

# Developmental Observer

The Official Newsletter of the NIDCAP<sup>®</sup> Federation International

## NIDCAP Federation International (NFI)

Founded in 2001, the NFI is an international, non-profit membership organization. The NFI encourages highly attuned implementation of the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) for all intensive, special care and newborn nurseries around the world. The NFI serves as the authoritative leader for research, development, and dissemination of NIDCAP, and for the certification of trainers, healthcare professionals, and nurseries in the NIDCAP approach.

“We are all visitors to this time, this place. We are just passing through. Our purpose here is to observe, to learn, to grow, to love... and then we return home.”

AUSTRALIAN ABORIGINAL PROVERB

## Table of Contents

In Conversation with Heidelise Als .....	1
Editorial .....	1
Family Voices .....	4
A Novice Trainer's Look: Shining Moments and Early Lessons Learned .....	6
Advanced Practicum Experience .....	8
NIDCAP Profile .....	11
Global Perspectives of Developmental Care - Belize.....	14
NIDCAP Training Centers Around the World.....	16
The Science Desk .....	18
Published Resources .....	20
NIDCAP on the Web .....	25

## In Conversation with Heidelise Als

Kaye Spence, AM

In May this year I had the opportunity to have a conversation with Dr. Heidelise Als in Auckland, New Zealand as she was the invited keynote speaker at the Council of International Neonatal Nurses (COINN) 10th international conference. It was such an honour to have her speak and network with over 400 neonatal nurses from 23 countries.

In a quiet corner of the hotel café we had a most enjoyable conversation. As Heidelise sipped on her cappuccino she shared many stories, reflections and insights into NIDCAP and the impact it has on newborn infants and their families. I learned so much about this remarkable woman and the passion that has shaped her life. I would like to share parts of this conversation as I asked about her experience at the conference to trigger some thoughts about NIDCAP.



*Dr. Als giving her keynote address at the Council of International Neonatal Nurses (COINN) 10th international conference.*

**KS:** *After three intense days at the conference would you like to share your overall impressions?*

**HA:** When I was invited and saw the conference theme, Enriched Family – Enhanced Care, I knew I wanted to attend. It was so in tune with the philosophy of NIDCAP. I was

Continued on page 2

## Greetings from the Editor



It is with pride that I present this issue of the *Developmental Observer*. It has been a fascinating few months for NIDCAP and in this issue we showcase the expansion of the global work of NIDCAP.

Earlier this year I had the pleasure of attending the COINN (Council of International Neonatal Nurses) International Conference that was held in Auckland, New Zealand. This time it was particularly memorable as Dr Heidelise Als was one of the invited keynote speakers. I must say Heidi was in her element as nurses from many of the 23 countries represented sought her out for photographs and short conversations. She was always surrounded by groups of enthusiastic nurses, many of whom had studied her work in their university courses and knew what an honour it was to meet her. I took the opportunity to have a conversation which is included in this issue. This was enlightening for me as I have known Heidi for nearly 20 years and yet this conversation revealed a different side to her.

This issue also features stories about NIDCAP Training, from the point of view of a novice NIDCAP Trainer and a NIDCAP Trainee challenged by her Advanced Practicum. These stories from Dalia Silberstein and Kristen James Nunez challenge us to think about our own practice and training. Hopefully these stories may encourage others to share theirs. We also feature a profile on Dominique Haumont who provides us with

Continued on page 3

## In Conversation with Heidelise Als (continued from page 1)

happy to see the concurrence of all strands of the presentations and the themes which were complimentary to NIDCAP. Each presentation was well thought out; the presenters were articulate with a certain seriousness and sincerity. I found the science presenters were diligent in their longitudinal research, the follow-up years and the large numbers of infants was impressive. Seeing the outcomes of our work causes us to pause and reflect. The nursery world is so different from the womb. It's like witnessing the evolution of our own species and looking at it from the outside. It was wonderful to hear the parents present; they have so much to teach us.

**KS:** *Many of the delegates were impressed that you were in attendance for each session and you were taking notes.*

**HA:** Why wouldn't I? I have so much to learn.

**KS:** *What did you think of some of the futuristic presentations, for example the one on the artificial womb? I noticed you were quite absorbed.*

**HA:** I found it a thoughtful and sensitive presentation and the intellectual drive of the neonatologists and physiologists is impressive; they haven't given up for nearly 50 years. This gives babies a chance, the more we learn the better we can make the experience for the newborn. You know I was present at some of those early trials in Philadelphia. It was early in my career, around 1968 and I had come to the USA and had just completed my master's degree. For my doctoral work I was in the nursery watching babies and doing pre-publication Brazelton observations. I remember one of the pediatricians asking me what I was doing and I explained I was observing the baby. She asked if I would like to see babies more fascinating than the full-term infants I was observing; of course I was curious, so she took me into a room on the side of the nursery. The room was full of various equipment, oxygenators, monitors and, in the middle, a table for the immature baby, who was about 28 weeks - pre-viable in those days. I was given the job of bagging the baby, who was flat on the table with the limbs restrained. I asked if we could help the baby tuck and place the hands to face and arms midline. As she spoke Heidi took on the flexed position demonstrating the ideal position for the baby's limbs and hands. She was demonstrating what she wanted to happen. I was told this was not possible as it could interfere with the tubes and wires!

**KS:** *Did this influence you in any way on your early concept of NIDCAP?*



Heidelise Als enjoying the Gastby Dinner at the conference

**HA:** Yes, this was my first encounter with preemies. It made me think about their experiences and how they are looking for support and nurturing when surrounded by all the technology. Developmental care and NIDCAP started. There were many challenges to getting these concepts into practice at the bedside and if you want to overcome those barriers you have to have the right persons. The Psychologists have the ideas, but the doctors and nurses actually do it in practice. Early on there were some real nursing champions (Pat Linton and Gretchen Lawhon) who were given the opportunity when developmental specialist positions were created. These were the early adopters, who helped make it happen, who made NIDCAP happen.

**KS:** *What do you see as the impact of NIDCAP? At this conference as well as globally.*

**HA:** The number of nurses who spoke of their knowledge and awareness of my work surprised me. People seem hungry for information and they appear dedicated in using this for their interactions. You know this is only the second nursing conference to which I have been invited. The amount of research that has been accomplished is fantastic and there is an appreciation of the impact on the brain and the changes that occur. However, there remains a lack of recognition in one's own local environment. This

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#### Contributions

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

manifests in lack of support for development or research. In order for early intervention work to succeed, there must be support and this includes financial support. Ultimately there are costs to the community, supporting families with babies who, early on, experienced less than optimal care and now require life-long support.

**KS:** *As one of the neonatologists said on the opening day – the nurses at the conference have a once in a lifetime opportunity at the conference to hear you speak. You received a standing ovation following your last presentation at the conference. How did this make you feel?*

**HA:** Very humble. Maria Maestro's beautiful video had a lot to do with it.

**KS:** *I think you gave many hundreds of nurses a glimpse of what NIDCAP is and the work and research that have gone into making it the model of choice. You also showed them that you are also prepared to have fun. Did you enjoy the Gatsby dinner?*

**HA:** Yes, it was fun, but I can't dance the way I used to. I enjoy watching the young people enjoy themselves.

**KS:** *What would you say is your 'pearl' of NIDCAP?*

**HA:** Everything matters, for what we experience once we can't do it over or change what has happened. We always make the best of what we experience, and nothing is without cost. We all make mistakes and if we reflect and think about it we will figure it out so it won't happen again. I have learned a lot from being the mother to a child who was different from birth. There is a consciousness that makes life enjoyable, happy and good. A baby has no way to pretend, so you must consider how you touch a baby, work with a baby, and the voice you use, as these all have an effect on the baby and potentially cost the baby. You must be aware and keep your focus on the baby.

**KS:** *NIDCAP was born 40 years ago - what do you see as the biggest change that has occurred for NIDCAP over the past 40 years?*

**HA:** Awareness of NIDCAP varies greatly and depends on where you come from. There must be more articulation and communication about the detail required. For example, the reports cannot

be condensed, as you want the detail that describes the core of the baby, the observations and the recommendations. The baby's goals are essential for the report. There have been many changes and more are required. A psychologist developed NIDCAP and is free of the burden of keeping the baby alive. It is the doctors and nurses who implement NIDCAP in partnership with the parent. If NIDCAP is embraced by nurses the direction can quickly change, the nurses drive the change. We have the unifying umbrella of the NIDCAP Nursery Program (NNP) to help with the system change. This together with programs such as FINE and NIDCAP will ultimately benefit the baby and the family. Of course if we are going to have programs to support the baby and family we also must support the staff. They have to have time away from the bedside for time out, self-awareness and reflection; this is very important and has to be part of the implementation plan. Globally, we are expanding and we must engage those drivers who are interested and prepared to embrace NIDCAP and respond to requests for training. I think we are still figuring it out.

**KS:** *Thank you, Heidi, this has been very enlightening for me. I must say the video you showed in your presentation really had an impact on the audience. To see all those interventions being done, eye exam, cardiac echo while the baby was skin-to-skin with little reaction was truly NIDCAP.*

**HA:** Yes, Maria Maestro from Spain allowed me to share this video. It shows how a neonatologist, who is a NIDCAP Trainer together with a NIDCAP Professional nurse, can provide these opportunities that embrace NIDCAP and ultimately benefit the baby and mother.

**KS:** *On that note, thank you for your generosity of time for this conversation.*

We said our farewells and I watched this diminutive and powerful woman walk towards the elevator. As she did so, a group of nurses walking by turned and chatted amongst themselves and I overheard 'that was Heidelise Als, wasn't she inspirational'.

Photo of H.Als presenting courtesy of COINN.

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## Greetings from the Editor *(continued from page 1)*

insight into the challenges of establishing NIDCAP and provides many ideas of negotiating health systems. We also have an enlightening story from Amanda N'zi sharing her story of Kayden's journey.

We have introduced a new regular feature of Global Perspectives of Developmental Care. The aim is to explore different countries and health care systems and how developmental care and NIDCAP is being implemented. We start with Belize and Melissa Johnson gives us her perspective of the work she and her team have been doing there. We look forward to moving around the globe in future issues. Our regular feature from the Science Desk returns after great feedback from the last issue. Jeff Alberts shares a light on research on fathers. Other regular features of profiling NIDCAP Training Centers continue and this issue we feature the Australasian NIDCAP Training Centre.

As editor, I welcome your feedback on the content and look forward to reading your letters. Send to: [developmentalobserver@nidcap.org](mailto:developmentalobserver@nidcap.org) I would also like to acknowledge the encouragement from the editorial team and their hard work in generating ideas and reviewing the content for each issue.



Kaye Spence AM

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## #everyhourstronger

*Having a baby in the neonatal intensive care unit (NICU) is a heart-wrenching, anxiety-inducing, and challenging experience. No family wants to have a less-than-perfect baby at birth, and yet every day, babies are born prematurely or with other health complications who need additional intensive care. When this happens, parents find themselves visiting their newborns in the NICU instead of taking them home to the nursery room that they so lovingly decorated and prepared for their baby.*

*Amanda shares her personal journey – from the moment she was rushed to the hospital, to the emptiness she felt when her baby was whisked away after being born, to the unpredictability of having a son with special healthcare needs. But through it all she has learned that she is stronger and more brave than she ever thought possible. And so is her son.*

“Congratulations and I am so sorry.” These were the first words my friend and fellow mom of a micro preemie said to me after my son was born and they are so true. The journey into parenthood is challenging, and when the journey begins with the NICU, it is terrifying.

At 3 a.m. on the first day of my 26th week of pregnancy, I woke up bleeding with what we later learned was a placental abruption. My husband and I rushed to the hospital where we were told I was in preterm labor. My only thought was, “I can’t be in labor. We don’t even have a car seat.” I was in disbelief, and it was surreal to see the doctors and nurses rushing around while I was still trying to figure out what was happening. IVs were placed, magnesium was started as a neuroprotectant, steroid shots were given to help with lung development, and the NICU team came to speak with us. They told us about the different organ systems that would be monitored after our son was born and what were possible complications. My only question was, “what is the chance he will live?”

As a child psychologist working at the time in a rehabilitation department for children with various types of brain injury, I knew too many stories of children born prematurely and with medical complications. My mind flooded with worst case scenarios. Fear swept over me. This could not be happening.

Once magnesium was started, my labor slowed and I spent four days in the hospital, always within “6 hours of delivery.” The NICU team visited several times to answer questions as my husband and I adjusted our expectations of birth. We were going to have a micro preemie. I kept reminding myself that every hour I stayed pregnant gave him just a bit more time to get stronger, and it kept me going. I did a few “bucket list” items like having my husband read a story to my belly.



Amanda and Kayden

When my body and my son’s body could hold on no longer, I had an emergency c-section. My husband was with me at his birth; I heard my son cry and then he was whisked off to the NICU with my husband close behind, and I was alone.

I went to the recovery room and then learned how to pump. Four hours later, they wheeled my bed to the NICU where I saw my son for the first time. He was intubated, under blue lights, so tiny, and the most beautiful (slightly alien-looking) child I had ever seen.

The first week of the NICU went well. Premies are born with a valve in the heart that hasn’t closed yet called a PDA (patent ductus arteriosus) and my son’s closed after receiving medication. He was weaning down on breathing support at a steady pace and we felt hopeful we would have an uneventful NICU stay and were amazed at the strength in that 2lb 10 oz child fighting to live.

We helped with diaper changes and our son’s first “bath.” We prioritized bonding and self-care. My husband made sure we

slept at home and left the hospital. All the monitor beeping in a NICU can become overwhelming at times. We learned about bradycardia episodes and how to help when they happened. We held our son for the first time three days after his birth. We wouldn't hold him again for two more weeks because the rollercoaster was about to take a turn.

Our son seemed sick. He was more lethargic, he needed more breathing support, and his condition was less stable. This means more alarms going off and more intense looks from staff. My son had a blood infection that began a chain reaction of terrifying moments. The PDA in his heart reopened, he was too sick for surgery to close, and too sick to be held. We comforted him through the holes in his incubator. He was reintubated and put on an oscillating ventilator. Our son had a spontaneous intestinal perforation and had to be transported with the Flight for Life team to a higher level of care NICU where he could be monitored by a surgery team. The hospital he was transferred to was the hospital where I worked.

We watched our son struggle for his life two floors under my office. We watched nurses "chase" his blood pressure all day. We watched him need resuscitation several times. We watched helplessly as he fought to hold onto life. I pleaded, "I just want him to live."

With medication and a skilled NICU staff, we saw our son recover from his blood infection, make it through heart surgery, heal from his intestinal perforation without surgery, and come off intubation. Although the rollercoaster did not end there, the scariest turn was over.

The late-night emergency calls from the hospital continued because of his underdeveloped lungs and the difficulties he had learning how to breathe with less support. As the days dragged on, we were surrounded by family, friends, texts, meals, and love.

I returned to work at the hospital after my 8 weeks to heal from the c-section and visited my son every day. I was grateful to be near him and came down to visit during the day and to pump. My husband and I became experts at giving our son a bath and changing diapers while navigating cords and breathing tubes. We learned how to comfort him during diaper changes and medical procedures and flooded him with love during kangaroo time. Our son had a hard time tolerating kangaroo time very long because of his breathing, so we found lots of way to let him know he was loved. We visited him every day and checked in every night until he was ready to come home, 105 days after his birth.

As we prepared to go home, my husband and I encountered changed expectations for what home would look like. We learned that breastfeeding would not be his feeding plan because he needed supplemented nutrition and that we would be going home with oxygen and numerous medications. We learned infant CPR.

We learned we could not put our son in daycare. We learned we would need to limit visitors and practice good hand hygiene, all the time. We learned our current lifestyle and the ideas we had about life with a baby were not a match for what our son needed. We began to make changes to support this new path.

The journey that started our son's life has continued to be a rollercoaster. He has needed multiple surgeries since his discharge and has had additional readmissions to the hospital, including one more ICU stay. Our son has broken a bone, sprained his ankle, needed glasses, and used supplemental oxygen for 18 months.



*Kayden aged 4 days with parent's enfolding him*

I often say our son has had a lifetime in two years. He continues to need a daily inhaler to help him breathe. He has attended and still attends physical therapy, occupational therapy, developmental services, numerous doctor's appointments, and specialty visits. We have missed family outings and have stayed in our home during two respiratory seasons to keep him healthy. We have become experts in changing oxygen tanks, monitoring a pulse-ox, and checking for signs of respiratory distress. We have experienced first hand the impact of medical trauma on ourselves, our marriage, and our family. We have learned to look at the world differently. We have learned to be our son's guide and support through the hard times. We have learned how little we can actually control. And, as the scary moments become less frequent and less intense, we have learned that NICU families are brave, that we are brave, and that we will always be **#everyhourstronger**. Kayden is now two and a half years old.

*Amanda N'zi, PhD is a licensed child psychologist. She works in private practice in Denver, CO.*

# A Novice Trainer's Look: Shining Moments and Early Lessons Learned

Dalia Silberstein, PhD

Israel NIDCAP Training Center

In this article I share my personal perspective on what NIDCAP training means to me. Not any training, but specifically that in which I became a NIDCAP trainer; in which my trainees and I did that very special journey for the first time. The article does not bring an all-encompassing perspective of that experience, but rather a few salient revelations that became important lessons for me. It does not propose a generalizable view of what NIDCAP training is or should be, nor pretends to offer clear-cut guidelines to the new Trainer. And yet, it might provide others the possibility to appraise and reflect on their own training experiences.

## The freedom to reflect

*"Freedom is nothing else but a chance to be better".*

— Albert Camus

NIDCAP practice is about observing, articulating what you observed, and reflecting on it. The NIDCAP observation write-up, and its depiction of infant behavior in terms of the infant's strengths and sensitivities, developmental goals and suggestions for care, is no doubt one of the main "outputs" of a NIDCAP observation. A good write-up allows us to actually depict in our mind the intricacies and complexities that took place between the infant and the caregiver, and to grasp the infant's behavioral flow in a smooth, natural and logical way- even when we have not actually witnessed it. A NIDCAP write-up, thus provides a unique and quite structured window to infant behavior. However, it is the *reflective* process intrinsic to an observation - whether it is written or spoken - that affords us a window to the observer's (i.e., the trainee's) soul.

I captured the wholeness and richness of the learning process involved in NIDCAP training, only when the trainees' reflections were articulated and shared with me. Although I cherished reflection and have always felt affinity to the reflective processes involved in NIDCAP work, it was while guiding my trainees through the Advanced Practicum that I distinctly felt there is a hidden magic to it. Even when the trainees made huge progress and excelled in their observations and write-ups, it was only when they reflected about them that I felt their more vivid and multifaceted "selves" emerged. It was indeed in the reflections they shared that I more readily perceived each trainee's freedom to relate to her own experiences, insights and feelings in regard to the observation performed.

That *hidden magic* of the reflection component of training, lays in the fact that when articulating it, trainees do not follow a specific structure or script, nor are constrained to address a particular theme, or compelled to consider each and every aspect of the caregiving interaction. Quite the opposite. I prefer to think of the reflection piece of training as the one in which I prompt my trainees to actually "go wild"; the part in which they decide what they are focusing on – whether on their own feelings, the infant's experience, the family constellation, the caregiver's



From left to right: gretchen Lawhon, master trainer, Adi Freund-Azaria, MOT, Abigail Marashli, RN, BN, Liat Michli, BPT, Andy Levy, RN, MN, Ita Litmanovitz, MD and Trainer, Dalia Silberstein, RN, PhD and Trainer.

input, the environment, the shining moments they will cherish forever, or perhaps the mismatches they would rather not have witnessed. Every thought and perception stemming from an observation is certainly legitimate and beneficial for developing a trainee's reflective competences, and to deepen our understanding of each caregiving situation.

The framework for reflection involved in the NIDCAP training process, and even more so, *the formal requirement to write those reflections down*, is a crucial component of training for a wide variety of reasons, one of them being the liberating experience it affords both to the trainee and the trainer.

And yet, is a sense of *liberation* at all important for infant care in the NIDCAP approach? As we constantly evolve and improve our practice as healthcare professionals, we look for innovative techniques, refine our skills, and acquire new competence. Nevertheless, for many of us the ability to reflect has not traditionally been an integral part of our training nor has been cultivated and respected as an important professional attribute. Even today, and in spite of the continuous evolution of our professions and work places, reflective abilities are not necessarily a valued component in a health professional's identity.

Reflection on our own practice requires some dose of introspection, sensitivity, tolerance, open-mindedness, and readiness to slow down. It demands our readiness to abandon our zone of comfort and requires our willingness to look at a situation anew. It turns out that as NIDCAP professionals and trainers, we might often be invested in conveying a not so popular message in the intensive care scenario: that reflection is a fundamental tenet of good neonatal care. In this context, the reflective experience afforded by NIDCAP training might well be the trainee's first "exercise" of an open and genuine reflection. By genuine, I mean taking the liberty and affording the time to wonder and to question, to think out of the box, to be humble and honest enough to be able to see both the lights and the shadows in each caregiving interaction.

My first experiences as a NIDCAP trainer taught me that to foster and protect the trainee's liberty to think and reflect, is one of the trainer's more rewarding roles.

### "Tribal" power

*"Individually, we are one drop. Together, we are an ocean".*

— Ryunosuke Satoro

My initial perception was that NIDCAP training is a learning and personal growth process that takes place essentially between two people: the trainee and the trainer. However, in my first experience as a trainer, the power of group work became clearly apparent. It turned out to be a critical - yet quite unexpected - ingredient of the training process.

Our first group of trainees' ability to function as a consolidated group was one of the group's decisive strengths. Regardless of each trainee's professional and individual characteristics, the group managed to make progress in a well-coordinated fashion. Much energy is invested by trainees who undertake NIDCAP training and integrate it in their already demanding personal and professional lives. I believe this essential energy was maintained by virtue of the trainees becoming a group moving forward together.

There was a "tribal" atmosphere to this initial NIDCAP training experience which enabled mutual motivation, reinforcement and support. While each trainee managed to keep her individuality and to personally imprint the process, they spontaneously maintained an emphasis on the group's common goals. It seems to me that fostering the power of our trainees as a group is an important part of our role as trainers as well. After all, NIDCAP care is about strengthening individualities (the infant's, the family's, the trainee's) while reinforcing a sense of belonging and being held.

### A microcosm in each Advanced Practicum (AP)

*"If everyone would look for that uniqueness then we would have a very colorful world".*

—Michael Schenker

I learned that a fraction of life's complexities is represented in each and every Advanced Practicum experience. When reading our trainees' APs, it was as if each of them provided me with a fine telescope to look into a delicate, detailed and ever changing microcosm that, otherwise, would remain distant and out of sight. It is in fact the emerging story of an infant within his or her family that is captured in that sequence of observations that conforms to the Practicum. As such, the AP provides both the trainee and the trainer with the opportunity to look closer at that microcosm and, if fortunate enough, to be able to contribute to a better beginning for that family.

At some point, I intently tried to capture that ultimate single essence I believed there was in each observation and each AP I read. At a first glance, that may seem like an inappropriate simplistic approach to a complex phenomenon. Yet, this kind of "synthetic" thinking, in which I tried to identify the core, the very essence of each infant-caregiver interaction, was extremely helpful for me. I thought it could perhaps be so for my trainees also. I learnt that the mental exercise of giving *an imaginary title* to the observed interaction, contributes to the reflection process.

For I realized that even long and complex essays have titles; deep and intricate poems have titles; refined and detailed research studies are given a title. In my view, giving that imaginary title - to what is observed and experienced in NIDCAP observations - does not necessarily reduce our understanding or lacks the possibility of a broader insight, but rather helps us to focus our reflection on the topics we would like to emphasize in the training process. Thus, when observing an infant or while reflecting and giving feedback on a NIDCAP write-up, I often asked myself, and prompted my trainees to ask themselves: "what was the infant's *main message*"; "is there something the infant is saying sound and clear?"; "what would be the *headline* for the infant's story in this specific observation?".

There was therefore an essence to capture by each trainee in each of their APs. For one trainee, it was about finding the strength to engage in a new and fresh relationship after experiencing the loss of the baby she originally attempted to follow and support. For another, it was about developing the endurance and resources that were necessary to sensitively guide and support a baby girl that did medically well, yet had a very prolonged hospitalization. For a third trainee, it was about the challenges of supporting a baby whose parents spent limited time in the NICU, and about the concerns that arose during the home visit. And still for another trainee, it was about creating the necessary confidence and closeness to properly support a single mother of twin girls.

### The construction of dialogue

*"Give me the gift of a listening heart".*

—King Solomon

We bring our own perceptions and mental working models to the NIDCAP training process. As trainers, we need to be careful and have a better understanding of our trainees' perceptions, while also making our own ones explicit without assuming they would be taken for granted. The process of giving written feedback to observation write-ups provided me with an excellent opportunity to learn that. Trainees seemed to be quite unfamiliar with discussing a text (the write-up) to which many margin notes and topics for reflection were added. Coming, as most of us do, from formal educational systems in which the neater and less corrected a piece of work is, the better - I realized they were challenged by my notes and commentaries. They seemed to think that their work might not be good enough if they got notes and remarks. That required from me to further elaborate and explain my own perception of what is a good fundament for trainer-trainee exchanges. I consider margin notes and comments as an intrinsic part of the training process. They are to be viewed as still another way to develop an open, free and creative "dialogue" between a trainee and a trainer. This might prove especially meaningful and useful when a trainee and a trainer are able to share only limited time together at the bedside or in face-to-face conversations, as is the case in many training experiences.

There are actual persons behind my reflections. They are Abigail, Andy, Adi and Liat - our NIDCAP trainees - and Ita, my NIDCAP companion, co-trainer, and Training Center co-director. I have learned from them all.

# Advanced Practicum Experience: A Bitter Sweet Symphony

Kristen James Nunezn, RN, MN (Advanced Practice)

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## Background

A component of NIDCAP training and the final project prior to NIDCAP certification, is the NIDCAP Advanced Practicum (AP). This involves following the journey of a newborn infant and their family through their NICU stay, completing systematic observations and formal write-ups of their progression. The provision of feedback to nursing, medical and allied health teams as well as the newborn's family aims to support their growth and development in the NICU.

This is a reflective paper of my experience following the death of the baby I had chosen for my advanced practicum. Having worked closely with the family for almost four weeks when the baby died following complications from his congenital disease, I was left feeling quite devastated. In this paper I discuss the impact of this event on my NIDCAP training, and my subsequent progression to a certified NIDCAP professional. I describe the challenges I faced following this death and have titled this paper, *A Bitter Sweet Symphony* as I reflect on this experience with sadness, gratitude and hope.

## Introducing William

I would like to introduce you to William Schrader, the baby I chose for my advanced practicum. William is a beautiful little boy born at 38 weeks gestation on the 13th September 2012. He entered this world after his mother had an elective caesarean section following an antenatal diagnosis of a congenital anomaly. At birth William weighed 3400 grams or 7 pounds, 5 ounces. He was born at a high risk obstetric centre and transferred to the adjoining Grace Centre for Newborn Intensive Care at The Children's Hospital within 24 hours following birth for management of a left congenital diaphragmatic hernia.

William is the second child to parents Olivia and Grant and a little brother to sister Elenor.

I chose to work with William and his family for my advanced practicum to demonstrate the importance of having NIDCAP training in a surgical newborn intensive care unit as a way of supporting these complex and fragile infants.

## William's Story

William was incredibly fragile in his pre-surgery period and required intubation and mechanical ventilation soon after birth. He also required high level intensive care including inotropes for circulatory support, nitric oxide for respiratory failure, heavy sedation and muscle relaxation to support mechanical ventilation. He was deemed stable on day four following birth which enabled him to be transferred to the operating theatre for surgical repair of his diaphragmatic hernia. William underwent surgery on the 17th September requiring a patch closure of his left diaphragm.

His post-operative course was also turbulent requiring high frequency oscillatory ventilation (HFOV), nitric oxide, steroid



*William at 4 days of age*

therapy, multiple inotropic drugs, heavy sedation and muscle relaxation for prolonged periods over the course of the next 20 days.

He was able to be weaned from mechanical ventilation to continuous positive airway pressure (CPAP) for a brief period, however his condition deteriorated requiring escalation in medical management. He required sensitive and individualised nursing care to minimise the stress and to avoid physiological fluctuations that could compromise his stability.

William's condition deteriorated further and with maximum support being offered in the NICU, he was transferred to the adjoining Paediatric Intensive Care Unit for extracorporeal membrane oxygenation (ECMO). After six days on ECMO with no improvement in his condition, and following discussions with his parents and the health care team, a decision was made to discontinue ECMO as it was deemed a futile treatment at this stage. William died on the 7th October 2012 at 24 days young in the arms of his mother being cradled by his father.

An estimated 140 pregnancies are diagnosed with congenital diaphragmatic hernia (CDH) in Australia and New Zealand each year, with less than half expected to survive.<sup>1</sup> Being the largest referral centre in New South Wales, the Grace Centre for Newborn Intensive Care sees approximately 10 babies each year, with a survival rate of 97% across the NICU.

## Advanced Practicum - NIDCAP observations

I first met William and his parents Olivia and Grant on the 14th September 2012 when he was transferred to our unit at two days of age. I spoke to Olivia and Grant about the role of developmentally supportive care for babies who have had surgery, the NIDCAP philosophy and the NIDCAP Advanced Practicum (AP). Olivia and Grant were keen for William to have this opportunity so I commenced my AP working closely with them throughout William's stay in the NICU. I completed my first NIDCAP observation and report that included my observations and subsequent recommendations for William's care on this day. My further observations and reports occurred throughout his

time in the NICU. I took the opportunity to have members of my team record some videos which enabled me to adjust my recommendations for William. Babies who have had surgery and/or complex medical issues often have rapid changes in their condition requiring changes in the recommendations for support. These small videos often occurred in my absence due to my work schedule and provided a quick snapshot of William that supported adjustments to my recommendations.

I placed a folder at William's cot-side [bedside] with copies of the reports and recommendations. This enabled his parents as well as the nurses caring for William to read them each day. The goal was to enable the recommendations for William's care to be used by all staff to provide a consistent approach when his condition was quite unstable. When William was transferred to the adjoining Paediatric Intensive Care Unit for ongoing medical care and ECMO, I met frequently with Olivia and Grant to remain current with William's condition and fragility.

Due to William's condition and his need for such intensive medical support, heavy sedation and prolonged periods of muscle relaxation, his NIDCAP goals and recommendations were limited and unable to progress throughout his short life. However the benefit of observing William and discussing these observations with his parents were an instrumental focus of the AP.

## Challenges and rewards

This experience came with many challenges but also great rewards. The challenges I faced included:

- **Time:** I had a lot of things going on at the same time as my NIDCAP training and completing the advanced practicum component. I was completing my Master of Advanced Practice at the University part time, in addition I was also preparing for the birth of my first child and the commitment required for my Advanced Practicum became stressful.
- **Distance from NIDCAP trainer:** This was slightly difficult with me in Australia and my trainer in the USA. Although I always felt supported throughout my NIDCAP journey, the distance between myself and Joy Browne, my NIDCAP trainer, did not allow for immediate feedback and consultation which left me feeling a little stranded. I felt in this situation I would have benefited from having my trainer closer. In addition the time difference of 15 hours made communication difficult.
- **Unfamiliar situation:** The distance was confounded further as I was not familiar with the recommendations in this situation and it was my understanding the death of a baby during a NIDCAP AP was a rare occurrence which left me unclear of what direction to take. I also found it difficult to articulate the relationship I had formed with the Schrader family through emails, missing that face-to-face discussion and simultaneous support.
- **Shift work:** Working shifts was also a challenge. At the time of this AP I worked three 12 hour shifts each week. The acute clinical work load on a specific shift sometimes meant completing NIDCAP observations and the write-up work required commitment outside of my working hours.

- **William's Medical condition:** William was extremely unwell from birth to his death which placed a great deal of difficulty on completing NIDCAP work and was a huge personal and emotional commitment for myself.
- **My own personal health:** I was 27 weeks pregnant when commencing this AP journey. This challenged me from a lethargy perspective as it added another component to my already busy life. My pregnancy also challenged Olivia and Grant as through their own stress and grief they showed great concern about the effect my commitment to William and their family may be having on my unborn child, something I had not anticipated.

Although difficult, the significant challenges made the rewards much more meaningful. The rewards I gained from this experience were immense:

- **I am incredibly proud of the relationship I formed with the Schrader family .** The AP work involved speaking with them about their son aside from the medical care, diagnosis and treatment, and focusing on their baby, their William. They commented often that these conversations allowed them to see through the tubes, machines and alarms forming memories they hold onto even today. Following William's death I provided them with a small video of all the movies and photos taken throughout our NIDCAP journey. I said my goodbyes to William when I attended his funeral, for which Olivia and Grant were so grateful.
- **Professional learning and personal growth:** This experience amplified to me the importance of supporting families through the medical haze of the NICU environment. It is so vitally important to support parents to have glimpses of their babies as just that, a baby, and not the '24 weeker' with chronic lung disease or the term baby with multiple congenital anomalies. I will forever take this into all my interactions with parents and this remains a focus of my care. I know I have William, Olivia and Grant to thank for that.

## Outcome

Death and dying are an unfortunate part of the NICU journey for a small number of babies and families. This experience has shown me the relationships we make with these families is THE most important part of our NIDCAP work. The NIDCAP Federation International (NFI) now specifically addresses the importance of this relationship with the goal of supporting NIDCAP trainees during their AP.

*"If the infant you are observing is or should become severely ill, and perhaps die, be aware of the importance of your supportive role, which becomes even more valuable in such circumstances. The family will greatly appreciate the developmentally focused input you provide and will treasure the diary of their infant. Avail yourself of the guidance of the professional in your setting skilled in the support of parents who experience the severe illness or death of their child. Depending on the length of the infant's life, you may wish to observe another infant, in order to gain sufficient experience in the context of your practicum."*<sup>2</sup>

## Conclusion

My journey to become a NIDCAP certified professional came with many challenges but also immense rewards and significant learning. I take the lessons I learned working so closely with William and his family into my clinical practice each day. My role within the NICU as a Neonatal Nurse Practitioner allows me to continue to work closely with families, guiding them through the uncertain world of the NICU and supporting them to achieve a greater understanding of their baby's achievements. William and his family showed me the importance of celebrating each moment.

I strongly believe NIDCAP certification and training is essential for all health care workers, as the benefits it provides to families support these newborns long after their NICU journey ends. NIDCAP training has become more accessible to the southern hemisphere with the establishment of the Australasian NIDCAP training centre, opening these benefits to many more vulnerable newborns and their families. An additional benefit is having an on-site NIDCAP Trainer to closely supervise and support trainees throughout their NIDCAP journey.

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William with his parents Grant and Olivia

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### Disclosure

The images and identities used in this presentation have been included with the consent of Olivia and Grant Schrader.



## SAVE the DATE

## Open 1-Day Conference

*Gut Feeling: The Other Brain. Exploring the Connection of Microbiome, Stress and Infant Behavior*

Monday  
October 7  
2019

### OPEN ONE-DAY CONFERENCE

#### KEYNOTE SPEAKERS

AMY D'AGATA, RN, PHD  
University of Rhode Island

JEFFREY ALBERTS, PHD  
University of Indiana

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

Register at:  
[www.nidcap.org](http://www.nidcap.org)

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## Dominique Haumont PhD

Introduction by Joy Browne, PhD

Dominique Haumont has been a trendsetter and a visionary when individualized, developmental care was not typical in most Belgian Newborn Intensive Care Units (NICU), or for that matter, in many NICUs world-wide. I have watched in amazement at how she has uniquely and sensitively brought about changes in her own hospital, in her country and in international settings. The vision of making sure babies and their mothers are never separated, her original goal, reflects an inspiration and has now been realized through her efforts over the last three decades. Her novel and progressive approaches to making system change happen have been not only effective, but have given us a template for what can be achieved. They are reflective of our collective knowledge that change does not happen fast, but with perseverance and sensitivity it can be accomplished. We have much to learn from her stories of accomplishments, her perseverance and her ability to think “outside the box”. She is an enabler, a visionary and a true friend. Thank you, Dominique, for sharing the story of your journey with us.

During my pediatric specialty training (1975-80), I was already preoccupied by the mother infant separation in the children’s wards and in the Newborn Intensive Care Unit. At that time, fetal medicine was developing very fast and I started a very close collaboration with the obstetricians/midwives where I was working at the university hospital. Our first approach to studying the behaviour of the preterm infant was to compare their intra-uterine behavior observed by ultrasound (eye movements, general movements, respiration, etc.) with sleep-wake cycles after birth by polysomnography. This was my first understanding of ontogeny of sleep in the 1980’s.

In the 1980’s it was not yet understood that the proximity of mothers and babies had implications beyond the technical aspects. There were two approaches in those days: on the one hand the development of perinatal centers to keep high risk pregnancies in the proximity of well-equipped NICUs. On the other hand, many pediatricians were fighting for children’s hospitals centralising pediatric expertise, especially for artificial ventilation. I tried very hard to convince the hospital authorities that sick newborns in the obstetric department needed to have building plans that included access to a NICU next to the delivery room. It took them 20 years to come to that idea on their own. I left in 1985 and moved to Saint-Pierre University Hospital where there was no plan to move the NICU away from the delivery room.

From the beginning, I shared with the vast majority of the nursing staff the need to move away from traditions like visiting hours for parents, lack of attention to pain during procedures, uncomfortable positioning and/or no respect of sleep cycles. In the late 1980’s and 1990’s, we initiated skin to skin, positioned the babies in hammocks, tried to reduce painful procedures by



*Dominique Haumont: Her Story of System Change and Implementation*

suppressing routine blood sampling and allowed permanent parental presence. All these approaches were quite innovative at the time.

When I supported the practice of permanent parental presence, I was called by the Head of the Department of Pediatrics asking me to stop, because he did not want it to happen in all the wards. I told him that these were the new official recommendations of the Scientific Societies of Neonatology. That was of course not true. I bluffed and it worked! The suffering of the mother having a baby in the NICU appeared so deep to me that I started a collaboration with the psychiatrists and psychologist to have a professional vision for parental mental health support in the NICU.

I also had the idea of not only diminishing pain and stress but including some policies that related to promotion of “well-being”. We started a study having babies listening to music or mother’s voice and recorded the reactions on video and observation sheets. Unfortunately, because of lack of staff we could not conduct the study that would have provided relevant conclusions and publications, but we had observed that each baby had his individual pattern of response to that auditory stimulus.

During those days, I realized that I had to contribute to neonatal research in a traditional way in order to insure the credibility of the unit and of the novel approaches to NICU care. My papers on nutrition and surfactant were published and I was a member of numerous scientific societies which contributed to the realization that our research was credible and necessary. Simultaneously, pushed forward by Jacques Sizun from Brest, a European group “The Early Developmental Care Network” contributed to the general sensitivities and need for culture change in the European units (see article *Developmental Observer*, Vol. 3, No. 2, 2009). Through this group’s efforts we conducted and

published several surveys about practices in NICUs in Europe.

Being interested in the assessment of babies' behaviour I found a publication from Björn Westrup in 1997 where he described what happened in his unit in Falun. He had returned from the United States (US) and introduced NIDCAP in Europe. This approach appeared to me to be the one we needed to structure teaching of developmental care.

From the beginning of implementing the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) work, I wanted our unit to become a Training Center. It seemed the most efficient way to assure the consistency of the change we aimed for in the newborn units.

My role in supporting NIDCAP was first finding the funding, explaining to the staff about the need for sensitive developmental care, and also explaining in national conferences why we had to change. Since the beginning of the NIDCAP journey, I have put enormous efforts into finding the necessary funding for sending collaborators to the US, hosting NIDCAP and APIB trainers in Brussels and achieving the steps for becoming a NIDCAP Training Center. Two major personal grant applications (in 1999 and 2002) gave me the necessary financial support to start building the Brussels Training Center.

As Head of the Neonatal Unit, and also having national and international commitments I could not enter the training process myself, but I had been the translator (French-English) for many observations of the trainees. This provided me the opportunity to infuse NIDCAP approaches on a daily basis by integrating the new vision in organizing the care and encouraging consideration of parents to be collaborators with staff. We had all kinds of working groups among which Early Developmental Care with a weekly discussion around specific aspects of implementing NIDCAP in the unit.

Delphine Druart engaged herself in the process and appeared to have the qualities of an exceptional trainer. She consistently worked toward and was successful at becoming a NIDCAP Professional and then a NIDCAP Trainer. Once the Training Center was opened, we wanted the unit to be an example to other Belgian units. Despite Delphine being called for training in many other NICUs in Belgium and France, she insured and verified our level of NIDCAP care on a regular basis. I must say, the whole staff was very supportive of our efforts, including the obstetricians.

Due to the context of the different university NICUs in Brussels, I started with a small unit and was very close to the families. My resulting partnerships with parents have been very intense. Together we created an association "NeoNid" to promote NIDCAP and family-centered care. I have been very lucky to work with neonatologists to whom I delegated the tasks in the caregiving; one of the reasons they worked in Saint Pierre Hospital was because of the innovative approach of family-centered care. Our unit and the staff grew and the unit ended up being the biggest in Brussels. I became the conductor of the whole team.

While we were building our Training Center, we experienced growing interest inside Belgium and Europe towards Early Developmental Care, whether it was NIDCAP or something

different. The variety of approaches aimed to provide proximity between families and include other elements of Early Developmental Care. Having started the movement of these approaches concretely in the NICU, I was invited to talk about our experience in many hospitals or meetings. Often many visitors came to see how we had implemented our caregiving approaches.

In Belgium, the Ministry of Health appointed, by law, "Colleges of Physicians" to insure quality control. Being a member

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**Initiating that extent of change in the NICU was not an easy task and it was very challenging. The most important challenge to me was to be sure I was going the right direction.**

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and then the President of the College of Neonatology (2008-2013), I had close contact with the Ministry's administration. I knew they were implementing incentives to increase breastfeeding rates by supporting the Baby Friendly Hospital Initiative (BFHI), and that mother infant closeness was accepted as being an important issue. I went several times to see our authorities where I presented the evidence for moving away from potential harmful traditional NICU environments. They understood the need for a structured tool to achieve our goals toward family centered care and agreed that the program which was the most evaluated was the NIDCAP approach. We obtained a four year contract (2006-2010) between the hospital and the Ministry to increase the staff. Once the Training Center was opened, other hospitals could apply for and obtain financial support to benefit from our teaching. They could combine BFHI and/or NIDCAP.

It took roughly from 1985 to 2010 (25 years) to reach maturity of the concept. The proximity of the parents with their infant is the key issue, and without appropriate environmental supports and policies it is very difficult to apply. We started, like everywhere else, with common (often crowded) rooms and the very first fight was to obtain space for a comfortable chair for kangaroo mother care. When the NICU had to be rebuilt, the hospital directors decided to send me and some NICU parents to one of the Florida conferences about NICU design which Dr. Joy Browne was co-organizing. The newly built NICU opened in 2005. With the new design we could host mothers on a small bed in the single rooms. At that time it was quite progressive, but I already started to prepare the next step which was the concept of "couplet care" with a big family room. This process is still ongoing, but since it started, I have retired.

Initiating that extent of change in the NICU was not an easy task and it was very challenging. The most important chal-

lenge to me was to be sure I was going the right direction. In the masculine world of scientific societies the issues on developmental care were not very popular. It was considered important for nurses or for emotional issues of parents but not really science.

Having understood that about my profession, I presented to my colleagues the impact of the different elements of EDC and NIDCAP separately. There is scientific interest for pain, for colostrum, for effect of light and noise, for later outcomes and so forth. Presenting the work in that way has proven to gain more interest. However, I still think that we cannot study NIDCAP easily because the sophisticated level of implementation and priorities of the program are difficult to measure.

The other challenges I faced were comparable to “normal”

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**I still think that we cannot study NIDCAP easily because the sophisticated level of implementation and priorities of the program are difficult to measure.**

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challenges of the head of a department. As head, I continually faced personal and relationship issues within the staff. A NICU has very difficult periods when facing death, malformations, impairment, etc. It is very important to take care of emotions or feelings of patients, but the staff need special attention too, and sometimes psychological support. Introducing NIDCAP provided positive returns from the team and I felt happy to have a happy staff most of the time.

I have so many good memories of my life as Head of the NICU in Saint-Pierre. The teamwork to provide a different way of caring is probably what made me most happy. Initiatives taken by staff members and parents feeling at home are a few examples of what made me feel good.

The situation has evolved, so many things which were “avant-garde” have become routine. With the foundation that I have described, the future of the Training Center in Brussels now relies on the new team directing the unit. They will decide what they want at local, national and international level. They have the skills.

Personally, I am now running an international network eNewborn, registering data on Very Low Birth Weight Infants. I again want to move away from the traditional approach of looking at data. For instance, I think parents could, on a voluntary basis, provide information using special Apps. PREM (Patient Reported Experience Measure) and PROM (Patient Reported Outcome Measure) could be a next step telling us how families see things.

— Dominique Haumont  
Brussels, May 28, 2019



## Mission

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

*Adopted by the NFI Board, July 1, 2019*

## Vision

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

*Adopted by the NFI Board, October 20, 2017*



# Global Perspectives of Developmental Care – Belize

Melissa R. Johnson, PhD

Senior Trainer, Carolina NIDCAP Training Center, Raleigh, NC, USA

Of all the advances in neonatology in the past several decades, developmentally supportive, family-centered care is arguably one of the most powerful tools for improving outcomes in countries with limited economic resources. Developmental care does not require expensive technology, and rather it is based on sensitive observation, responsive hands-on care, and strengthening relationships among infants, families and caregivers. While some aspects of the highest quality, Newborn Individualized Developmental Care and Assessment Program (NIDCAP) based developmental care can be relatively costly (for example, single-room NICU design including family accommodations), resourceful and adaptive planners in developing countries are no strangers to finding creative solutions to such challenges. We have only to look at the history of kangaroo care to see strong proof of this concept, as countries as diverse as Colombia, South Africa and Argentina have led the way in developing and implementing this critical strategy.



## A Collaboration Opportunity

These issues were clearly demonstrated in a recent educational effort that this trainer was fortunate to participate in during a visit to the beautiful country of Belize in the fall of 2017. Belize is a fairly small independent and sovereign country located on the north-eastern coast of Central America bordered on the northwest by Mexico, on the east by the Caribbean Sea, and on the south and west by Guatemala. Belize is about 180 miles long and 68 miles wide on the mainland, with a population of around 370,000 people, a relatively low density. It is geographically impressive, with famous coral reefs, rain forests, and mountainous areas. The population is extremely diverse culturally, ethnically and linguistically. Though the official language is English (independence from Great Britain was obtained in 1981), over half the population is multi-lingual, with Creole and Spanish spoken by many. The health care system is a complex combination of advances and limitations, with an active health ministry working hard to improve outcomes, but limited numbers of locally trained professionals available to serve the geographically dispersed population. One of the strategies currently in use is close collaboration with high-quality nonprofit agencies to provide not only direct care, but also training and professional development. The non-profit agency *World Pediatric Project* (WPP), based in the United States (Richmond, Virginia and St. Louis, Missouri) has been a leader in this work, by coordinating visits from leading pediatric specialists from the U.S. who work closely with professionals in Belize to help children with

complex medical and surgical needs. WPP works with physicians and families to bring children who require specialized care to U.S. facilities (arranging visas, transportation and financial support for parents as well as children). Of equal importance in WPP's work is the facilitation of professional visits that provide intensive, person-to-person training on issues requested by the local medical staff. The physicians, nurses, and other specialists donate their time and expertise, with WPP providing logistical support and maintaining ongoing relationships with the facilities and professionals involved. (Note: WPP operates in twelve countries in Central America and the Caribbean.)

## Newborn Care in Belize

One important activity for WPP in the past several years is enhancing newborn care in Belize, which has one Newborn Intensive Care Unit for the entire country, located at Karl Heusner Memorial Hospital in Belize City. Local leaders have drawn on multiple resources, including support from such varied donors as the government of Japan, to allow the construction of an immaculate and fairly spacious new facility that includes not only impressive technology but also parent sleep rooms and a roomy family lounge. Additionally, the hospital has achieved Baby-Friendly designation and is strongly committed to breastfeeding for all infants. However, the staff of the NICU, including administrative leaders, nursing leaders, and physician leadership including Belizian and Cuban physicians, strongly desired to continue to improve the quality of care. They were able, with the help of WPP, to link with a number of U.S. specialists, in fields just as pediatric surgery and urology. Volunteer physicians include North Carolina-based neonatologist Dr. Claudia Cadet, who has training and experience in international health. Dr. Cadet began her work in Belize focusing on improvement in respiratory care. As she planned a return visit in close conversation with the professionals in Belize, she was asked to include developmental care in the materials to be shared during her next visit. In response to this request, she included this trainer on her team, which also included an experienced nurse practitioner and a nurse educator who is actively pursuing NIDCAP professional status. The team was very clear that the goal of the visit was to support and strengthen the efforts begun by the local professionals, who had made a great start but wanted to continue to progress, with formal training programs belonging in the future.

The visit by the team of four (all current or recently part of WakeMed's NICU) was a wonderful experience due to several key factors. A primary factor was the relationship that Dr. Cadet



*The WakeMed Neonatology Team and Belize leadership*



*Local headquarters for the sponsoring organization, World Pediatric Project*

had built with the staff of WPP and the local medical team, who were able to discuss in detail what their needs were prior to the team's visit. Another factor was the caliber of the WPP staff in Belize, whose understanding of the local health care system, the hospital's history and structure, and the cultural issues impacting care, were all critical. The nursing leadership in the unit was paramount to success, with the head nurse demonstrating the qualities of leadership of her staff, dedication to quality, and

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**The nursing leadership in the unit was paramount to success, with the head nurse demonstrating the qualities of leadership of her staff, dedication to quality, and motivation to strengthen developmental care that would be the envy of any nursery.**

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motivation to strengthen developmental care that would be the envy of any nursery. It was especially striking when several supervisors, including the nurse manager, took over the care of all the infants for an hour so that the entire afternoon shift could attend a developmental care lecture. An additional key component, as is so often the case, was flexibility. For example, topics needed to be shortened or expanded depending on issues noted at the bedside (i.e. more time on issues of nutrition and a last-minute addition of a talk on developmental follow-up), and many key concepts were so much better communicated through demonstration than lecture (i.e. four-handed care). Finally, we quickly discovered that the word “can’t” was not in the vocabulary of these professionals; some of the recommendations that we made

fairly tentatively, not sure if they would be possible, started to be implemented before the end of the first week (i.e. dimmers on light switches).

### Lessons Learned

What were some of the key lessons learned during this visit that might be useful to other NIDCAP professionals with an interest in sharing this work in countries not yet included?

- Begin by building on existing strengths, where nurseries have the creativity and motivation to push forward even with the existence of real challenges.
- As always, relationships are critical, and time spent discussing local priorities and interests is perhaps even more important than when you are training in your own culture.
- Flexibility is everything; think of your original itinerary and curriculum as gentle suggestions to get you started, with the real schedule emerging based on what is happening that week or that day.
- Never assume that something is impossible; professionals in developing countries have resilience and adaptive skills, from which we have much to learn.
- Identify an existing organization that has experience and expertise in facilitating health care improvement in the region in which you will be working.
- Take advantage of the “low tech high touch” aspects of our work, such as skin-to-skin and four-handed care, as you help build confidence and capacity.

In thinking about these lessons, it also appears that some of them apply to work in the trainer's own cultural context. Developing and building relationships, starting with strengths, and adapting to the unique needs of each nursery and community are important in all training and consultation activities.

As the work of the NIDCAP Federation International continues to expand throughout the world, sharing our knowledge with countries who have fewer financial resources will pay us dividends as we gain from their resources of energy, commitment and creativity.

## NIDCAP TRAINING CENTERS WORLDWIDE



### NIDCAP Training Centers Around the World

#### Australasian NIDCAP Training Centre- Sydney Australia

In October 2017 we achieved our goal of becoming a NIDCAP Training Centre, this was nearly 20 years after Dr. Heidelise Als had come to Australia in 1998 to begin training in the Grace Centre for Newborn Care at the Children's Hospital at Westmead in Sydney Australia. Over this time we changed trainers to Dr. Joy Browne in 2000 and we saw many nurses, neonatologists and occupational therapists commence training. In 2008 we had our first successful NIDCAP Professionals. In 2017 we had our first NIDCAP Trainer – Nadine Griffiths.

The Grace Centre for Newborn Intensive Care is a quaternary service at the Children's Hospital at Westmead in Western Sydney for the state of New South Wales. There are approximately 600 admissions each year of out-born neonates who require surgery in the newborn period. We work closely with the High-risk birth unit at Westmead Hospital across a one kilometre link bridge. We also have a close working relationship with Medipole De Koutio Hospital Centre Territorial Gaston-Bourretin Noumea, New Caledonia which is a special collective of France in the southwest Pacific Ocean, located about 1,210 kilometres east of Australia. The focus of care within Grace Centre for



*NIDCAP Professionals, Kristen James Nunez, Jane Pettigrew, Nicola Oste, Nadine Griffiths (NIDCAP Trainer), Catherine Turner, Joy Browne (APIB Trainer), Kim Psaila, Kaye Spence (Co-director)*

Newborn Intensive Care is for complex newborns requiring cardiac management and surgery, general surgery and specialist medical conditions with a focus on improving outcomes, effective pain management, neurodevelopmental assessments, expert psychosocial support for families and evidenced based medical care.

There are approximately 150 staff members consisting of neonatologists, neonatal fellows, registrars, nurse practitioners, clinical nurse specialists, educators, consultants, managers, occupational therapists, speech pathologists,

physiotherapists, family support volunteers, social worker as well as translators, administrative and ancillary staff. There is a strong and active clinical research unit with a focus on developmental outcomes, translational research, critical appraisal and quality improvement. In 2019 there were two doctorally prepared staff, Cathryn Crowle and Natalie Fairbairn both OTs and NIDCAP Professionals. Currently there are three nurses undertaking doctoral studies and the majority of nurses have a post-graduate qualification.

Families are very important in our

team and we have an open access policy for their participation. They are welcome during ward rounds and their contribution is encouraged. A Parent Advisory Council was established nearly 20 years ago and has evolved in various forms. We value parent feedback and work with them on ideas for improvement. In 2018 a Family Support Volunteer program was introduced to enable families to use the volunteers when unable to be with their baby and to entertain siblings to allow parents more one on one time with their baby when in the unit.

In establishing the Training Centre we decided on a structure that could ensure sustainability of the centre. Two co-directors, Alison Loughran-Fowlds and Kaye Spence were appointed. At the same time a Board of Directors were appointed to oversee the work and financial costs of the Centre. The current Board consists of: Angela Casey (Nurse Manager), Robert Halliday (Neonatologist representative), Kristen James Nunez (NIDCAP Professional representative), Cathryn Crowle (Allied Health Representative), Eleni Gerassis (Parent representative), Nadine Griffiths (NIDCAP Trainer), Gordon Thomas (Head, Department of Surgery), Daphne D-Cruz (neonatologist for external organisation) and Donna Waters (Dean, Sydney Nursing School, Sydney University). The meetings are held quarterly and chaired by the Co-directors.

The centre is very active and, since establishment in 2017, there have been six successful NIDCAP Professionals complete their training. NIDCAP Training is planned on a tier system with applicants required to have completed both FINE 1 and FINE 2 prior to commencement. To date 13 FINE 1 courses have been delivered with 435 participants from all eight states and territories as well as Indonesia. Six FINE 2 programs have been held with 46 participants. The FINE programs are taught and mentored by NIDCAP Professionals under the leadership of the Trainer Nadine Griffiths.

The centre has a Facebook page and webpage which is very active and used to promote the work of the centre, NIDCAP and developmental care strategies. Exciting strategies are used to ensure all babies, families and staff are aware of specific



*Parents are actively involved in their baby's care*

benefits based on scientific evidence. Initiatives include 'Light it Purple' for World Prematurity Day, Kangaroo-a-thon, Read-a-thon, Mothers' day, as well as a monthly newsletter with updated information. We are actively involved in fundraising initiatives supported by Eleni Gerassis, our parent representative. Staff and families have participated in the Race for Grace (keeping stationary bikes running for 24 hours), auctions and gala balls.

We are very proud of our staff and this year Nadine Griffiths (NIDCAP Trainer) received the coveted Consumer Award at the annual hospital awards. We aim to be actively involved in the NIDCAP Federation International and Kaye Spence has served on the Board of Directors and is the current Senior Editor for the Developmental Observer. Our team has attended

most NIDCAP Trainers Meetings and has contributed with many presentations over the years. Last year we were delighted to have Joy Browne become an affiliate of the Centre as an APIB Trainer.

Our goals for the future are to continue to develop and expand as resources allow. We are planning for a second trainer to enable the training program to expand to other centres. There is considerable interest in NIDCAP and we are currently looking at unit design as we plan to move into a new unit in a new building in 2021. This gives the opportunity to redefine our focus to ensure neuroprotective care remains not only our focus but that of the organisation's administrators and Government ministers.



*Cathryn Crowle, OT (NIDCAP Professional) assessing Oscar at 3 months follow-up.*



## “Who is that masked man?”

Jeffrey R. Alberts, PhD  
Indiana University, NFI Science Committee, Associate Editor for Science

Target article: Cyr-Alves, H., Macken, L. and Hyrkas, K. (2018) Stress and Symptom of Depression in Fathers of Infants Admitted to the NICU, *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, 47: 146-157.

In 1933, *The Lone Ranger* was a favorite on U.S. radios. In 1946, the show debuted on the new medium of television and became a cultural icon in the States. The Lone Ranger character was a mysterious, heroic cowboy. He wore a black mask and did good with humble anonymity. At the end of each episode, after a successful, selfless exploit, as our hero rode off on his white steed with his trusted Indian companion, grateful townspeople would ask, “Who is that masked man?”

There seems to be an emerging realization that fathers of babies in the NICU are Lone Rangers. They are little known, but heroic. Babies hold center stage in the NICU, often with a mom that becomes known, understood, and integrated into the daily routines. The dad is more likely to be off stage, in the wings, and kind of mysterious. In my experience, fathers of babies in the NICU are often “hard to read”. It is as if they are behind a mask. Who is that masked man?

Cyr-Alves, Macken, and Hyrkas (2018) describe our woeful state of knowledge about fathers of babies in the NICU. There is little systematic information. So they turned to a 51-bed NICU study site in the northeast of the U.S., where they probed into phenomena of stress and depression among NICU fathers. They studied 104 dads, beginning with their infants’ admission to the NICU (Time (T) 1), then 3 weeks later (T2), again at discharge (T3), and finally 2 months after discharge (T4).

At each of the four time points, trained staff administered two, oft-used questionnaires. The specific tools used were the Parental Stress Scale (PPS), an 18-item, self-report questionnaire, and the 10-item Edinburgh Postnatal Depression Scale (EPDS), also a self-report questionnaire. Because each father was tested at each time point, the data describe stability and change over time for each subject and, thus comprises a *longitudinal study*. This was practically the first of its kind.

The PSS expresses level of stress with a composite score that can range from 18 -90. In the hands of previous researchers, a score of 43 or more was indicative of “high” level of stress. In the present study, the average stress levels reported by the NICU fathers was a moderate, 32. Statistically, there was no overall change in reported stress levels from T1 and T4, but the authors dug more deeply into the numbers and found that significantly more fathers scored as highly stressed (above 43) at T1 and at T4, suggesting that circumstances surrounding admission to the NICU and when the baby is settling into the home, can bring notable challenges.

The researchers sought to measure the incidence of depression

in NICU fathers and assayed for symptoms with the EPDS. Fathers in the present study consistently produced low average scores, suggesting no depressive symptoms. Again, the authors looked more deeply into the results by asking about the frequency of depressive symptoms – for this can get lost if we look only at averages. They found that 41% of the fathers reported minor signs at T1; 16% showed major symptoms at that time.

Amid the statistical metrics in this paper, “Chronbach’s  $\alpha$ ” was used and this ominous-sounding term might need explanation. Chronbach’s  $\alpha$  represents the degree to which there is internal consistency between different tests or test items. The idea is that such consistency indicates that the tests are measuring the same construct, implying reliability and accuracy. According to conventions guiding interpretation of such scores, Chronbach’s  $\alpha$  in the present study scores indicated “satisfactory” internal consistency.

In all, this thoughtfully-designed and well-reported investigation identified only modest representations of stress and few symptoms of serious depression. I think one can detect some surprise in the authors, which I found comforting, because I was shocked. The stress and depression scores do not correspond to the severity of the babies’ condition or to the realities of the impact of having a newborn requiring intensive care. Why might this be?

The authors considered a range of possible explanations, including a subject population lacking diversity, unknown psychological status of each father before the baby’s hospitalization. They acknowledge that self-reports are susceptible to modifications shaped by social expectations. For these or other reasons, these tests were not sensitive to reflect fathers’ experiences or were incompatible with the dads’ abilities to report their condition.

I believe that this is an important and valuable research report. Although the findings were mostly ‘negative’, meaning they didn’t reveal big effects, this is not failure. The research question is not *whether* NICU dads are stressed or get depressed, it is *how* do we recognize and measure the important elements that comprise the fathers’ stressed and depressed conditions? These are vital matters of well-being, also important to the health of the mother, the strength of the parental bonds, and to the development of the infant.

Once more sensitive measurements are identified, it will be advantageous to incorporate a control group to learn more about the tests and, importantly, to learn more about how NICU fathers differ from new fathers with healthy babies. Do they show

more or different kinds of stress or depression? How much more? Carefully constructed, matched sample controls will someday be a useful part of a serious, systematic analysis of these important questions. When these fathers are better understood, it will be possible to develop and validate interventions and protections for them. More and different populations must be included. There is much to be learned about fathers in different cultures and different health care systems.

We are at a most fundamental, basic starting place. We are just beginning to ask, what is behind that mask? What is hurt and what is intact? What can we provide to facilitate his fatherhood and through the derived benefits to mother, buttress a loving family that will help a sick baby recover and travel on a healthy developmental path?

## The Gold Standard for Excellence in Newborn Individualized Developmental Care

### Model of the NIDCAP Nursery: From Self-Assessment to NIDCAP Nursery Certification

(Deborah Buehler, PhD, Sandra Kosta, BA, Heidelise Als, PhD, September 2018)

The figure graphically describes the relationship of training and support opportunities to nursery change from conventional care to consistently well-integrated NIDCAP care. It depicts the roles and relationships of newborn nursery components and the support opportunities offered to nursery professionals and staff engaged in this change process.

The infant and family are depicted at the nursery's core, cared for by the professionals and staff within the nursery and hospital. The hospital is understood as part of a greater community, a community from which infants and families come and to which they hope to return. The core of the figure shows the infant-parent relationship as it moves from one of infant isolation from the parents (Conventional Care; bottom) to one of full emotional and physical integration of infant and parents (NIDCAP Care; top) within the nursery.

### Model of the NIDCAP Nursery

Highly Attuned NIDCAP Care - Nursery Certification

#### PROCESS of NIDCAP CARE IMPLEMENTATION

Consistently Well-Integrated NIDCAP Care

Variable NIDCAP Care

NIDCAP Beginnings

Conventional Care

Nursery Self-Assessment: Identification of Strengths & Challenges

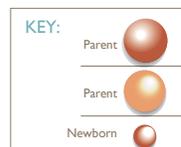
#### SUPPORTS FOR NURSERY CHANGE

Continued Mentorship for Self-Assessment, Reflection, Education and Training

NIDCAP & APiB Training for Core Teams and Nursery Assessment Review

Introductory/ Foundational Education (e.g., NFI Nursery Foundation Education, FINE, and other NFI-Endorsed Conferences & Courses) for all Professionals & Staff

Interdisciplinary (incl. Parents) Goal Setting and Planning



D. Buehler, S. Kosta, H. Als



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This is a selection of recent publications relevant to NIDCAP.

1. Makris NF, Vittner D, Samra HA, McGrath JM. **The PREEMI as a measure of parent engagement in the NICU.** *Applied Nursing Research* 2019, 47: 24–28.

Individualizing the infant's plan of care, can support mothers and fathers to attain the confidence and skills necessary to manage their infant's care: which introduces the concept of self-management in the NICU. Using the PREEMI instrument to assess engagement has the potential to promote collaboration and communication with the health care team that emphasizes individualized care that is personal, holistic, and comprehensive while at the same time identifying and supporting at risk parents.

2. Mirlashari J, Fomani FK, Brown H, Tabarsy B. **Nurses' and physicians' experiences of the NIDCAP model implementation in neonatal intensive care units in Iran.** *Journal of Pediatric Nursing: Nursing Care of Children and Families* 2019, 45: e79–e88

This qualitative study highlights how NIDCAP provides a comprehensive and effective care model for premature infants, with the goal to promote neonatal growth and development while also facilitating the self-efficacy of caregivers. Implementation of the NIDCAP model requires attention to the social context, infrastructure, the facilities and resources of each country, and the needs of caregivers. Health care resources are required to sustain NIDCAP specialists and a favourable environment is necessary for its multidimensional application across NICU's around the world.

3. Dall'Oglio I, Mascolo R, Tiozzo E, Portanova A, Fiori M, Gawronski O, et al. **The current practice of family-centred care in Italian neonatal intensive care units: A multicentre descriptive study,** *Intensive and Critical Care Nursing*, 2019, 50: 36-43.

A multi-centered study showed a variability in the organization of family-centred care practices in Italian neonatal intensive care units and the need to involve parents as partners in their infant's care team. Although family-centred care is considered important by Italian neonatology healthcare professionals, much remains to be done to improve family-centred care practices in newborn intensive care units in Italy.

4. Segers E, Ockhuijsen H, Baarendse P, van Eerden I, van den Hoogen A. **The impact of family centred care interventions in a neonatal or paediatric intensive care unit on parents' satisfaction and length of stay: A systematic review.** *Intensive and Critical Care Nursing*, 2019 50: 63-70.

There was strong evidence for a significant decrease in length of stay when parents were participating in caring for their infant in a newborn intensive care unit. Moderate evidence was found in parents' satisfaction, which increased when collaboration between parents and professionals in a newborn intensive care unit

improved. However, studies performed in a paediatric intensive care setting were of weak to moderate quality and were too few to show evidence regarding parents' satisfaction and length of stay.

5. Turan T, Erdoğan C, Serap Ceylan S. **The validity and reliability study of Turkish version of the fathers' support scale: Neonatal intensive care unit.** *Intensive and Critical Care Nursing*, 2019, 50: 125-130.

Fathers whose infants are cared for in the newborn intensive care unit have negative experiences and thus require support. This study was carried out with the aim of performing a validity and reliability study of the Turkish version of the "Father's Support Scale: Neonatal Intensive Care Unit" (FSS: NICU). It was found that the Turkish version of the FSS: NICU was a valid and reliable measurement tool.

6. Skene C, Gerrish K, Price F, Pilling E, Bayliss P, Gillespie S. **Developing family-centred care in a neonatal intensive care unit: An action research study.** *Intensive and Critical Care Nursing*, 2019, 50:54-62.

Understanding the context of the neonatal unit can support cultural change when change is actively facilitated and owned by the staff concerned. Acknowledging parents as the main caregiver can be challenging for nurses and they require support and education to enable them to manage the changes necessary to provide Family-Centred Care.

7. Benzies KM, Shah V, Aziz K, Lodha A, Misfeldt R. **The health care system is making 'too much noise' to provide family-centred care in neonatal intensive care units: Perspectives of health care providers and hospital administrators.** *Intensive and Critical Care Nursing*, 2019, 50:44-53.

This qualitative study found that the health care system was making 'too much noise' for health care providers and hospital administrators to provide family-centred care in ways that would benefit infants and their families. Recommended improvements included: refining staffing models, enhancing professional development, providing tools to deliver consistent care, recognising parental capability to be involved in care, strengthening continuity of care, supporting families to be with their infant, and designing family-friendly environments.

8. Mitha A, Piedvache A, Glorieux I, et al; for the EPIPAGE-2 Neurodevelopmental Care Writing Group. **Unit policies and breast milk feeding at discharge of very preterm infants: The EPIPAGE-2 cohort study.** *Paediatric Perinatal Epidemiology*, 2019;33:59–69.

In total, 47.2% of very preterm infants received breastmilk at discharge (range across units 21.1%-84.0%). Unit policies partly

explained this variation. Breastmilk feeds (BMF) at discharge was associated with Kangaroo Care (adjusted odds ratio (aOR) 2.26 (95% confidence interval (CI) 1.40, 3.65)), with policies supporting BMF initiation (aOR 2.19 (95% CI 1.27, 3.77)) and maintenance (aOR 2.03 (95% CI 1.17, 3.55)). Adopting policies of higher performing units could be an effective strategy for increasing breastfeeding rates at discharge among very preterm infants.

9. Baghlani R, Hosseini MB, Safaiyan A, Alizadeh M, Arshadi-Bostanabad M. **Neonatal intensive care unit nurses' perceptions and knowledge of newborn individualized developmental care and assessment program: A multicenter study.** *Iranian Journal of Nursing and Midwifery Research* 2019;24:113-7.

This cross-sectional study was conducted on 120 nurses working in Iranian NICUs of Alzahra, Taleghani, and Children hospitals affiliated with the educational and treatment centers of Tabriz University of Medical Sciences as well as 29 Bahman Hospital affiliated with Tabriz Social Security Organization. The results of this study showed that the majority of nurses participating in the study had high knowledge about NIDCAP.

10. Lisanti AJ, Vittner D, Medoff-Cooper B, Fogel J, Wernovsky G, Butler S. **Individualized family-centered developmental care an essential model to address the unique needs of infants with congenital heart disease.** *Journal of Cardiovascular Nursing* 2019, 34 (1):85-93.

The incorporation of Individualized Family-Centered Developmental Care (IFDC) interventions is essential for the infant with cCHD and should be a standard of care. Applying IFDC with a recovery perspective in all aspects of caregiving will provide opportunities for individualization of care and parent engagement, allowing infants in the CICU to recover from surgery while supporting both short- and long-term neurodevelopment.

11. Finch-Edmondson M, Morgan C, Hunt RW, Novak I. **Emergent prophylactic, reparative and restorative brain interventions for infants born preterm with cerebral palsy.** *Frontiers in Physiology*. 2019;10:15.

This review discussed the emerging prophylactic, reparative, and restorative brain interventions for infants born preterm, who are at high risk of developing cerebral palsy. The authors examined the current evidence, considering the timing of the intervention with relation to the proposed mechanisms of action. The description of the development of novel markers of preterm brain injury, which will undoubtedly lead to improved diagnostic and prognostic capability, and more accurate instruments to assess the efficacy of emerging interventions for this most vulnerable group of infants.

12. Schenk K, Stoffel L, Bürgin R, et al. **The influence of gestational age in the psychometric testing of the Bernese Pain Scale for Neonates.** *BMC Pediatrics*. 2019;19(1):20.

The modified Bernese Pain Scale for Neonates (BPSN) that includes facial expression, crying, posture, and heart rate is a reliable and valid tool for assessing acute pain in full-term and

preterm neonates. The results of this study suggest that adding different cut-off points for different GA-groups will improve the BPSN's clinical usefulness.

13. Chuang LJ, Wang SH, Ma MC, Lin CN, Chen CL, Huang MC. **A modified developmental care bundle reduces pain and stress in preterm infants undergoing examinations for retinopathy of prematurity: A randomised controlled trial.** *Journal of Clinical Nursing*. 2019, 28(3-4):545-559.

The modified developmental care bundle included environmental modifications, positioning and containment, oxygen supplementation, interaction and approach and cue-based individual care, were applied before, during and after the ROP examination. Results showed a bundled developmental care intervention significantly reduced pain and stress responses and the time needed for infants to recover their physiological status following the procedure. Since the results show the benefits of developmental care in an ROP examination, it can be the practical evidence basis by which to develop a standard of procedure or guideline for clinical practice.

14. Liao JH, Hu RF, Su LJ, Wang S, Xu Q, Qian XF, He HG. **Nonpharmacological interventions for sleep promotion on preterm infants in neonatal intensive care unit: A systematic review.** *Worldviews on Evidence-Based Nursing*. 2018, 15(5):386-393.

Nonpharmacological interventions included the Newborn Individualized Developmental Care and Assessment Program (NIDCAP), music, non-nutritive sucking, touch, cycled light, co-bedding, rocking, oral sucrose, remolding mattresses, and family nurturing. The meta-analysis of 36 studies showed that: 1. NIDCAP had no significant effect on total sleep time efficiency (TST%;  $p = .34$ ); 2. mattress interventions had significant effects on TST% ( $p < .001$ ); and active sleep efficiency (AS%;  $p = .006$ ) but no significant effect on quiet sleep efficiency (QS%;  $p = .75$ ); 3. cycled light increased TST ( $p = .02$ ); and 4. Co-bedding had no significant effects on QS% and AS% ( $p = .63$  and  $p = .88$ , respectively). Remolding mattresses and cycled light had significant effects on sleep promotion in preterm infants, but the quality of the evidence was very low. Further high-quality studies are needed to strengthen this evidence.

15. Masri S, Ibrahim P, Badin D, Khalil S, Charafeddine L. **Structured educational intervention leads to better infant positioning in the NICU.** *Neonatal Network - Journal of Neonatal Nursing*. 2018, 37(2):70-77.

A quality improvement (QI) project was initiated to increase knowledge and improve the compliance of 39 nurses and 52 physicians in infant positioning using the Infant Positioning Assessment Tool (IPAT). The project was part of Newborn Individualized Developmental Care Assessment Program (NIDCAP) training. The mean knowledge assessment test score improved significantly for both nurses ( $p < .0001$ ) and residents ( $p < .0001$ ) post intervention; IPAT scores increased significantly from 3.4 (+/-2.5) to 8.1 (+/-2.7) ( $p < .001$ ). Nurses' education

with hands-on practice improved infant positioning in the NICU; this may lead to fewer positional deformities and possibly an improved developmental outcome.

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16. Poets CF, Wiechers C, Rudiger M. **Optimal discharge of very immature preterm infants: Current evidence and own approach.** <Optimale Entlassung sehr unreifer Frühgeborener: Aktuelle Evidenz und eigenes Vorgehen.> *Monatsschrift für Kinderheilkunde*. 2019, 167, 1:26-33.

Discharging very immature preterm infants requires maintenance of a normal body temperature, full feeds and an adequate weight gain and no relevant hypoxia/bradycardia. In addition, considerations for discharging the baby on a home monitor or caffeine, sociomedical aftercare and nutritional status. Breastfeeding with a fortifier is optimal for nutrition; which is promoted from birth, e.g. by early skin-to-skin contact and baby-driven feeding. Breastmilk supplementation may also be indicated after discharge. Interdisciplinary aftercare is essential to guarantee treatment success and to avoid re-admission. Measures to increase parental competence, such as the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) should be initiated prenatally and immediately postnatally in order to enable an early discharge.

- 
17. Godarzi Z, Zarei K, Shariat M, Sadeghniat K, Nikafs N, Sepaseh H. **Correlations of handling procedures and sleep patterns of the infants admitted to the neonatal intensive care unit.** *Iranian Journal of Neonatology*. 2018, 9 (3):35-41.

This observational cross-sectional study has a sample population of 15 preterm infants, and duration of the handling procedures was 15 days or 360 hours. Handling procedures were recorded within an uninterrupted 24-hours period. Sleep patterns of the infants were checked at 8 AM - 8 PM using Als' behavioral states scale of Newborn Individualized Developmental Care and Assessment Program (NIDCAP) observation sheet. According to the results, supportive handling could increase sleep duration in preterm infants. Therefore, it is recommended that this technique be applied for the comfort of preterm infants in the presence of parents.

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18. Berne-Audeoud F, Marcus L, Epiard C, Debillon T, Ode C, Nidcap G. **NIDCAP: Appropriate care for preterm infants and their families, because their future is a challenge.** <Le NIDCAP: Des soins sur mesure pour les bébés prématurés et leur famille, car leur avenir est un défi.> *ANAE - Approche Neuropsychologique des Apprentissages chez l'Enfant*. 2018, 30 (152):63-69.

The current challenge aims to provide care that enables preterm infants to reach their optimal cognitive, psychomotor and emotional development. NIDCAP is an early and individualized program based on systematic observations of the infant's behavior in order to provide recommendations of care for each infant and their family. It is one of the few programs scientifically validated and approved by families and associations for its beneficial impact on the infant and his/her family.

19. Gardner FC; Adkins CS; Hart SE; Travagli RA; Doheny KK. **Preterm stress behaviors, autonomic indices, and maternal perceptions of infant colic.** *Advances in Neonatal Care*. 2018, 18(1):49-57.

Thirty preterm (mean +/- SE = 32.7 +/- 0.3 weeks postmenstrual age [PMA]) infants underwent direct NIDCAP (Newborn Individualized Developmental Care and Assessment Program) observation during routine care and had HRV measurements during their first week post-birth. Sixty-three percent of mothers completed the Infant Colic Scale at 6 to 8 weeks adjusted postnatal age. Nonparametric tests were used to determine associations among behaviors, HRV, and maternal perceptions of infant colic. Self-consoling behaviors were positively associated with HF-HRV (vagal tone). Stress behaviors were positively associated with low-frequency/high-frequency HRV (sympathetic dominance). Infants who displayed more stress behaviors also demonstrated more self-consoling behaviors. HF-HRV provides information on the infant's capacity to modulate stress and is a useful, noninvasive measure when behaviors are more difficult to discern.

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20. Kugelman A, Borenstein-Levin L, Jubran H, Dinur G, Ben-David S, et al. Haddad J. **Less is more: modern neonatology.** *Rambam Maimonides Medical Journal*. 2018, 9(3):30.

Risk factors for iatrogenesis in NICU include prematurity, mechanical or non-invasive ventilation, central lines, and prolonged length of stay. Less invasive strategies such as delayed cord clamping, no routine suction for the airways for meconium-stained fluid, lower levels of oxygen saturations were used during the first 10 minutes of life. Endotracheal ventilation is avoided and non-invasive respiratory support of continuous positive airway pressure is started in the delivery room. Non-invasive methods of surfactant administration are utilized. The shorter duration of central lines, and early feeding of human milk is routine. "Kangaroo care" and Newborn Individualized Developmental Care and Assessment Program (NIDCAP) together with a calm atmosphere with parental involvement are encouraged.

## CALL for EXPRESSION of INTEREST to JOIN the EDITORIAL TEAM

We are calling for expressions of interest from NFI members to join the Editorial Team. We would like global representation. Email Senior Editor Kaye Spence at: [developmentalobserver@nidcap.org](mailto:developmentalobserver@nidcap.org)

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## NIDCAP Care in the Moment



*Family*

## Developmental Observer Submission Guidelines

The *Developmental Observer* is the official newsletter of the NIDCAP Federation International. We would like to receive submissions from the membership on any topic related to NIDCAP work either training, experiences or on the broader issues that support our work. We will also consider creative works that reflect NIDCAP work.

If you have an idea please let me know and we can work through the submission process. If English is not your first language we can help with some of the language issues.

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All articles are to be submitted to the Senior Editor Kaye Spence AM via the email [developmentalobserver@nidcap.org](mailto:developmentalobserver@nidcap.org). You will receive acknowledgement of your submission. An editorial review process occurs and once complete you will be notified of publication of your article.

### Article submission guidelines

Title of your article/story

Name of the author(s) and professional credentials

Organization and/or affiliation

An email contact address and a WhatsApp contact if available.

Submitted in MS word

Arial font– size 12 pitch

Double spaced

Number each page

Word length – 800 – 1500 words

Pictures 300dpi (please ensure you have permission to use and include a statement indicating this).

Diagrams, graphs and tables (embed in your document and send as a separate file)

We would also like to receive 'Letters to the Editor' for publication. These can be between 50-150 words.

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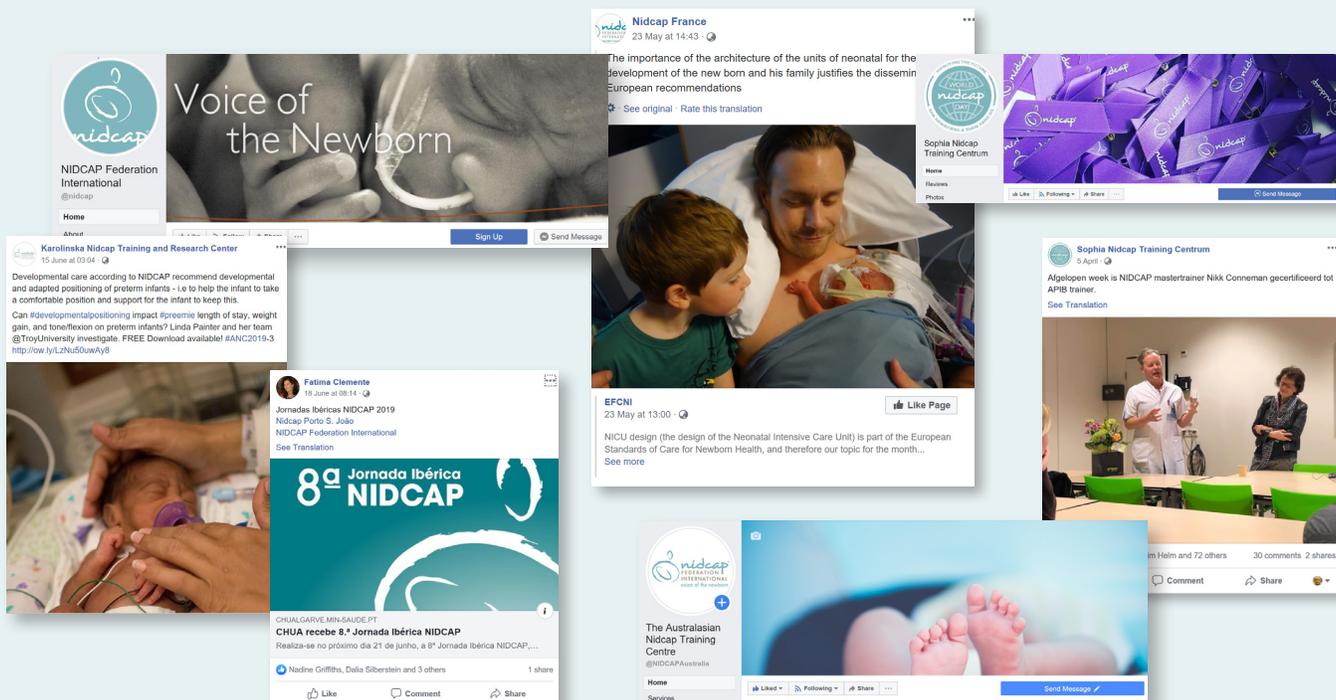
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# NIDCAP on the Web

## NIDCAP Training Centers – Facebook Pages

Many of the Training Centers and NIDCAP groups have established their own Facebook pages. These pages provide useful resources for members and by joining the groups and sharing the pages you are helping to spread information about NIDCAP. Here are a few to get you started. If you know of others please send an email to [developmentalobserver@nidcap.org](mailto:developmentalobserver@nidcap.org) and let me know for inclusion in the next issue.



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

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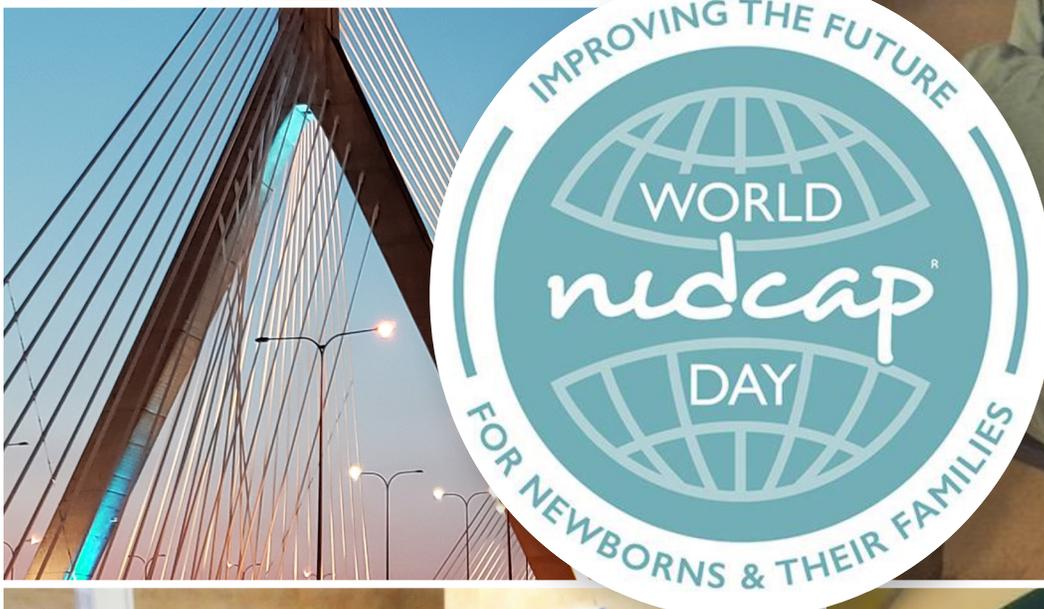
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# First Annual World NIDCAP Day!

This year, March 20th marked the first official World NIDCAP Day. This is an exciting new tradition for our NIDCAP Federation International organization and its supporters. World NIDCAP Day (and Month) is an opportunity to raise awareness of NIDCAP and to celebrate the incredible work that is being done every day around the world by NIDCAP Professionals, Trainers and Supporters to improve the experience of hospitalized infants and their families. Please see our website for more information and for images of the many of the NIDCAP celebrations held around the world. We invite you to join, celebrate and promote NIDCAP care next March and throughout the year to be a part of our powerful global community shaping the future for premature and ill infants and their families.



## Annual NFI Membership Meeting

Sunday, October 6, 2019  
2:20PM – 4:20PM

Sheraton Portsmouth Harborside Hotel  
250 Market Street  
Portsmouth, New Hampshire, USA



## The 30<sup>th</sup> Annual NIDCAP Trainers Meeting

October 5-7, 2019

Sheraton Portsmouth Harborside Hotel  
250 Market Street  
Portsmouth, New Hampshire, USA

*Hosted by Jim Helm on  
behalf of the NIDCAP  
Federation International  
(By Invitation Only)*



### Upcoming other conferences

**Save the Date:** March 4-7, 2020    **Call for Abstracts:** Due Monday, October 28, 2019



## The 33<sup>rd</sup> Annual Gravens Conference

*on the Environment of Care for High Risk Newborns*

*Biophysiology of  
Human Interaction*

Sheraton Sand Key  
Clearwater Beach, Florida  
March 4-7, 2020

Provided by:



Visit [www.TheGravensConference.com](http://www.TheGravensConference.com)

# NIDCAP TRAINING CENTERS

## AMERICAS

### North America

#### CANADA

##### **Edmonton NIDCAP Training Centre**

Stollery Children's Hospital  
Royal Alexandra Site  
Edmonton, AB, Canada  
Co-Directors: Andrea Nykipilo, RN and  
Juzer Tyebkhan, MB

Contact: Juzer Tyebkhan, MB  
email: [Juzer.Tyebkhan@ahs.ca](mailto:Juzer.Tyebkhan@ahs.ca)

#### UNITED STATES

##### **St. Joseph's Hospital NIDCAP Training Center**

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

Co-Directors: Bonni Moyer, MSPT and  
Marla Wood, RN, BSN, MED

Contact: Windy Crow  
email: [windy.crow@dignityhealth.org](mailto:windy.crow@dignityhealth.org)

##### **West Coast NIDCAP and APiB Training Center**

University of California San Francisco San  
Francisco, California, USA

Director and Contact: Deborah Buehler, PhD  
email: [dmb@dmbuehler.com](mailto: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 & Jean Powlesland, RN, MS

Contact: Jean Powlesland, RN, MS  
email: [jpowlesl@uic.edu](mailto:jpowlesl@uic.edu)

##### **National NIDCAP Training Center**

Boston Children's Hospital and  
Brigham and Women's Hospital  
Boston, Massachusetts, USA

Director: Heidelise Als, PhD  
Contact: Sandra M. Kosta, BA  
email: [nidcap@childrens.harvard.edu](mailto:nidcap@childrens.harvard.edu)

##### **Carolina NIDCAP Training Center**

WakeMed, Division of Neonatology Raleigh,  
North Carolina, USA

Director and Contact: Dorothy Vittner, PhD,  
RN, CHPE  
email: [dvittner@wakemed.org](mailto:dvittner@wakemed.org)

##### **NIDCAP Cincinnati**

Cincinnati Children's Hospital Medical Center  
Cincinnati, Ohio, USA

Director: Michelle Shinkle, MSN, RN  
Contact: Linda Lacina, MSN  
email: [Linda.Lacina@cchmc.org](mailto:Linda.Lacina@cchmc.org)

### South America

#### ARGENTINA

##### **Centro Latinoamericano NIDCAP & APiB**

Fernández Hospital  
Fundación Dr. Miguel Margulies and  
Fundación Alumbrar, Buenos Aires, Argentina  
Director and Contact: Graciela Basso, MD, PhD  
email: [basso.grace@gmail.com](mailto:basso.grace@gmail.com)

### OCEANIA

#### AUSTRALIA

##### **Australasian NIDCAP Training Centre**

The Sydney Children's Hospitals Network  
Westmead, Australia

Co-Directors: Alison Loughran-Fowlds MBBS,  
DCH, FRACP, PhD and Kaye Spence AM, RN, MN

Contact: Nadine Griffiths - Aust NIDCAP trainer  
email: [SCHN-NIDCAPAustralia@health.nsw.gov.au](mailto:SCHN-NIDCAPAustralia@health.nsw.gov.au)

### EUROPE

#### BELGIUM

##### **The Brussels NIDCAP Training Center**

Saint-Pierre University Hospital Free University of  
Brussels Brussels, Belgium

Director: Inge Van Herreweghe, MD

Contact: Delphine Druart, RN  
email: [delphine\\_druart@stpierre-bru.be](mailto:delphine_druart@stpierre-bru.be)

#### DENMARK

##### **Danish NIDCAP Training and Research Center**

Aarhus University Hospital, Aarhus N, Denmark

Director and Contact: Hanne Aagaard, RN,  
MScN, PhD

Co-Director: Eva Jörgensen, RN  
email: [aagaard@clin.au.dk](mailto:aagaard@clin.au.dk)

#### FRANCE

##### **French NIDCAP Center, Brest**

Medical School, Université de Bretagne  
Occidentale and University Hospital  
Brest, France

Director: Jacques Sizun, MD

Co-Director and Contact: Nathalie Ratynski, MD  
email: [nathalie.ratynski@chu-brest.fr](mailto:nathalie.ratynski@chu-brest.fr)

##### **French NIDCAP Center, Toulouse**

Hôpital des Enfants Toulouse, France

Director: Charlotte Casper, MD, PhD

Co-Director and Contact: Sandra Lescure, MD  
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#### GERMANY

##### **NIDCAP Germany, Training Center Tübingen**

Universitätsklinik für Kinder- und Jugendmedizin  
Tübingen, Germany

Director: Christian Poets, MD, PhD

Contact: Natalie Wetzfel, RN  
email: [natalie.broghammer@med.uni-tuebingen.de](mailto:natalie.broghammer@med.uni-tuebingen.de)

#### ITALY

##### **Italian Modena NIDCAP Training Center**

Modena University Hospital, Modena, Italy

Director: Fabrizio Ferrari, MD

Contact: Natascia Bertoncelli, PT

email: [natafili@yahoo.com](mailto:natafili@yahoo.com)

#### THE NETHERLANDS

##### **Sophia NIDCAP Training Center**

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

Director: Nikk Conneman, MD

Co-Director and Contact: Monique Oude Reimer, RN  
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#### NORWAY

##### **NIDCAP Norway, Ålesund Training Center**

Ålesund Hospital, Ålesund, Norway

Director: Lutz Nietsch, MD

Contact: Liv Ellen Helseth, RN

email: [nidcap@helse-mr.no](mailto:nidcap@helse-mr.no)

#### PORTUGAL

##### **São João NIDCAP Training Center**

Pediatric Hospital at São João Hospital  
Porto, Portugal

Director: Herclia Guimarães, MD, PhD

Co-Director and Contact: Fátima Clemente

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#### 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: [jperapoc@vhebron.net](mailto:jperapoc@vhebron.net)

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

Hospital Universitario 12 de Octubre, Madrid, Spain

Director: Carmen Martínez de Pancorbo, MD

Contact: María López Maestro, MD

email: [nidcap.hdcc@salud.madrid.org](mailto:nidcap.hdcc@salud.madrid.org)

#### SWEDEN

##### **Karolinska NIDCAP Training and Research Center**

Astrid Lindgren Children's Hospital at Karolinska  
University Hospital Stockholm, Sweden

Director: Stina Klemming, MD

Co-Director: Björn Westrup, MD, PhD

Contact: Ann-Sofie Ingman, RN, BSN

email: [nidcap@karolinska.se](mailto:nidcap@karolinska.se)

#### UNITED KINGDOM

##### **UK NIDCAP Centre**

Department of Neonatology,  
University College Hospital, London, UK

Director: Neil Marlow, DM FMedSci

Contact: Gillian Kennedy, MSc, OBE

email: [gillian.kennedy@uclh.nhs.uk](mailto:gillian.kennedy@uclh.nhs.uk)

### 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: [dalia.silberstein@clalit.org.il](mailto:dalia.silberstein@clalit.org.il)

## Become a Member of the NFI

The NFI has expanded opportunities for membership. Please join us! For more information and the online application form, visit our website at: [www.nidcap.org](http://www.nidcap.org) or email us at [nfimembership@nidcap.org](mailto:nfimembership@nidcap.org)