



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 and special care 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.

“In the long history of humankind (and animal kind, too) those who learned to collaborate and improvise most effectively have prevailed.”

CHARLES DARWIN (1809-1882)

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Message From the NFI President

Lamarck, Darwin and the Science of NIDCAP: Epigenetics in the NICU



Compared to what we ought to be we are only half awake. Our fires are dampened, our drafts are checked. We are making use of only a small part of our physical and mental resources. Stating the thing broadly, the human individual lives far within its limits. William James (January 11, 1842 – August 26, 1910).

Jean Baptiste Pierre Antoine de Monet, Chevalier de Lamarck, or simply Lamarck, was born in France on August 1, 1744, and died in poverty on December 28, 1829. He was one of the first evolutionists and is best known for his *Theory of Inheritance of Acquired Characteristics*.¹ This theory

proposes that an organism, forced by environmental pressures to change in order to adapt, will pass such changes on to its offspring. Lamarck believed for example that elephants had to stretch their trunks to reach deepwater sources and high branches, and thus their offspring inherited long trunks. Charles Robert Darwin (1809 – 1882) an English naturalist thought very highly of Lamarck, and built on his theory. He established that all species have descended over time from common ancestors, and that this branching pattern of evolution resulted from a process he called natural selection, which he published in his 1859 book *On the Origin of the Species by Means of Natural Selection*.² Darwin's thinking largely prevails today. Trofim Denisovich Lysenko (1898-1976) a Russian biologist, although much later than Darwin, tried to reverse Darwinism by going back to Lamarck and taking Lamarck's theory to the extreme. He argued for exclusively environmentally acquired inheritance, and attempted to discredit any genetic influence.³ In recent years it has become increasingly apparent that the dichotomy of genetic versus acquired inheritance is not only unnecessary but incorrect. The field of epigenetics has begun to identify that both Darwin and Lamarck are correct and that phylogenetic and ontogenetic variability are the product of natural selection on the basis of genetics and of acquired traits. A whole new vista has opened.

Why would this column concern itself with such basic biological processes? I would like to draw all NIDCAP Professionals' attention to the emerging field of epigenetics which is potentially relevant for the understanding of processes underlying the effectiveness of NIDCAP, and likely will increase the urgency with which NIDCAP will become the care in all NICU settings. At its most basic, epigenetics is the study of changes in gene activity that do not involve alterations to the genetic code yet,

nevertheless, get passed down to at least the next generation, and in some cases to further generations as well. These patterns of gene expression are governed by cellular material—the epigenome—that sits on top of the genome, just outside or above it, hence the prefix *epi-*, meaning “above.” It is these epigenetic “marks” that tell the genes to switch on or off. Through epigenetic marks, environmental factors like diet, prenatal nutrition, and stress may make an imprint on genes that are passed from one generation to the next.⁴ Epigenetics brings both good and bad news. The bad news is that lifestyle choices like smoking and over-eating may change the epigenetic marks on top of the genes’ DNA in ways that cause the genes of obesity, for example, to express themselves too strongly, and the genes for longevity, to express themselves too weakly. It is known that those who smoke and overeat have shorter life expectancies. It is now clear that those behaviors will also predispose the next generation (i.e., the children of smokers and overeaters), even before they are conceived, to disease and earlier death. The good news is that as a first step, epigenetic marker drugs are beginning to be developed for the suppression of disease (i.e., the turn-off of disease genes such as cancer, schizophrenia, Alzheimer’s and likely many others). Joseph Ecker, a plant biologist at the Salk Institute and a leading epigenetic scientist, likens the genome to the hardware, and the epigenome to the software, of the exquisitely complex human body. (The Biology of Genomes (2008) with Joseph Ecker; Interviewed by Jan Witkowski, Cold Spring Harbor Symposium, April 7, 2009; Making Science Visible www.scivee.tv).

Darwin taught that it takes many generations for a genome to evolve. Researchers are finding that it takes only the addition of a methyl group to change an epigenome. A methyl group is a basic unit in organic chemistry—one carbon atom attached to three hydrogen atoms. When a methyl group attaches to a specific spot on a gene—a process called DNA methylation—it may completely change the gene’s expression; it may turn it off or on, it may dampen it, or make it stronger. The importance of DNA methylation in altering the characteristics of an organism was proposed in the 1970s. It was verified in 2003⁵ by experiments with a prenatal mouse diet rich in B vitamins (folic acid and vitamin B12) that initiated changes which altered the gene expression for obesity in a mouse species to produce normal offspring, without altering the genomic structure of the mouse; the changes

lasted for 13 generations from the original Vitamin B supplementation. Other studies have shown epigenetic changes that lasted over 40 generations.^{6,7} The question becomes whether epigenetic changes can become permanent. It is important to remember that epigenetic changes are not evolution. They do not change DNA but represent a biological response to an environmental stressor. That response may be inherited through many generations via epigenetic marks, but if the environmental pressure is removed, the epigenetic marks will eventually fade, and the DNA code will—over time—begin to revert to its original programming. At least that is what the literature appears to indicate.

Moreover, it is becoming increasingly clear that epigenetic changes take place not only in terms of physical aspects, but also in behavioral psychological aspects of organisms, such as memory ability, which may be improved from one generation to the next via epigenetics. Mice with genetic memory problems, when exposed to an environment rich with toys, exercise and extra attention, show significant improvement in neural transmission key to memory formation. Their offspring also show long-term neural transmission improvement, even when the offspring received no extra attention.⁸ Epigenetics is perhaps the most important discovery since the gene.⁹ Marcus Pembrey^{10,11} speculates that the environmental pressures and social changes of the industrial age may have become so powerful that evolution has begun to demand that human genes respond faster. Human DNA may have to react within a few generations not over many generations and millions of years. This compressed timetable would mean that while the genes themselves would not have had enough years to change, the epigenetic marks atop the DNA would. Examples include the well-documented findings from the ALSPAC (Avon Longitudinal Study of Parents and Children) study, based on a sample size of 14,024 pregnant mothers in 1991–1992. It was designed to show how the individual’s genotype combines with environmental pressures to influence health and development. This study found that baby lotions containing peanut oil are responsible for the rise in peanut allergies; that high maternal anxiety during pregnancy is associated with the child’s later development of asthma; that small children who are kept too clean are at higher risk for eczema; and that the sons of men who smoke in pre-puberty are at higher risk for obesity and other health problems well into adulthood, than the sons

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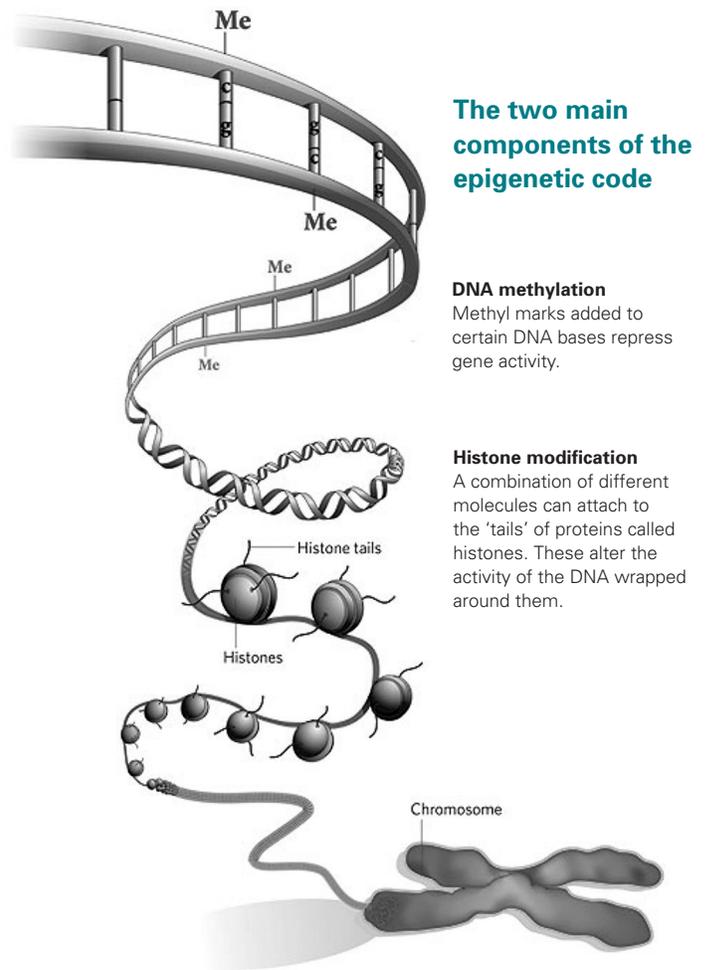
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of fathers who did not start to smoke so early. The implications of these studies are incredible. The human genome contains approximately 25,000 genes; the human epigenome thus contains an as yet unknowable number of patterns of epigenetic marks, that may be due to DNA methylation (silencing) and histone production (activation and potentiation) or both, and which may be passed onto the next generation and beyond. Qiu's¹² illustration depicts these processes.

Memory is not the only psychological function addressed to date. Recently epigenetic regulation differences due to early maternal behavior have been shown to alter glucocorticoid receptors in human brain especially in the hippocampus. Glucocorticoid receptor expression has been found to be closely associated with a developmental history of familial adversity such as child abuse. Child abuse has also been shown to be associated with an increase in pituitary adrenocorticotrophic hormone (ACTH) responses to stress,¹³ of particular relevance since pituitary ACTH directly reflects central activation of the hypothalamic-pituitary-adrenal (HPA) stress response, and hippocampal glucocorticoid receptor activation dampens HPA activity.¹⁴ These findings are consistent with those from studies with rodents and primates that show that persistent disruptions of mother-infant interaction are associated with increased hypothalamic corticotrophin-releasing hormone expression and increased HPA response to stress.¹⁵⁻¹⁷ A study of human cord blood found a correlation of maternal mood and neonatal methylation status of an important glucocorticoid receptor.¹⁸ Increased site specific methylation of a response element of this glucocorticoid receptor is linked to an increased cortisol response in the infant. Maternal mood disorders are known to be associated with decreased maternal sensitivity and impaired mother-infant interactions¹⁹ as well as increased risk for offspring depression.²⁰ Thus transmission of vulnerability for depression from mother to infant likely occurs at least in part through epigenetic modification of genomic regions that are implicated in the regulation of stress.

Thankfully epigenetic changes may also work to make up for an otherwise likely detrimental situation. Evidence²¹ demonstrates that rat mothers that show increased licking of their pups, and increased arched-back nursing (i.e., the expected form of nursing of rat pups) will alter their offspring's epigenome at the glucocorticoid receptor gene promoter level in the hippocampus; such that, rat pups who receive this form of good mothering have lower DNA methylation and higher histone acetylation, and transcription factor binding to the glucocorticoid receptor promoter gene. As a result, these pups handle stress more adeptly and display calmer behavior over the first weeks after birth, than do pups who receive less licking by their mothers and arched-back nursing. The negative effects of the poor mothering were shown to be reversible by cross-fostering the methylated pups to good mothers (and to prove the mechanism, by an infusion of histone de-acetylase inhibitor that removed the DNA methylation and its negative effects.) Thus the epigenomic state of a gene may be established for the good or bad through behavioral programming and in turn appears reversible in either direction.

This overview of recent epigenetic research makes it quite plausible that separation of the mother from the infant, in the



The two main components of the epigenetic code

DNA methylation

Methyl marks added to certain DNA bases repress gene activity.

Histone modification

A combination of different molecules can attach to the 'tails' of proteins called histones. These alter the activity of the DNA wrapped around them.

Figure: Stretches of DNA may be inactivated by covalently attaching methyl groups, which may interfere with the binding of transcriptional enzymes, and may also be signals to recruit enzymes that modify associated histones. Cells have enzymes called methyltransferases that bind to specific dinucleotides (a cytosine adjacent to a guanine) and attach a methyl group to the cytosine. Methylated DNA is silent DNA. (With permission from: Qiu J. *Unfinished symphony*. *Nature*. 2006;441(11):143-145. [page 144]).

very immature state of a preterm birth, and the experiences of the NICU for such a preterm infant, trigger a whole cascade of negative effect methylation of genes with alterations at many different sites too daunting to envision. Such changes, no doubt, are to a large extent responsible for these infants' cumulative increases in stress and maladaptive responses that may lead to lifelong, if not intergenerational altered brain states and functioning.

NIDCAP thus may work at the level of preventing such untoward epigenetic effects by supporting the infant's optimal genomic rather than distorted epigenomic blueprints. "Good mothering" and "good parenting" in the NICU becomes even more critical as does reversal of the detrimental stress-induced epigenetic changes that likely accompany the many, while necessary, often very painful procedures that assure the infant's survival. The mother and her surrogates who have an affective long-term caring investment in the infant will limit and possibly extinguish these harmful effects by their dedicated continued

care and nurturing. Seen from this vantage point, the NICU demands extraordinary mothering and parenting, conscious and fully present, while simultaneously meditative, and intuitive. Only then will the affective bond and epigenetic protection for the infant throughout hospitalization be realized. The original paradigm of the mother's breast and parents' body in close and direct contact will insure this protection. This model will declare incubators and other separations not only unnecessary, but detrimental for infants' development. Mothers, fathers and families deserve and are owed, the NICU's full support and caring so that their support and caring in turn will guarantee the best opportunity for the infant's appropriate growth and development. So much for one psychologist's current epigenetic perspective on the science of NIDCAP...

Heidelise Als

Heidelise Als, PhD

This column was prompted by an invitation to the Behavioral Epigenetics Conference organized by the New York Academy of Sciences, in Boston, Oct 29–30, 2010, a discussion with a neurologist colleague, and an article by Cloud J, "Why Your DNA Isn't Your Destiny." Time.com - Health & Science, 2010.

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Developmental Care in the Moment

Relaxation with supportive caregiving



Photograph by Ann-Sofi Ingman, RN, BSN



Monique Oude Reimer, RN and Nikk Conneman, MD

The Sophia NIDCAP Training Center

The Sophia NIDCAP Training Center opened in 2004 celebrating with a symposium, “From Behaviour to Behave,” that brought together topics like general movement and NIDCAP and its training and implementation. We succeeded in uniting the main players in the Dutch developmental group that worked in Leiden and Amsterdam. There was an enthusiastic response from the audience. The symposium ended with a strong theatrical piece performed by teenagers and professional actors and dancers who addressed the issue of how the environment influences individuals, specifically inner city children and immigrants.

The phase of preparation and initiation of the Center took us nearly one year. Foremost, our Center’s activities involved NIDCAP Training of nurses working in our own unit, followed by nurses working in various peripheral hospitals in our region. The Sophia NIDCAP Training Center is strongly tied into the NICU of the Erasmus Medical Center-Sophia Children’s Hospital. The NIDCAP Trainer is a neonatologist and the Center Co-Director works as the main developmental specialist in the NICU.

In the Dutch newborn intensive care system, the care for infants who need ventilatory support within their first 28 days after birth is centralized. When infants are breathing on their own and no longer need the academic diagnostic services, they are transferred to High Care Units in our region. Rotterdam, being the largest region in the Netherlands to service four million families, has five of those centers spread out in three provinces. The criteria for transfer to a High Care Unit includes a minimum gestational age of 30 weeks and a minimum weight of 1000 grams. The infants can be on CPAP support, since this service is also available in the High Care Centers. High Care Centers have neonatologists and NICU high care trained nurses on staff. The first hurdle of NIDCAP implementation we faced was how to provide good NIDCAP service when the babies are in the High Care Units. They spend more time there than they do with us. Just an example: when born at 29 weeks, and transferred at the age of 30 weeks, infants are in high and medium care for at least six weeks before going home.

Listening to parents’ comments, they seemed to be insufficiently prepared and not yet ready for their infant’s transfer to another unit. After the first shock of their infant’s premature birth, parents seem to settle into the NICU. They get to know the nursing and medical team. Sometimes, however, within 24 hours, the decision is made to transfer their child. Suddenly, parents find themselves in a new unit with less nursing support and a feeling that they have to start all over again. The nursery staff tells them that their infant “is doing great and doesn’t need all that extra support any longer.” Often this is difficult for parents to adjust to in such a short time period.

Our main goal was to support parents to provide care for their infant and to get to know their infant through reading his



Nikk Conneman and Monique Oude Reimer

or her behavioral cues. A way of accomplishing this goal was to have a NIDCAP trained, developmental nurse on our team support this process. When our NIDCAP Center first opened, this was a part-time job, but it soon developed into a full time position. Apart from supporting families, the Center’s other goal was to educate the nursing and medical staff. Initially, we tried this by organizing lectures and workshops complemented by occasional bedside support. We learned that this was not enough. With support from our nurse manager, who is also part of our Sophia NIDCAP Training Center management team, we developed a “NIDCAP Individual Clinic.” The clinic was offered to the nursery staff. Each participant completed a questionnaire about NIDCAP and formulated questions he/she had concerning this approach to caregiving. Each professional was videotaped while providing care to an infant. Afterwards, the nurse or doctor received an individual lecture from the developmental specialist and reviewed the videotape together. Each participant was asked to read the infant’s behavior and, based on this observation, determine what goals the infant appeared to be working towards. During this time the participant was guided and supported by the developmental specialist. After this session, the nurse/doctor returned to the infant’s bedside to: provide caregiving to the same infant; support the infant’s goals; and implement the recommendations that were created together by the professional and developmental specialist. This proved to be a very powerful teaching tool.

We received many requests for practical support from nurses around Holland who wanted to learn how to apply NIDCAP in their daily work, even though they did not fully understand the background and importance of NIDCAP Training. It was because of the many requests received for this kind of developmental support, that our NIDCAP Team decided to provide a teaching model to many units around the country. This model was linked to their specific needs while simultaneously attending to our goal of teaching the essentials of NIDCAP. NIDCAP is

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Tracy Price-Johnson, MA



Pippa Jones with her sons Jonah (left) and Noah.

Pippa Jones is the Chief Executive of the Winnicott Foundation whose aim is to provide support, equipment and training to medical staff, families and their infants who are currently living in the newborn intensive care nursery. Pippa and her husband have two sons, Noah and Jonah. Noah was born at 29 weeks and weighed 3.14 pounds. He spent eight weeks at St. Mary's Hospital in London and is now doing great things with his friends at school. Jonah is almost four years of age. He was born at 37 weeks, after a difficult pregnancy, but uncomplicated birth. He and his brother, Noah, love to swim and play games together. They have taught both of their parents much about the joys of life! Pippa shares her story of the birth of her sons and how developmental care made such an important contribution to the life of her sons and family.

Six years ago I discovered an almost secret world that few people experience, but one that leaves a large impact on those who do...newborn intensive care. It is a world that I have not left since.

My eldest son, Noah, was born at 29 weeks and four days, weighing 3.14 pounds or 1.41 kilograms. It was unexpected and the most surreal experience of my life. I knew nothing about premature babies or neonatal care but I now feel lucky to have chosen a hospital, St. Mary's London (now part of Imperial College Healthcare NHS Trust) with a newborn intensive care unit (NICU) that leads the UK in developmental care.

I experienced the family-centered approach to care when I first went to the Winnicott Baby Unit at St. Mary's Hospital. Noah had been born by emergency Cesarean-section and whisked up to the NICU in bubble wrap, in an incubator, and on a ventilator. That was my first, brief glimpse of my son. I would meet him properly six hours later when I went to the unit for the first time.

My partner, Ben, and I sat and looked at this little miracle—our son. He was so long, but also, so skinny and fragile. He seemed to be covered in so many wires. His face was obscured by his CPAP mask, as he was nested in his covered incubator. I felt rather helpless, nervously taking in this new environment. The nursery felt calm, the nurses were welcoming, and his doctor was reassuring. Noah's nurse, Elisa, said the words that filled me with joy. "Would you like to hold him?" Suddenly I felt like his mother, that I was important, that I could do something. Her manner, tone, and confidence gave me the confidence that, no matter how scared I was of hurting him, this was my role... and I could do this. Later, Jo, the Lactation Consultant, showed me how to express my breastmilk. Again, I was being shown, hand-held, that I was an important person in my son's life.

The next day Ben and I met the Parent-Infant Interaction

Coordinator, Cherry Bond, who told us about positive touch and it all made sense. Again, we felt well supported. Noah's nurses and the developmental care team showed us how to hold the feeding tube; how to change his nappy so that it didn't cause him distress; how to hold his feet to give him positive experiences to lessen the pain of regular heel pricks; how to clean his mouth with expressed breastmilk; and how to massage his tummy. We were given leaflets about his development at different stages. Between us—Ben before and after work, and me a little later in the morning—we spent 12-14 hours a day in the unit with Noah. We talked to him, read to him, sat quietly and watched him and, as he grew stronger, were able to hold him for skin-to-skin cuddles for longer and longer periods. I remember sitting there for three hours once, desperate to express my milk and go to the loo, but unwilling to give up this wonderful moment. When I wasn't with Noah or expressing milk I could take a break in the parent rooms next to the unit; this chance to have a relaxing change of environment made it easier to stay all day. Family and friends visited—strictly observing hygiene and privacy of other babies—and this made us feel like Noah truly was a part of us.

I remember a nurse being asked how she could look after these four babies in the room on her own; she said that it was because the parents were always there and that they took care of all their infant's needs. She'd taught us well and left us to parent our infant, while being a constant reassurance.

As Noah grew stronger, and came off his breathing support, Ben gave him his first bath. He was shown how to wrap him and position him to make it a pleasant experience. The staff made this into a really special moment for us.

At times, there were little hiccups along the way—the reflux, the blood transfusion, fears of infection—we were very lucky that Noah was stable. My emotions leapt up and down. Early on, the shock and exhaustion took over from the elation when

my hormones rushed in. Leaving my baby in the hospital to go home every night was upsetting. Seeing women who were heavily pregnant was hard. I fought to hold back the tears when tests or medical treatments were needed.

New nurses, who didn't know Noah, sometimes took over his feeds or care without involving me. Oftentimes this would leave me feeling helpless, until I found a way of letting these new nurses know that this wasn't how it was done. I now know that individualized care is not the norm and that some nurses had to work to change their practice.

After Noah started feeding, again, supported by nurses and the lactation consultant, we roomed in for three nights next to the unit. This opportunity, to be on my own with my baby for the first time since he was born, seven and a half weeks earlier, was scary and magical. I felt ready to take him home. Janice, the Community Nurse, came to visit us for a few weeks after our transition from the unit, for which we were very grateful.

Noah has a brother, Jonah, who was delivered at 37 weeks, two years later. After Jonah's birth, by c-section, he began grunting and the doctors planned on sending him up to the NICU for observation if it continued. Cherry Bond, came to visit us and advised me to put him upright, skin-to-skin. He stopped grunting and we spent his first night together. This "normality" was a wonderful feeling.

Both of our children are incredible, bright, happy and healthy individuals. It is hard to know what effect Noah's experience had on him; although we may assume some, I feel that the individualized care helped to reduce this. Maybe it has even given all of us qualities that we would not have had before.

The Winnicott Baby Unit is, like all NICUs, a special place. Named after Donald Winnicott, the pediatrician and psychoanalyst who said that "you can't think of the baby without thinking of the mother." He stressed the importance of the family rather than just focussing on the baby's problems. Developmental care was introduced in the unit by Inga Warren, a Consultant Occupational Therapist who worked with the medical and nursing team to train and support them in individualized, family-centered care. Inga is now a NIDCAP Trainer and from my meetings with her as a parent, in and after leaving the unit, to working with her now, I have always been amazed by her insights.

A year after Noah was born I volunteered for a charity entitled "The Winnicott Foundation." This charity provides additional funding and support to the Winnicott Baby Unit at St. Mary's Hospital. Later I became the Foundation's Chief Executive. The charity was formed 25 years ago by doctors and parents who wanted to do more for babies and families; the trustees are still parents and doctors who combine their passion and experience with advice from nursing, medical and other newborn intensive care staff. Supporting family-centered care is at the heart of the charity's work.

Based near to the unit, my role as Chief Executive involves talking to staff and families, understanding their needs and fund-raising to provide the resources to meet those needs in line with the aims of the charity and the newborn intensive care

unit. I attend parent support groups, as a parent, with the unit's Family Liaison Nurse and psychologist, as well as the weekly post-discharge infants and massage group that the charity funds. The charity aims to help parents to be with their infant... and be comfortable there. We provide funding for comfortable chairs, parent facilities, information for families, breast pumps for mothers to take home (to supplement those provided in the unit), and travel and accommodation costs. We also fund staff training and education and equipment.

In 2006, the UK NIDCAP Training Center, based at St. Mary's and supported by the Winnicott Foundation, was established. The charity supports the practice of developmental care in the unit through funding St. Mary's staff to undergo their NIDCAP Training and developmental care competencies as well as buying materials to support the care of infants and their families. We are also funding the cost of training another NIDCAP Trainer to secure the future of the NIDCAP Center.

In my years in the unit, I have seen how each family and infant is different...everybody's needs are different. I can see that strong teamwork, strong leadership, and good communication in a newborn intensive care unit supports an individualized, relationship-based approach to care that is offered to both infants and their families. I can also see that this, at times, can also be hard.

As people walk along the busy London street, past St. Mary's Hospital, as they come and go from Paddington train station, most will have no idea of the type of incredible care that is happening through a window just above them.

I feel privileged to be part of this world, to meet families who become part of it, to work with people who have made a difference to my family's life, and who continue to make a difference in other families' lives.

Pippa Jones

www.winnicott.org.uk

From the Editors

We invite you to write us with your comments regarding the content of any of the columns presented in this newsletter.

We are also interested in any suggestions that you have with regard to future topics that you would like to see addressed in the *Developmental Observer*.

Please contact us at: developmentalobserver@nidcap.org.

Developmentally yours,

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For this issue, I have chosen to profile Josep Perapoch, a neonatologist at the Vall d'Hebron Hospital in Barcelona, which is the capital of Catalonia, a county of Spain. As NIDCAP spreads across Europe, we are learning a lot about newborn care in many countries. Josep shares insight

into Spain and how NIDCAP has become truly a focus for the advancement of newborn care.

Kaye Spence (KS): Josep, can you tell me about yourself and your work?

Josep Perapoch (JP): I am a person who likes to keep in touch with nature, and being with my family (my wife and two teenagers) and friends. I also enjoy my job, supporting babies and their families to grow and develop. As a neonatologist, I am responsible for the care of preterm babies, from birth to follow-up, and therefore I am involved with the implementation of NIDCAP into the unit.

KS: We hear a lot about newborn care in various European countries, can you tell me about newborn intensive care in Spain?

JP: In Spain, there are more than 520,000 births annually. Of these, about 87,000 are in Catalonia, the main catchment area of our hospital. Over the past 10 years, there has been a 56% increase in the number of births, with a small reduction in 2009, and we are expecting a decline in the coming years. The rate of prematurity is around 7.7% of births, with 0.8% of births weighing less than 1500 grams or less than 32 weeks gestation. Across Spain, there are more than 50 hospitals which provide care for infants less than 1,500 grams. The perinatal mortality rate is around 4.5%, and for premature babies of less than 1,500 grams, neonatal mortality is about 9-10%. In general, most preterm infants are discharged home around 36 weeks corrected gestational age. The smallest at birth and those who are suffering [lung disease] are the infants who have an extended hospital stay.

KS: How big is your NICU and who makes up your newborn team?

JP: The unit of Vall d'Hebron Hospital is one of the largest in Spain. It has 69 cots, twenty-five of which are intensive care. It is a level IIIC unit attached to an obstetric and high-risk perinatal

center. We have more than two hundred nurses and twenty-two neonatologists working in the service. The availability of social workers, psychologists and physiotherapists depend on central services, and are not always available to spend the time in the NICU that we would like.

KS: This appears to be a very large unit with many staff. What models of care are you using in your NICU?

JP: We are trying to introduce a new model based on relationships as part of NIDCAP. We are moving from a classic model which is essentially based on technology. Until very recently, there were very few Spanish units that allowed free entry of parents. We introduced a change three years ago and now parents are free to enter the unit.

KS: Can you tell me more about the work you do with families in your NICU?

JP: Currently, families are invited to participate in the care of their children 24 hours a day. We try to facilitate their stay with different initiatives. We have a room for parents to relax, prepare food, and talk. We also have rooms where parents can live with their children prior to discharge. For those families living near Barcelona, a home care service facilitates early discharge from the unit. In addition, for immigrant parents, who represent more than 25% of admissions to our unit, a cultural mediation service provides not only translation but also mutual understanding from different cultural views.

KS: It seems like you have numerous supports for families. Can you tell me more about some of the changes that have occurred in your NICU?

JP: Parents now share the care of their children from the first moments of admission. Recently psychologists have joined our newborn team, with the intention of helping parents as well as other health professionals. We try to take care of infants by preventing the excess of stress which we know they can not tolerate. We are also trying to support the individual needs of each infant through relationship-based developmental care while simultaneously providing the most sophisticated care and technology.

KS: How are you incorporating developmental care and NIDCAP into this change?

JP: We have started an ambitious training program in developmental care for all professionals. At the same time, we have begun to undertake weekly observations of all infants under 27 weeks and others who we feel are most vulnerable. These infants are detected through a triage system that takes into account both the infant's biomedical and psychosocial characteristics.

Change is difficult for some professionals and sometimes there is an unwanted variability in care that can effect families.

However, we are full of optimism and believe that this is a process that will continue in a forward motion. The conviction of the majority of professionals and the directions of the hospital are a major factor.

KS: I think you have described some of the challenges we all face when we try to make changes. It is valuable to hear about the work of others involved in NIDCAP. When did you first become involved with NIDCAP?

JP: I started my NIDCAP formal training five years ago, thanks to my good fortune in meeting Graciela (Grace) Basso, MD, PhD. Grace has been critical for the development of NIDCAP in our hospital and in Spain. In addition to the professional bond, from the beginning, a great friendship unites us.

Before meeting Grace, my understanding of NIDCAP was through meetings and conferences where I had heard of and met Nikk Conneman, MD, Bjorn Westrup, MD, PhD, Agneta Kleberg, RN, PhD, Inga Warren, Dip Cot, MSc, Jacques Sizun, MD, and especially through the work of Heidelise Als, PhD. My evolution from a more technological form of neonatology was influenced by many factors such as my curiosity of perinatal results in the Nordic countries; my experiences through the follow-up of infants and their families; and also the fact that my wife is a psychologist and the opportunity to discuss with her many of these aspects. In addition, a large part of this journey has been shared with a good friend and professional, Dr. Keka Pallas.

KS: This highlights for me the importance of having a good mentor. How is NIDCAP Training being achieved in your unit now?

JP: Currently we have two certified nurses, besides myself, and a doctor who has completed the Advanced Practicum, and a total of twelve professionals who are in the training process. I am doing my APiB training and am fortunate to be doing it with Grace and Heidi. There are many professionals in the hospital wanting to start their training. We plan to develop a NIDCAP Training Center, which is a big responsibility for all of us.

KS: What do you think is the future for NIDCAP in Spain?

JP: The future, and present, is very good. Spain has awakened late but forcefully. There are three hospitals with NIDCAP professionals: two hospitals in Barcelona (Vall d'Hebron and Sant Joan de Deu) and another hospital in Madrid (Hospital 12 de Octubre). There is a lot of interest in starting NIDCAP Training in many other hospitals. In parallel, there is great interest in developmental care in the majority of Spanish newborn intensive care units.

KS: What do you see as the most important aspect of providing best practice for preterm and sick newborns in Spain?

JP: One important aspect in providing best practice will be the value that nurses and also doctors, are giving to NIDCAP and developmental care. Another aspect is the involvement of governments. They have begun to include it in their plans. The key point is that parents become caregivers of their children during

admission. Most Spanish units are opening their doors to parents. This will definitely help to change the way to provide care for preterm and sick newborns.

KS: Thank you Josep. Many of us will benefit from your insights and the NIDCAP approach to newborn care.

In the Hallway

One Hallway

Two mothers

Two different realities

One me

I run into you in the hallway outside of the NICU
You smiled, cell phone to your ear

“He is better, he is much better,
I am calling the family,
I can finally breathe”

I punch my arms to the sky with a silent shout
Then reach out to you,

We hug tightly
Celebrating this victory

I run into you in the hallway on the way to the NICU
You try to smile, but your eyes are sad
I ask, “How is he?”

Your shoulders slump, your lips tremble
“He went backwards last night again,
I thought he was doing better,
Then this...”

I find no words, with tears cresting
I reach out my arms,

We hug tightly
Trying to comfort each other

One Hallway
Two mothers
Two different realities
One me

Bess Heliker, RNC, MN, Feb 6, 2010

Melissa R. Johnson, Ph.D.

A NICU Parent Support Group Using Scrapbooking: The PAGes Project

Many different strategies may enhance our support of parents; strategies that draw on family strengths and creativity are especially consistent with the NIDCAP approach to care. Laurie Mouradian, ScD, OTR/L, Program Director of the Oklahoma Infant Transition Program at Children's Hospital in Oklahoma City, OK, writes about a very successful activity that fits this description perfectly. The team describes not only the details of developing and running such a program, but also data demonstrating its effectiveness in reducing anxiety experienced by NICU parents.

The PAGes (Parents Are Great) Project is a parent support group that uses scrapbooking as an activity to help parents navigate the experience of having a baby in a newborn intensive care unit (NICU). It is provided by staff of the Oklahoma Infant Transition Program (OITP) at Children's Hospital in Oklahoma City, OK.

Naturally, parents with a baby in the NICU worry about infant survival and possible long-term effects of prematurity. Researchers²⁻⁴ have shown that additional stressors for parents during hospitalization include the infant's appearance, sights and sounds in the unit, alterations in the parents' roles and in their relationship with their infant. Even three years after having a child in NICU, mothers recall vivid memories of the stress associated with the NICU experience.⁵ As a therapeutic activity, making scrapbook pages, which typically include a photograph and journaling about the photograph, may incorporate the potential stress reducing benefits of both photography and writing.^{6,7} Therefore, to help parents with the experience of having a baby in the NICU, we developed a weekly parent support group using scrapbooking as an intervention to reduce parental stress. To test the benefits of this group we received a small grant from the Department of Pediatrics, Neonatology Section, to fund a research study.

One afternoon a week, we held a two-hour session in the NICU Education Room. Flyers were posted and also left in each care room to let parents know about the group. Each week, we brought a cart with art supplies and rearranged the chairs and tables to create an inviting environment that included soft music in the background. All parents who came to the group were eligible to participate in the activity and parents 18 years or older, were offered study enrollment. Parents who agreed to participate in the research portion of the program received a prepaid gift card at completion. To document the effects of group participation,

we chose to measure state anxiety, which refers to anxiety "in the moment." We used a self-report paper and pencil test, the State-Trait Anxiety Inventory⁸ (STAI) before and after the group experience. We also interviewed parents briefly after the group session about their experience.

When a parent arrived, the research component was described and age eligibility (18-45 years) was determined. For parents who agreed to participate in the study, a consent form was reviewed and signed. Those parents who did not bring a photograph signed an additional photograph consent form and then accompanied a staff member to take a picture of their baby. Upon return, the parent was given the STAI while waiting for the photograph to be printed. A staff member then reviewed the supplies provided, and showed samples that were available. Additional suggestions and assistance were available at parent request. Once a parent indicated they were finished with their page, the STAI was administered again. For privacy, we stepped out of the room with the parent to conduct a brief closing interview and for distribution of the gift card.

Statistical analysis compared scores on the STAI taken before making a scrapbook page to scores after making a scrapbook page. We enrolled three to four families per session for a total of 40 families who completed both the pre- and post-intervention tests completely. We found that state anxiety levels declined an average of 12.7 points as measured by the STAI. Statistically this was very significant ($p < 0.0001$), clinically meaningful, and larger than we anticipated. Qualitative analysis of the brief parent interview demonstrated that, from the parent's perspective, participation appeared to support these findings. Parents described the group as being relaxing, and as providing an element of distraction while reducing boredom.

They also described that it gave them an opportunity for emotional support and reduced their sense of isolation. Finally, it gave them an opportunity to do something meaningful for their infant. Anecdotally, parents repeatedly report how relaxing the experience was and how much they appreciated being able to participate in this group.

The study data collection phase concluded at the end of December, 2008. With the generous support of the Children's Hospital Volunteer Auxiliary and numerous other individual donors, including nurses, doctors and family members, we have been able to continue offering a weekly scrapbook group for NICU families. From January, 2009 to May, 2010 we served over 500 additional NICU family members and look forward to continuing to offer this valuable service to families of newborns at Children's Hospital. This program has been replicated in a Chicago NICU and we would be happy to give input to anyone who would like to start a similar program in their NICU (please contact Laurie-Mouradian@ouhsc.edu).

We would like to thank the families who participated in this study. We would also like to acknowledge Beth DeGrace, PhD,

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Detecting the Bias in Randomized Controlled Trials: A Healthy Attitude to Good Scientific Research

Evidence-based medicine (EBM) is defined as *“the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients,”*¹ and also incorporates the patient’s values, including religious or moral beliefs, and patient autonomy. EBM is a way to evaluate and manage medical uncertainty. Around the world, the drive to increase quality of care while reducing costs raises the demand for cost effective strategies and it will be argued that money is best spent on interventions with the highest level of evidence.²

The randomized controlled trial, the gold standard for EBM, offers a higher level of evidence than observational studies or non-randomized trials. Critical analysis of trials includes the search for bias, which is the *“tendency of an estimate to deviate in one direction from a true value”*³ and is *“...not necessarily associated with a conscious or malicious attempt of investigators... more commonly unintentional, and often unrecognized even by the researchers themselves...”*³ Therefore, searching for bias is an approach that helps clinicians to understand the limits of current trials and to imagine the next step for research.

It is difficult to completely eliminate bias and it can take many forms; different types of study are subject to different forms of bias. We have highlighted some forms of bias that may be of particular interest when considering a NIDCAP study design.

Bias of Recruitment

Bias of recruitment can occur if some potentially eligible individuals are selectively excluded or included in the study because the investigator knows the group to which they would be allocated if they participated; for instance, enrolling a patient with a better prognosis into the investigator’s preferred treatment. This bias could arise from the investigators’ subjective concerns about the risk of adverse effects.⁴ Usually bias of recruitment is suspected if the method of allocation can help the investigator to predict future allocations based on knowledge of past allocations, for instance, using blocks of sealed envelopes. This bias is also suspected if the recruitment rate is low compared to the high number of eligible patients hospitalized in the research site. This bias can be reduced by “allocation concealment,” which is rarely reported in clinical trials.⁵ Decentralized randomization by telephone or the Internet are ideal methods for allocation concealment.

Ascertainment Bias

With this bias, the results of a trial are distorted by knowledge of

which intervention each participant is receiving. This bias could occur if the main outcome is evaluated by an investigator who participated in the intervention or has access to the allocation data. The risk is important if the investigator belongs to the team in charge of the patient. The solution is to have examiners fully independent from the team and/or with two independent and blind evaluations of the outcome.

Contamination Bias

The contamination bias can occur when a patient from the control group inadvertently receives the intervention. This is crucial for NIDCAP trials when infants from the control and intervention groups are cared for in the same unit. In this case, there is a risk of masking a true positive impact of the intervention. One solution is to perform a cluster randomization. This means that instead of randomizing patients the trial will randomize units: “intervention units” and “control units”. Unfortunately, this method needs a higher number of patients than a trial with patient randomization and exposes the trial to other forms of bias and difficulties with informed consent.⁶ Moreover, in the case of NIDCAP, it will be necessary to train more units before sufficient numbers would be available for cluster randomization.

Complexity Bias

This bias is observed when a trial is used to study complex interventions needing the skills of health professionals that are not available in other settings. This does not affect the absolute value of the results, however, it may effect the generalization of the conclusions. When new techniques are introduced, the results are generally not as good as they are after a period of practice when the professionals delivering care have learned from experience.

Choice-of-Question Bias

This bias occurs when a trial is designed to demonstrate a pre-required answer but not to answer the main question. For instance, as it could be complex to demonstrate the long-term positive impact of an intervention, it could be easier to measure the impact on a short-term outcome, such as the length of hospitalization.

Conclusion

Searching for bias is a scientific approach that helps to enrich medical discussion and to avoid emotional conflict. It is also an important exercise for students as part of their scientific training. The main recommendations for designing a future multi-site NIDCAP study are:

- » Decentralization of randomization;
- » Randomization by clusters;
- » Blinding the evaluation by using at least two independent examiners; and
- » Long term neurodevelopment as the main outcome.

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Diane Ballweg, MSN, RNC, CCNS

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We invite you to send in information that you may encounter, such as upcoming conferences, websites, books, journals, articles, videos, etc., that may be shared with our readers. Please send items for inclusion in the Developmental Observer to Diane Ballweg at: developmentalobserver@nidcap.org.

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 NNCP Director at: nncpdirector@nidcap.org or 785-841-5440.

very much in demand in Europe, thus part of the Trainers' time is spent training Trainees in other European countries. More general developmental knowledge is spread through lecturing at international conferences on various topics, from NIDCAP to developmental implementation and teaching, as well as providing information on developmentally supportive architecture.

The Sophia NIDCAP Training Center also provides lectures and motivational support for teams from different national and international NICU's. Many European nurses and doctors have since spent time in our unit in Rotterdam; visiting anywhere from a few weeks to an entire month. Prior to their visit, each nurse/doctor submits a formal application and identifies the specific goals of their visit. To help them reach those goals we provide individualized support to these visitors. Each visitor is paired with their professional counterpart. For example, our Nurse Manager will spend time with the visiting Nurse Manager and a visiting administrator is paired with our hospital's administrator.

In the Netherlands, we have a very strong group of individuals invested in the training and implementation of the Infant Behavioral Assessment and Intervention Program (IBAIP®).¹⁻⁴ The IBAIP is based on the Model of Synactive Organization of Behavioral Development^{5,6} and on the work and training of NIDCAP.⁷⁻¹⁰ It offers a continuum of neurobehavioral support for infants who receive care in the hospital from NIDCAP trained professionals. Once the infant has been discharged home with his or her family, this neurobehavioral support is continued with the implementation of IBAIP by early interventionists in the community. In June 2008, an IBAIP Training Center was established in Amsterdam at the Academic Medical Center,

University of Amsterdam. The IBAIP Training Center has recently been funded by Dutch insurance companies to support IBAIP implementation once the infant is discharged home.

The Amsterdam and Rotterdam Academic Centers are very supportive of NIDCAP. We hope to prove that a solid, NIDCAP-based start in the hospital, complemented with IBAIP implementation at home, will become the standard of Dutch newborn intensive care and community early intervention services.

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Submitted by Laurie Mouradian, ScD, OTR/L

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