

Developmental Observer

The Official Newsletter of the NIDCAP® Federation International

NIDCAP Federation International (NFI)

Founded in 2001, the NFI is an international, non-profit membership organization. The NFI encourages the implementation of developmental care and assures the quality of the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) approach in 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, health care professionals, and nurseries in the NIDCAP approach.

“Love and compassion are necessities, not luxuries. Without them humanity cannot survive.”

DALAI LAMA

“Love is the way of all the babies in the World!”

CHRISTOPHER DUFFY,
10 APRIL 2012

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Message from the NFI President

Of Jazz, NIDCAP and the Process of Becoming

“Men are wise, not in proportion to their experience, but in their capacity for experience. This is the true joy in life, the being used for a purpose recognized by yourself as a mighty one; the being a force of nature... I am of the opinion that my life belongs to the whole community and as long as I live it is my privilege to do for it whatever I can. the harder I work, the more I live. I rejoice in life for its own sake.”

G. B. Shaw, *Man and Superman: A Comedy and a Philosophy*. Epistle Dedicatory to Arthur Bingham Walkley. Penguin Books, 1958. p18.



Jazz has a spontaneity and vitality in which improvisation plays a role. The individuality of the performing jazz musician plays a key role.¹ Travis Jackson states that jazz is music that includes qualities such as improvising, group interaction, developing an individual voice and being open to different musical possibilities.² In jazz, the performer will interpret a tune in very individual ways, never playing the same composition exactly the same way twice. Depending upon the performer's mood and personal experience, interactions with fellow musicians, or even members of the audience, a jazz musician may alter melodies, harmonies or time signature at will. Jazz, is often characterized as the product of egalitarian creativity, interaction and collaboration, placing equal value on the contributions of the composer if there is one, and the performer, and adroitly weighing the respective claims of the composer and the improviser. Similarly this is the case in NIDCAP at its best. A NIDCAP nursery is a setting where interactions among equals make a harmonious and always evolving whole, exhilarating to behold and affirming to experience. While analogies are doomed to fall short in most cases, contemplation of the differences between Jazz and classical music may be helpful when tempting to grasp and appreciate the differences between a traditional nursery and a NIDCAP nursery. In classical music the composer sets the direction and rules. The players in the performing orchestra make every effort to play the written music as true to its notation as their talents permit. Yes, there may be slight differences in phrasing from one orchestra to another and one conductor to another, yet a specific piece of classical music is recognizable wherever it may be played. Playing classical music draws attention to flawlessness, virtuosity, and accuracy and highlights mistakes. It may serve as a metaphor for the nursery that is guided by a set of protocols, reinforced by hierarchical leadership, and recognizable as such from location to location. Perhaps its size, underlying tempo

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and complexity might vary, the number of players differ. Yet the piece played is the same. A NIDCAP nursery is more like a piece of jazz music. Playing jazz draws attention to creativity, give and take, and relationship. It is a nursery with an interactive individuality that is recognizable in the way that jazz music is easily recognizable as jazz; yet each set played is unique, new and different, developed each time in its dynamics and harmonies, solos and resolutions depending on the individuality and relationship of voices with one another of those playing together. Each player trusts the other; the interplay is the essence rather than the goal. The infants and families set the themes, as it were, that penetrate and are returned to over and over again, no matter the crescendo of surrounding voices and themes of the staff. Around the infant and family themes the contra-points surge and are resolved again and again yet differently each time. This makes it a challenge to move from a traditional to a NIDCAP nursery. It may be as difficult as moving from being an accomplished classical musician to becoming a jazz musician.

As NIDCAP Trainers teaching, guiding and helping nurseries, i.e. complex jazz ensembles, to come into their own, to trust themselves as partners, trust their interplay and continuously become anew, and create themselves, Trainers must have trust and confidence themselves as well as patience and vision. Teaching the other the basic NIDCAP ingredients and tools is essential until these ingredients are mastered and have become second nature. Such ingredients include among others, astute observation of the interplay of the social and physical environments and the individual infants' behavior; tuning of writing to convey information that retains the emotional dimension of the interactions observed; deriving of specific and guiding interpretations that engender creativity in developing suggestions for next steps; and attunement and emotional presence to become astute in listening and proactive guidance. Once these are achieved and a sufficient core of such basic skills is available the transformation process from the traditional to the NIDCAP nursery is inevitable. Moving forward and creatively becoming is the emerging new theme. Much has been written about the process of change and the ways it may be facilitated. The NIDCAP Trainer's role becomes that of imparting the confidence that everyone counts and is accountable as individual for who he or she is. That

presents the teacher's opportunity and yet also the main challenge. To paraphrase Sanford Meisner³: The NICU is "an arena where human personalities interlock in the reality of doing." The "elements in a person's training that will make him [or her] a distinctive... [NIDCAP professional] are... the most delicate factors that a teacher can impart.... One can use standard principles and textbooks in educating people for law, medicine, architecture, chemistry or almost any profession – but not for [NIDCAP]. For in most professions every practitioner uses the same tools and [techniques] while the [NIDCAP Professional's] chief instrument is himself [or herself] and since no two persons are alike, no [universal] rule is applicable to any two [persons] in specifically the same way."

NIDCAP training is ultimately only successful in the one-to-one shaping and tuning of teacher and student. The NIDCAP Nursery Certification Criterion Scales (NNCCS)⁴ provide a kind of script, a loosely assembled accumulation of themes, sketched for consideration and contemplation of those invested in the care of infants and families in the NICU. They are far from a prescription, textbook or detailed 'How To' manual. Rather they represent a vision, a set of themes pictured from various angles and vantage points. Once sampled, they are intended to become the intriguing impetus and catalyst for the NICU, to tune to and be realized into a live process of continued becoming.

Thus the timing of the introduction to this collection of themes and sketches poses a delicate issue for the teacher; that the players have come to embrace the realization of the dynamic nature of the process of NIDCAP and of themselves as the agents and instruments in the process, likely is an important prerequisite. The players' intrigue and fascination with the promised beauty of the whole to be created as their own is the motivation best suited for the timing. Confidence to get to the level of active daily becoming is the threshold when success is assured.

Heidelise Als .

Heidelise Als, PhD

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Contributions

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A Mother's Story

In Her Own Words, Dina Cansinos-Levy's Story

Dina and Rafael Cansinos-Levy, and 3 year old sister, Noa'le, are the proud family of Yael, who was born at 27 weeks gestation, weighing 890 grams. Yaeli's family lives in Spain and her birth came as a total surprise when her parents and sister were in Israel for a family visit. What was originally scheduled as a brief trip to Israel, scheduled only to last a few days, ended up lasting several months after Yaeli's unexpected birth at the Meir Medical Center, in the city of Kfar Saba, Israel. Yaeli's mother, Dina, shares her very powerful story with us in this column. Dina's story reminds us what it is like for families to endure such a prolonged hospitalization in an intensive care nursery and the importance of nurturing the infant and family in their journey.

In another two days, our daughter Yaeli will celebrate one year of life outside the womb. In honor of her birthday, and out of our deep gratitude and recognition of the Newborn Intensive Care Unit team at the Meir Medical Center, my husband, Rafael built a website so that parents of preemies could have a place to go. It was just as important to my husband that the fabulous NICU staff that took care of our daughter, also have an easy way to check on the progress of infants who had graduated from the nursery.

Despite the fact that a year has passed, it is still difficult for me to write about our days in the NICU. Maybe one day I will find the strength to cope with these times and write about the experience. In the meantime, I have mustered up the energy to share some chapters of the book about Yaeli's birth.

Over a year ago, when I was 25 weeks pregnant, Rafael, Noa'le and I travelled to Israel for a Passover visit. It was a great and fun time! Two weeks after we had landed, on a Friday morning, I was planning a shopping trip to a supermarket while Rafael stayed with our daughter in a place called Udim. I took advantage of the free time to go for coffee with two of my dear friends, Noam and Nurit. While we were at the coffee shop, I suddenly jumped with pain. Nurit, who would later be my marvelous birth coach, said to me "it looks like a contraction." Of course, I had no idea what she was talking about, and we parted with our goodbyes and my friends left for a weekend in Jerusalem. I continued on to the supermarket, which was, of course, one of the last activities I would do for a while. After spending over two hours at the supermarket, I returned home with my



Yaeli "kangarooing" with her mother during her first few days in the NICU.

5 kilos of chicken, which I remember was on sale, and did not feel well. It was obvious that something was going on in my body. I lay on the couch with a bottle of mineral water, but it did not help.

After a few hours and before supper, I decided that I should go get checked out to ensure everything was okay. I just wanted to be on the safe side and I called Udit, one of my beloved friends, to give me a ride to the hospital. When I got in the car, I announced to her that we were just going to "pop in" to the Laniado Hospital for a moment. Fortunately for me, she refused to take me there, and insisted on driving me to the Meir Medical Center instead. What luck for all of us that Udit took me to Meir.

After spending some time at the hospital eating sweets, counting fetal movements, and being monitored, I was sure that I would be discharged. But the doctor insisted on following protocol and did an ultrasound. In the meantime, a more complicated case arrived. We waited patiently in the waiting room. Several hours later, we were called into a darkened room and the doctor announced, to my surprise, that my cervix was totally effaced. After tears and making silly comments like "I have a plane to catch"...and "I'm not a good enough human being to be a mother to a preemie, etc.," it became obvious I was going nowhere but the delivery room to receive my first dose of celestone



Yaeli and her family relaxing at home.

(an injection that helps a infant's lungs to mature), and of course, to be monitored. This is how our 79 day NICU stay began.

We had many long exhausting days, and days of feeling helpless. It is a silly cliché but the truth is, you would have to be there, in that situation, to understand. I am not sure that I can adequately describe the experience.

I was admitted to the high risk ward. The following day, Sabbath, I received my second and what would be my last dose of celestone. Now the task at hand was to try and hold off delivery as long as possible. But my pains continued, and although no contractions were identified on the monitor, it was obvious that something was going on. It seemed to be just a matter of time until I would give birth and as one of the residents put it "every minute counts." So I decided I would keep my legs tightly together and try and prolong the inevitable. In the meantime, important staff from the NICU came by to give me a general idea about what was happening and what to expect. It was obvious that I understood nothing.

I had my own thoughts about it all. Yaeli had ideas of her own (even then she had a stronger will than mine) and against all odds on May 3, 2010 at 6:00 pm, she was born at 27 weeks gestation weighing 890 grams with Apgars of 9 and 10. Also present during my short labor in the delivery room was my professional and favorite labor coach, and older sister, Rachaeli. It was such a speedy delivery that the doctor asked me to wait until an incubator could arrive. It was stressful delivering a preemie baby... not only was the pregnancy finished abruptly, but my baby was snatched away immediately, which did not help. Luckily, I had asked the doctors earlier what would happen and they explained to me that my baby would be taken away at once to be cared for when she was delivered. Still, when she entered the world so quickly and was taken away crying and wrapped in a warming blanket, I was left with a feeling of shock. From that moment on, I counted the minutes until I could walk (not "walk" but run) to the NICU and see Yaeli.

Many beloved visitors came to the recovery room to see me, including Rafael. He had not gone through the labor and delivery with me and was able to go see Yaeli and name her and then came back to report to me about how perfect she was. During this time my sister-in-law, Dalit took care of Noa'le and we will forever be in debt to her for being there to help during this time and on several more occasions.

Two hours later, I ran to the NICU myself (and I could, since this short pregnancy made my body unaware it had been pregnant or that I had just delivered a baby). I entered the NICU which would become my home for the next two and-a-half months...and there I saw Yaeli, lying naked in the incubator. Seeing her like this will always remain one of the most difficult memories of my life. She was such a tiny baby and it seemed that any similarity to a newborn term baby was purely coincidental. I remember telling people that asked about her, that she was a close relative of E.T.'s! I remember thinking, she is mine but I did not get to hold her after she was born. However, by the next day, I was able to hold Yaeli skin to skin (the fabulous "kangaroo care"). Eventually, I started to count the hours that I held her, which just proves how many hours I did not. There are not enough days for us to live together to lessen the feeling of abandonment I felt at that time. The horrible fact was that every day I left her I felt that I abandoned her again. I knew logically and rationally that Rafael and I were doing the best we could but that feeling of abandonment remained extremely strong...that's just how it was.

Yaeli was like a panther, and did not seem to be bothered by anything at all. She was strong and insisted on breathing on her own. Yaeli seemed to think that the NICU was some type of health resort! She slept and gained weight. Our good fortune, which began when we arrived at the Meir Medical Center, continued on. You see, there are significant differences between various NICU's. Despite Yaeli's severe prematurity at less than 30 weeks and weighing less than a kilo of sugar, our NICU days were viewed as "easy" ones. There were no severe complications or frightening incidents. The staff in the NICU would often pass by Yaeli's incubator and say to us "she's a cutie pie" and move on. My husband Rafael thought this statement was Hebrew medical terminology. Most of the time there was nothing major for the staff to report about her. As I already said...we were lucky. But despite our "easy" NICU stay, I think back and realize that these were some of the hardest days of our lives. We are so thankful to everyone who helped us get through this experience more or less in one piece.

Even though Yaeli is no longer in the NICU, the NICU is not out of us...other parents of NICU graduates claim that some part of the experience always stays with you. Nonetheless, we don't spend each and every moment dwelling on Yaeli's prematurity. Yaeli has grown to be an adorable and "normal" infant. Even though it is her first birthday (although in real terms she is 9 months corrected age according to calculations), she is perfectly healthy. Knock on wood!



Carmen Rosa Pallás, MD

Carmen Rosa Pallás, MD, or Keka, as all who work with her know her, has wanted to look after infants ever since she can remember. She worked diligently on her studies and she always stood out because of her passion for medicine. From very early on she became convinced that to have a good life, the first few days of human beings are fundamental; we need to get to know mothers' and infants' needs better and look after them quickly and with suitable methods.

Dr. Pallás opted in 1984, the start of her professional career, to train at the 12 de Octubre University Hospital which had opened four years earlier. Located in a populated area in the South of Madrid, the 12 de Octubre has a population with modest to impoverished social and financial resources. The choice of this hospital was not by chance; the 12 de Octubre stood out from the remaining hospitals in Madrid, because it maintained a policy in the maternity and pediatrics departments of parent-centered care, as an important part of its care provisions. This approach was the right one for Dr. Pallás, the care children and their families should receive in spite of the significant complexity of the Hospital 12 de Octubre neonatology unit, which sees all kinds of patients, especially the most serious, with a total of 19 intensive care beds and 30 intermediate care beds.

When her residency was completed and once incorporated into the neonatology unit, Dr. Pallás considered creating and opening a follow-up clinic as a top priority. She put all her energy into this goal and with the help of her colleagues she achieved the creation of a follow-up clinic in 1990 for children up to seven years of age, who had previously been seen in the neonatology department.

Dr. Pallás' brilliant professional career and her commitment were rewarded in 2000 with the Renia Sofia Award for Research on the Prevention of Deficiencies by supporting the development of children who had been born too small and too soon. In the study which won the award, she brought together 10 years of observation and clinical research in the context of a follow-up program.

Dr. Pallás has published a large number of papers in the most important scientific publications in Spain and the European Union. Since April 1996, she has been an Associate Professor of Health Sciences, attached to the Department of Pediatrics of the Faculty of Medicine, "12 de Octubre" University Hospital, Madrid Complutense University.

From her initial steps in the department of pediatrics she threw herself into the well being of the children, always concerned about implementing new care methods beyond technology. One result of her concern was the creation of the first Spanish population registry for children affected with cerebral palsy in the Hospital 12 de Octubre area; included in the collaboration network *Surveillance of Cerebral Palsy in Europe (SCPE)*. The



aim of this network was to develop a central database of children with cerebral palsy in order to monitor trends in birth weight-specific rates, to provide information for service planning and to provide a framework for collaborative research.

In 2004, Dr. Pallás, after several interviews with families decided to publish *Antes de tiempo. Nacer muy pequeño* (Ahead of time. Being born very small, Exlibris Ediciones), a book whose purpose is to improve the information received by parents of premature infants and dealing with their real needs.

In 2005, Dr. Pallás began to collaborate with Dr. Natalie Charpak, who visited the unit several times, collaborating with the team for correct implementation of kangaroo care, already in place but lacking a suitable protocol. Since then kangaroo care has been the cornerstone of the care offered by the hospital. Keka has worked continuously with Dr. Charpak on different publications and conferences. In 2008, Dr. Pallás participated in the development of the European Perinatal Health Report: Better statistics for better health for pregnant women and their babies (Available at www.europeristat.com).

After 16 years of experience as an Assistant Doctor, Dr. Pallás became head of the neonatology unit. She was supported and recognized by her colleagues for her involvement and contribution to the unit's quantitative and qualitative development and growth. One of the fruits of her labor was ensuring that the Hospital 12 de Octubre led the way for Developmental Care in Spain. Since Dr. Pallás became head of the unit she has continuously insisted on offering children the best care and the best attention to their families, this is one of the hallmarks of the unit today.

To tackle the new challenges, she believes that the participation and undertaking of all members of the unit is essential, for doctors and nurses to work together harmoniously and in tune with one another; she has always given an essential role to the training of personnel as the driving force for change. She has favored the mobility of professionals to personally enrich them

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Jacqueline M. McGrath, PhD, RN, FNAP, FAAN

Involving Fathers in the Care of the High-Risk Newborn: What could we be doing better?

Last fall, I was asked to design a research column for the Developmental Observer. I thought OK how fun; that would be easy! Well it hasn't been so easy since I believe this is a tough audience. That being said I decided to format the column into an evidence-based brief. Individualized developmental care encompasses a wide array of interventions. For each column, I will begin with why I believe this topic deserves attention (Background). What this research adds to what is already known about the developmental care issue or the particular intervention (Objective - conclusive statement that sets-up a focus). Then a summary of the evidence found will follow with a discussion. In addition, I will provide recommendations for integration into practice. When appropriate I will highlight who the stakeholders might be and whether they might support integration of the intervention or not and why. My overall effort will be to provide a compelling argument for integration of the practice or not, given the state of the current science. Please feel free to contact me or provide feedback about what you would like to read or want to see in this column. I am definitely open to suggestions.

Background

Much of individualized developmentally supportive intervention with newborns and high risk infants focuses on supporting and improving the mother-infant interaction. Even family-centered care initiatives often have a fundamental focus on this dyadic relationship yet, the role of fathers in the family is changing in our society and many families are not as traditional as they once were. Overall the role of fathers is evolving to one that is much more involved with childcare and childrearing than was evident in past generations.

Objective

Supporting fathers during the crisis of newborn intensive care is important but what are the research findings to help us provide the best care to fathers? What are their needs during intensive

care and how can we foster their participation in care? It is my premise that fathers want to participate but often don't know how and may feel they cannot ask because they need to be strong, and supportive of their partner. Stress may actually be greater in fathers during newborn intensive care because fathers often have several roles to juggle during a time when their emotions may be stretched to their limits. In general, fathers initially may have greater responsibility for supporting their partner, communicating with friends, families and professionals while simultaneously providing for their household while their newborn may be struggling to live in the newborn intensive care unit (NICU).

Methods

A search of the recent literature in PubMed and CINAHL for studies, particularly about fathers and the care of their newborn in the NICU, were used to provide the evidence to support the recommendations made from this review. This review is not comprehensive and represents the findings of only a few recent studies. A systematic review about the experiences of fathers in the NICU was published in *Pediatric Nursing* in February of 2009. Deeney et al.,¹ found only seven studies that focused primarily on the experiences of fathers who have a baby in the NICU. They found that fathers cope and respond to the experience differently from mothers and their burden may be heightened because of the stress they feel as they struggle to balance both hospital, home and work responsibilities. Fathers reported considerable anxiety related to the need to be everything to everyone. Fathers of preterm infants were found to have less contact with their infant and this appeared to decrease their attachment to their infant. The recommendations of Deeney et al. were to support and increase caregiving and holding of the infant by fathers in the NICU as soon as possible. These authors also recommend that more research needs to occur to increase the understanding of the role of fathers especially as the roles of both parents in our society are changing with parenting/childrearing becoming a much more shared responsibility.

Summary of Evidence

The findings of three studies are highlighted in this review. These studies were not included in the previously published systematic review. Mackley and her team² examined the emotional status of fathers of infants born before 30 weeks gestation in the NICU. A convenience sample of thirty-five fathers from a single NICU participated in the study and completed two self-report questionnaires (Center for Epidemiologic Studies Depression Scale [CES-D] and the Parent Stress Scale [PSS:IH]) three times during the course of their infants' hospital stay. Fathers of infants who were expected to die or had congenital anomalies were excluded from

the study as well as those who could not speak or read English. Initially, 60% of the participating fathers had elevated depression scores and although these scores decreased overtime, 35% of fathers still reported having elevated depressive symptoms at discharge. The rates of depression reported in this study are higher than previous studies reported in the literature; however most other studies include infants in the NICU of all or varied gestations not just infants less than 30 weeks gestation. Total stress scores from the PSS:IH were also initially high and did not change overtime, however, for fathers who were also depressed these scores were significantly correlated. Interestingly fathers' depressive symptoms did not correlate with infant illness severity. Socioeconomic factors were found to be highly related to depressive symptoms while being married was found to be somewhat protective (odds ratio of 1.70; 95% confidence interval of -3.49-0.07) over time for the participating fathers. Although no data additional data were gathered during this study from mothers, it appears that fathers in a more stable relationship (married) managed their depression and stress better, as compared to unmarried fathers.

Two qualitative studies have also been recently published. Thomas et al.,³ conducted a qualitative descriptive study with five Canadian first time fathers who had a very low birth weight (VLBW) infant in the NICU in the last two years. All infants were discharged at the time of the interviews and all were at home with no major neurodevelopmental handicaps. Four of the participants were married and one was living with his partner. All of the fathers described the first week of their child's life as overwhelming and traumatic. The uncertainty during that time was fraught with many questions and they also reported a sense of powerlessness. However, these same fathers reported that they took on more caretaking over time than they had anticipated doing, because they felt the need to do something, and they felt the need to support their partners. Five factors were found to influence the development of their self-efficacy as a parent: 1) learning from professional role models and female family members; 2) learning by doing; 3) personal beliefs and values; 4) praise and positive reinforcement and 5) the wellbeing and health of the infant. Although these fathers were of several cultures, all of them had a "good" NICU outcome which could have affected the results of the study.

The results of the Thomas study are comparable to a qualitative study conducted by Lindberg and associates⁴ in Sweden. Eight fathers were interviewed about their experiences with having an infant in the NICU. Two themes emerged from the data. First, fathers shared their experiences about becoming a "real father." They talked about how being in the NICU provided them with an opportunity to get to know the baby and over time, as the infant became more stable, to become attached to the infant. Fathers who were able to visit more often spoke about gaining confidence in caring for their infant and about how they would not change the experience of having a preterm infant.

They felt the gains were somehow worth the other experiences in the NICU. Many of the fathers expressed how the birth of their child had changed their values of life and how spending time with their child also changed their relationship with their partner in a way they had not anticipated. None of the fathers who participated in this study spoke about being stressed or depressed, however the focus of the study appeared to be more about their relationship with their baby and partner and not more globally on how they were balancing or managing things outside the hospital setting. Interestingly, none of those issues were discussed by any of the fathers in this study.

Recommendations for Practice

The depressive symptoms and stress of fathers during the initial NICU crisis must be acknowledged and treated as needed. Screening of both fathers and mothers for depressive symptoms needs to be routine in the NICU environment. Those parents that have elevated depression scores need to be referred for counseling and treatment. Parents with depressive symptoms must be treated by staff with the same respect as all parents regardless of whether they are mothers or fathers. These parents may need more support from staff than parents who are not suffering from depression, as these parents need to know that being stressed and depressed is often a "normal" response to the crisis of having an infant in the NICU. Sometimes the first step in treating depression is accepting that it is real and requires treatment. Fathers need assurance that it is not considered "weak" to ask for or to need help during this difficult time. They also need to know that their presence in the NICU is important and that their participation in caregiving is supported and encouraged. Asking fathers "how" they would like to participate rather than "would" they like to participate is a better way of encouraging them to be involved. Asking in this way says, "we want and expect you to participate in some way – you (fathers) can choose how, and your participation is important to the recovery of your newborn infant."

Conclusions

Both fathers and mothers need our care as much as their infants who are critically ill. Finding strategies to better meet the needs of fathers, as well as mothers, needs to be a greater focus of our care.

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Liv Ellen Helseth, RN and Unni Tomren, RN

NIDCAP Norway, Ålesund Training Center



From left: Hilde Austad Foss, RN (NIDCAP Norway Nursing Director), Liv Ellen Helseth, RN and Unni Tomren, RN (NIDCAP Trainers).

The NICU at Ålesund Hospital is situated on the west coast of Norway. It is a small, level three unit with room for 14 infants; four of them receive intensive care. We have nurses, neonatologists, pediatricians, a social worker, a speech therapist and a physiotherapist working in the unit. In March 2011, we moved into the new Children’s Hospital and our new NICU which has single, two-bed, and family rooms that parents can live in with their infants.

We would like to share with you our experience of implementing NIDCAP and becoming a Training Center. One of the things that has been essential for the process is the constant positive support from our leadership and also the medical staff. Our head nurse describes the Ålesund NICU staff, both nurses and physicians, as very open to change and new knowledge.

Our NIDCAP History

It all started after one of our nurses attended a Neonatal Conference in Washington DC in 1992. When he returned to the NICU, he started to cover the incubators, but this lasted only through his shift. A couple of years later the idea of implementing the NIDCAP approach to care within our nursery began to emerge as a serious possibility. For the next few years we heard several speakers presenting on NIDCAP and some of our nurses visited Falun in 1996, where Agneta Kleberg, RN and Bjørn Westrup, MD worked. Inspired from our meeting with these two NIDCAP Professionals, a developmental group was formed. We had regular meetings and the goal was to start implementing the NIDCAP approach to care. When Agneta Kleberg and two of her colleagues came to Ålesund to speak about NIDCAP

for two days, the process really grew. The similarity between the culture and health organization in Norway and Sweden often has made us look to our neighbors for inspiration and help during the implementation process. From 2001 to 2005, six of our nurses became NIDCAP Professionals under NIDCAP Trainers Anna Karin Asp, RN, BA from Sweden and Karen Smith, RNC, BSN, MED from the USA.

After becoming NIDCAP Professionals, the urge to learn more grew stronger. In 2006, the two of us started working towards becoming NIDCAP Trainers and developing a NIDCAP Training Center with the guidance of Trainer Karen Smith, and Senior Master Trainer Heidelise Als, PhD. After one of Dr. Als’ and Karen Smith’s visits during our training, we decided to arrange a congress. The title of the congress held in June 2008, was “NIDCAP – a Link between Neonatal Intensive Medicine and Child Psychology” and it drew speakers and an audience from around the world. The congress was a great success. We were thrilled to see so many of our NIDCAP colleagues in Norway.

One of the biggest changes in the unit during these years was the acceptance of the family and its important role in the life of the infant. We have moved from seeing the parent as a person that could participate, to being a natural collaborator in the care of the infant. The parents are welcome in the unit 24 hours a day and they are encouraged to spend as much time as possible together with their infant. We recognize that parents are the most important persons in their infants’ life and that they are the infants’ primary caregivers.

During the process we have been working to support families in understanding their infants. Guiding the parents and staff at the bedside and using the APIB as a way of increasing awareness of the infants’ strengths and sensitivities, has been a very powerful tool. The interaction between the infant, its family and the caregiver, combined with our new knowledge continuously increases our awareness of the importance of NIDCAP. We continue to learn from our experiences in the implementation of the NIDCAP approach to caregiving and we have become more reflective in the way we take care of the families. We see that parents are more confident and have begun to develop a relationship with their infant from the very beginning.

Along with our training education, we have collaborated with three other NICUs in Norway to translate several of the NIDCAP documents into Norwegian. This process is funded by the Children’s Nursing Foundation. We have found that having training documents in one’s own language is most helpful, and we would like to share this with our Trainees.

During our training, we have also found that there has been increased interest in the NIDCAP approach to care in Norway. We have had requests for training from several NICU's, especially from the nursing staff. More recently, the nursing staff has been attracted to the NIDCAP way of caring for premature and ill newborn infants. The human, ethical and developmental implications within the framework of NIDCAP have received broad support within the nursing staff and also from the families in the NICUs. The description of the infant's language via the NIDCAP approach to caregiving, and the way to view each infant as an active individual participating in his own development from the start, appears to make sense. However, some physicians are reluctant to implement developmental care. They believe that the published NIDCAP studies have been relatively few in number; with a small number of participants enrolled in each study; and with questionable research methodology. There is a disagreement in how much power and importance NIDCAP should



*Lutz Nietsch, MD,
NIDCAP Norway Director
and Medical Director.*

have, if the program is feasible, and if one should use resources in implementing the NIDCAP method.

In Ålesund, 16 % of the nurses in the unit are NIDCAP trained. During the training process we have had support not only from our leaders, but also from many of the physicians. One of our neonatologists, who also is the Medical Director of the NICU, Lutz Nietsch, MD was one of the driving forces behind the development of the NIDCAP Training Center. In the process he completed

his NIDCAP Training with Karen Smith, and is the first physician in Norway to become NIDCAP certified. Lutz Nietsch is now the Director/Medical Director of our new NIDCAP Center. The unit's assistant head nurse, Hilde Austad Foss, is the Nursing Director and has been closely involved in the education process.

During our training period, the annual NIDCAP Trainers Meetings have been an inspiration. Each year interesting topics have been presented that are useful in our training efforts. Topics, ideas and a lot of support, which we brought home to share with our colleagues in the nursery.

As a result of attending the NIDCAP Trainers Meeting in Cincinnati, 2011, our NIDCAP group celebrated the "World Prematurity Day" on November 17, 2011 for the first time. It was a great success. Preterm born infants and their parents came from around our country. Some of these families travelled for many hours to come and celebrate with us, including families with their infants, toddlers, teenagers and even adults, who were born premature. An exhibition displayed some equipment from our NICU including a fully equipped incubator, and premature sized infant clothes. This was very popular amongst the older children, teenagers and adults. A very touching moment occurred when the mother of a 30 year old man, who was born prematurely, came to this celebration, bringing a marzipan tart decorated with a picture of her son during his stay in the NICU.

His birth date and "Thank you for all of your help," was written on the cake. It was such a humbling experience and a reminder of how much the work we do means to the families involved.

Another program we, together with our colleagues, have found very interesting and helpful is the NIDCAP Nursery Certification Program (NNCP). We recognize that this program is a useful tool in supporting the implementation of NIDCAP and integrating this approach throughout the NICU. NNCP assists us to identify areas of need within our unit as well as supporting our efforts to address these needs.

In June 2011, we completed our training and are currently working to raise funds for our new center. We are looking into how to get NIDCAP Training recognized within the Norwegian education system. In the meantime we are communicating and providing information to potential students, planning to start training soon. We have a network that includes all the Norwegian NIDCAP Professionals. This supports our efforts to keep each other updated. Giving lectures in other units in the country has also been a way to maintain and make new connections.

The theme NIDCAP and child psychology continues to be a topic of great interest here in Ålesund. We are collaborating with the Child Psychologists follow-up clinic, "Team Small," to ensure that every family that might need additional support after going home is offered an opportunity to be enrolled in the program.

This spring we conducted a two-day long workshop on research in early intervention for Nordic countries. The goal was to create more interest and awareness on this topic. This provided us with the opportunity to have several great speakers from the NIDCAP Federation International to present at this workshop. We hope to inspire more research in the field. As new NIDCAP Trainers we have found that the presentation of evidenced-based research on developmental care helps to support NIDCAP education here in Norway.



*Ålesund Training Center's
Celebration of World Prematurity
Day, November 17, 2011.*

Feeding the Most Fragile: Supporting Feeding Opportunities in the NICU

Erin Ross, PhD, CCC-SLP



The acquisition of eating skills in the NICU is a major focus of staff and families, in large part because discharge to home is directly correlated with the ability to take in adequate nutrition.¹ Therapeutic and nursing research has often focused on accelerating the acquisition of full oral feeding, with little attention paid to the long-term effects of interventions. Given the poor long-term outcomes in both eating and growth, it is reasonable to advocate for a shift in the focus of interventions towards improving the quality of the feedings (skill and parent-child interaction) and building a strong foundation for later eating. Recently several articles have been published that integrate the principles of NIDCAP and acknowledge the role of experience on the development of eating skills. This article is a brief synopsis of three articles, published by Ross and Philbin², Philbin and Ross³ and Browne and Ross.⁴

Background

A variety of therapeutic interventions have been proposed in the literature, with the majority of intervention studies focused on either oral stimulation or non-nutritive sucking. Oral stimulation is generally a protocol driven stimulation program involving five-fifteen minutes of tactile input to the face, lips, gums and tongue of the infant. Typically, this stimulation is provided for ten sequential days, in infants as young as 29 weeks gestational age (GA). While results have shown a decrease in the interval between initiation of oral feeding attempts and the acquisition of oral feedings, the majority of published reports demonstrate neither: 1) a decrease in gestational age at the time full oral feedings are attained; nor 2) a decrease in length of stay.⁵⁻⁹ The

only article to show a shorter length of stay (two point six days) was published in *Advances in Neonatal Care* and is fraught with methodological problems.¹⁰ The author conducted oral stimulation on ten infants for five minutes per day for seven consecutive days, beginning at 29 weeks GA, with nine infants in the control group. Methodological problems include a statistically significant difference in birthweight between the two groups. All statistically significant in terms of outcomes was lost when birthweight was entered as a covariate; however, the author took the variable out of the equation and published the results. The abstract does not mention this very important point, and misleads readers into thinking that this intervention can save thousands of dollars in hospital costs. Despite this (and other methodological problems), this article will likely become the newest in a growing list of studies that garner a great deal of attention using interventions that do not include the infant as a partner in a relationship. Another study showed a difference between control and experimental groups using the N-Trainer (a pulsating pacifier), but the control group data suggests that the control group lagged behind in the mean age of acquisition of full oral feeds most often cited in the literature.¹¹ Unfortunately, many professionals working in the NICU do not critically read the available literature. Rather, they read the abstracts and then quickly implement programs such as oral stimulation because they are easy to implement without training and without the need to understand the behaviors of the infant. While these programs may be easy to implement, the available research has not included the effect of the stimulation on the stability and behavioral organization of the infant, nor presented any information on the long-term eating outcomes for infants graduating from the NICU after the use of these programs.

Through the NIDCAP research, we know that supporting the stability and the emerging competence of infants improves outcomes – both short- and long-term. The experiences of the infant create neural pathways that build behavioral repertoires, and the theoretical framework of this research can be applied to feeding. The long-term feeding/eating and growth outcomes in infants who were premature and in the NICU are poor, with over half of parents reporting stressful mealtimes where young children are gagging, vomiting, coughing, and refusing to eat.¹¹⁻¹² Samara and colleagues found eating problems were more common among the preterm than the comparison group, with an odds ratio of 3.6.¹³ It is reasonable to argue that the actions within the NICU contribute to these poor outcomes. Professionals in the NICU should consider supporting parent and infant competence in feeding and eating to improve the long-term

outcomes for infants in their care. Three articles recently published attempt to shift the focus from accelerating the acquisition of full oral feedings, to building a foundation for long-term feeding success, based upon the Synactive Theory of Infant Development and the Theory of Neuronal Group Selection.^{15, 16}

In *Clinics in Perinatology*, Browne and Ross published a review article that describes the neurodevelopment of eating, and includes a framework for the development of eating.¹⁶ The Baby Regulated Organization of Subsystems and Sucking (BROSS) framework serves two purposes. The first is to highlight the necessity of baseline physiologic, motor and behavioral state stability for enjoyable and safe feeding and eating experiences. We know that infants with medical comorbidities have the longest transition time to full oral feeds, and the most difficulty in eating after discharge.¹⁷⁻¹⁸ The BROSS also focuses on maintaining stability while being held, and subsequently while sucking on a pacifier and progressing to eating. The second purpose of the BROSS is to identify developmental milestones in the acquisition of eating skills. The eating steps in the BROSS are taken from a combination of clinical experiences and research findings related to oral-motor patterns observed in preterm infants. The first of these oral-motor steps is entitled “Obligatory,” and describes infants who begin to suck and swallow fluid and do not initiate any respiratory effort – losing all stability in the process. The next three steps have been described by several researchers and represent a progression from: 1) An immature sucking pattern that consists of three-five sucks/burst alternating with a period of spontaneous respirations (Alternating); to 2) a more mature pattern where the infant intermittently and inconsistently takes a small breath within the sucking burst, allowing the sucking burst to lengthen (Intermittent); and finally to a mature suck-swallow-breathe pattern with breathing smoothly occurring within the sucking burst (Coordinated). Unique to the BROSS is the final step, entitled “Integrated.” The defining characteristic of this step is the integration of infant social interaction with the feeder during a feeding. Until an infant is able to eat and engage with the feeder, the process of eating skill development is not considered complete.

Data presented at the Physical and Developmental Environment of the High-Risk Newborn in 2002, revealed a significant positive correlation between BROSS stage and gestational age. However, observations using the BROSS have shown that caregiver handling and decisions either improve or interfere with the infant’s attempts at regulation and eating. Infants often demonstrate more mature eating stages when fed by a primary caregiver (preferably the parent), using supportive techniques designed to support skill development.

The two articles published in the *Journal of Perinatal and Neonatal Nursing* were a culmination of many years of training professionals and parents in the NICU by Erin Ross, PhD, CCC-SLP as well as preparatory work for an NIH grant. In 2006, Barbara Medoff-Cooper, PhD, RN and Kathleen Philbin, PhD, RN sought the collaboration of Ross for an NIH grant

focused on evaluating the effectiveness of training staff to focus on enjoyable and positive feedings, with a goal of improving feedings both in the NICU and after discharge. Ross has been providing one-two day trainings for therapists and nurses for several years, and as part of the evaluation of the effectiveness of the training for the NIH grant, developed the first feeding decision algorithm, entitled Supporting Oral Feeding in Fragile Infants (SOFFI). The SOFFI was designed to: 1) be a method for assuring that the training would result in a change in the way infants were being fed; and 2) measure whether the decisions that the bedside caregiver was making were similar to a “gold standard” – which would be provided by intermittent reviews of videotaped feedings by the Principal Investigators. The two Appendices (Flow Rate and Pacing) were also part of the training algorithms.

While the initial NIH grant was not funded, SOFFI proved to be a valuable teaching tool. Ross began piloting it during trainings and collecting feedback on its usability. In 2008, Philbin collected pilot data and submitted a second NIH grant focused on improving short- and long-term feeding outcomes. At that time, she advocated for the creation of the Reference Guides that are the companion SOFFI article, by compiling the training information as well as developmentally supportive care information into a manual and included Appendices for the interventions of flow rate and pacing.

The SOFFI Algorithm takes the information from the BROSS regarding subsystem stability as the foundation of eating, and leads the caregiver through a series of decision-points. The algorithm is designed as a flowchart. As such, the caregiver begins at the “START,” and is guided through the decisions regarding overall stability of the infant and into decisions regarding the stability of the infant to eat at the current feeding time. Stability is defined as stability across the systems of the Synactive Theory of Infant Development. At each decision point (identified by a diamond shape), if the infant is not engaging in the task or is not stable, the algorithm directs the caregiver to stop the feeding or interaction, re-stabilize (or co-regulate) the infant if necessary, and determine the need to: 1) provide the feeding using an NG or OG tube; or 2) implement specific, evidence-based interventions to improve the quality of the feeding. Once the caregiver determines that the infant is ready to attempt a nipple feeding, the algorithm directs the caregiver to offer the feeding (either breast or bottle feeding) and determine the infant’s response. If the infant responds with a significant loss of stability, the feeding stops and the focus shifts to co-regulating the infant. However, if the infant is maintaining stability, the feeder assesses whether the infant is participating and actively trying to nipple. If the answer is “yes,” the caregiver assesses efficiency and skill. The additional algorithms of Flow Rate and Pacing (Appendix A and B respectively) guide the caregiver through the process of determining the need to change the flow rate of the bottle nipple or to pace the feeding. Throughout the entire feeding, the Algorithms direct the caregiver to attend to the behavioral cues of the infant and to respond to any signals of distress/instability by increasing the support.

The decision points and the interventions within the SOFFI are supported by published literature as well as clinical experiences. Professional caregivers at a Midwest Children's Hospital have used the SOFFI to determine its effectiveness in improving feeding outcomes not only in the NICU with preterm healthy infants, but also with medically complex preterm and term infants. They enrolled a convenience sample of 57 infants prior to the SOFFI Method training, and collected data regarding feeding/eating parameters within the hospital as well as three-five months after discharge. The nursing leadership and educators then attended the two-day NICU training provided by Ross, based upon the SOFFI Method. They used the SOFFI Algorithm and created a 60-90 minute presentation for their staff (including 150 nurses), that was provided as part of the mandatory yearly education. After all of the staff attended the training, 72 infants were enrolled in the post-SOFFI training group. Data from this research study presented at the Physical and Developmental Environment of the Newborn conference in Florida, January 24-28, 2012, indicated that the length of stay and

gestational age at oral acquisition did not differ when the focus shifted to quality of feedings. However, several behaviors that have previously been reported in the literature to be problematic (gagging, arching, spitting/vomiting, general feeding problems) as well as use of services (seeing a feeding specialist) were lower by parental report. The nursing/therapy research team is in the process of writing several publications highlighting these and several additional findings.

Drs. Browne, Philbin and Ross are joined by many NIDCAP professionals as well as a growing number of NICU nurses and therapists who are striving to bring the theoretical foundation of the Synactive Theory of Infant Development and the respect and understanding of the process of eating development to the NICU. The hope is that we can shift the focus from accelerating this developmental process to improving the experiences of both the parent and the infant. Skill becomes the focus, resulting in feedings that are comfortable, enjoyable experiences for both the parent and the child. Through skill acquisition, volume and growth are achieved.

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Assessment of Preterm Infants' Behavior (APIB)

The Assessment of Preterm Infants' Behavior (APIB) is a comprehensive and systematic neurobehavioral assessment of preterm and fullterm newborns developed by Heidelise Als, PhD and her colleagues (published in 1982, see www.nidcap.org for details). The APIB requires in-depth training and provides a highly valuable resource in support of developmental care provision by professionals and families.

Newborn Individualized Developmental Care and Assessment Program (NIDCAP)

The Newborn Individualized Developmental Care and Assessment Program (NIDCAP), originated in 1984 by Heidelise Als, PhD, is a developmental, family centered, and evidence-based care approach. NIDCAP focuses on adapting the newborn intensive care nursery, including all care and treatment and the physical environment, to the unique neurodevelopmental strengths and goals of each high risk newborn and his or her family, the infant's most important nurturers and supporters. For a complete description of training centers and the training process please visit our website: www.nidcap.org.

NIDCAP Nursery Certification Program (NNCP)

The NIDCAP Nursery Certification Program (NNCP) under the auspices of the NIDCAP Federation International (NFI) recognizes the excellence of a hospital nursery's commitment to and integration of the principles of the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) for infants and their families. NIDCAP Nursery Certification is both a goal and a process. Nurseries that apply for this certification will, by the process of the application and by their self evaluation, define the areas of their current strengths and areas for future growth. Successful NIDCAP Nursery Certification represents distinction in the provision of a consistently high level of NIDCAP care for infants and their families, as well as for the staff, and as such is to be commended and celebrated as an inspiration for all. For information on eligibility requirements and the certification process please see: www.nidcap.org; and/or contact Rodd Hedlund, MEd, NNCP Director at: nncpdirector@nidcap.org or 785-841-5440.

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How Many Adults Can One Family Manage?

This question was sent out via the NIDCAP listserv and many thoughtful statements emerged about how we organize “staffing” around the family of the preterm infant. From my experience of working in Scandinavia, Europe and as a member of the NIDCAP Federation International I am familiar with different “cultures” and their ways of organizing newborn intensive care. Our primary team views the infant as an active participant in caregiving and social interactions, and the parents as the primary caregivers. This core concept of family-centered care is not controversial. Although our health care systems differ around the world, human needs are the same. The Newborn Individualized Developmental Care and Assessment Program (NIDCAP) and Kangaroo Mother Care (KMC), two evidence based, family-centered care models, have contributed significantly to “give back the baby to whom he or she belongs.”^{1,2} Implementation of necessary intensive care in the framework of family-centered care requires knowledge and understanding of the infant, parents and family development, and an appreciation of the interplay of the infant’s medical issues with the developmental process. To realize this potential a strong system is fundamental. The NICU leadership must: 1) Take responsibility for the application of evidence-based safe medical and nursing care; 2) provide time and resources for education, implementation and evaluation; and 3) delegate this responsibility to health care professionals to carry out this work, as well as support and encourage this process. Each individual caregiver needs knowledge, and time to reflect on his or her actions. The multidisciplinary team needs to encourage and acknowledge each other’s achievements as well as support each other as they address the day-to-day challenges of implementation. Working towards a common goal is complex, and changing systems is challenging. *In this article I will stress essential issues to support implementation of family-centered care with the purpose of reducing the number of caregivers parents have to interact with during their stay in the newborn intensive care nursery.*

Families should not be expected to interact with a multitude of caregivers—they become frustrated with each introduction of a “new face,” or when encountering a new source of information about their infant’s condition, or ways of caring for their preterm infant. Mothers often complain about conflicting advice on how to care for and feed their infant. Implementation of family-centered care is a long process. “The shift from being an expert of caring for preterm infants to becoming an expert of supporting parents in caring for their infant,” is from my experience, the biggest and most significant issue for the bedside nurse. Health care professionals need time to reflect on this change, as well as knowledge to increase their understanding and support during this paradigm shift.

Mothers and fathers are primary caregivers of their infant, the most important persons in their baby’s life. They are recognized by their baby via their familiar smell and voice, and caressing hands and warm bodies. These factors support the evolving relationship between the infant and his or her parents. To facilitate this relationship, parents need to be supported as the primary nurturers and caregivers of their infant, the natural role of all parents. The bedside nurse is responsible for medical and technical care procedures, as well as supporting the infant’s wellbeing and development. The “new paradigm” includes guiding and supporting parents in observing and interpreting their infant’s behavioral cues as well as responding to their needs.

To support and guide parents of preterm infants, health care professionals need knowledge of both the normal pregnancy and the process of becoming a parent prematurely. During the course of a full-term pregnancy, the pregnant woman becomes increasingly psychologically prepared to become a mother to her newly born infant. Stern et al.³ describe three stages of the pregnancy: 1) “the physical fetus growing in the mother’s womb;” 2) “the motherhood mindset developing in the mother’s psyche;” and 3) “the imagined baby taking shape in the mother’s mind.” The father-to-be is also experiencing parallel psychological and emotional preparation.³ Rafael-Leff⁴ distinguishes the pregnancy in three trimesters, where “the focus shifts from pregnancy, to fetus, to infant.” After a preterm birth “the infant needs the biorhythm and pulsations of the mother as well as her milk, and the mother needs the infant to complete her pregnancy.”⁴ The mother of a preterm infant will lose the last part of pregnancy, including the final psychological and emotional preparation of becoming a mother. The “real infant” arrives when she is still highly involved with the infant of her dreams and wishes. The infant’s need for technological and medical support for survival may compromise the mother’s feelings of competence and possibly interfere with the parent-infant relationship.³

The evolving parent-infant relationship may become disturbed by several other factors when an infant is born prematurely. Incubators and medical care, necessary for the infant’s

survival, result in the physical separation of the preterm infant from his or her parents. The preterm infant may not have opportunities for sustained eye contact or auditory input from the parent,⁵ that is often readily available to the healthy term infant. Furthermore, during the intensive care period, the infant's energy may be depleted as he reacts to painful medical procedures and overwhelming environmental stimuli; resulting in even less energy for parental interaction. The NICU staff may at times suggest to parents that the caregivers understand their infant better than they do. These circumstances are less than ideal for parents and their infant to begin the process of developing an ongoing relationship. Several investigations have suggested that mothers experience premature birth, and the NICU environment, as very traumatic and stressful. These mothers often express feelings of anxiety, guilt, anger, helplessness, and fear that their infants will not survive or survive with disabilities.⁶⁻⁹ Such feelings may negatively influence the parent-infant relationship and may be further weakened by the preterm infant's faint behavioral cues and lower alertness and responsiveness.^{5,10-13}

Becoming a parent to an infant with very low birth-weight (VLBW) involves several stages, starting in an unfamiliar and intimidating environment of the NICU and continuing home after discharge. McHaffie¹⁴ identified six maternal emotional states, three while the mother was in the hospital (anticipatory grief, anxious waiting and positive anticipation) and three following discharge to home (anxious adjustment, exhausted accommodation and confident caring). Heermann and colleagues¹⁵ analyzed how mothers developed from being viewed as an "outsider" to becoming an "engaged mother." These researchers suggest that this transition occurs in four steps: 1) The mother's focus of attention transitions from the often intimidating high-tech environment of the NICU and the expertise of the nurses, to focusing just on her baby; 2) from feelings that "the baby belongs to the nurses" to actively "claiming the baby as her own;" 3) from passive to an active caregiver role; and 4) from silent observer to the role of advocacy.

Jackson and colleagues⁹ interviewed both mothers and fathers. The parents stated that their experiences of having an infant born prematurely as a synthesis of alienation, responsibility, confidence and familiarity. Both mothers and fathers described concern for their child. These researchers also found that the mothers expressed a need for participation and control of care, while the fathers expressed more confidence in delegating the care to the NICU staff. Somewhat contradictory results were found by others: Lundqvist and Jakobsson¹⁶ found that fathers expressed feelings of being outsiders and wanting to be active participants in the care of their infants, whereas Lundqvist and colleagues¹⁷ described fathers' experiences as a process from feelings of distance towards feelings of proximity. Jackson¹⁸ concluded that the parents' identity in a preterm birth was a process of integrating the unexpected start of parenthood into the parents' sense of identity and their way of being. Important to this process, was the health care staff's support and acknowledgement of the parental role as well as their interactions with their infant.

However, despite the staff's good intentions to support and encourage the parents' partnership in the care of their infant, and to view parents as the primary nurturers and caregivers of their infant, parents may continue to feel like "outsiders." There are several books, published by Swedish parents, that describe such experiences. To advocate "good care models" is easier to do, than to carry out "good care."

Health care professionals need time and forums (e.g., discussion groups, reflective supervision and processing) to reflect on the concept and meaning of "family-centered care." Time to reflect on: 1. Obstacles in the hospital system that thwart the implementation of family-centered care; 2. the "culture" and "value base" of the unit; 3. the role of the staff to support parents in their role as parents; and 4. how to decrease the number of professionals that the family is required to interact with on a day-to-day basis.

As health care professionals, we have the responsibility to work from an evidence-based model and with a humanistic approach. To clarify these goals, open communication with time for reflection is essential. As a NIDCAP Trainer, I meet with units that have open forums once a week; others that meet 15 minutes at the end of each shift; as well as units that have no formal forum for reflection. Units that have a multidisciplinary leadership with a strong desire to support caregivers in their new professional role are – according to my opinion - more successful in implementation of family-centered, individualized, developmentally supportive care (infants and parents interact with fewer health care professionals). The infant's and family's need for privacy is acknowledged and respected. The NIDCAP and KMC models are based on theoretical frameworks that support parents during their stay with their infant in the hospital. It is very common in Scandinavia for parents to have a bed close to their infant's incubator and later on, as the infant develops, the parents stay with their baby in a family room on the unit. However, this is still not a guarantee that parents will not have to interact with "too many adults" but it is an important aspect of the "primary caregiver model." Parents who stay with their infant on the unit are more likely to assume their rightful role as the primary nurturer and caregiver of their infant, and to advocate for private times to be together; a mother, a father, an infant together... a family together. Parents, however, may still perceive that they must wait before being allowed "access" to their infant. With this knowledge, we have to find ways on how to organize "staffing" that will support primary caregivers for each individual family.

How we act matters. This means that we also need time to reflect during all interactions with the baby and the parent. Examples of issues to reflect on include:

- How many caregivers does each family interact with?
- How do we approach infants and their parents?
- Feelings of efficacy versus lack of control.
- How do parents view us in our professional roles: As "experts?" "primary caregivers?" or "facilitators?"

- Do we see parents as “visitors” or “primary caregivers and partners in the care of the infant?”

In a Swedish study of mothers of full term newborns, four types of attitudes among health care professionals were identified: The “regulators;” the “facilitators;” the “disempowering;” and the “breastfeeding opponents.”¹⁹ The parents, cared for by “facilitators,” appeared to talk more to their infants, were more likely to perceive the infant as their own, enjoyed breastfeeding, and understood their infant better.²⁰ Nursery leadership is challenged to take responsibility for providing “a few facilitators for each baby and family.” Compassion and humanity is the foundation of good and safe care. Our challenge is to see the parent and infant as fellow human beings and to combine science and a humanistic approach—to see and meet the whole person.

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Developmental Care in the Moment



Photograph by Melissa Barnes

A father and his son, together.

The 23rd Annual NIDCAP Trainers Meeting

September 29th – October 2nd 2012
Sopwell House, St. Albans, UK



By invitation only.

Seeking the Evidence for a System Change in a Surgical NICU

Kaye Spence AM, RN, RM, MN

Implementation of NIDCAP® into a surgical neonatal intensive care unit (SNICU) has been met with many challenges. The required system changes need the effort of all staff and a commitment to the NIDCAP philosophy.

The initial challenge was to incorporate NIDCAP philosophy, observations and care-planning for newborns who require surgery within the first month. The SNICU is an environment of constant change where infants undergo life-saving surgery for major birth defects, and their families face many life threatening conditions and situations. Each year, the infants admitted to the unit come from a mix of ethnic backgrounds. Length of stay ranges from two to ninety days, with an average stay of ten days. Antenatal referrals account for approximately 30% of the patients admitted, the remainder are post-natal diagnosis or referrals from other NICUs for surgical interventions.

In the SNICU, the professional staff consists of neonatologists, advanced medical trainees, junior medical doctors on newborn intensive care rotation, registered nurses, clinical nurse specialists, nursing management and support personnel and an Allied Health team of a social worker, an occupational therapist and a physical therapist. In addition there are about 10 specialist teams (e.g. surgery, cardiac, neurology, genetics) who visit the unit routinely and undertake daily rounds. This number of personnel makes the implementation of NIDCAP a real challenge in terms of education and awareness.

In order to meet the challenge of providing an environment where NIDCAP becomes a standard model of practice, first the appropriate evidence was sought. The SNICU is an active research center

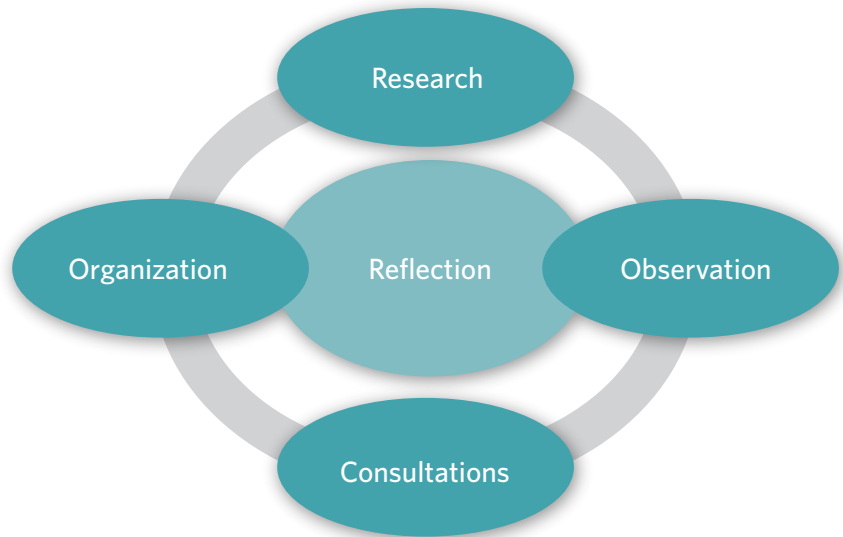


Figure 1—Reflection Model for Using Evidence

where the focus of the research program has been on behavior and development of the surgical infant and their families. Therefore the evidence sought came from research outputs and provided a focus for the implementation of practice change.

A reflective model was used (Figure 1) where: organizational challenges and barriers were identified; research outputs were used to provide a background for further integration into practice; specific components of care were examined on the basis of NIDCAP observations of the past and current Trainees; and feedback from NIDCAP consultations with the Trainer were incorporated into a model for systems change.

The current organizational systems were examined and a decision was made to accept the fact that some things cannot be changed. For example: 1) the unit design and layout were fixed in the current configuration of four open bays and two isolation rooms with no funding available for modifications; 2) visiting specialist

surgical and medical teams remain part of the system and were identified as a particular challenge for education and awareness of the model of care; 3) patient allocation to nurses was based on patient acuity and nursing skills; 4) staff shortages necessitated continual recruitment of staff and the levels of experience and expertise varied across shifts; 5) a mix of eight and twelve hour shifts made it to make patient assignments so as to meet patient and staff needs and, as a first priority, to ensure the safety of the infant. Frequent changes in management and education teams, required continual adjustment to new ideas and methods.

Rather than being constrained by all these potential barriers, a decision was made to focus on what could be changed. Leadership within the unit was seen as one way to influence how things were done and to effect change in care practices such as: 1) Quiet time for infants and families; 2) unit leaders serving as role models for visiting teams; 3) supporting parent-infant

interactions enabled parents to be more competent in the care of their complex need infant; 4) a forum was established to offer the families more opportunities to share their experiences and stressors given the strong psycho-social support that was available in the unit; and 5) staff education and awareness was improved through creative ways of introducing staff to the NIDCAP model.

Evidence was gathered to support the change model through the research outputs of the unit. The main issues identified from the evidence were parental stress (from seeing their infant in pain), being separated from their infant, and feeling helpless while their infant was in the NICU.¹ The infant's behavior following newborn surgery was found to be non-optimal and early intervention to improve mutual competence in mother-infant interactions is recommended.² Parent targeted interventions are also suggested to alleviate psychological distress in families³⁻⁴ as well as identifying specific challenges of feeding and maintaining growth.⁵ Infants following newborn surgery are at high risk of developmental delay and multi-disciplinary follow-up is required.⁶⁻⁷

Parent satisfaction is an important component of family-centered care. Families asked for more consistency in nurse allocation, consistency in the information provided, consideration of ways of supporting and involving them more in their baby's care, and supportive communication.⁸ Parents of surgical infants identified that they require a high level of support from nurses to reduce their stress.⁹

Understanding the culture of the work environment and what nurses find as interesting, exciting and frustrating, can help in implementing the philosophy of developmentally supportive care.¹⁰ The organizational culture has an effect on the nurses' thinking and ways of working.¹¹ Encouraging nurses to reflect on the effect of their care requires an allocation of time in the busy workday for learning and reflection to take place.¹²

Further evidence was obtained from the NIDCAP Trainees, Trainer and research involving NIDCAP implementation.¹³ Consistent challenges to modify care practices, the environment, and how the team works with families were identified. The behavioral observations demonstrated a need for integration of specific interventions for surgical infants whose care needs often change on a daily basis and long-stay infants often with varied chronic needs. The challenge was to meet the differences within the constraints of the environment and staffing challenges. The NIDCAP Nursery Templates¹⁴ were administered and the resulting scores provided a baseline to monitor improvement in caregiving and areas to target education.

This evidence was collated and a plan for change (Figure 2) was developed and was based on the concurrent needs of the baby, the parents, the staff and the organization. This is described in detail using the four components of the model.

Infant

Infants who require newborn surgery for a variety of congenital abnormalities or acquired conditions present many challenges. Their acuity can change on an hourly

basis and several co-morbidities make care planning difficult. There is a lot of movement between hospital departments such as the operating theater, diagnostic imaging (MRI) and isolation. Multiple medical and specialist teams have their own priorities and preferences. The biggest challenge for the infants is establishing feeds which may take weeks to sustain growth. Quiet time for three hours is a time for the parents to get to know their infant, lights are dimmed and procedures kept to a minimum.

Parents

Over 30% of the admissions to the unit are through antenatal referral and bookings following a perinatal diagnosis.¹⁵ A perinatal support program has been established that offers counseling and site tours of the NICU between 32-36 weeks to enable the families to meet key staff, the social worker and have an introduction to developmental care.

In the NICU, parents write care plans with the nurses and use growth charts to plot their baby's progress. Kangaroo care is supported for both parents, and visiting by the extended families for support is encouraged. The NIDCAP observations and following discussion enables families to gain a greater understanding

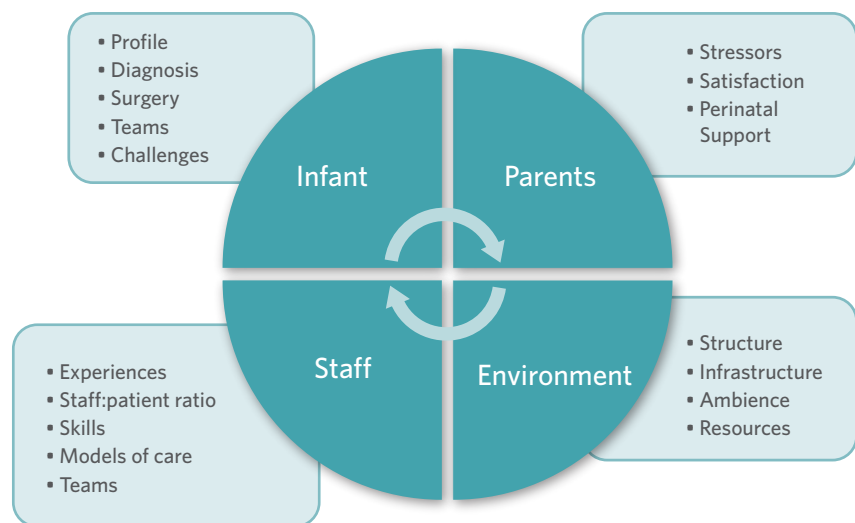


Figure 2—Plan for Change

of challenges their infant faces as they recover from surgery and establish enteral feeds. The various ethnicities and different languages spoken by the parents are a specific challenge and the nurses often use 'Google-translate' on the bedside computers to communicate in Arabic, Mandarin or French. Baby diaries are started when the infant is admitted and these provide a journal of the infant's progress; entries are made by parents, nurses, siblings and others. These are a keepsake and enable the parents to be creative in their scrap-

book skills. A parent support group is held weekly and a library is available with booklets to help explain the various complex conditions that the infants may have.

Staff

Providing opportunities to learn about developmentally supportive care is a priority for the staff with varying levels of experience. A Multidisciplinary Developmental Care Implementation Team was started and meets once a month to review the progress of implementing the model of

practice. Case studies and bedside rounds with families are used to demonstrate the use of care-plans and recommended interventions. The orientation program for new staff includes an introduction to NIDCAP. A competency program on developmental care is used as well as educational worksheets. All nurses coming to work in the NICU are part of clinical supervision groups where reflection becomes part of their learning to adapt to change and new experiences. An information brochure for visiting medical specialist teams is being developed to assist with their understanding of infant behavior, including states and cues.

Environment

The biggest challenge for change is the environment. A culture of chatting between staff and parents exists and sound as a stressor is often not appreciated. An environmental sound audit has been completed and staff are made aware of the infant's responses to sound. The SNICU uses open-care cots so the protective barrier of the incubator is not always available. The large number of personnel creates a high traffic area and NIDCAP Trainees are constantly reminding staff to walk and talk softly. An orientation walk through the unit by a NIDCAP Trainee has proved to be useful in raising the staff's awareness of their surroundings and to experience the NICU environment from the perspective of the infant and parent.

Using this information as model for system change was developed to give a focus for implementing change (see Figure 3). Table 1 below what is currently available to support the system change and the challenges as targets of change.

Next Steps

Having used the available evidence to identify and support a system change, the next steps are to review progress regularly, implement changes as they arise and then evaluate the success. An important component of any change is to set criteria for evaluation so measurements can occur over time to enable success to be celebrated and improved. This is the next component of the plan.

Table 1

CURRENTLY AVAILABLE	CHALLENGES
Infant and Family	
Opportunities to build relationships	Maintaining the focus of care
Support strategies	Creating time to implement change
Developmental care plans	Language /communication of families
NIDCAP Observations	Electronic records a barrier for sharing information with families
Developmental resources	
Education	
Evidenced based practice	Using evidence in practice
Competency based	Introductory training programs
Certificate/diploma	Electronic resources
Higher Degrees	Gen Y approach to learning
Developmentally supportive care	Multiple teams
NIDCAP readings	
Organizational Culture	
Culture of learning ¹⁵	Large workforce
People take responsibility and support one another	Part-time staff
Experiences are shared and individuals learn from mistakes as well as successes	Ritualistic practices
Good ideas are heard, acted upon and rewarded	Rotating staff
A learning culture is developed from the top of the organization /unit.	Larger health facility undergoing organizational change
Practice Environment	
Developmental Care model of practice	Workload and time pressure
Shared care	'The way things are done here'
Parents in partnership	
Multiple specialist teams	
High acuity patients	

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Figure 3—Model of focus for change

The NIDCAP and NIDCAP Nursery Certification Program (NNCP) Exhibit Display

With the generous support of the Buehler Family, the NIDCAP/NNCP Exhibit was unveiled at the Contemporary Forums/NFI Conference, Developmental Interventions in Neonatal Care, in Las Vegas, Nevada on November 13-16, 2011. The display, consisting of a free standing 10 foot lit background banner, 2 side banners, logo imprinted tablecloths, and NFI and NNCP brochures and postcards, is the NFI's latest effort at "getting the word out."

More recently the NIDCAP/NNCP Exhibit was displayed at The 25th Annual Gravens' Conference on the Physical and Developmental Environment of the High Risk Infant, January 25-27, 2012, Clearwater, Florida, and at the Ultra-Early Intervention Conference and the Nordic NIDCAP Conference in Stockholm, Sweden, March 15-16, 2012.



Pictured above, from left to right: Dorothy Vittner, RN, MSN, Julie Swanson, BSN, RN, Heidlise Als, PhD, Tammy Casper, MSN, MEd, RN, and Monique Oude Reimer, RN.



NFI Display Exhibit



Joke Wielenga, RN, PhD

This column provides our readers with current information regarding developmental resources related to NIDCAP.

Articles

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Special Journal Issues

1. Special issue of *Newborn and Infant Nursing Reviews* 2011; 11(3) on Neuroprotective Strategies. Edited by McGrath JM:

- a. Altimier L. Mother and child integrative developmental care model: A simple approach to a complex population. *Newborn and Infant Nursing Reviews*. 2011; 11(3): 105-108.
- b. McGrath JM, Cone S, Samra HA. Neuroprotection in the preterm infant: Further understanding of the short-and long-term implications for brain development. *Newborn and Infant Nursing Reviews*. 2011; 11(3): 105-108.

2. Special issue of *Clinics in Perinatology*, 2011; 38(4) on Foundations of Developmental Care. Edited by Browne JV and White RD:
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 - b. White RD. Designing Environments for Developmental Care. *Clinics in Perinatology*. 2011; 38(4): 745-749.
3. Special issue of *Current Women's Health Reviews*, 2011;7(3) on Kangaroo Mother Care:
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 - b. Ludington-Hoe M. Evidence-based review of physiologic effects of kangaroo care. *Current Women's Health Reviews*. 2011; 7(3): 243-253.
 - c. Tessier R, Cristo M, Nadeau L, Schneider C. Prematurity and morbidity: Could KMC reverse the process? *Current Women's Health Reviews*. 2011; 7(3): 254-261.

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Book and Book Reviews

Berryman, R. Book review: *Developmental Care of Newborns and Infants: A Guide for Health Professionals* (2nd Edition). *Advances in Neonatal Care*, 2011; 11 (3): 223.

Conferences

The 7th International Conference on Brain Monitoring and Neuroprotection in the Newborn. United States, Tampa (FL), September 13 – 15, 2012. www.cme.hsc.usf.edu

Marjorie Palmer's Feeding Conference. United States, New York, October 23-27, 2012.

Developmental Interventions in Neonatal Care. United States, Orlando (FL), November 7–10, 2012. <http://www.contemporaryforums.com/>

3rd International Congress of UENPS November 14 - 17 / 2012, Porto, Portugal. There will be a pre-congress course on “ Family Centred Developmentally Supportive Care”. (14 November)
Speakers : Bjorn Westrup, Silka Mader, Matthias Keller, Nikk Conneman and Rodd Hedlund.

International Network on Kangaroo Mother Care. Conference on Kangaroo Mother Care. India, Ahmedabad, Gujarat, November 22-25, 2012. <http://www.ipaworld.org/brochure%208-12%20For%20Website.pdf>

IPOKRATES Foundation Clinical Seminar/ Comprehensive Brain Care for Newborn Infants including fostering development (NIDCAP, parent-infant relationships). Torino, Italy - Centro Congressi Torino Incontra, Via Nino Costa 8, Torino, Italy. November 26 - 28, 2012. http://www.mcon-mannheim.de/ipokrates/download/Program_Torino_2012.pdf

The 26th Annual Gravens Conference on the Physical and Developmental Environment of the High Risk Infant, in collaboration with the March of Dimes. United States, Clearwater Beach, (FL), February 27–March 2, 2013. www.cme.hsc.usf.edu

Websites of Interest

<http://www.ene-mene-mini.eu>

<http://www.babybloom.nl/>

http://www.nurturedbydesign.com/NIDCAP_nurse

<http://www.youtube.com/watch?v=9VKX2KUntLA>

Video and Movie (fragments) in English

How do Neonatal Therapists help with Developmental Care in NICU?

<http://www.youtube.com/watch?v=4wZBWX1N13Q>

Developmental Observer Contributor Transitions

As of this edition, we will have completed the publication of five volumes, and ten issues of the Developmental Observer, The Official Newsletter of the NFI (Vol.1, No. 1; first published in 2007). Over the course of these past five years we have drawn upon the valued expertise and experience of professionals who have generously given of their time and energy to contribute articles to this growing publication. We wish to thank the following individuals for their assistance in the provision of an educational newsletter that supports the NIDCAP approach to care and is greatly appreciated by the NFI membership and the readership of the Developmental Observer. These individuals and the columns that they contributed to, include:

1. Diane Ballweg, MSN, RNC, CCNS: Developmental Resources
2. Tracy Price-Johnson, MA: Family Voices
3. Kaye Spence, AM, RN, RM, MN: NIDCAP Profile
4. Dorothy Vittner, RN, MSN: NIDCAP Profile
5. Inga Warren, Dip COT, MS: Current Developmental Research
6. Victoria Youcha, EdD: Family Voices

Thank you all for your time, energy, commitment, expertise, and support. You all have been of great help in producing this high quality newsletter.

We would also like to take this opportunity to welcome our new contributors to the Developmental Observer. We look forward to closely working with them in the development of articles and know that they will continue to produce the high quality, reflective and insightful vision of this newsletter in years to come. These individuals and the columns that they will contribute to include:

1. María López-Maestro, MD, PhD: NIDCAP Profile
2. Jacqueline McGrath, RN, PhD: Current Developmental Research
3. Debra Paul, OTR: Family Voices
4. Joke Wielenga, RN, PhD: Developmental Resources

Welcome to the Developmental Observer family!

And finally, we wish to thank **Melissa R Johnson, PhD** for her continued time, energy, thoughtfulness and expertise in the contributions she has made to the Supporting Families column. We very much look forward to your future columns and we greatly appreciate your insightful contributions. Thank you, Melissa!

Developmentally yours,
Rodd Hedlund, MEd
Senior Editor, Developmental Observer

Deborah Buehler, PhD
Sandra Kosta, BA
gretchen Lawhon, RN, PhD
Associate Editors, Developmental Observer

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NIDCAP PROFILE Continued from page 5

and the care that they provide. These approaches have generated a feeling of pride of belonging to the unit.

The unit has made it possible for 12 de Octubre Hospital to be the first major hospital in Spain to achieve the award from UNICEF, “The Baby Friendly Hospital Initiative (BFHI),” or the “Baby Friendly Initiative” (BFI),” a global World Health Organization and UNICEF program following the adoption of the *Innocenti Declaration* on breastfeeding promotion. The initiative is a global effort to improve the role of maternity services to enable mothers to breastfeed babies for the best start in life. It aims to improve the care of pregnant women, mothers and infants at health facilities that provide maternity services for protecting, promoting, and supporting breastfeeding, in accordance with the International Code of Marketing of Breast-milk Substitutes.

Using the knowledge from the NIDCAP approach to care, Dr. Pallás identified a productive path for the unit’s improvement and growth and the principles that provide inspiration for its activity. The NIDCAP approach has turned into a priority aim for the training of professionals who, in collaboration with the remainder of the team, can contribute to improving the daily care of infants and their families.

A team of young doctors and nurses from the 12 de Octubre Neonatology Unit was designated to be trained as NIDCAP professionals. In 2005, the team met with Dr. Graciela Basso, whose help has gradually laid the foundations of another way to think, see and care of infants and their families. The first NIDCAP professionals started to work in the unit in 2007.

Once this initial challenge was attained, the work and search for resources carried on, which enabled the unit to continue to grow. Together with Dr. Basso and the invaluable help of Dr. Als, we now have an APIB Professional and NIDCAP Trainer in the unit. Today, we are proud to say that the 12 de Octubre Neonatology Unit is a NIDCAP Training Center, led by Dr. Pallás. Her presence benefits the children and families seen in the 12 de Octubre Hospital, in both Madrid and the rest of Spain.

Dr. Pallás is currently supervising and developing an important challenge for health in Madrid: The implementation of a project that trains in developmentally-centered care in 20 newborn intensive care units in Madrid’s public hospitals. The developmentally-centered care courses are being financed, by means of subsidies to improve normal birth care, from the Ministry of Health, Consumer Affairs and Social Policy and approved by the Autonomous Community of Madrid.

The death of her sister Pilar two years ago, to whom Dr. Pallás dedicated daily care and attention during a long illness, has only served to strengthen her desire to transform health services for better patient care. Everybody in the unit is convinced that we need to care for patients and their families as we ourselves would like to be looked after. Everyone fortunate enough to work with Dr. Pallás is convinced that we are building the foundation to increase the quality of neonatology departments and ensure that the infant, family, and their needs are the center of our entire occupation and concern.

FEEDING THE MOST FRAGILE Continued from page 12

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