observational tool, by epoch

Scale component	Epoch 1 Pre-caregiving	Epoch 2 Caregiving	Epoch 3 Post-caregiving
Infant state	0.72	0.71	0.53
Stress responses	0.91	0.84	0.78
Self-regulation behaviours	0.90	0.90	0.74

ICC agreement grading: Poor <.40, Good to moderate .41 to 0.75, Excellent >.762

ABSTRACT - NIDCAP TRAINERS MEETING 2023

reported as median scores. For infant states: GIT infants - drowsy/alert/crying (4.2); cardiac infants - drowsy (5.5). Stress responses: GIT infants - extend legs (8), splay fingers/toes (6), squirm (6); cardiac infants - splay fingers/toes (8) and squirm (7.5). Self-regulation behaviours were similar for both groups; GIT infants - hand to face (5), suck/foot clasp/leg brace (3); cardiac infants - hand to face (4), suck/hold on/leg brace (3.5). The most offered support during caregiving was, in descending order - supportive holding, voice, patting/stroking.

Relevance to NIDCAP

This research provides NIDCAP Trainers, NIDCAP-certified Professionals, bedside clinicians, and families with information to support infants requiring surgery in the neonatal period and specifically the application of developmentally responsive caregiving.

Conclusion

To our knowledge, there is no published research on surgical infants' physiological and behavioural responses during nurse caregiving. We found that infants post-surgery demonstrate physiological stress during nurse-delivered caregiving. Differences were observed between groups and may represent the differing physiological effects of congenital anomalies. It appears that infants post-surgery express similar repertoires of behavioural stress cues and self-regulation behaviours.

Ongoing analysis of the study sample will add to these preliminary results and the findings may assist bedside clinicians.

References

- Allinson LG, Denehy L, Doyle LW, Eeles AL, Dawson JA, Lee KJ, Spittle AJ.
 Physiological stress responses in infants at 29-32 weeks' postmenstrual age during
 clustered nursing cares and standardised neurobehavioural assessments. BMJ Paediatr
 Open. 2017;1(1):e000025. doi: 10.1136/bmjpo-2017-000025. https://doi.org/10.1136/bmjpo-2017-000025.
- Fleiss JL. (1971). Measuring nominal scale agreement among many raters. Psychological Bulletin, 76, 378-382.

NIDCAP Federation International Board of Directors and Staff 2024

PRESIDENT

Deborah Buehler, PhD

NIDCAP Master Trainer APIB Trainer

Director, West Coast NIDCAP and APIB Training Center

email: nfipresident@nidcap.org

VICE PRESIDENT

Dorothy Vittner, PhD, RN, FAAN

Senior NIDCAP Trainer
West Coast NIDCAP & APIB Training
Center

email: dvitt8@gmail.com

CO-TREASURER

Gloria McAnulty, PhD

National NIDCAP Training Center email: gloria.mcanulty@childrens.harvard.edu

CO-TREASURER

Jennifer Hofherr, MS, OTR/L, CNT

National NIDCAP Training Center NIDCAP Trainer Children's Hospital of University of L

Children's Hospital of University of Illinois NIDCAP Training Center

email:

jennifer.hofherr@nationwidechildrens.org

SECRETARY

Jean Powlesland, RN, MS

NIDCAP Trainer

Director Children's Hospit

Director, Children's Hospital of University of Illinois NIDCAP Training Center **email:** nidcapchicago@gmail.com

Fatima Clemente, MD

NIDCAP Trainer

Co-Director, São João NIDCAP Training Center

email: clemente.fatima@gmail.com

Mandy Daly, Dip. H Diet and Nutrition, ACII, DLDU

Family Representative, Dublin, Ireland email: mandy.daly@yahoo.co.uk

Jennifer Degl, MS

Family Representative, New York, USA email: jenniferdegl@gmail.com

Dalia Silberstein, RN, PhD

NIDCAP Trainer

Co-Director, Israel NIDCAP Training Center

email: daliasil1960@gmail.com

Apoorva Sudini, BS

Healthcare Associate
PricewaterhouseCoopers, New York, NY
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

Rodd E. Hedlund, MEd

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

FOUNDER OF THE NIDCAP FEDERATION INTERNATIONAL, INC.

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

The Impact of the Parent-To-Parent Peer Support Program on the Disenfranchised Grief Severity of Mothers with Preterm Infants

Hasanpour M¹, Zarezadeh M², Rahimi S³, Kazemnejad A⁴

DOI 10.14434/do.v17i1.37043

¹Ph.D. and Professor of Nursing, NIDCAP Professional, School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran, ²MSc of NICN, School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran, ³PhD of Educational Psychology, Department of Psychiatric Nursing School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran, ⁴Professor of Biostatistics, School of Medical Sciences, Tarbiat Modares University, Tehran, Iran.

Aims

A preterm infant's birth and admission to the Newborn Intensive Care Unit (NICU) cause parents to experience the loss of their 'ideal' child and reactions of grief, which are known as disenfranchised grief. The incidence of grief reactions in parents makes them susceptible to mental disorders. This reaction to grief and loss is considered an emotional crisis and can persist even after discharge from NICU to home. The purpose of this study was to investigate the effect of a peer support program on the disenfranchised grief severity of mothers with preterm infants.

Methods

This study was a quasi-experimental quantitative study, which was conducted by convenient sampling on 108 (45 control and 45 intervention) Iranian mothers with preterm infants admitted to the NICU. Sampling was done first in the control group and then in the intervention group sequentially. The control group did not receive any training. However, the intervention was carried out in the intervention group. The intervention included accompanying and empathizing with mothers with preterm infants and supporting them in accepting the conditions by peer-supportive parents in a period of two weeks. Peer-supportive parents were selected from experienced volunteer mothers with preterm babies hospitalized in the NICU. The mental health of peer-supportive parents was checked and confirmed using the GHQ28 questionnaire, and then they underwent eight hours of training to implement the intervention. Study data were collected using a researcher-made, valid, and reliable demographic and grief questionnaire. The participants in both groups completed the pre-test and post-test questionnaires immediately before and after the intervention. Data were then analyzed using descriptive and inferential statistics such as paired t-tests, Wilcoxon, and Mann-Whitney tests, using SPSS software version 16.

Results

The results of the Wilcoxon test revealed that in the control group, there was no significant difference in the average scores of grief of mothers of preterm infants before and after the intervention. However, in the intervention group, the

paired t-test showed that the difference between the mean scores of grief before and after the intervention was significant (P<0.001). In addition, the results of the Mann-Whitney test indicated that before the intervention, there was no significant difference in the mean scores of grief between the control and intervention groups. However, after the intervention, the results of the Mann-Whitney test showed that the difference between the mean scores of grief between the control and intervention groups was significant (P=0.001).

Relevance to NIDCAP

The Newborn Individualized Developmental Care and Assessment Program (NIDCAP) is one of the current priorities of the Neonatal Health Office in the Ministry of Health in Iran and many other countries that emphasize the increasing presence of parents in NICUs and support them by staff. Infant and family-centered developmental care is one of the core principles of the NIDCAP Model. Mothers, as an essential component of the NIDCAP Model, need emotional and empathetic support when they are grieving for their ideal child.

Conclusion

The findings of the current research showed that parent-to-parent peer support intervention was an effective program to decrease grief severity in mothers with preterm infants. Therefore, researchers emphasize the importance of receiving support from a parent who shares similar experiences and providing emotional and psychological support by maintaining respect and confidentiality and without prejudice to help mothers with premature babies admitted to the NICU. Furthermore, they recommend the implementation of the parent-to-parent peer support program as a part of infant and family-centered developmental care/NIDCAP care to decrease the preterm infants' mothers disenfranchised grief severity that this may result in increased secure mother-infant attachment.

Keywords: Preterm Infant, Disenfranchised grief, Preterm Infant's Mother, Prematurity grief, Parent-to-Parent Peer Support Program, Neonatal Intensive Care Unit

Is Early Kangaroo Care Safe in Preterm Infants Under 28 Weeks Gestation?

López Maestro M, Collados L, Jimenez L, Serrrano A, Melchor P, Martinez P

DOI 10.14434/do.v17i1.37045

12 de Octubre Hospital Madrid Spain

Introduction

The protective effects of Kangaroo mother care (KC) on the neurodevelopment of preterm infants are well established, but we do not know whether the KC is safe on infants under 28 weeks gestational in the first days of life.

Aims

To describe safety in early KC on preterm infants under 28 postmenstrual weeks.

Methods

This study is part of a primary randomized parallel clinical trial conducted to evaluate the equivalence or non-inferiority of lateral kangaroo care posture versus prone conventional posture. (Cangulat Study. Trial registration at clinicaltrials.gov: NCT03990116) RCT was conducted at the Neonatal Intensive Care Unit (NICU) of the 12 de Octubre University Hospital (Madrid, Spain), from May 2019 to November 2021. A total of 105 infants < 28 GA (Gestational Age) at birth were assessed for eligibility; 35 of them were excluded and 70 were enrolled.

During their first five days of life, all KC sessions were monitored. All infants in KC were covered by polyethylene bags to keep humidity and decrease hypothermia risk while keeping maximal skin-to-skin contact.

Ethics Considerations

The Clinical Research Ethics Committee of the Hospital 12 de Octubre approved the study (no. CEIM 19/206). Informed consent was obtained from the parents of all subjects involved in the study.

Results

During the study, 285 sessions of KC were taken throughout the first five days of life. The main results are shown in Table 1.

Of the 285 sessions studied, 78% took place in a single room (SR) and 22% in an open bay room (OB). An umbilical catheter was present in 60% of the sessions (168/285) and peripherally inserted central catheter in 58% (165/285). In 5.6% (16/285) of the sessions, infants were intubated and 94.4% were assisted on duopap/cpap.

Two of the sessions lasted only 60 minutes due to infant temperatures < 36.5°C and an accidental extubation occurred. In 80% (228/285) transference was performed by a health profes-

Table 1

N=70	Media	DS	Min- Max
GA (wk)	26.2	1.2	24-27.8
Weigt (g)	859 ± 63	196	510-1460
Apgar 5 min < 4	7 (10%)	2.3	2-10
Days of admissión	52.17	24	3-141
Sex (male)	46 (65,7%)		
C- section	39 (55,7%)	8.2	
Hours of life of the 1st KC	38.1		8-99
Duration of KC sessions (min)	130	56	50 - 365
Oxygen saturation	95%	3.4	
Oxygen supplementation %	25.4	8.5	
Heart rate	153	12	
T ^a 60 min after beginning KC	36.7 °C	0.4	
Infants with apnea during the first KC session, % (n)	30% (21/70)		

sional, and in 20% (57/285) by the parents. Ultrasound follow-up detected 8.5% (6/70) of IVH I and 4.3% (3/70) of IVH II.

Activity in the room during the kangaroo sessions was measured using the Profile of the Nursery Environment and of Care Components Template Score Sheet1. When children were in the SR the activity was calmer and quieter (>4-5) than OB (66% vs. 90.3% p< 0.005). As light and noise were softer (6.8 lux vs 3.7 lux p<0.005) and (62 dB vs 58 dB p<0.005).

Relevance to NIDCAP

As professionals working in neonatal units, we should have as much knowledge as possible about KC and be able to make parents as autonomous as possible in the KC.

Conclusion

Our findings suggest that extremely preterm infants keep normothermia during kangaroo care in their first days of life. And there are no risks concerning devices such as umbilical catheters and endotracheal tubes, IVH is not increased, as all IVH cases were grade 1 or 2. If KC takes place in a single room, a calmer environment and a more appropriate noise and light level surround children.

References

Als H, Buehler D, Gilkerson L, Smith K. Profile of the Nursery Environment and of Care Components Template Manual Part 1. NIDCAP Training Manual. NIDCAP Federation International, 2015.

Time for Change: Let Parents Assess Neonatal Pain in the NICU

Kottos E, Druart D, Van Herreweghe I

DOI 10.14434/do.v17i1.37044

NICU, Saint-Pierre University Hospital, Brussels, Belgium

Introduction

Newborns are exposed to many painful procedures in Neonatal Intensive Care Units (NICUs). Neonatal pain has been recognized in the eighties and many scales have been developed to assess and manage pain. Despite this, pain management in NICUs is often suboptimal and remains challenging. Over the last decades, parents have become more and more involved in the care of their babies.

Aims

The primary aim of this study is to compare the EDIN pain scale assessed by parents with the assessment made by caregivers. This is to determine if parents could be reliable resources to optimize pain management in ill newborns. The secondary aim of the study is to evaluate the Swedish ALPS-Neo scale compared to the EDIN pain scale as a potential and more appropriate tool for assessing stress and pain in newborns.

Methods

A prospective study was conducted in the NICU of Saint-Pierre University Hospital in Brussels, Belgium. The study compared the EDIN pain scale assessed by parents to the one assessed by caregivers. From January 1st to May 31st, 2022, informed consent was obtained for fourteen newborns. Parents of these newborns who were enrolled in the study were trained (one hour) in assessing the EDIN scale by an experimented caregiver. Both parents and caregivers assessed the EDIN pain scale. EDIN scores of parents and caregivers were compared. Caregivers also assessed the ALPS-Neo pain scale for each EDIN score.

Results

The results showed that the EDIN scores assessed by parents were significantly higher in absolute value compared to the scores assessed by the caregivers. However, there was an agreement between parents and caregivers in identifying positive pain scores (EDIN≥ 5) in 77.8% of the cases. Parental pain assessments were particularly amplified during painful

procedures. Parent's pain assessment is more constant during the day while caregivers assess pain mostly during the morning. The ALPS-Neo pain scale was found to be more efficient, precise, and supportive of nonpharmacological pain management compared to the EDIN scale. A larger study in the unit is currently underway to confirm these findings.

Relevance to NIDCAP

The study highlights that parents' assessment of the EDIN pain scale is as reliable as those of caregivers. Furthermore, parents consistently evaluate pain throughout the day, indicating that their involvement can contribute to more optimal pain management. This underscores the importance of a family-centred approach in NICUs.

Conclusion

To improve pain management in the NICU, parents should receive training in assessing pain and stress and become active collaborators in the assessment process. ALPS-Neo is suggested as a validated, user-friendly pain scale that could be more suitable for use by parents compared to the EDIN scale. ALPS-Neo promotes nonpharmacological pain management and may offer a more appropriate tool for parents to assess their newborns' pain.

The editorial team of the Developmental Observer is looking for NFI Members who may be interested in becoming a reviewer for the DO. If interested please send an email and a copy of your CV to the Senior Editor at developmentalobserver@nidcap.org

Creating Awareness of the Impact of Neurodevelopmental Care in a Level 4 Multicultural Greenfield NICU: A Quality Improvement Project Implementing FINE

Mazlan M¹, Qureshi N¹, George B², Dela Cruz A², Motala R¹, Tscherning C³

DOI 10.14434/do.v17i1.37046

¹ Allied Health, Sidra Medicine, Qatar, ² Neonatology, Sidra Medicine, Qatar, ³ Neonatology, Oslo University Hospital, Norway

Introduction

Sidra Medicine is the only 4 Neonatal Intensive Care Unit (NICU) in Qatar and was opened in 2018. Eastern and Western practices of neonatal care converge in this NICU. A multidisciplinary team was formed to identify the challenges of the NICU and address areas where incremental changes would have a significant impact on neurodevelopmental care.

Aim

The aim is to improve and promote awareness and implementation of neurodevelopmental care.

Methods

A plan-do-study-act cycle (PDSA) was used (Figure 1) by a core multidisciplinary team known as the Managing Infant Neurodevelopment (MIND). An initial survey was carried out in the NICU to get a baseline understanding of the overall knowledge and awareness of neurodevelopmental care. Based on the results, the team was divided into subgroups to address the individual issues identified. A key intervention was Family and Infant Neurodevelopmental Education (FINE 1) training for all NICU staff with a selected team (n=10) to continue on FINE 2 training. Weekly education sessions on various topics related to neurodevelopmental and family centered care were implemented to the wider multidisciplinary team followed by a follow-up survey aimed at understanding changes in awareness of neurodevelopmental care.

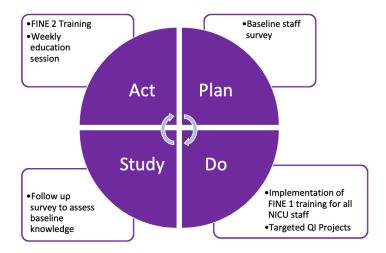
Results

In the initial survey, 89% of staff acknowledged the importance of neurodevelopmental care, but only 4.6% of staff had completed any formal training. All staff were mandated to complete FINE 1 training during a four-month period (n= 250). In the follow-up survey, 93% of staff acknowledged the importance of neurodevelopmental care, 64% could identify that the baby was stressed and needed a break and 73% could identify the baby's strategies to self-regulate.

Discussion/Relevance to NIDCAP

Implementing FINE training in the NICU improved the

Figure 1: PDSA cycle



knowledge around developmental care and observation of the newborn. Response rates were low in the two surveys [68% response rate (n=179) versus a 30% response rate (n=49)]. It may be reflective of the high turnover encountered as a response to the Covid-19 pandemic and subsequent lockdown. During the pandemic, there has also been an influx of quality improvement projects within the NICU. While having the commitment to change is encouraging, it can also be overwhelming and mentally exhausting to continually overcome challenges to facilitate positive change.

Protecting dedicated time for the core group to be able to educate the wider team was challenging and this was addressed by a proposal from the core group to the leadership team emphasizing the importance of implementing neurodevelopmental care. Weekly protected education time was granted and such training for the professional healthcare team and managing resources is also a part of the NIDCAP philosophy.

Implementation of the FINE program which focuses on an understanding of the interconnection of the autonomic, motor, and state subsystems and reading the subtle cues of the baby's communication through their behavior and self-regulation

ABSTRACT - NIDCAP TRAINERS MEETING 2023

before, during, and after caregiving procedures will enable caregivers to maximize comfort during caregiving, alleviate pain and support infant's organization, which are components of NIDCAP's philosophy for infant care.

Conclusion

This quality improvement project has succeeded in creating

awareness of the importance of neurodevelopmental care and its lasting impact, opening the door for targeted education sessions and further bedside learning. Each member of the multidisciplinary NICU team has a responsibility to ensure they follow standards of practice and understand its implications.

OUR SPONSORS



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

Sponsor of the NFI and the 34th Annual NIDCAP Trainers Meeting.



Dandle+LION Medical, the leader in neurodevelopmental care, makes it easy to provide consistent, effective, evidence-based care for hospitalized babies. Our patented positioning aids provide a womb-like experience while our education programs meet ongoing clinical needs. Becoming part of our Dandy Pride of Lions means providing the best care for your patients, support for your clinicians, and value for your organization.

Sponsor of the 34th Annual NIDCAP Trainers Meeting

Developmental Observer

The official publication of the NIDCAP Federation International published on-line three times a year. © 2024. The statements and opinions contained in this publication are solely those of the individual authors and contributors and not necessarily of the NIDCAP Federation International. Articles from the *Developmental Observer*, duly acknowledged, may be reprinted with permission. Please contact us at: developmentalobserver@nidcap.org.

Contributions

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

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



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

ISSN: 2689-2650 (online)

All published items have a unique document identifier (DOI)

Growth and Other Clinical Outcomes in Very Preterm Infants Before and After NICU Single-Family Room Implementation

Morillo A¹, Izquierdo M¹, Norato Castro P², Agut T¹, Cervantes R¹, Riverola de Veciana A¹

DOI 10.14434/do.v17i1.37078

¹Hospital Sant Joan de Deu, Barcelona, Spain, ²Universidad Nacional de Colombia, Bogata, Columbia

Aims

- 1. To describe the growth trajectory of very preterm infants during their hospitalization in the Neonatal Intensive Care Unit (NICU), before and after an infrastructure change to family-single rooms (FSR).
- 2. To describe the differences in the environment, collected through systematic assessments of NIDCAP observations before and after this change.

Methods

A descriptive and retrospective study was undertaken by reviewing medical records and NIDCAP environmental profile forms, of newborns admitted to the NICU of the Hospital de Sant Joan de Déu in Barcelona.

Two periods were analysed: The first period (P0: January 2019-April 2021) and the second period (P1: May 2021-December 2022). Patients in P0 were cared for in the old Unit with large rooms of 8-10 cribs and patients in P1 were in the newly built unit with FSR.

All admitted preterm \leq 32 weeks of gestational age in the first 48h of life without congenital malformations or genetic alterations were included.

Variables included epidemiological [gestational age, sex, small for gestational age (SGA)], anthropometric (weight, length, and head circumference at birth/discharge and Z-Score change in weight from birth to discharge), clinical outcomes (days of admission, ventilation and venous catheter days and incidence of bronchopulmonary dysplasia, retinopathy, and neurological complications). The environmental profile was assessed using the Profile of the Nursery Environment and of Care Components Template scale1.

Results

The number of recruited was 202; 120 in the P0 group and 82 in the P1 group. Patients who had NIDCAP observations were 28 in the P0 group and 21 in the P1 group.

Regarding the clinical variables, only length of admission, days of oxygen, and mechanical ventilation were statistically different (longer in group 1).

Table 1 shows the baseline characteristics of the two populations and the change in weight Z-score

	PERIOD 0 (N=120)	PERIOD 1 (N=82)	Р
GA (weeks)	29.4 ± 2.2	28.6 ± 2.2	0.017
SGA	10/120 (8.3%)	19/82 (23.2%)	0.004
Crib score	1.8 ± 2.8	2.7 ± 3.2	0.056
Birth weight (g)	1300 ± 405	1076 ± 409	<0.0001
Zs birth weight	0.38 ± 1.1	-0.27 ± 1.4	<0.0001
Differences in weight Z score discharge-birth	-1.60 ± 0.98	-1.11 ± 1.02	0.001

Table 2: The environmental profile, statistically significant differences were found in the variables shown in the table

	PERIOD 0 (N=28)	PERIOD 1 (N=21)	Р
Physical layout	4.29 ± 0.763	4.86 ± 0.359	0.001
Density. cradle space	4.32 ± 0.772	4.86 ± 0.359	0.002
Design. crib spacing	4.14 ± 1.008	4.86 ± 0.359	0.001
Family participt.	4.67 ± 0.620	4.86 ± 0.359	0.189
Easy access to professional support services	4.57 ± 0.742	5.00 ± 0.000	0.005
Light level	4.00 ± 0.943	4.57 ± 0.507	0.009
Sound level	3.82 ± 0.983	4.14 ± 0.573	0.158
Activity level	3.39 ± 0.940	4.48 ± 0.512	0.020
Specific aids for self-regulation	4.39 ± 1.066	5.00 ± 0.000	0.006
Care between two caregivers	6/28 (21%)	4/21 (19%)	0.150

Table 2 note: Aspects of environment and care are measured on 5-point rating scale. A score of 1 reflects lack of consideration or misunderstanding of developmentally supportive opportunities; a score of 5 reflects a high degree of developmental support and/or sensitivity

After adjusting for confounding variables such as gestational age at birth, being SGA, and severity of illness, being born in Period 1 remained associated with a lower change in weight Z-Score from birth to discharge (B-coefficient 0.283 IC 95% 0.318-0.866; p <0.0001)

Relevance to NIDCAP

Moving to single rooms resulted in better environmental profile scores. Also, the weight gain of the babies was higher in the new NICU. We hypothesize that this could be because the environment was better than previously, and favored families' privacy.

Conclusion

Preterm infants were found to have better growth during admission after the architectural change, despite a higher prevalence of SGA infants and a lower gestational age in this period. Due to the retrospective design of the study, we cannot rule out that other factors could have influenced our results.

References

Als H, Buehler D, Gilkerson L, Smith K. Profile of the Nursery Environment and of Care Components Template Manual Part 1. NIDCAP Training Manual. NIDCAP Federation International, 2015.

The Skincubator: A Novel Device for Early Prolonged Skin-to-Skin Care for Very and Extreme Preterm Neonates

Nitzan I, Bin Nun A, Hammerman C, Kagan T, Metrikin-Gold A

Shaare Zedek Medical Center, Jerusalem, Israel

Background

Skin-to-Skin Care (SSC) reduces morbidity and mortality in preterm newborns (PN) and is an important part of developmental care. However, extremely preterm infants are generally ineligible for early, prolonged SSC because of the need for increased humidity, and visibility, which is currently available only in incubators. To address these issues and enable continuous SSC in this population we invented the Skincubator – a novel, wearable, bottomless incubator (Figure 1). The Skincubator creates an enclosed environment with all the advantages of a neonatal incubator (humidity, temperature regulation, and good visibility) on the parent's torso. Enabling early prolonged SSC for very preterm newborns.

Aims

To evaluate the feasibility, safety, and thermal management of SSC in the Skincubator versus traditional SSC.

Methods

A safety trial comparing thermal stability during traditional-SSC (t-SSC) sessions, and Skincubator sessions was conducted. Population: Step 1: five PN, GA 29-34 weeks from Day of Life (DOL) four with no respiratory support. Step 2: five PN, 26-33 weeks from DOL 4. Step 3: fifteen PN, GA 26-33 weeks from birth or 24-28 from DOL 4. Temperature stability, humidity levels, and parental feedback were assessed during both types of SSC sessions.

Results

Eighteen preterm newborns were enrolled in steps 1-3. In steps 2-3 we compared 35 paired sessions of Skincubator and t-SCC performed on 12 babies. (One baby– treated in the Skincu-

Figure 1 Figure 2





DOI 10.14434/do.v17i1.37076

Figure 1. A 660-gram preterm baby in the Skincubator, in skin-to-skin contact with his father, with 85% environmental humidity.

Figure 2. The updated model of the Skincubator that we are developing following learning and feedback from the parents and staff who participated in the trial. It includes: an opening for parents to see, smell, and talk with the infant; easy access for staff from multiple points; and allows most nursing and clinical procedures while in SSC. It has disposable covering to reduce contamination risk, dedicated anchors for all lines and tubes, and safe anchoring of the baby on the caregiver's chest.

bator in delivery room, was excluded from session analysis because parents did not participate in the study in the NICU). Demographics of included PN were (average (range): GA 29 (26-32); weight 1288 gram (660-1590) DOL 5.2 (1-11).

No safety issues occurred during Skincubator care. Skincubator humidity was >70%, 95% of the time. Parents appreciated the Skincubator as safe and comfortable. The average time out

ABSTRACT - NIDCAP TRAINERS MEETING 2023

of the axillary temperature target $(36.5^{\circ} - 37.5^{\circ})$ was 7.4 ± 13.5 and 19.7 ± 27.8 min during Skincubator and T-SSC respectively (p=0.002). Initial temperature drop during Skincubator care was smaller than in t-SSC $(0.2^{\circ}\pm0.1 \text{ vs } 0.5^{\circ}\pm0.3 \text{ P}<0.001 \text{ n}=35)$.

Six babies had PICC lines or umbilical venous catheters, and one received phototherapy during Skincubator care. No line dislodgment occurred. No baby had moderate hypothermia during Skincubator care. Five babies experienced moderate hypothermia of 35.5-35.9 during 6 t-SSC sessions.

Relevance to NIDCAP

The Skincubator may promote early SSC for very and extreme

preterm newborns, aligning with the principles of NIDCAP by providing individualized, developmentally supportive care in the NICU.

Conclusions

The Skincubator can effectively create a humidified and warm environment on the human body for PN. The Skincubator seems to be safe and may be superior to t-SSC in maintaining PN temperature, this may be clinically significant for extreme PN. Further research is needed to validate these promising results and assess the long-term benefits of the Skincubator in improving outcomes for premature neonates.

Historical Roots of Developmental Care in Newborn Infants: A Bibliometric Analysis Using Reference Publication Year Spectroscopy

Smith M¹, Marx W², Anand KS³, Haunschild R², Sizun J⁴, Roué JM¹

DOI 10.14434/do.v17i1.37077

¹University Hospital, Brest, France, ²Max Planck Institute for Solid State Research, Stuttgart, Germany, ³Department of Pediatrics, Stanford University School of Medicine, USA, ⁴University Hospital, Toulouse, France

Currently, some kind of developmental care is to be found in most Neonatal Intensive care Units (NICU), and the presence and participation of the parents are considered fundamental by neonatologists worldwide. The history of developmental care has rarely been studied. Bibliometrics as a quantitative method is not only useful for research assessment purposes, but also for analyzing the history of science. Reference Publication Year Spectroscopy (RPYS) was proposed to objectively analyze the roots of a research field. PPYS has been used for example for neonatal pain. PYS has been used for example for neonatal pain.

Aim

We investigated the historical origins of developmental care in newborn infants using RPYS to reveal the most important publications for the evolution of this research field and to evaluate their relative importance within the field.

Methods

A Web of Science search query combining infant- and intervention-related synonyms was performed on February 2, 2022. The search retrieved 5,633 papers containing 7,248 distinct cited references. RPYS analysis was performed on this dataset to identify the most referenced historical publications for developmental care in newborn infants. Median deviation analysis identified peak publication years including the most cited historical references. Landmark papers were defined as those belonging to the top 10% of the most frequently referenced publications for longer than 20 years.

Results

The RPYS peaks showed an early phase (1936-1986), during which infant development was studied and analyzed, leading to a conceptualization of developmental care for newborn infants. The following years (1986-2015) showed an explosion of interest in developmental care, highlighting two main programs: the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) and the Infant Health and Development Program (IHDP) with many publications during those years striving to demonstrate the evidence of their clinical benefits.

Relevance to NIDCAP

A major turning point was the conceptualization of the Synactive Theory of Development by H. Als in 1982. NIDCAP (and the IHDP) provided the basis of the broad concept of infant and family-centered developmental care, implemented at various levels in most NICUs since the turn of the century.

Conclusion

Developmental care has become increasingly important through the implementation of two programs: NIDCAP and IHDP.

Published 2024, Acta Paediatricia https://doi.org/10.1111/apa.16996 References

- Marx W, Bornmann L, Barth A, Leydesdorff L (2014). Detecting the historical roots of research fields by reference publication year spectroscopy (RPYS). J Assoc Inf Sci Technol 65(4):751-764. doi:10.1002/asi.23089
- Anand KJS, Roué JM, Rovnaghi CR, Marx W, Bornmann L (2020). Historical roots of pain management in infants: A bibliometric analysis using reference publication year spectroscopy. Paediatr Neonatal Pain 2(2): 22-32. doi: 10.1002/pne2.12035.



34th Annual NIDCAP Trainers Meeting Summary and Reflection

gretchen Lawhon, PhD, RN, FAAN, Master NIDCAP Trainer

Presented to the delegates on the final day of the meeting

DOI 10.14434/do.v17i1.37080

Good afternoon,

Our NIDCAP work is all about seeing the lived experience of others, specifically the infant within the context of their family. As a NIDCAP Professional, I have both the privilege and the responsibility to function as the voice of the individual infant and to facilitate others to understand their vulnerability, strength, and effort to navigate this strange new world outside of their mother's womb.

It is through nurturing relationships that we strive to support each infant, family, healthcare professional, and one another within the global community of the NIDCAP Federation. For 34 years we have taken the time and energy to rededicate ourselves to this mission of improving the future for all infants in hospitals and their families with individualized, developmental, family centered research-based NIDCAP care.

Families are essential for the infant's wellbeing. This is true from a biological perspective, through the family's experience and in an effort to change our systems to provide a most supportive context to support families nurturing their infants. Rarely an infant does not have an identified family. That is true for us as grown-up infants, as adult family members, as Professionals who dedicate our careers to supporting infants and families – one infant at a time, one family at a time, one hospital at a time across the globe.

Families are complicated and made up of complex individuals. Therefore, being a member of a family as well as supporting one another through our growing relationships is far more easily said than accomplished. Many of you are aware of my somewhat unique family experience. My chosen family consists of myself and my husband of 47 years, in a multi-generational home with our son, his wife and their three amazing



gretchen with 11 of her 12 siblings

children. We honor the boundaries of our various relationship roles as parent, child and grandparent. We support one another through strong and close relationships nurturing one another through meals and childcare with mutual collaboration as we celebrate milestones of both young and old.

Then there is my experience of my family of origin – being one of thirteen adult children navigating our lives as individuals and family members beyond those of our deceased Mother and Father. We honor our parents' wishes and dreams by sharing an amazing lake property and coming together for a full week every summer—

And just as we the NIDCAP family are finding our way beyond our deceased fearless courageous leader Heidelise Als, we are struggling during the transition – trying to honor and be true to Heidi's mission and vision as our relationships understandably reconfigure. And just to complicate things a bit—both these losses in my family of origin as well as my NIDCAP family occurred within the context of the global pandemic.



In person participants at the 34th NIDCAP Trainers Meeting

Nonetheless, here we are for our 34th year of meeting. This is what I think of as the annual reunion of my professional family. We have been trying to reconnect and to nurture ourselves and one another – building and strengthening our relationships – both new and old. We have learned a style of didactic presentations interspersed with small group discussions where we share ideas and experiences in a more personal manner. We are nurtured by our local hosts with food, drink, and social gatherings to further facilitate shared experiences and building relationships.

Deborah Buehler (NFI President) provided the inaugural Heidelise Als Lecture reminding us that the origin of Heidi's work included the concept of integrating the technological advances for our most vulnerable infants with the affective humanness of infants and their neurobiologically expected environments of the womb, parents' body and family social group.

Throughout the first day not only did we have the joy of seeing PowerPoint introductions of each individual attending in person but also those joining us virtually. For myself, and no doubt many others, this time dedicated to acknowledging each person provides us with feelings of pleasure, pride, and joy.

In addition, Stina Klemming (Sweden) and Kaye Spence (Australia) provided us with not only a summary of our work over this past year, but also coordinated and put together an amazing array of every NIDCAP Center's individual accomplishments in the words, through video, of a representative of each center. For me, this was clear evidence supporting Heidi's statement that Deborah mentioned "that we are all connected, we mutually support, teach, learn from, and enrich one another". This speaks to me of relationships, both familial and professional. The other meaning, I took from our accomplishments was a strong sense that we have come out of the dark tunnel of the pandemic. As an organization, as a professional

family – not only have we survived the pandemic, but we are thriving with renewed interest, enthusiasm, and growth of the NIDCAP Federation.

Of course, with growth, there is some disorganization, sibling rivalry, and necessary, although sometimes painful, reorganization. Our membership meeting and small group sessions on nurturing NIDCAP and the next steps for the NIDCAP Federation provided a safe space for individuals to express some frustrations, sometimes courageous honest, yet difficult feedback which I believe will lead to much more valuable discussion with upcoming creative strategies and increased communication.

As all families, we as the NIDCAP family have some traditions when we come together. We enjoy sessions such as our NIDCAP Nursery small group exercise where we can look at a videotaped infant-caregiver interaction and discuss, evaluate, and assess, bringing our different disciplinary perspectives. Another regular session we had was to think about and share various ways our NIDCAP work is translated to foundational education. We heard from Diane Ballweg about her experiences in various hospitals in the USA as well as Nadine Griffiths' Australian experience and Graciela Basso's program for neonatologists in South America.

Woven throughout our three days were quite a variety of abstract presentations, a dozen of them which whet our appetite, generated further discussion and potential collaborations. This reminded me of being a child at the dinner table in my family of origin when it was expected that each of us would talk about our school day. Some abstracts were a bit provocative, some quite novel, and overall, both reinforce our NID-CAP work and suggest further avenues for exploration.

On Day 2, we were able to get into our small groups to discuss and share moments of joy experienced with infants, their families and healthcare team. This topic had been delayed from

last year due to our somber meeting with our first gathering since Heidi's death. It was wonderful to share the moments of joy found within our emotionally exhausting work.

On Day 3, our NIDCAP family welcomed friends and guests, both in person and virtually, to join us as we concentrated on the essential importance of families to the wellbeing of the infant. In my work as a clinical nurse scientist, I often share with families that the most influential variable in long term outcome of infants is a nurturing adult infant relationship.

With much appreciation Jacques Sizun (France) provided the tone for the day when he reflected on the legacy of Heidelise Als reminding us of how brilliant she was and so much ahead of time in her insights. We then had the opportunity to have Jeff Alberts enlighten us on the science of skin development and research on the development of touch, realizing that the most crucial containing touch has yet to be explored.

Joy Browne (USA) gave us a great deal of information on the importance of sensitive periods in both infants and parents beyond the newborn period through the first months of early development. Mandy Daly (Ireland) was incredibly generous in facilitating our understanding of the lifelong implications of prematurity from the family perspective.

The afternoon was such a treat to have the enthusiasm of Liz Rogers (USA) on creating the culture of care in her setting with numerous wonderful ideas for each of us to take to our clinical homes. Kiera Sorrells was an inspiration to one and all as she shared her own experience with her premature daughters and how she took that difficult experience and translated it into the creation of an organization to support other parents in the USA. Nick Conneman (Netherlands) shared his vision for achieving developmental care through the NIDCAP model

emphasizing the importance of trust in the process.

Debra Paul (USA) took her difficult situation of becoming a lone NIDCAP Professional in a busy clinical setting and managed to strategize ways to continue to move forward on her own. She inspired me and I much appreciated her practical approach. Saadieh Masri (Lebanon) finished our presentations with a very practical approach to how NIDCAP crossed frontiers – as she said, walk the talk.

So, as we leave the 34th Annual NIDCAP Trainers meeting in Chicago, what I call our professional family meeting, whether you have attended in person or virtually, for all three days or the open day, let us reflect on each of our own experiences. Despite my initial fear and trepidation in returning to this prestigious group, the same feeling I have when heading to my family reunion each summer, I have no regrets. I am so pleased to have met new people, reconnected with friends and colleagues from as long ago as 1980, and gained a much more positive sense of the accomplishments of this organization. I felt much joy in spending time with you all and building relationships. We strive to mentor caregivers and change hospitals and when we do this work as well as possible it may be emotionally exhausting. Let us go forth and continue to live the NIDCAP values of appreciating another's lived experience and to improving the future for all infants in hospitals and their families with individualized, developmental, family centered research-based NIDCAP care. Through our mutual support of one another, we can navigate our organizational transition successfully and continue to meet our mission. I hope to see each of you next year for our 35th Annual NIDCAP Trainers Meeting in Toulouse, France or what I call my professional family reunion.



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

Behind the Scenes: Rob Catalano

BEHIND THE SCENES



The Developmental Observer relies on many individuals for each issue that goes into production. To launch this feature I would like to introduce Rob Catalano, the Graphic Designer for the Developmental Observer. I put some questions to Rob to learn more about the man and his experiences as part of our team.

Rob Catalano (RC). I am a graphic designer and I live with my wife and two sons in Lexington Massachusetts. I graduated many years ago from the University of Massachusetts, Amherst with a fine arts degree in sculpture and a minor in graphic design. I've had some adventurous jobs over the years (building bicycles, lobster fishing...) but it's been graphic design that has stayed with me, keeping me grounded.

In the past, I have worked for newspapers, magazines and design agencies but have been on my own now, for over 25 years. I do a lot of print design work; newsletters, annual reports and branding, mainly working with Adobe InDesign, Photoshop and Illustrator. Over the past 5 plus years I have been doing more web design.

KS. What would you say is most important to you?

RC. What's most important to me is certainly my family and friends. My wife and I will be celebrating our 30th wedding anniversary this coming year, and our two sons are now both in college. All together we have a large extended family and many friends. I'm grateful for the life I have, and the people in it.

KS. What do you like most about being a creative designer?

RC. I can't picture my life NOT doing creative things. Being a graphic designer satisfies my need to be creative while also providing a source of income, which is important. As they say "do what you love, love what you do".

What I enjoy most about work is the collaboration with clients; working on an idea or project that they aren't quite able to express themselves. Collaborating with them and bringing it to fruition, together, gives me great satisfaction. It's also very gratifying seeing your work out there in the world.

KS. How did you first become involved with the *Developmental Observer*?

RC. It was back in the Spring of 2007 and NIDCAP was looking for someone to come up with a new, professional look for their newsletter. I believe Sandra Kosta had initially reached out to some friends of mine, but they were too busy to take on new work and referred her to me. I had already been doing work for Boston Children's and Mass General Hospitals at the time. I showed her some ideas for a design and we proceeded to lay out Vol. 1 No.1. We've been working together since!

KS. We are now up to Volume 17. What do you see as the changes that have occurred over the years?

RC. Most of the changes I have seen over the years are to NIDCAP itself, as an organization. When I started work on the newsletter, I think there were 15 training centers in 5 countries. Now there are about 30 training centers in 18 countries. NIDCAP training and practices seem to have grown from a niche approach to becoming much more mainstream, practiced at hospitals worldwide. All this has been reflected in the writing and contents of the newsletter. It all keeps growing.

KS. Do you have a favorite article/feature in the DO?

RC. It's hard not to feel emotional when you read the Family Voices pieces. They are written by families who have experienced intense, life changing experiences related to childbirth, with some of those experiences having happy endings, and some not. But they all praise the care and guidance they received from their NIDCAP teams. Those testimonials are strong endorsements of the great work being done.

KS. How do you see the DO advancing in our technological world?

RC. I've already witnessed the technological progression of much of the work I do. Sandra Kosta and I used to go on "press runs" to sign off on the two-color printing of the first editions as they came off the printing press, ink still wet. Now the newsletter is distributed digitally and accompanies the website and social media pages. Also, every article now has a Digital Object Identifier (DOI) so it can be easily found on the web.

(continued on p. 25)

Column Editor: Debra Paul OTR

Katie Reginato Cascamo is a champion. A classic overachiever that holds herself to the highest standards. Good and noble. Right up until it's not. Katie shares her story about not being heard professionally, the frustrations that go along with that, and what ultimately led to stress and trauma during her pregnancy. Thanks to compassionate NIDCAP trained nurses in the NICU following the arrival of her son, Katie's voice was heard and respected. Katie learned how to read the voice of her newborn son and how to support him. In her story, Katie shares with us how her NICU journey had a transformative impact on her career path and contributed to her taking on a role as a parent leader in the NICU. Katie is a shining example of the positive influence of NIDCAP.

From Corporate Climber to NICU Advocate: How NIDCAP Transformed My Life as a Parent in the NICU

Katie Reginato Cascamo

DOI: 10.14434/DO.V17I1.37082

efining moments can alter our life course in unimaginable ways. That moment came into my life on December 12, 2009, when my son Giovanni was born prematurely at 30 weeks and three days gestation, weighing two pounds and eight ounces (1270 grams). Little did I know that this experience would lead to a profound transformation, both personally and professionally, and that NIDCAP trained nurses would become my greatest teachers.

Before Giovanni's birth, my life was consumed by a relentless pursuit of corporate success. I was entangled in the world of corporate insurance, where external values for performance awards overshadowed my well-being. The pressures of meeting unrealistic performance standards set by management eroded my self-esteem, pushing me to internalize the stress. My physical health began to deteriorate, and I became a hollow representation of myself.

The word burnout was a word that had yet to exist in my vocabulary in 2009. The World Health Organization defines burnout as a syndrome arising from chronic workplace stress that remains unmanaged. Burnout manifests through three dimensions: 1) feelings of energy depletion or exhaustion, 2) increased mental distance from one's job, encompassing negativism or cynicism towards the job, and 3) reduced professional efficacy.1 Burnout transcends a mere reluctance to go to work; it is a persistent state leading to fatigue, disengagement, self-doubt, and a sense of being trapped and defeated. As a small business owner, my financial investment and liabilities, left me feeling trapped without exit. Threats by my District Manager to "ruin" me led to toxic burnout, an idea that the environment or circumstances contributing to burnout are physically and psychologically harmful or detrimental to one's human nature. Toxic burnout may occur because of a toxic work culture, unrealistic expectations, poor leadership, lack of work-life balance, or other factors that negatively impact a person's well-being.

Toxic burnout while pregnant substantially impacted the growth and health of my unborn son. My obstetrician neglect-



Giovanni and Katie in the NICU

ed to consider my concerns and downplayed the significance of my personal experiences, particularly regarding the potential adverse outcomes of toxic stress and burnout.² Throughout my seven-month pregnancy, numerous crises hindered any opportunity for excitement or joy associated with the experience. These crises ranged from a flood in our home and a fractured



hand to workplace bullying, resulting in a 55% reduction in income and the abrupt end of my career. I faced challenges such as jury duty, H1N1 Swine Flu, hand reconstructive surgery, and a clinical failure to address early signs of pre-eclampsia.

On December 8, 2009, a blizzard blocked the emergency airlift helicopter's attempt to transport my unborn son and me to a regional hospital with a Neonatal Intensive Care Unit (NICU). The fear of being stranded triggered a freeze response, causing me to dissociate and complicating my ability to advocate for my health. My proactive decision to purchase airlift insurance months earlier proved lifesaving. I was transferred by ambulance to a fixed-wing plane, over a 5500-foot mountain, and then by ambulance to a regional health system known for its excellent neonatal healthcare. Upon arrival, a team of nurses and physicians seamlessly coordinated my care, demonstrating a level of collaboration and skilled expertise that starkly contrasted with my own professional experiences. This pivotal moment not only instilled feelings of trust, but also planted the seed that would go on to shape my future role as a NICU Parent Leader.

I underwent four days of bed rest, hopeful that reducing stress would support the extension of my pregnancy. During this time, we consulted with a neonatologist who detailed the various stages of the neonatal journey at 30 weeks, 32 weeks, and 34 weeks. This meeting proved instrumental in helping me visualize the possibility of an extended stay in the NICU, enhancing my reserves of courage and strength as I prepared for my son's premature birth.

The experience of trauma during pregnancy revolved around the absence of listening. Distinguishing between hearing and listening is important. Hearing involves the physiological processes of receiving auditory sensations through the ears and transmitting them to the brain. Listening is a more

psychologically complex activity that involves interpreting and understanding the significance of the auditory information.³ Our clinical records document healthcare providers acknowledging the information transmitted in writing. The lack of action following this acknowledgment indicates a failure to truly listen and respond appropriately.

My husband John, and my parents, Jim and Caroline Carter supported me as primary caregiver for our 56 days in the NICU. Our two months in the NICU led me to appreciate *active listening* that equipped me with wholehearted healing. Our NICU nurses did not just care for Giovanni; they became our mentors, guiding us step by step in caring for our fragile infant. Our NICU nurses understood the voice of fear that came with this responsibility and provided individualized care that empowered me to overcome my uncertainty and gain the skills needed to care for Giovanni independently.

As my confidence grew, so did my ability to listen and empathize with others. Our nurses listened to my story of professional burnout and toxic culture and helped me navigate my identity crisis that was rooted in my professional endeavors.

The practice of listening, modeled after my NIDCAP trained nurses, became one of my pillars of leadership. Our nurses not only taught me how to care for Giovanni, but also how to recognize signs of stress in both him and me. I began to understand the value of wholehearted connection and used these skills to calm my son and myself.

According to Otto Scharmer, Ph.D., there are four types, or levels, of listening:

- 1. Downloading: Listening is limited to reaffirming what we already know, and new information struggles to break through our established understanding.
- Factual listening: We let the data speak to us and pay attention to information that contradicts our existing views.
 This requires opening our minds and setting aside habitual judgments.
- 3. Empathic listening: We try to understand the situation from another person's perspective. This involves opening our hearts and using our feelings to tune into and appreciate someone else's point of view.
- 4. Generative listening: We actively listen for the emergence of the best possible future outcome, creating a space for new and innovative ideas to take shape. (Scharmer, 2018, p. 48)

As I recovered from my traumatic birth experience, my nurse's unwavering commitment to listening played a crucial role in my ability to practice the skills I acquired to care for my son. Our NICU journey gained attention in local media, prompting me to volunteer for our NICU and actively fundraise for its expansion (Aho, 2010).⁵ The NICU transformed my heart into a space of healing and renewal, prompting a shift in my values. I no longer prioritized corporate success at any cost.



Giovanni (aged 13 years) and Katie in January 2023

After completing our NICU journey, my focus shifted toward understanding the impact of leadership on shaping organizational culture. My personal experience as both a patient and a parent of a premature baby deepened my connection with NICU practitioners and heightened my interest in the dynamics of these relationships. Long before the crisis of burnout in healthcare providers was as prevalent as it is today, my redefined purpose in life was to deeply care for NICU practitioners. The idea that a NICU parent could provide credible, professional leadership as an equal to physicians, nurses, occupational therapists, and technicians had yet to exist.

Intuition became my second pillar of leadership. In 2012, I began graduate school with the vision of a NICU Parent Leader reshaping health systems. Though an unsubstantiated notion, my commitment to NICU practitioners, coupled with intuition learned from my NICU nurses, evolved over two years during my career transition. Early exploration of the NICU Parent Leader role led to identifying crucial workforce skills, reinforcing the idea that NICU parents could apply pre-NICU experiences to serve maternal-infant health. I had

a notion to empower NICU parents with transferable skills, fostering economic self-sufficiency beyond the NICU.

At 14 years old, Giovanni is 5'6" and 125 lbs (170 cm and 56.7 kg). He loves caring for others, a reflection of his own evolving recognition of his lived experience. Giovanni has an extraordinary sense of humor and aspires to become a YouTube star and professional video gamer. He attends an arts academy charter school that cultivates creative thinkers in visual and performing arts with a focus on career and technical education.

As a Ph.D. Candidate in Leadership Studies at Gonzaga University my dissertation explores the credibility of the NICU Parent Leader. As the Founder and Principal Consultant of Courageous Steps, I aspire to exemplify profound listening skills cultivated during my NICU journey, offering valuable insights into this shared pain.

At the heart of our collective journey through the NICU is the commitment of our NICU provider's practice of listening. NIDCAP trained staff impact babies and families. It was our NICU nurses' training in NIDCAP that led to my healing and courageous journey. The NIDCAP approach to observing and listening to babies and the parent's skills and developmental training extends beyond the NICU. For those of us who accept the invitation to serve as a Patient Leader and improve the way neonatal care is delivered, we have an incredible opportunity to pay NIDCAP forward for generations.

References

- Burn-out an "occupational phenomenon": International classification of diseases. (n.d.). Retrieved December 7, 2023, from https://www.who.int/news/item/28-05-2019-burn-out-an-occupational-phenomenon-international-classification-of-diseases
- Coussons-Read ME. (2013). Effects of prenatal stress on pregnancy and human development: Mechanisms and pathways. Obstetric Medicine, 6(2), 52–57. https://doi. org/10.1177/1753495X12473751
- Bolton R. (1987). People skills: How to assert yourself, listen to others and resolve conflicts. Simon & Schuster
- Scharmer CO. (2018). The essentials of Theory U: Core principles and applications (First edition). BK, Berrett-Koehler Publishers, Inc., a BK Business book.
- Aho J. (2010, January 8). Early arrivals. Herald and News. https://www.heraldandnews.com/top_story/early-arrivals/article_2fab2447-36c6-57a5-ac58-e4e8cd341dae.html

(Behind the Scenes, continued from p. 22)

It's easier and faster to reach a greater audience now, and that's a good thing, but sometimes I miss the tactile experience of seeing and hearing the printing presses running, and holding the finished product.

KS. What have you learned about NIDCAP during your years with the DO?

RC. Everyone I have worked with at NIDCAP over the years has been wonderful, and they are a very caring group.

As we rely more and more on technology, we lose some personal connectiveness and touch. What I have learned about NIDCAP is the practice of medicine, though rooted in science and technology (i.e. all the technology in a neonatal intensive

care unit), can be practiced un-scientifically. After laying out many newsletters filled with many abstracts and research articles, I have no doubt the NIDCAP teachings are heavily rooted in science, but what I enjoy seeing is the touching/caring/bonding, the un-scientific things that unite these parents and their children. And they all seem very grateful to have had the experience.

KS. Thank you, Rob, for sharing these insights. I have learned a lot about you and look forward to working with you as the *Developmental Observer* continues to grow and to hear more about your creative ideas.

Global Perspective on Developmental Care

China

Xiaojing Hu, PhD, Vice Director, NIDCAP Professional Children's Hospital of Fudan University in Shanghai



DOI 10.14434/do.v17i1.37081

am from the Children's Hospital of Fudan University where I am the deputy director of the nursing department of the hospital. I obtained a PhD and now am a doctoral supervisor. I am also the chairman of the Society of Neonatal Nursing of China Medicine Education Association and have been engaged in neonatal nursing for more than 20 years.

Children's Hospital of Fudan University is a "stand alone" children's hospital. In 2017, it was approved as a national children's medical center. For over a decade, it has consistently held the top position in the list of best hospital specialties from Fudan University and the best clinical disciplines from Beijing University. The hospital serves as a diagnosis and treatment facility for difficult and critical pediatric diseases in China and as a training ground for top-level medical professionals. Additionally, it possesses the ability for clinical research transformation in pediatrics. The hospital places great emphasis on the development of talents and technology, and highly values international exchanges. It maintains close ties with more than 40 international children's hospitals. The neonatal department of the Children's Hospital of Fudan University was established in 1953. It has 200 beds, with a daily occupancy rate of over 160 inpatients. This department is among the first group of national clinical key specialties, serving as the specialized department for neonatal health care under the National Health and Health Commission, an administrative Government organization. It also serves as the national training base for neonatal specialists and is recognized as a key discipline of medicine in Shanghai. Additionally, the department serves as the referral center for critically ill newborns in Shanghai. The key laboratories of neonatal diseases of the National Health and Health Commission, the China Newborn Collaborative Network (CHNN), and the Shanghai Clinical Quality Control Center for Neonatal Departments are based at the hospital. It is among the top neonatal medical centers, talent training centers, academic exchange centers, and scientific research bases in China.

In 2022, approximately 10 million babies were born in China, with a prematurity rate that amounts to almost 7-8% of all newborns. All the babies are born in hospitals and doctors and midwives deliver them. The mothers spend two to five days in the hospital and receive training on how to breastfeed their babies, yet the rate of exclusive breastfeeding for six months remains low. Newborn care is categorized as level 1-4 according to the international classification of Levels of Care. The average length



Xiaojing Hu and Heidelise Als

of stay in the NICU varies depending on the institution. For us, in our NICU, due to the presence of numerous very premature infants, the hospital stay is somewhat lengthy. We are extending an invitation to parents to stay with their babies in the unit. An increasing number of institutions in China are participating in the transformation of the care model. The parents are capable of providing hands-on care for their baby. All the nurses possess a graduate qualification from a university or college. There is, however, no specific discipline for neonatal nursing in the university; neonatal nursing belongs to pediatric nursing.

My NIDCAP journey

In 2003, I started to learn NIDCAP through literature and became adept at understanding the impact of the environment on newborns, especially premature infants, as outlined in NIDCAP. We began to cover the incubators and protect the newborns in the NICU from light and sound to offer the most favorable environment for their growth and development. However, I didn't truly comprehend NIDCAP at that time. In 2007, I became the head nurse of the NICU, and realized that I had the responsibility and obligation to lead the nursing team in the NICU to provide the best possible care for the infants, to maximize their growth and development, to offer appropriate stimulation care, and to actively learn new care strategies. Under the recommendation of Professor Cao Yun in the



department, I was fortunate to study NIDCAP with Professor Heidelise Als. Professor Heidi came to China many times, and each time she taught us how to observe newborns, understand their needs, and provide them with the best support. I remember that our NICU environment at that time was still very rudimentary, but Heidi's way of treating infants, behavior, and love amazed us. Every time she observed the baby, she would stay for at least two hours, and although we were much younger and slightly tired, we admired her professionalism even more.

I have immense respect for Professor Heidi and studied NIDCAP with her on and off for a considerable period of time. In 2019, I made a special trip to Boston Children's Hospital for a few days of study, and subsequently engaged in an intensive course on NIDCAP observation and report writing with Professor Dorothy Vittner for another few days. After returning from the United States, I continued to study NIDCAP online with Professor Heidi. I persisted for over a year in this manner and eventually obtained the NIDCAP Professional certificate from Professor Heidi. I am extremely thrilled that Heidi encouraged me to pursue my studies and become a NIDCAP Professional. I hope to become a NIDCAP Trainer and am following Nikk Conneman and Dorothy Vittner to learn about NIDCAP. I am currently sharing some basic knowledge of NIDCAP at China's Newborn Nursing Conference and various other education programs. I hope to contribute to the future development of NIDCAP in China.

The current situation and future expectations for NIDCAP in China

Due to the significant number of neonatal patients and the shortage of nursing staff, implementing the process of observation and report writing is challenging. In the NICU of our hospital, one nurse takes care of three to five infants every shift. I have thoroughly acquired the skill of observation and have produced numerous observation reports, yet it remains a challenge to carry out standardized observations in the



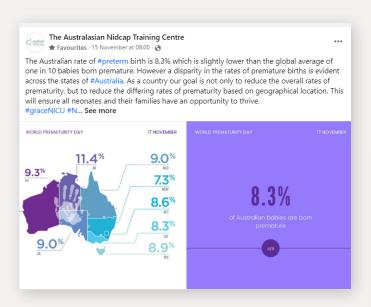
current context in China by each bedside nurse. However, the act of observation is crucial; hence we opt for an observation without documentation approach, mandating nurses to conduct 20-30-minute observation of each infant during their shift. Only through careful observation can we assess the developmental level and abilities of the infants and observe the response of the caregiver to the infants' treatment. The caregiver can provide better care for the infants based on these observations. We acknowledge that it is not feasible for one nurse to handle the care of one infant per shift, but we are also working on enhancing the specific details of clinical care.

We are working to involve more families in the care of newborns, with more parents engaging in this "kangaroo care" technique which helps to stabilize the clinical symptoms of infants. I am a postgraduate mentor, and the model of the synactive organization of behavioral development theory of NIDCAP also supports many studies on enhancing the stability of newborns in clinical practice which include family-centered care, kangaroo care, strategies to promote early full oral feeding, breastfeeding, and other related aspects. These specific measures can better contribute to the enhancement of infants' outcomes and the formation of stronger bonds between infants and their families. Based on the results of clinical research, various nursing measures derived from the NIDCAP concept have demonstrated remarkable effects on newborns, with a particular focus on small premature infants.

However, we still have a lot to learn from the professionals of the NIDCAP Federation (NFI), and we still need to learn and communicate with neonatal professionals from various international hospitals. Ultimately, we hope to apply what we have learned to benefit small babies. Professor Heidi, the board of directors of the NFI, and all the NIDCAP trainers have spared no effort to improve the prognosis of newborns, especially premature infants, worldwide through the NIDCAP method. It is the greatest kindness, and we also hope to fully implement NIDCAP in China to commemorate Professor Heidi and truly carry forward the NIDCAP approach to care..

NIDCAP Training Centers - Facebook Pages

World Prematurity Day was a focus in November for the NIDCAP Training Centers. Across the globe the aim is to raise awareness of preterm birth and the subsequent challenges faced by infants and their families.











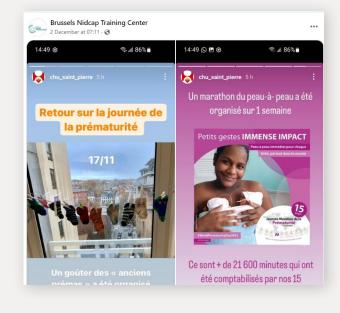












NIDCAP.org

NIDCAP BLOG







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-Director: 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,

Director and Contact:

Deborah Buehler, PhD email: dmb@dmbuehler.com

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

University of Illinois Medical Center at Chicago Chicago, Illinois, USA Co-Directors: Doreen Norris-Stojak MS, BSN, RN, NEA-BC and Jean Powlesland, RNC, MS Contact: Jean Powlesland, RNC, MS email: nidcapchicago@gmail.com

National NIDCAP Training Center

Boston Children's Hospital Boston, Massachusetts, USA Director: Samantha Butler, PhD Contact: Sandra M. Kosta, BA email: nidcap@childrens.harvard.

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, **Argenting**

Director and Contact: Graciela Basso, MD, PhD

email: basso.grace@gmail.com

OCEANIA -

MANUSTRALIA

Australasian NIDCAP Training Centre

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

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

EUROPE -

AUSTRIA

Amadea NIDCAP Training Center Salzburg

University Clinic of the Paracelsus Medical University, Salzburg, Austria Director: Elke Gruber, DGKS Co-Director: Erna Hattinger-Jürgenssen, MD Contact: Elke Gruber, DGKS email: elke.gruber@salk.at

BELGIUM

The Brussels NIDCAP Training Center

Saint-Pierre University Hospital Free University of Brussels Brussels,

Director: Inge Van Herreweghe, MD Co-Director: Marie Tackoen, MD Contact: Delphine Druart, RN email: delphine_druart@stpierrebru.be

UZ Leuven NIDCAP Training Center

uzleuven.be

Leuven, Belgium Director: Anne Debeer, MD, PhD Co-Director: Chris Vanhole, MD, PhD Contact: An Carmen email: nidcaptrainingcenter@

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@

Danish NIDCAP Training and Development Center, Copenhagen

Copenhagen University Hospital, Rigshospitalet Copenhagen, Denmark Director: Jannie Haaber, RN Co-Director: Porntiva Poorisrisak. MD, PhD Contact: Jannie Haaber, RN,

NIDCAP Trainer email: nidcap.rigshospitalet@ regionh.dk

FRANCE

bzh

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

Saint-Brieuc NIDCAP Training Center

Saint-Brieuc - Paimpol - Tréguier **Hospital Center** Saint-Brieuc, France Director: Marie-Cécile Andro-Garcon, MD Contact: Aurélie Guillou, RN email: aurelie.guillou@armorsante.

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 Training Center**

Sant Joan de Déu Hospital Barcelona, Spain Director and Contact: Ana Riverola, 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

III 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 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

