

# Developmental Observer

The Official Newsletter of 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.

"We cannot create observers by saying 'observe,' but by giving them the power and the means for this observation and these means are procured through education of the senses."

Margaret Mead, 1901-1978

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# NIDCAP Training Centers from Around the World

B uenos Aires, Argentina is home to the Centro Latinoamericano NIDCAP Otamendi which opened in April 2005. It is the most austral NIDCAP Training Center of the NIDCAP Federation International and is currently the only Spanish speaking center. Our working conditions may be different from the US and European



Working together in South America, Graciela Basso (Neonatologist), Stella Granatto (Speech Therapist), Marcela Castellanos (Neonatologist)

NIDCAP Training Centers due to the major socio-economical differences typical within a Latin American country. In Buenos Aires, however, we have the privilege to have a Level III Nursery that is situated in Otamendi Hospital, a private institution. Our hospital accepts high risk pregnant women from other hospitals as a referral perinatal center and has 4,200 to 4,500 deliveries each year. The Newborn Intensive Care Unit (NICU) census averages 35 infants a day and we care for many premature infants as early as 24 weeks gestational age. Our unit also has the capacity to perform surgeries in our own hospital. We have three medical doctors on duty each day covering the full 24 hours. There are 150 nurses on staff. As a private hospital in Latin America, it is common to have middle to high socioeconomic patients in addition to those who are less advantaged. The families usually live near the hospital, and they have the possibility to be in the unit all day long.

The unit is directed by Dr. Luis Prudent and nurse manager Stella Roa. Our NIDCAP training team consists of the following dedicated professionals: Stella Granatto (speech therapist), currently a NIDCAP Trainer-in-Training; Maria Luisa de Anchorena and Marcela Constanza Cerullo (psychologists); Clarisa Noales (occupational therapist); and Marcela Castellanos and Carlos Llama Figueroa (neonatologists). Since our center opened we have been very busy with a number of varied and challenging projects including the translation of the APIB introductory chapter and manual<sup>1,2</sup> as well as the training documents from the English to the Spanish language. Our NIDCAP Center is also working on a book based on developmentally supportive family centered care. In addition we presented on NIDCAP and attachment development in the premature baby within the NICU at the last NIDCAP Trainers Meeting.

For over a year we have been working on a second phase in our research: the evaluation of developmental care with babies in disadvantageous conditions. This work is being done with the support of the Argentinean Pediatrics Society, and the progress on it will be shared this year at the 18<sup>th</sup> Annual NIDCAP Trainers Meeting in Combrit, France, September 29 - October 2, 2007. One of our greatest satisfactions is receiving the parents' feedback and seeing how they contribute in the creation of parent groups. The parents and families are always ready and willing to help which keeps us learning.

We have also established a number of permanent activities as part of our discharge process, including: 1) home visits; 2) coordination of interactive working groups after medical discharge; and 3) meetings for continuous evaluation with the Follow-Up Team that contributes to our ability to improve communication and satisfaction among the families and all the team members. We believe that supporting parents as the primary nurturers and caregivers of their baby beginning in the first moments after birth and once discharged home, supports the developing and evolving relationship between parent(*s*) and infant. This support is obviously essential for parents that live in disadvantaged socio-economic conditions because it is through this early and strong affective parent-infant bond that parents can support their babies to grow to their optimal potential.

Dissemination of the NIDCAP work and developmental care has also been one of our priorities. Locally, we are working with public hospitals to help them understand how the NIDCAP approach supports infants and their families while the infant is undergoing necessary high technological care. The comprehension of the Synactive Theory helps us to understand not only the behavioral language of the preterm infant, but also family-centered care, including breastfeeding and kangaroo care. These are basic notions that can be applied to disadvantaged environments. We are individually working toward adapting the environment to these possibilities in each one of the newborn and special care units.

To further our efforts in training and dissemination of the NIDCAP work in our country, we have given conferences in many different provinces of Argentina: Salta, Córdoba, San Juan, Santa Fe, Mendoza and Buenos Aires, including congresses and workshops. Our training has also taken us outside of Argentina. We have crossed the Cordillera de los Andes and the Atlantic Ocean to begin providing NIDCAP training to health care professionals in both Chile and Spain. In addition, we have also welcomed health care professionals from other countries to work with us for several months to familiarize them with the working dynamics of a NIDCAP Training Center.

It is with great enthusiasm that the Centro Latinoamericano NIDCAP Otamendi, wholeheartedly supports and participates in changing the future for infants in intensive care here in the most austral region and beyond.

#### —Graciela Basso, MD, PhD

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#### **Developmental Care in the Moment**



Relationships: The Importance of Feeling and Being Connected

## Developmental Observer

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### Message from the NFI President

# Preparing to See and Seeing

ne of the perhaps less visible threads of the NIDCAP Journey is the life of my son Christopher Markoe Rivinus Duffy. Christopher, born fullterm, sustained brain injuries during the delivery process and has taught me the essence and importance of seeing a child, seeing the child's strengths, while being fully aware of and embracing his disabilities as part of him. Seeing him and seeing the world, including myself, with his eyes has opened my own eyes, and continues to make me more aware and conscious. It has shaped my life and career, and has offered me the gift to see infants and parents in a deeper way. Christopher informed my decision to study human behavior in greater depths. I learned that intuitive parenting<sup>1</sup> must become conscious parenting when the child's individuality portrays behaviors other than human expectation has prepared us for in the thousands of years of evolution to be good enough parents. I also learned from Christopher that each child actively shapes the adults and the environment around him or her, and that the adult, who becomes aware and has the emotional where-with-all to open earlier well-practiced ways, and see the child, becomes the better for it. This mindfulness and the attunement to grow oneself, shape the environment and all interaction to nurture, bring out the best in, and cherish the other person, is the mark of a trusting relationship. Children, who are unusual, help us better appreciate the dynamics of all children's development, and help us understand that all children are unusual, uniquely talented, and individual. We learn that what is good, and perhaps necessary to support the unusual child, is good for all children, and for all persons, and all relationships. Bowlby's volume on Attachment<sup>2</sup> partly validated my thinking. Yet I disagreed that the human newborn infant only keeps the mother close by crying, until at about 5 to 6 weeks. I found it difficult to imagine that as a species, we would survive if no other infant stimulus but crying kept us engaged for the first six weeks. Our ancestors likely would have discarded us a long time ago. As it turns out the newborn's eye opening and eye contact is the great reward that as adults we quite intuitively work and live for.<sup>3-5</sup> When that eye contact is hard to come by, when its occurrence, characteristics, or frequency violate the adult's expectation, the interaction threatens to derail. However, when the parent becomes conscious of the infant's profile and the intuitive interaction's difference, the ensuing self-awareness and awareness of the child's individuality may help the parent right the relationship and interaction.

In order to understand these neuro-biologic-social-affective processes more fully, I spent a year rich in experience and learning at the Behavior Development Research Unit (BDRU) at St. Mary's Hospital in London, UK. Anthony (Toni) Ambrose, PhD,<sup>6,7</sup> Director of the BDRU, studied the dynamic parameters of pregnant women's walking in order to test a gait-simulating moving cradle, in an effort to soothe unusually irritable newborns. Genevieve Carpenter, PhD,<sup>8, 9, 10</sup> also at the BDRU, identified how very early newborn infants reliably distinguish



Frank H. Duffy, MD, Christopher M. R. Duffy and Heidelise Als, PhD

their mother's face from another woman's face. Olga Maratos<sup>11</sup> then a Greek doctoral student at the BDRU in 1972, now Professor of Psychology at the University of Athens, discovered the newborn's capacity to imitate specific facial expressions and arm movements of the interacting adult, including sticking out the tongue. Andrew Meltzoff made famous this finding.<sup>12</sup> I had contact with Nick Blurton-Jones, the first human ethologist to my knowledge,<sup>13-15</sup> who observed young children's interactions on the playground. My own research in London focused on the observational study of relationship-based mutual goal sharing of healthy fullterm newborns and their mothers, who experienced rooming-in from birth to 30 days, a new concept at the time. I also serially assessed the infants with the Brazelton Neonatal Behavioral Assessment Scale.<sup>16</sup> I learned of the mutual interplay and shaping of infants' and parents' goals as expressed in the infants' levels of arousal and irritability and the mothers' efforts to regulate their infants. Infants, who were hypersensitive, easily overly aroused, and irritable, tended to have mothers who actively attempted to soothe them; the infants gradually became calmer and the mothers less concerned with soothing activities. Infants who were placid, low active and difficult to wake and engage, tended to have mothers, who attempted to stimulate and arouse their infants. These infants gradually took more initiative, and more actively engaged their mothers; the mothers responded to them in increasingly calmer ways.<sup>17</sup>

In an effort to deepen my knowledge and understanding, I then joined T. Berry Brazelton at his newly founded (1972) Child Development Unit, at Children's Hospital Boston. His generous mentorship and brilliant teaching convinced me of the importance of translation of clinical expertise into empirically testable questions. The opportunity to operationalize clinical skill and insight helped me focus my research on the fullterm infant's strengths and capacities, the openness of the parents<sup>18-20</sup> to hear and see, and to seek and accept support as at no other time in their lives. I learned about the infants' and parents' striving for connection and relationship from the first moments on. I learned that infants will struggle to connect with the parent, and vice versa, even in the face of an infant's intrinsic difference,<sup>21-25</sup> and in the face of experimentally imposed violation of expectation such as in the still-face mother paradigm.<sup>23, 26-29</sup> Not least, my growing son Christopher helped me understand this striving manifold, and at times at more cost to him than I wished, he had

to pay. These experiences prepared and motivated me to venture and attempt to see anew, with better skilled eyes, the preterm infant requiring intensive care.

In 1975, now at the Boston Hospital for Women, Lying-In Division, my goal had become to learn to read and understand the language of the preterm infant, to learn and document what the preterm infants experienced, how the NICU experience influenced and shaped and perhaps inadvertently changed and possibly damaged the infant. For the next year or so I observed, wrote, rewrote, and edited repeatedly the basic dictionary of the infants' communications in the face of various events and circumstances. I realized that the behavioral messages involved various subsystems and that depending on the challenge and/or the immaturity or illness of the infant, even the most basic autonomic system functioning might be overtaxed and become overwhelmed.<sup>30</sup> The infant might simply stop. Often my own helplessness frightened me, yet the infants' and the caregivers' determination in turn assured me that they somehow tried their best to work together at this life too early outside the womb. I felt pressure to translate my observations into a coherent system that would be usable by others. I wanted to articulate the subsystems in their interplay and fluctuating relationship to one another and to the environment and events that occurred with, to, and around the infants, in order to support those who cared for the infants to see them as their collaborators and recognize their goals, determination, and their strengths, as well as their thresholds to stress. The Assessment of Preterm Infants' Behavior<sup>31, 32</sup> took shape together with its core, the systems sheet. I sketched and re-sketched the complex sub-systems in interaction, struggled with images and words, and wrote and rewrote what became the Synactive Theory of Development.33

In the effort to see and take seriously the support to the infant in helping the infant achieve his or her own goals, close communication and collaboration became essential with those who cared for the infants in the NICU, and who structured their environments. Pat Linton Thompson, and soon gretchen Lawhon, NICU nurses at the time, were the brave pioneers, who first removed the ties that held an infant's arms and legs in place; bedded an infant on the side; made soft nests for the infant to cuddle and tuck into; covered the infant to feel more secure; and the incubator to shield the infant from the bright lights; assured a comfortable chair for the parents at their infant's bedside; supported the parents to hold their tiny infant; and assured the neonatologists that all this was not only safe, but also supportive of the infants' and their parents' development. All the while, the detailed infant behavioral observations helped us stay true to each individual infant and assured us of the current appropriateness of the modifications and adaptations of care. Rita Gibes, RN, MSN, NICU Head-Nurse at the newly merged Brigham and Women's Hospital, quickly recognized the great advantages this approach entailed, and became the first leadership professional to support the individualized developmental approach to care. She was a courageous change agent par excellence and insisted on the first ever installation of individual lights with dimmer switch capacity above each warming table, incubator and crib; an invitation to the parents

to be with their infant at all times; and advocated for us and our observations and care modifications. She established the first ever "developmental care clinical nurse specialist" position for gretchen Lawhon. In addition, she insisted that the approach required its own name in order for others to adopt it. She coined the acronym "NIDCAP."

Elizabeth "Liz" Brown, MD was painfully familiar with infants who struggled to breathe and to eat; who did not sleep, had trouble gaining weight, vomited often, and arched their backs all the time; infants with retracted shoulders, wideeyed panicked facial expressions, and extended limbs. She cared for them in the NICU and after NICU discharge in the "BPD (bronchopulmonary dysplasia) Clinic." Liz was the first neonatologist who expressed her hopes that NIDCAP would improve these infants' quality of life and perhaps reduce the severity of their lung disease. Together we wrote the first grant application to the H. P. Hood Foundation in order to test foremost the safety, and perhaps even the efficacy of the NIDCAP approach to care. This first small NIDCAP study, published in Pediatrics in 1986,34 had very encouraging results, and fueled our courage to continue to pursue this individualized approach and learn more about it, how to teach it, and how to make it systems effective.

Around the same time, Christopher, now a young man, prompted my husband Frank Duffy and me to find an environment and life setting that built on similarly synactive principles as did the NICU work. After heart breaking searching, visits, and experiences at the traditional adult environments for persons with disabilities, we miraculously found Camphill Village Copake, an anthroposophical village, based on the principles of Rudolf Steiner, (1861-1925) an Austrian philosopher, who mainly worked and lived in Germany. His conceptualizations also underlie the Waldorf Schools. He inspired Karl König (1902-1964), the Austrian pediatrician and specialist in learning and developmental disabilities, who then founded the Camphill Movement, an international movement of therapeutic "intentional" communities for those with special needs or disabilities, where all may thrive, as they live and work together. Just as in the NIDCAP work, the Camphill social and relationship-based fabric, and work and life environments aim to bring out, liberate, develop, and cultivate the competence, creativity, fulfillment, and mutual caring in every person, no matter their talent. While ending this essay, I continue to learn from Christopher, from my husband, all those who make Camphill the special place it is, from those engaged in the NIDCAP work and world with me, and from all the infants and families and the professionals who care for them. We are all connected; we mutually support, teach, learn from, and enrich one another.

To be continued.

Heidelise the

Heidelise Als, PhD

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# **Brain Development and the Expression of Human Consciousness**

K. J. S. Anand, MBBS, D.Phil., FAAP, FCCM, FRCPCH

C ince the advent of Neonatology, clinical **O**assessments of brain development in the newborn are mostly based on somatomotor development at birth, with almost complete disregard for sensory, cognitive, emotional, or other regulatory functions in development. Across the mammalian species, developmental comparisons<sup>1</sup> show that more than two months before birth, the human brain is at the developmental stage of the newborn macaque, a species considered quite precocious at birth.<sup>2</sup> Most clinicians may not realize that human newborns are capable of complex processing, including abstract processing of the shapes or objects, or the properties of numbers, implying relatively advanced prenatal development of sensory processing. Arguments against the possibility of fetal/neonatal pain have been based on immaturity of cortical neurons and the thala-mocortical connections conveying inputs from the periphery.<sup>3, 4</sup> Immaturity or suppression of cortical neurons are not, by themselves, sufficient to preclude the occurrence of early pain.

#### Developmental Roles for the Subplate Zone located below the Cortex

The subplate zone of the forebrain, which later separates to provide the interstitial neurons in the subcortical white matter and neurons in cortical layer I, forms a complex synaptic network of neurons and glia. Within this network synaptic communication occurs via release of glutamate, GABA, acetylcholine, neuropeptides, and calcium-binding proteins. The somatosensory subplate zone receives distinct inputs from the thalamus and the neocortex<sup>5</sup> and reaches four times the width of the somatosensory cortex in the human fetus (and twice the width in the monkey). Subplate zone neurons can



stimulate excitatory N-methyl D-aspartate (NMDA) or peptidergic activity in the cortex, influencing the development of fetal cortical circuits.<sup>6,7</sup> Differentiation of the subplate neurons at 17–25 weeks' gestation produces five cellular subtypes whose distinct dendritic and axonal patterns correspond to different functional roles in development. Changes in the subplate zone are evident in the lamination patterns of the developing human fetal cerebral cortex.<sup>8,9</sup>

Limited understanding of their role has led scientists to label subplate neurons in deep cortical layers as "vestigial remnants," simply because other subplate neurons undergo programmed cell death during development. Huge numbers of spinal cord neurons also die during development, with no suggestions those remaining neurons are vestigial. Maintaining "vestigial" neurons would be metabolically expensive and unlikely to occur in evolution. On the other hand, subplate neurons are optimally positioned for efficient communication, with sparse connections across time and space and rich inputs from cortical and thalamic sources. They play essential roles in the formation of ocular dominance columns, sensory receptive fields, or cortical gyri. Thus, they are particularly vulnerable to the preterm

injuries that produce cognitive and sensory deficits during later childhood.

Selected apoptosis of subplate cells in superficial layers leaves behind wellconnected subplate cells in deep cortical layers, thereby forming the earliest cortical circuits. Their connectivity give rise to the behaviorally relevant component of evoked responses termed "N1," which represent sensory perception in primates and is initiated in cortical layer I.<sup>10</sup> These cortical connections, initially formed in the subplate zone, are essential components of the cognitive processing by which sensory information is primed, guided, and interpreted.<sup>10, 11</sup>

# Does Consciousness depend solely on the Cerebral Cortex?

As the starting point for the observation of all natural phenomena, consciousness is required to prove the existence of anything, but there can be no proof of consciousness.<sup>12</sup> More than 50 years ago, Wilder Penfield (a neurosurgeon) and Herbert Jasper (a physiologist) noted that large cortical excisions, even as radical as hemispherectomy, could be made while their conscious, awake patients continued to converse with them. Despite the extent of this surgery, patients showed no evidence for an impairment of consciousness.<sup>13</sup> Surgical removal of cerebral cortex containing epileptic foci deprived these patients of stored information or discriminative capacities, but did not affect consciousness itself. Based on observations from more than 750 patients, Penfield and Jasper proposed that "the highest integrative functions of the brain are not completed at the cortical level, but in a system of highly convergent subcortical structures supplying the key mechanism of consciousness."13 Various cortical areas were stimulated electrically,

which revealed that the reflective, conscious capacities of these patients proceeded in parallel with the artificially stimulated effects such as elaborate fantasies or dream-like experiences, suggesting that the observing function of consciousness is separable from its cortical contents.<sup>13</sup> In patients with stroke or head injury, lesions in the reticular activating system, but not the cortex, lead to loss of consciousness.

During petite mal or "absence" epilepsy, a brief lapse of consciousness occurs associated with a distinctive electroencephalogram (EEG) pattern of bilaterally synchronous spike and wave discharges. The bilateral discharges show a symmetrical coincidence of even the very first abnormal EEG spike, which is inconsistent with epileptic spread across interhemispheric pathways. Instead, they may result from paroxysmal discharges in the midline subcortical structures, which are radially and symmetrically connected with both cerebral hemispheres. This EEG pattern cannot be produced by experimental stimulation of cortical areas, but is evoked by stimulation of the midline thalamus.<sup>14</sup> The Nobel laureate Edelman and colleagues also discussed the criteria for consciousness in animal species, concluding that the mechanisms for consciousness are not exclusively cortical.15-17

Infants and children with hydranencephaly, a brain disorder with complete absence of the cerebral hemispheres, provide further clinical evidence for conscious perception mediated by subcortical centers.<sup>18, 19</sup> These children clearly possess a discriminative awareness of their environment, despite a total or neartotal absence of the cortex. They can distinguish familiar from unfamiliar people (the same for their environment) and are capable of social interaction, visual orienting, musical preferences, appropriate affective responses, and associative learning.20

A subcortical system comprising the basal ganglia, medial and midline thalamic nuclei, substantia nigra, ventral tegmental area, superior colliculi, midbrain, and pontine reticular formation mediates the organization of consciousness.<sup>21</sup> In the words of Penfield and Jasper, this system does not function "by itself alone, independent of the cortex," but "by means of employment of various cortical areas."<sup>13</sup> The fact that the corpus callosum or other forebrain commissures are not required for high levels of cognitive function,<sup>22</sup> provides supportive evidence for the subcortical integration of both cerebral hemispheres, symmetrically and radially connected to this midline system.

Therefore, multiple lines of evidence corroborate that the key mechanisms of human consciousness or conscious sensory perception may not depend on cortical activity. Consistent with this evidence, the responses to painful stimulation of children with hydranencephaly are purposeful, coordinated, and similar to those of intact children.<sup>20</sup> Preterm neonates or adolescents with severe cortical parenchymal injury mount biobehavioral responses to pain that are indistinguishable from those of normal controls. Whether consciousness is required for sensory perception has also been questioned by recent studies of adult patients in a persistent vegetative state.<sup>23, 24</sup>

# Recent Reviews have a Faulty Scientific Rationale

Several authors have recently tried to deny or discount the occurrence of neonatal or fetal pain. A closer examination of these papers reveals three major flaws in their scientific rationale, on the basis of which they have ruled out the occurrence of neonatal/fetal pain.3,4,25 First of all, they represent pain perception as a hard-wired system, passively transmitting nociceptive impulses until "perception" occurs in the somatosensory cortex.<sup>3, 25</sup> In contrast, pain research over the past 40 years, beginning with the Gate Control Theory of Pain and extended through vast amounts of clinical and experimental data, has long outgrown this Cartesian view of

pain. These data assert that nociceptive signaling in early development depends not only on the context and characteristics of the stimulus, but also on the behavioral state at that time. Fetuses undergoing intrauterine invasive procedures were reported to manifest coordinated behavioral responses trying to avoid tissue injury.<sup>26, 27</sup>

Secondly, these reviewers incorrectly assume that pain perception during fetal or neonatal life must engage the same structures as those used by adults. Immature development of these areas is then used to support the argument that neonates cannot feel pain until late gestation. Voluminous clinical and experimental research shows that the fetus or neonate is not a "little adult," that the structures and mechanisms used for pain processing in early development are unique and very different from those of adults, and that many of these structures and mechanisms are not maintained beyond specific periods of early development. The immature pain system thus uses the neural elements available during each stage of development to carry out its signaling role.

Third, such reviews presuppose that cortical activation is necessary for pain perception.<sup>3, 4, 25</sup> Based upon this assumption, the lack of evidence for pain-specific thalamocortical connections thus supports their contention against fetal/neonatal pain. This line of reasoning, however, ignores clinical data cited above that ablation or stimulation of the primary somatosensory cortex does not alter pain perception in adults, whereas thalamic ablation or stimulation does. The thalamus plays a pivotal role in regulating the spinal-brainstem-spinal loops that mediate context-dependent descending facilitation or inhibition, coordinated via the key mechanisms of consciousness. In addition, recent studies have noted robust activation of the somatosensory cortex in preterm neonates exposed to tactile or painful stimuli, modulated by gestational maturity, postnatal age, sex, laterality and sleep/wake states.<sup>28, 29</sup>

> Acknowledgments and references may be found on page 19



## Laurie Mouradian, ScD, OTR/L

This column has been designed to highlight individuals who have been involved with NIDCAP and to share their experiences. Dr. Laurie Mouradian has facilitated the emerging competence of infants, families, and professionals in newborn intensive care for over twenty-five years. She is the Program Director of the Oklahoma Infant Transition Program, and Co-Director of the Sooner NIDCAP Training Center. In addition, Dr. Mouradian is Clinical Associate Professor of Research, Department of Pediatrics, College of Medicine, University of Oklahoma Health Sciences Center (OUHSC), Oklahoma City, Oklahoma.

Laurie has been fascinated by the growth of the NIDCAP program in the United States as well as throughout the world. She realized the significance of cultural differences early in her career as she reflects: "One of my first inklings of the challenges for newborn intensive care units (NICUs), was when a nurse, embarking on NIDCAP Training in Boston, asked me how it was that an occupational therapist came to be in a NICU. This was apparently an unheard of role for an occupational therapist in her country, which completely caught me by surprise."

Occupational therapy as a profession developed in the United States early in the twentieth century out of the discipline of psychiatry. Many of the early leaders and educators came from the disciplines of nursing and social work. When Laurie enrolled in the Boston School of Occupational Therapy at Tufts University in Boston, close to half of the therapists employed were working in the field of mental health which is where Laurie had intended to work. However, as Laurie reports: "In a few short years, with the dramatic reductions in funding for mental health, and the disbanding of mental health institutions, those jobs disappeared and the majority of positions shifted to physical medicine and rehabilitation. Nevertheless, I have maintained an interest and orientation towards mental health perspectives that have contributed to the fit between NIDCAP and my professional training."

As an occupational therapist, Laurie began working at a day program for children and adults with severe physical and cognitive disabilities in Bangor, Maine. She quickly became frustrated by the lack of a rationale or connection between what she was taught and what she was expected to do as a therapist. "I thought if only I could understand the brain better, I could be a better therapist!" So after working five years in Bangor, Maine, Laurie returned to graduate school at Emory University in Atlanta, Georgia, and received her MS degree in Anatomy and Cell Biology. Laurie reports: "It didn't take long for me to realize how little was known about brain plasticity, and that the theories I was trying to apply had very little scientific support." After finishing her masters degree she enrolled in the doctoral program at Boston University designed for pediatric occupational and physical therapists.

While in Boston, working clinically in early intervention, Laurie had the opportunity to attend a lecture at Wheelock College given by a gifted educator by the name of Jean Cole. "Jean at that time was a Trainer of Brazelton's Newborn Behavioral Assessment Scale and was working for Project Welcome at Wheelock College. Her enthusiasm and presentation of the Synactive Theory struck a cord with me and I immediately recognized that the theory's complexity, yet relative simplicity, was a perfect fit for many of the pieces that I had been struggling with throughout my professional career." Shortly after hearing Jean Cole speak, Laurie and a social worker went on a home visit to assess an infant recently discharged from a hospital NICU. As the social worker was interacting with the infant's mother, Laurie was attempting to engage the baby in simple social interaction. "The baby, however, became fussy and began to flail his arms and legs. Reflecting upon what Jean had spoken about in her lecture, I simply tucked the baby's arms and legs in, up close to his body, and supported this position with my hands. To my astonishment the baby began to calm and looked briefly into my face. It was during this 'Aha!' moment that I realized the potential for applying the Synactive Theory clinically in my work with very young and sick infants."

Jean Cole had encouraged Laurie to contact Dr. Heidelise Als, and from there, a small pre-dissertation project turned into a ten year doctoral project which completely changed her understanding of infants and herself. Laurie reflects that "learning to administer and score the Assessment of Preterm Infant's Behavior (APIB) gave me a level of appreciation of infants that was a perfect fit with my occupational therapy background. I found the Synactive Theory to be the theoretical 'glue' that brought all the pieces together into a cohesive whole for me." Over the course of her doctoral project, Laurie studied the behavioral repertoire of the healthy yet prematurely born infant.\* The APIB was used 10-14 days after birth in a cross-sectional comparison of forty-two healthy newborn infants: 16 fullterm infants (gestational age at birth (GA) = 40 weeks), 13 close to fullterm infants (GA = 37 weeks) and 13 preterm infants (GA= 34 weeks). As Laurie reports: "In spite of studying very healthy infants we found group differences

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## FAMILY VOICES

As interviewed by Deborah Buehler, PhD

# Sarah Tueller

Sarah and her husband, Tom, have three sons. Their youngest, Truman, was born at 26 weeks and 6 days post conception. During Truman's 16 and a half week hospitalization, he experienced a number of medical complications, including a perforated bowel leading to an illeostomy. Now Truman is 21 months old (18 months from his due date) and "is happy, loves to be around his family, adores his [two older] brothers and his dog Tucker!" The following are excerpts from a telephone interview with Sarah on her reflections of her experiences in the NICU at St. Luke's Hospital in Boise, Idaho.

#### Please share your experience in the NICU.

I had never experienced anything like that before. It was pretty scary while at the same time the nursery staff made you feel pretty comfortable. I was there every day. I didn't take a day off. Truman was in the NICU for 115 days. It was very scary at first. The first couple of months it was touch and go. He got pretty sick. He had a perforated bowel which caused the fluid to leak out into his stomach and he had to have an illeostomy which is partial removal of the small intestine. So he had an illeostomy bag for six months. But every day, we'd come in and I'd take our middle child, Carson, in with me and we would just go and hang out and read to him. I'd try to do as much as I could, as much as I was allowed to do with Truman. I was there all the time.

[During that time,] it was pretty difficult to decide where I needed to be because no one wants to leave their infant in the hospital and go about their daily life. It was hard to find the balance of what the two older boys needed from me and what Truman needed from me.

#### How did you care for Truman in the nursery?

In the first few weeks, we could put our hands on Truman to calm him down. Basically we kind of just sat in there with Truman. We weren't able to do a whole lot because he was so sick and so little. Mostly just our hands comforting him. And after a few weeks we were able to do kangaroo care, which was very helpful for all of us. It was wonderful for all three of us. We would hang out together.

[As he got older,] I would change his diaper, take his temperature. I would change his bandages from his bag for his illeostomy. For a while he was fed by a tube, just the formula out of a syringe. So I would hold that. Anything that I could. Give



Truman (center) with his parents, Sarah and Tom, and his older brothers, Carson and Boston

him a bath. Help make his bed. Read to him a lot. I thought that Truman just needed the presence of me being there. To do anything that I can to help. Just having me be there.

#### How did you know when Truman's needs were met in the nursery?

His overall presence would just be like he was very comfortable and happy. You could see it in his face and feel it in his body.

# Please describe what parts of the NICU experience worked well for you and your family.

Mostly, [the nursery staff] letting us do everything that we could. That we were allowed to be in there and just hang out in the room with Truman was the most important to us.

Everyone communicated very well with us. They showed us and talked about what they were doing. I have a friend who is a social worker in the unit and I felt very comfortable in talking to her and expressing my feelings. Truman had four primary nurses that were wonderful. We felt very comfortable with them and in expressing how we felt about things and what we would have liked to have seen done. They went to battle for us quite a few times.

And just knowing that if we were gone that the doctors and nurses would call us immediately.

#### What parts of the NICU experience were the most difficult for you?

The most difficult part would be when we had to leave Truman. [Also] the changing of shifts of the nurses was hard on us. With him being in there so long, he had so many different people working on him and with him. There were just a lot of nurses and a constant changing of staff.

#### What suggestions for changes might you recommend for the NICU?

For the "long term babies," having a couple primary nurses is very important and keeping the babies that are there in the same room. Truman was going to be moved a couple of times and that was pretty stressful on all of us. He would have completely changed his whole team. Keeping the babies in their same rooms and not transferring them for staffing purposes. It is more about what those babies need and consistency with the nursing and the doctors.

There were quite a few nurses that weren't very patient with us as far as learning new things. To them they do [caregiving procedures] every single day but with us it was completely new. Just being a little bit more patient and understanding the feeling of what it would feel like if it was them in our situation. Some [nurses] were super busy and ready to get going and then others were willing to take the time to teach you and explain things.

One thing that got really hard was when there were too many babies in the room. It got noisy. It just seemed like the nurses were busy. Which I'm sure that they were with taking care of all of the other babies that were in their room.

Another thing that was concerning, the nurses would leave the room to go on lunch break and then the nurses in the other room would watch your children too. That was kind of hard to see.

# Please share the experience that you had with your nursery's developmental specialist.

Julie [the developmental specialist] came in to observe Truman. She was training to write these little stories, like an hour long worth of observation, about the surroundings, the environment and how it was in the room for the babies. Just a complete observation and wrote it down in a story. She asked if she could do that with Truman and I was completely open with it. I asked for copies. She wrote a story about once every three weeks. I have every observation that she has written in his scrap book.

[Reading these observations] felt like I was right in the room. I was like a person standing in there observing everything and it was down to whether the curtain was open or closed. How Truman appeared to be reacting to things. [How he responded when] the machines were beeping. How comfortable he looked. What position he was in. What he might have been wearing or not wearing when she came in. Whether there were other babies in the room [or] whether we were there. It was pretty neat. It felt like it was coming out of my eyes. What she observed he was getting agitated with and what might help him to feel more comfortable. [Soothing him could be] as simple as placing your hands on him or just sitting quietly next to him and talking to him or reading. But mainly [he seemed comforted by] just touching him to have him feel our comfort. [The observations] were beautiful.

People who go through something like that with their children block a lot of it out because it is pretty difficult. But just being able to read through that later on and remember what it was like is comforting. I've had times where I've gone back and

> read through the stories. I have forgotten things that she has written. It brings it all back to my memory. It's kind of an experience you don't want to forget but at the same time you don't want to remember having to see your children go through something like that.

I think that it would be a phenomenal thing for any parent who had to go through something like this to help remember the experience. We were very lucky to have Julie do that for us. She will be a person

that we will never forget through this whole experience. We actually learned a lot about her personally and that helps to. It makes you feel like you are not just a patient, you have a purpose.

Truman's days are filled with the joys of being a toddler playing with his family, especially with his big brothers and dog. In and around these family rhythms, he is being regularly followed by a number of health care providers, some weekly, some every other week, including a: kidney specialist, eye doctor, neurologist, orthopedic surgeon, developmental pediatrician, pediatrician, developmental therapist, occupational therapist, speech therapist, physical therapist, and vision therapist. As Truman continues to grow, Sarah described her wishes for him:

I honestly hope for him to be able to speak and to be able to get around on his own. Right now, as far as we know, he will never walk. I just want him to become as independent as he can. And to be happy.

Sarah's days are filled with parenting. She described staying connected with the NICU through her social worker friend and the nursery staff that she sees during hospital follow-up appointments for Truman. These touchpoints have led her to work as a volunteer giving support to parents currently in the NICU. As Sarah reports:

I help with the parent support group. Every other week I go in for an hour and I put in a movie for parents to come in and watch about being a parent in the NICU and pop some popcorn and be there to listen. It's interesting. It was probably a year and a half after Truman had been out [of the hospital] that I started going back. The smells brought back memories. It has been helpful for me to see other parents, to help them and to just listen.



This column will often feature an invited essay by a NIDCAP professional who has given special attention to family support in his or her research or clinical practice. For this issue, our guest shares ideas generated by her many years of work in the ICN in both capacities. Joy V. Browne, PhD, RN, is Associate Professor of Pediatrics and Psychiatry and Director of the Colorado NIDCAP and FIRST Training Centers at the University of Colorado at Denver and Health Sciences Center, affiliated with The Children's Hospital of Denver. She is also Director of the Fragile Infant Feeding Institute, a NIDCAP Master Trainer, and a licensed psychologist.

# The Essential Parent

Joy V. Browne, PhD, RN

How often when parents come to their infant's bedside do we say softly and with a big smile "Oh, how wonderful that you are here! Your baby is ready to hear your voice, feel your gentle hands, and smell your unique odor. She knows you best, you know! She needs you as a parent more than anything else today"? Better yet, do we believe it so that we can fully support the parent's role in regulation of the baby's autonomic, motor, state and self-regulatory systems?

In our important role of providing the best medical, nursing and therapy support possible, we sometimes don't recognize the essential regulatory aspects of the parent's intimate presence with their baby. We also don't often recognize the importance of the baby's regulatory effect on the mother's physical and psychological recovery from an often traumatic birth experience. It goes both ways, and if we believe Winnicott's saying that "There is no such thing as a baby...there is only the baby and the other," we would practice parent/baby care in all its challenging aspects.

What does the baby get from close, intimate, uninterrupted contact with the mother and father? Autonomic system regulation, such as more stable temperature, oxygen saturations, and respiratory and heart rate. Babies are also typically more "relaxed" and are held in a more flexed posture than when in the incubator or bed. They also sleep more deeply, have opportunities for arousal and looking en face with the mother or father, and have less irritability. Babies held in intimate contact have readily available regulatory supports from the mother's body and support of their own efforts to grasp upon their own clothing or body, push with their feet against a supporting surface, and mouth and/or suck upon their own hand or pacifier.

What does the mother get from close, intimate, uninterrupted contact with the baby? Physiologic regulation by secretion of oxytocin, production of higher chest temperatures, reduced heart and respiratory rates, and increased milk production. In addition, mothers and fathers are calmer, less stressed and show more attachment behaviors with their infant.

Developmental goals in the hospital newborn intensive care unit (NICU) that use the NIDCAP model include support of the infant's autonomic, motor, state and self-regulatory organization. How better to provide this support than by insuring that the most familiar, consistent, and physiologically essential interventions are readily accessible to the infant.

For many NICUs, an emphasis on this practice is selfevident, and policies and protocols to support intimate interactions between parents and babies are paramount. However, in many other NICUs, what we think we are providing fall short of what we envision. Several practices send subtle (and sometimes not so subtle) signals that parents are not on the top of the list to provide the essential regulation that their infant needs. For example:

**Visiting.** Times when parents are restricted from being with their infants indicate that there is an unwritten hierarchy in how we view the role of parents in NICUs. How often do we refer to parents as "visitors" rather than essential partners in their baby's care?

**Bathing.** Is bathing of the baby an essential parent role or a nursing task? Bathing is one of the most intimate and rewarding interactions that parents and babies will have. Reserving our need for giving the baby a bath in promotion of the parent's need for that intimate and regulatory opportunity is essential.

**Fragility.** Infants may be too fragile or have too many tenuous lines, tubes, etc. to be moved from the bed to the parent's arms. However, there is typically a large range of what we consider "too fragile" from one shift and one staff member to another. Studies have shown that even the smallest, sickest infants can be held with few or no adverse consequences, in fact, holding can be extremely beneficial. The most confusing aspect for parents is when one staff member says "yes he's too fragile" and another says "no, he's not too fragile to be held."

**Sleep protection.** Parents come to the NICU when they are able to, not when they know their baby has just gotten to sleep, however it may seem to the busy nurse at the bedside. For a variety of reasons, parents need to touch, rouse and interact with their babies when they are with them. Their presence at the bedside should be a time of opportunity for the parent to provide essential regulation for the baby, and the staff member to provide essential regulation of the parent to know just how to interact with their fragile infant.

**Staff assignments.** As staff assignments become more difficult and busy, the role of parents in regulating their infant's autonomic, Continued on page 18

## NIDCAP REFLECTIONS

Jean Powlesland, RN, MS

Each newborn intensive care unit's unique practices, culture, and concerns shape the way developmental care practices are integrated. Here, Monique Flierman, MSc, PT and Monique Oude Reimer, RN, developmental specialists in Rotterdam, the Netherlands, share how their first Developmental Practice Change Project resulted from their experience doing NIDCAP observations.

he Sophia Children's Hospital is part of the Erasmus Medical Center and has a Level III NICU consisting of three rooms with eight to ten bedspaces each. Babies who no longer require intensive care are transferred to outlying hospitals.

We implemented NIDCAP in 2003. As we practiced observing babies, we often saw their discomfort during the daily change of the nasal CPAP tube. The NIDCAP group decided that this procedure should only be done while properly supporting the baby. One nurse would support the baby while a second nurse changed the CPAP tube.

To prepare for this practice change, we educated the nurses. We explained the signals of the babies and the importance of supporting the baby during stressful procedures, and affirmed that this two person support was now mandatory. For the first three weeks the NIDCAP team was available to our colleagues during CPAP tube changing. We often heard remarks such as: "I can do it on my own" and "it takes more time to do it with two people." However, step by step, people became more positive: "I can see it makes the procedure easier for the baby and for me as a nurse." It was important for them to see that the baby stayed more comfortable with this support.

Each year we planned for and gradually implemented new items dealing with the environment, parents, caregiving and behavioral observations. Every three months new items were introduced and previous items evaluated. We communicated the schedule and results with a poster in the coffee room.

As we worked intensively with parents to help them support their baby, the nurses began to understand that the parents knew more about their baby then they did. We saw that the nurses were ready for more in-depth education and we designed a clinic with both practical and theoretical information.



Monique Flierman (left) and Monique Oude Reimer, developmental specialists at The Sophia Children's Hospital in the Netherlands

We videotaped each nurse while she cared for a baby. This was followed by a private one-on-one session with the developmental specialist and the nurse. The nurse watched the video and reflected on what she saw. The developmental specialist discussed brain development and NIDCAP and also practiced caregiving with a doll. Then the nurse cared for the same baby applying the newly acquired knowledge and skills, supported by the developmental specialist. We individualized this teaching based upon a questionnaire that each nurse had previously filled out. These clinics proved to be highly effective in promoting developmental care in our unit.

A nurse shared her thoughts with us:

I found the education about the brain development very impressive. I realized how vulnerable our patient population is. I also thought: "What did I do wrong during the last 18 years without knowing I did it wrong. I am fortunate that I have gotten information on how to do caregiving well. I will work slower and will take time for the child. I am able to make a good supportive nest. For parents, I do have the knowledge now to support them as they come to be with their baby and learn more about her each day.

The support of our management team, the Sophia NIDCAP Training Center, and our NIDCAP Trainer, has been essential in this implementation process, and has supported us to individualize our care for the babies and their parents. gretchen Lawhon, RN, PhD

## What does QAT mean and have you read the QATs yet?



Qat shrubs in Yemen

A ccording to the unabridged dictionary. com, a qat is a shrub in the Middle East and Africa whose leaves are chewed like tobacco or used to make tea and has the effect of a euphoric stimulant. Within the NIDCAP Federation, QAT is the acronym for our Quality Assurance Training policies and there are now fifteen that have been delineated. While this work is very stimulating and has been known to produce euphoria after long NIDCAP training days, there is little else of the NFI QATs similar to the Middle Eastern shrub.

Across the policies of the NFI QATs, there are a number of common themes throughout that clearly identify the eligibility, application process, training requirements and importance of quality control. With carefully evaluated exceptions, all professionals involved in NIDCAP and/or APIB training should be associated with or on staff of a newborn intensive care unit or special care nursery. It is essential that these professionals have communicated with and gained the support of the multidisciplinary administration of their nursery. This reflects the evolution of the NIDCAP training process from its historical beginnings of isolated individuals being

trained to the incorporation of the unit and hospital system embracing change in clinical practice.

The first two QATs (1 & 2) address those professionals seeking certification as NIDCAP and APIB professionals. The application process to the respective NIDCAP or APIB Trainer/Center is described as having a site assessment, 2-3 year plan including financial aspects, and the trainees' self assessments. The process of securing the commitment of a specific trainer is an important aspect of NIDCAP and APIB training. The training requirements, including the preparatory work, are listed as well as the training process.

QATs 3 and 4 involve professionals seeking NIDCAP and APIB Trainer certification. At this level the individual(s) and nursery leadership team either contact a NIDCAP or APIB Master Trainer and/ or seek guidance from the NFI Quality Assurance Committee to identify an appropriate Master Trainer who may be available. This process often involves the formal application to become a NIDCAP Training Center. Once the NFI Quality Assurance Committee has reviewed all the documents of the application a formal presentation to the Board of Directors is made and voted upon for approval. This thorough application process ensures the commitment necessary for the typical five year plan toward training center development. Naturally for a NIDCAP or APIB professional to become a trainer he/she will present evidence of very recent certification or obtain recertification.

The definition and requirements for being certified as a Senior NIDCAP or APIB Trainer are explained in QATs 5 and 6. The formal application is made to the Chair of the NFI Quality Assurance Committee and will show evidence of the nursery leadership team's commitment to the NIDCAP/APIB professional in addition to their meeting the requirements as clearly stated.

QAT 7 clarifies the rules that govern the relationship among NIDCAP Trainers, NIDCAP Training Center development and Master Trainer development. This relationship often involves the simultaneous work of center development and a NIDCAP Trainer working toward Master Trainer status. This policy assures an effective and smooth process for both.

The next phase in the evolution and experience of a Senior NIDCAP or APIB Trainer wanting to move to a more challenging level of training is to apply and work through the process of certification as a NIDCAP or APIB Master Trainer which is outlined in QATs 8 and 9. Naturally there is someone with further experience who can mentor and guide those who choose to become Master Trainers and that level of trainer is a Senior NIDCAP or APIB Master Trainer for whom the gualifications are delineated in QATs 10 and 11. Currently we have one professional who has attained Senior NIDCAP Master Trainer and Senior APIB Master Trainer with a few colleagues who are striving to achieve this level of training. The remaining four QATs, 12-15 have been written to clarify the specific requirements for NIDCAP and APIB Training Centers as well as those centers who qualify for certification as NIDCAP or APIB Master Training Centers.

The Quality Assurance Training Policies, known as QATs, are readily available to all members of the NIDCAP Federation and are accessible on the NIDCAP website in the member services area. They were discussed and made available at the 17<sup>th</sup> Annual NIDCAP Trainers Meeting held in Sun Valley, Idaho (October 2006). If you have not already done so, please take the time to review these important documents and address any questions to the Quality Assurance Committee, chaired by Dr. Als.

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Growing evidence that demonstrates the benefits of NIDCAP intervention has led to increased efforts towards unit implementation. The following recent publications focus on evaluating professional and family caregivers' perceptions concerning NIDCAP-based care, the NIDCAP implementation process, and the effect of education on parental understanding of infant behavior.

#### **Staff Perceptions**

van der Pal SM, Maguire CM, Le Cessie S, Veen S, Maarten Wit J, Walther FJ, Bruil J. Staff opinions regarding the newborn individualized developmental care and assessment program (NIDCAP). *Early Human Development.* 2007; 83:425-432.

NIDCAP implementation is challenging, time consuming and affected by staff attitudes. Multidisciplinary staff from two NICUs in the Netherlands were surveyed regarding NIDCAP implementation and impact. Surveys were distributed two years after the introduction of NIDCAP, which in turn, occurred two years after the introduction of general positioning and environmental changes. Of the 168 multidisciplinary staff surveyed, 124 responded (74% return). The majority viewed NIDCAP as effective and used NIDCAP-based care most of the time, yet many reported that caregiving required more time. The perception of personal control influenced the use of NIDCAP more than the intention to use NIDCAP. Physicians were less positive regarding effectiveness and reported less control over the use of NIDCAP than did nurses. The authors conclude that staff generally view NIDCAP as positive and recommend ongoing assessment of staff feedback, providing classroom and bedside guided learning, establishing multidisciplinary teams, supporting staff needs when introducing environmental changes, and exploring time-saving options such as summarizing key NIDCAP recommendations for quick staff review following the completion of NIDCAP behavioral observations.

# Hendricks-Munoz KD, Prendergast CC. Barriers to provision of developmental care in the neonatal intensive care unit: neonatal nursing perceptions. *American Journal of Perinatology.* 2007; 24(2):71-77.

Nurses' views regarding developmental care effect individual and unit-wide implementation. One hundred seventy NICU nurses from 24 hospitals in the northeastern United States were asked to complete a 12-item survey of perceptions regarding developmental care implementation with 146 responding (86% return). While 93% of respondents identified developmental care as essential for high-risk infants, only 14% perceived implementation as optimal at their facility. Multidisciplinary planning meetings were reported to be an implementation strategy by 76% of the nurses working in units perceived as having a high level of developmental care. In contrast, such meetings were reported by only 33% of nurses who believed developmental care to be suboptimal in their units. Of those nurses from units with meetings and/or developmental care leaders, 38% identified staff nurses or physicians as the primary barriers to implementation, compared with 90% of nurses working in units without such support, a highly significant difference. Additionally, nurses from units with multidisciplinary meetings were more satisfied with unit and facility leadership and their facility overall. The authors conclude that use of a multidisciplinary planning strategy may improve communication and reduce the perception of barriers and thus enhance developmental care implementation.

#### **Parental Knowledge and Perceptions**

Maguire CM, Bruil J, Wit JM, Walther FJ. Reading preterm infants' behavioral cues: An intervention study with parents of premature infants born < 32 weeks. *Early Human Development*. 2007; 83:419-424.

Parental knowledge of preterm behavior may enhance parent-infant interaction and caregiving confidence. A time lag study conducted over eight months at a tertiary NICU in the Netherlands evaluated the effect of an education program on knowledge and confidence. Education addressing preterm infant behavior was offered to ten sets of parents of infants born earlier than 32 weeks gestation. Four sessions were provided over a two-week period during the second and third weeks after birth. Intervention group mothers demonstrated significantly improved knowledge of infant behavior and reported significantly higher nursing support levels than did mothers in the control group. Intervention group mothers and fathers showed improved caregiving confidence that did not reach statistical significance. Parental feedback included the need for multidisciplinary understanding of infant behavior, the value of developmental specialists and infant observations, and the importance of establishing multidisciplinary teams that include parents of former NICU patients. The authors conclude the intervention is effective in increasing knowledge of infant behavior but question the sensitivity of the scale to adequately measure confidence in parents of high-risk infants.

#### Wielenga JM, Smit BJ, Unk LKA. How satisfied are parents supported by nurses with the NIDCAP model of care for their preterm infant? *Journal of Nursing Care Quality.* 2006; 21(1):41-48.

Customer satisfaction is increasingly valued as a measurement of care quality. A time lag study conducted at a tertiary NICU in the Netherlands evaluated the effect of NIDCAP on parent satisfaction with caregiving and nursing support. Control group data was initially collected for infants receiving standard unit care. Following a 6-month period of staff education, intervention group infants received NIDCAP-based care including serial behavioral observations. Parents of 49 (24 control, 25 intervention) infants born earlier than 30 weeks gestation were asked to complete two questionnaires. Response rates were 96% for control and 92% for intervention group parents. Overall parents were significantly more satisfied with NIDCAP-based care. Scores of nurse support were higher for the intervention group but did not reach statistical significance. The authors note that control group scores were high to begin with, possibly due to parents of control group infants being unaware that care and support could be different. Ratings of support and satisfaction were highly correlated in both groups. The authors conclude that assessing parent satisfaction is a necessary component of quality improvement and that measuring implementation progress should be continuous due to the lengthy process required to achieve culture change.

# Kleberg A, Hellström-Westas L, Widström A-M. Mothers' perception of newborn individualized developmental care and assessment program (NIDCAP) as compared to conventional care. *Early Human Development.* 2007; 83:403-411.

Premature birth disrupts relationships between mother and their infant. Twenty mothers of preterm infants at 36 weeks post

menstrual age completed a validated questionnaire exploring the effect of NIDCAP on early relationships. The infants, born at less than 32 weeks gestation, were enrolled in a randomized controlled trial evaluating the medical effects of NIDCAP care at Karolinska Hospital, Stockholm, Sweden. Infants in the study group received serial NIDCAP observations, which were used to guide care. Infants in the standard care group received caregiving, feedings, and skin-to-skin holding on a set schedule. Mothers of infants receiving NIDCAP-based care reported feeling significantly closer to their infants than did mothers of infants in the standard care group, regardless of their baby's gestational age, birth weight, or severity of illness. One of the interesting findings showed that when parents are provided care in the NIDCAP model these parents reported significantly higher levels of concern despite perceiving their parental role to be better supported by staff. The authors conclude that when parents are provided care in the NIDCAP model, they may form earlier and stronger relationships with their son or daughter in the NICU, and as a result, may experience greater concern about their infant's experience in the NICU.

#### NIDCAP PROFILE Laurie Mouradian, ScD, OTR/L Continued from page 7

on measures of autonomic, motor, state, attention/interaction, and self-regulatory systems as well as on a measure of overall behavioral organization. While full term and 37 week infants were behaviorally more similar to one another than either group was to the 34 week infants, there were important differences even between full term and 37 week infants. We tend to overlook the behavioral vulnerabilities of healthy babies born slightly early and this study demonstrated that even a few weeks of prematurity makes a behavioral difference. This can be important information for parents taking these babies home."

Upon receiving her doctoral degree in Therapeutic Studies at Boston University, Laurie moved to Oklahoma City, Oklahoma and assumed the position of Associate Professor, Department of Occupational Therapy, College of Allied Health, OUHSC. Laurie was enticed by the presence of the Sooner NIDCAP Training Center under the leadership of Martha Holmes, MSW and Roger Sheldon, MD. After teaching fulltime for a few years she missed the clinical work and accepted a position as an Infant Developmental Specialist for the Oklahoma Infant Transition Program (OITP). OITP provides clinical services for the NICU at Children's Hospital and is the umbrella organization for the Sooner NIDCAP Training Center. Laurie then embarked on the process to become a NIDCAP Trainer along with her colleague Rodd Hedlund, MEd. When Martha Holmes retired Laurie became the Program Director of OITP and shares responsibilities as Co-Director for the Sooner NIDCAP Training Center with Dr. Roger Sheldon who is also the Principal Investigator and Director of OITP. When Rodd moved on to other opportunities, Laurie hired one of his NIDCAP trainees, Bunny Hutson, RN, who had been a bedside nurse for many years in the NICU at Children's Hospital. Bunny is now a Developmental Specialist and a NIDCAP Trainer-in-Training at OITP. "I am incredibly fortunate to have Bunny as a co-regulator and co-facilitator of

the NIDCAP work we are doing in the NICU at Children's Hospital and with other units throughout Oklahoma and Missouri."

Laurie continues to teach at the University of Oklahoma Health Sciences Center and provides many lectures and NIDCAP Training opportunities within Oklahoma and Missouri. She has published articles on neurobehavioral development; the integration of neurobehavioral concepts into early intervention; as well as the influence that caregiving practices have on motor functioning for preterm infants.

As Laurie reflects: "I really cannot express how deeply I appreciate the mentoring and guidance that Dr. Als has provided over the past twenty years. Her insights and perspectives have changed my life in ways I could not have imagined when I first contacted her so many years ago. One of the highlights of my NIDCAP career was the opportunity to host the NIDCAP Trainers Meeting in Oklahoma City during the fall of 2004. It allowed me the opportunity to demonstrate to my NIDCAP colleagues how very much I appreciate being part of such an amazing group of professionals and friends, who are all so dedicated to making the world better for babies and their families."

Laurie is a continual learner and has recently enrolled in art therapy classes, something that she was interested in thirty years ago. For fun and refueling, she enjoys swimming and participating in art activities with her fifteen-year-old daughter, Monica.

Reference:

<sup>\*</sup> Mouradian LM, Als H, & Coster W. Neurobehavioral development of healthy preterm infants of varying gestational ages. Journal of Developmental and Behavioral Pediatrics. 2000;21:408-416.

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

### **DVD Series**

"Focus on the Brain" is a staff training program which reviews the current research on fetal and neonatal development and provides evidence that supports the implementation of individualized developmental family centered care within the NICU. There are three DVDs in this program. One addresses the science of early brain development of high risk newborns in the NICU and conveys what is now known about the impact of early birth on the brain. The second DVD provides demonstrated practical developmental intervention strategies, which have been proven to enhance optimal brain growth and development in infants living in the NICU. The third DVD, "No Matter How Small," is a parent's guide to preterm infant behavior and development. For more information, please visit: www.vidahealth.com or call Elizabeth Hamlin at 800-550-7047.

#### Conferences

The 23<sup>rd</sup> Annual Developmental Interventions in Neonatal Care Conference:

November 11-15, 2007 in Las Vegas, Nevada.

A two day **Preconference** (November 11 and 12) will include workshops highlighting nutrition in the high risk newborn, a specialized high risk feeding workshop, an introduction to individualized developmental care, and a half day session on post-discharge developmental difficulties. The Main Conference, opens November 13 and closes November 15 and includes a specialized multidisciplinary faculty of clinicians and researchers from medicine, nursing, psychology, education and rehabilitative medicine who will address the applicability of research and intervention strategies during a NICU stay and following discharge.

The Symposium on Asphysia: October 1-2, 2007, Modena, Italy. For further information please contact: Ms. Barbieri Valeria at: Telephone: (+39)-059-4225607/4222140. Fax: (+39)-059-4223770. Email: *barbieri.valeria@ policlinico.mo.it* 

Several upcoming Contemporary Forums conferences:

- » The National Conference of Neonatal Nursing Las Vegas, NV, April 1-5, 2008
- » The Young Child with Special Needs
  Las Vegas, NV, April 29-May 3, 2008

For further information go to: *www.contemporaryforums.com*.

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#### **Book Chapter**

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### **Special Booklet for Parents**

Early Arrival: Finding the magic of everyday moments with your baby in the neonatal intensive unit (NICU). Sponsored by Johnson & Johnson Pediatric Institute LLC and Zero To Three. A twenty-page booklet ideal for NICU parents that addresses the emotional and interaction needs of parents and their infants in NICU.

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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 the rest of our readers. Please send items for inclusion in the Developmental Observer to Kathleen VandenBerg, PhD, email: kvandenb@mills.edu

#### 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,

Rodd Hedlund, MEd Senior Editor

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gretchen Lawhon, RN, PhD Associate Editor

Sandra Kosta, BA Text Editor

#### The 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.com*.

#### The 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.com* for details). The APIB requires in-depth training and provides a highly valuable resource in support of developmental care provision by professionals and families.

Dear Editors,

Congratulations on the first copy of the Developmental Observer

newsletter. It is an excellent effort and I enjoyed reading it immensely. I was very impressed by Dr. Als introduction. How fascinating to hear about her early days in infant development. I well remember seeing her present the old 16mm Brazelton training film at Chapel Hill in the 1970's. That was my first introduction to a baby assessment and I was an immediate fan and wanted to know more about her work. How far it has all come. I especially liked seeing the photos of NIDCAP Trainers and learning about their work. Please continue to have their pictures included with the information. The inclusion of the status of Training Centers in Europe is fascinating. How NIDCAP has grown! What a wonderful journey it has been and how gratifying to know so many families all over the world are being reached and helped by the developmental approach that is the core of NIDCAP. Again, congratulations on a very fine newsletter. It is one of the best I have ever read. As a retired NIDCAPPER, I felt very nostalgic about no longer being a part of it. I wish you well.

#### Sincerely,

#### Jean Gardner Cole

Director Emeritus/NIDCAP Training Center Boston Medical Center

Dear Editors,

## Congratulations on the first issue of the Developmental Observer.

It comes at the right time, with the various components of developmental training and evaluation in place, the NFI well established, and training centers around the world. Without vision and persistence by the first pioneer among us, Miss Heidi (as we say in the south), none of this would exist, and thousands of peoples' lives and careers would have remained untouched by a spectacular program.

I am pleased to have witnessed and participated in the early history of

NIDCAP and APIB. For me, it all began with my co-neonatologist in Tucson handing me a thick manuscript to read back in 1974. It was the Brazelton exam. Soon I was in Boston meeting with T. Berry Brazelton who introduced me to my "trainer," Miss Heidi. It was not an easy task to learn first the Brazelton, then a modified Brazelton for premies, next the APIB, and finally the NIDCAP and how to train others--all while carrying on with clinical neonatology and academic responsibilities, and the NICU follow-up clinic. There were some extraordinary people in the Sahuaro Chapter who learned the APIB and applied it as an early evaluative tool for the follow-up program--Suzy Poisson, Susann Hill-Mangan, and Deanne Meyers (Phoenix). Back in those days, behavioral/developmental subjects were considered "fuzzy" and "soft" and were not respected in the medical field. In my later years of NICU work, I was sustained by the knowledge and application of NIDCAP.

Some of today's current trainers had their earliest APIB experience with the Sahuaro APIB Chapter in Tucson (now dissolved). Those people are Joy Browne (first in Albuquerque), Karen Smith, Laura Robison, Inga Warren, and Erin Ross. I am pleased, too, that several neonatologists who were pediatric residents in Tucson now strongly embrace the NIDCAP approach. I'd like to suggest that the newsletter include history of an aspect of the NIDCAP program. As examples, did you every wonder if you could put a numerical score to your NIDCAP observations and use those scores to measure change over time, and perhaps correlate them with APIB systems scores or later behavioral measures? Did you ever wonder how and why the NIDCAP practicum came into existence? What did videos of later behavioral evaluation of intervention and non-intervention subjects reveal? Understanding the history helps one make better sense of where the program is today, and it confers appreciation for the efforts

of pioneers. Other ideas for future issues are the recertification program and statistics on whether NICUs that begin NIDCAP training complete the process or not, and defining what support

not, and defining what supports foster success or what barriers exist.

Respectfully, Elsa Sell, MD

Retired neonatologist and active cattle farmer.

#### Dear Editors,

I was absolutely delighted to read the latest copy of the Developmental Observer. NIDCAP has grown and developed so very nicely over the years. From the time I was trained by gretchen in 1985 to now, 22 years later, the growth and acceptance of this approach has been phenomenal. This is, of course, due to Dr. Als, the other NIDCAP leaders, the outstanding professionals who are training and performing assessments, as well as the open-minded neonatologists who have come to accept this.

My hat is off to you as you journey to France for your Trainer's Meeting!

#### Martha Kendall Holmes, MSW, ACSW

Former Co-Director, Sooner NIDCAP Training Center Oklahoma City, Oklahoma

Dear Editors,

I would like to congratulate you on an excellent first issue of the Developmental Observer; it is an extremely interesting and informative read.

The work, tenacity and dedication of the NIDCAP association has been an inspiration to me in my own work as a nurse and infant massage instructor specializing in 'Positive Touch' in the neonatal unit. The newsletter is a great way to spread accurate information to the many neonatal units, worldwide, who are struggling to implement better care



## LETTERS TO THE EDITORS

for their families and may not have the support they would wish for.

There are an increasing number of companies and individuals who are jumping onto the developmental care bandwagon, especially now that there is more evidence to show its benefits. However, their methods are often questionable and it is great to see that the NIDCAP team has been influential in the making of the Vida Health Communications DVD, featured on the resources page. These DVDs show developmental care at its finest and will be an indispensable resource for us all. I look forward eagerly to reading the next installment of Dr. Als' fascinating story and wish the Developmental Observer the greatest success in the future.

#### Kind regards,

#### **Cherry Bond**

Parent-Infant Interaction Coordinator Winnicott Baby Unit St Mary's Hospital London W2 1NY www.cherrybond.com

#### SUPPORTING FAMILIES Continued from page 10

motor and state systems becomes an essential time-saver. Spending a small amount of time engaging the parent, settling them in with their infant, and providing supportive information about the effect they have on their baby will, in the long run, provide the busy staff member with more time for other tasks.

**Baby care, not parent care.** NICUs are baby care focused, but more and more we are expanding our notion of who the patient is. Because of the essential role in physiologic, motor, state, and self regulation that parents provide, caring for the parents must be a part of the consideration of caring for the baby. Comfort for the parents, both physically and psychologically, will benefit the outcome of the baby.

Providing the best care for the baby involves including the parents as an essential part of the care plan. We now have a substantial base of evidence to indicate that parents provide autonomic, motor, and state regulation, as well as support for self-regulation. Additionally, providing support for the dyad enhances the mother's physical and psychological recovery and ultimately, the baby's long-term development. Reflecting on our attitudes, beliefs, and behaviors when we interact with parents, as well as examining our policies, procedures, and rituals in the NICU will provide opportunities for optimal support for parents in their essential parenting role.

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#### Continued from page 6

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by order of establishment

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