

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.

“Wise (individuals) must remember that while (they are) descendant(s) of the past, (they are) parent(s) of the future.”

HERBERT SPENCER (1820-1903)

Table of Contents

NFI President Receives International Award of Recognition.....	1
A Message from the NFI Director of Development and Administration.....	3
The Advanced Practicum.....	4
NIDCAP Training Centers from Around the World.....	9
Understanding Developmentally Supportive Feeding with the Premature Infant.....	10
Family Voices.....	12
NIDCAP Profile.....	14
Supporting Families.....	15
Current Developmental Research.....	16
Developmental Resources.....	17

NFI President Receives International Award of Recognition

The “Power of One” is above all things the power to believe in yourself, often well beyond any latent ability you may have previously demonstrated. It means thinking well beyond the powers of normal concentration and then daring your courage to follow your thoughts.

—COURTENAY, 1996, p.360*



Heidelise Als holds the Graven Conference plaque honoring her lifetime of professional contributions to developmental care. She is joined by (from left) Joy Browne, Mavis and Stan Graven, and Bob White.

Each year at the International Graven Conference a special tribute is made to an individual or group who has contributed substantially to make the physical and caregiving environments in newborn intensive care units a reality. The 21st Annual Graven Conference on the Physical and Developmental Environment of the High-Risk Infant, *NICUs in Motion: The Kinetics of Babies, Families, Caregivers and Design* was held in Clearwater Beach, Florida. At this conference, Dr. Heidelise Als was awarded the Stan and Mavis Graven award on February 1, 2008 for Leadership in Enhancing Physical and Developmental Environments for High Risk Infants.

The Graven award was established in 2006 in honor of Stan and Mavis Graven, who laid the foundation for integrated, scientifically sound and family centered environmental design and caregiving practices in newborn intensive care units. Dr. Als' work in individualized developmental care, which has influenced caregiving practices worldwide made her the obvious recipient of this prestigious award.

Dr. Als' work was celebrated during a reception, dinner and tribute acknowledging “The Power of One” as a theme that has distinguished her career. As an individual, no one has influenced the way infants and families are cared for in newborn intensive care units more than Dr. Als. Her work, including the establishment of excellence in training, provision of a strong evidence base for clinical practice, and the organization of the NIDCAP Federation International has created a gold standard for practice, research and systems building. As such, her work has become the internationally

acknowledged best practice for the sensitive, individualized, and evidence-based practice of neonatology. Her contributions exemplify the notion of the power of one individual to change the way we view and care for infants and families.

Dr. Als provided the attendees at the celebration with a stirring retrospective of her life and her professional career, and proposed her vision for where individualized developmental care might go in the future. These reflections and insights held the audience spellbound, as her history is woven into the fabric of our progress in understanding early human development, the

necessity of the caregiving relationship for brain organization and later child and family outcomes.

Dr. Als received a plaque of a swaddled baby and was congratulated by Drs. Bob White and Joy Browne, co-chairs of the Gravens meeting, Dr. and Mrs. Graven, and several members of the NIDCAP Federation International who attended the meeting.

—JOY BROWNE, PhD, RN

*Courtenay, B. *The Power of One*. New York: Random House Publishing Group. 2008

Developmental Care in the Moment

photograph by Karin Schrage-Hoon



A mother and her infant, relaxing together in the newborn intensive care nursery.

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

Deborah Buehler, PhD
ASSOCIATE EDITOR

gretchen Lawhon, RN, PhD
ASSOCIATE EDITOR

Sandra Kosta, BA
TEXT EDITOR

Developmental Observer

A semi-annual publication of NIDCAP Federation International
© 2008. Articles from *Developmental Observer*, duly acknowledged, may be reprinted with permission. Please contact us at: developmentalobserver@nidcap.org

Senior Editor	Rodd Hedlund, MEd
Associate Editors	Deborah Buehler, PhD gretchen Lawhon, RN, PhD
Text Editor	Sandra Kosta, BA

Printed on recycled paper



**NIDCAP Federation
International (NFI)**

Contributions

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

A.L. Mailman Family Foundation
Bella Vista Foundation
Pritzker Early Childhood Foundation

A Message from the NFI Director of Development and Administration



David M. Wahl joins NIDCAP Federation International with over thirty years of experience in fundraising, planning, and management. He has served as senior executive of and consultant to educational institutions and non-profit organizations. He has worked with such institutions and organizations as Carnegie Mellon

University, Westminster College, Bryant University, Salve Regina University, AAA and a host of new and established educational, non-profit and social service organizations. David performed his undergraduate work at the University of Pittsburgh and has completed graduate work in management and education, most recently at the Currie School of the University of Virginia where he expects to soon complete his MEd. Born in Western Pennsylvania, he currently resides in Rhode Island. David is married to Gail, a New England native. They have three children: Jonathan, 12; Elizabeth, 10; and Anna, 8.

As the new Director of Development and Administration for NIDCAP Federation International, I have been asked to introduce myself to the NFI family. I come to my task with respect for the ideas developed in preceding years by individuals with great minds and good hearts. I have developed early on a sense of the importance of the ideas, as well as a genuine enthusiasm to be an integral part of the quest to make a difference in the lives of newborn infants and their families.

It is an exciting time to assume the administrative leadership of NFI. There are challenges, certainly, as there often are with a relatively young non-profit organization. Organizations start from the ideas, energy and commitment of a few, then grow and evolve to include new people, new programs, changing roles for all involved, an increased need for resources, and the necessity of administrative structures and procedures to help support and orchestrate all components. The Board and Martha Hopewell as Executive Director did marvelous work over the past couple of years developing strong frameworks in administration, finance, communications and membership. Initial funding sources were developed to support program initiatives and administrative

activities, to stride into the future in pursuit of our vision while addressing the practical needs of the organization. We can build on these efforts with confidence. This is the time for NFI to continue to move forward to the next level of its maturation and development.

The Board of Directors has thoughtfully assessed the needs of the organization at this point in time, and redefined my position to put increased emphasis on developing the resources necessary to ensure the implementation and optimization of the aspirations of NFI. The Board has also called out the importance of continuing to grow our membership, further enhancing our visibility, and, supporting the efforts of the volunteer Board.

One of my primary areas of focus, therefore, will be on solidifying current funding streams and expanding and diversifying additional sources of support. This is important both to sustain current initiatives and to be positioned to undertake new initiatives as needs and opportunities arise. Another area of focus for my activities will be on membership development. A well-defined and healthy membership base is important to NFI, its organizational integrity and ongoing viability. It will enable us to further disseminate our vision for care of newborn infants in intensive care and special nurseries, provide increased visibility in new areas throughout the world, and provide unrestricted revenues necessary to cover NFI's general operating costs.

Our initiatives in developing resources and membership can be supported through increased visibility and understanding of NFI. Thus, another important area of attention for me will be enhancing and supporting our outreach activities. We will continuously seek ways to extend the reach of our message.

I am impressed on a professional level, and moved on a personal level, by what I have learned over the past couple of months about the work of NFI. Most particularly, I am struck by its organizational culture, a culture that includes justifiable pride in a job well done so far, coupled with a desire to do even more. Nowhere is this more evident than in the burgeoning initiative with the NIDCAP Nursery Certification Program (NNCP) that is now in its pilot phase. Completion of the pilot phase, announcement of the NNCP, dissemination of information, and preparation and training for future NNCP applicants is scheduled for 2009. It is exciting to imagine the potential offered by the NIDCAP Nursery Certification Program for systemic change by further integrating the NIDCAP approach in our health care system.

I am pleased and proud to be part of NFI's vision for the future.

—DAVID M. WAHL

The Advanced Practicum

To understand the evolution, implementation and value of the Advanced Practicum, we have invited three NIDCAP trainers' contributions: Susann Hill-Mangan to describe its beginnings; Jennifer Hofherr to examine its present use; and Jean Powlesland to reflect on the experience of its implementation. It is our hope that this comprehensive look at the Advanced Practicum experience will serve to inform, clarify, and inspire. We invite you to share your own observations and comments by writing to the editors at developmentalobserver@nidcap.org.

Beginnings

Susann Hill-Mangan, MA, LPC, was a NIDCAP Trainer for the Sahuaro NIDCAP Training Center, Tucson, Arizona between 1986 and 1999. She currently lives in Yuma, Arizona and has recently begun her own private practice as a Licensed Professional Counselor, "Transitions, LLC". As Susann reflects "although I am no longer in a situation to be a NIDCAP Trainer, I continue to use my knowledge and experience gleaned from Heidi, Elsa, gretchen and others in my private practice working with infants and children involved with Child Protective Services (foster care) and adolescents involved with the Courts and Juvenile Probation (some of whom are pregnant or recent mothers themselves). What is once learned and embraced can always be utilized to the benefit of others. This is truly 'a good thing.'"

By the late 1980's, NIDCAP training was expanding to more hospital NICUs across the nation. Susan Burke, lead administrator for Arizona's Department of Maternal and Child Health (MCH), embraced the concepts and philosophy of NIDCAP and became a strong advocate for the implementation of developmental care throughout Arizona's NICUs. Ms. Burke offered a consultant contract to Susann Hill-Mangan, a NIDCAP trainer at the Arizona Sahuaro NIDCAP Training Center. She sought to bring nurses, therapists and practitioners to NIDCAP reliability in all Level II and III hospitals statewide. With these increased training demands, concerns arose with regard to the quality of integration of the family and NICU team members throughout the NIDCAP training process. Susann states "as a NIDCAP Trainer, it became increasingly difficult to assess whether NIDCAP trainees were supporting the desired level of connectedness with families and NICU team members in the implementation of developmental care."

As Susann reflects, "despite frequent bedside sessions and extensive reviews of write-ups, the actual implementation process could not be assured." Susann decided that perhaps one answer to this conundrum was to require the NIDCAP trainees to develop a journal which would describe their personal experiences as they implemented developmental care with the family and NICU team members. Thus the Advanced Practicum was 'born' in 1992. In Arizona, two phases of NIDCAP training were developed. Phase

I consisted of the NIDCAP trainee attaining reliability with the NIDCAP trainer on the development of the write-up, goals and recommendations for the care of the infant and family. Phase II (certification) was determined by completion of the journal or Advanced Practicum.

The specific requirements of the Advanced Practicum included four components. First, each trainee was to engage a family of a premature infant (< 28 weeks) to participate in weekly NIDCAP observations and provide feedback for the individualized care plan. Second, NIDCAP observations/write-ups, care plans were kept in a "scrapbook" along with pictures of interventions (sibling art work, family decorations, personalized blankets, mementos, etc.). Third, and as Susann states "probably the most challenging for many of the NIDCAP trainees," was that the final NIDCAP was to be completed in the family home as a transitional care plan to be used by the community early intervention professionals. Fourth, the trainee's journal writings and evaluation questionnaires (completed by the family and participating NICU staff) were then added to the scrapbook and given to the NIDCAP trainer for review.

The Advanced Practicum was found to be extremely valuable in discerning whether the NIDCAP trainee was able to synthesize the knowledge of the rigors of reliability into practical application. It was adopted and wholeheartedly supported by Elsa Sell, MD, neonatologist, University of Arizona College of Medicine, and NIDCAP Director and Trainer of the Sahuaro NIDCAP Training Center, Tucson, Arizona. As the Advanced Practicum became a standard for training at the Sahuaro Chapter, it was then adopted by all NIDCAP Training Centers at the Seventh Annual NIDCAP Trainers Meeting in 1996.

Present

Jennifer Hofherr, OTR/L, is a NIDCAP Trainer for the University of Illinois Medical Center at Chicago NIDCAP Training Center. She writes "after spending 15 years as an occupational therapy practitioner working in the NICU, I made the leap to work directly in the NICU as an employee of the nursing department. Working in this capacity, over the last five years, has been a wonderful opportunity to bring my skills and

perspective to the NICU in ways that are better integrated and understood. Sharing these insights and strategies effectively with the therapy community is an important goal for me as a therapist and NIDCAP Trainer.”

The Advanced Practicum, or “AP” as it is commonly referred to by NIDCAP trainees, provides an opportunity for NIDCAP trainees to operationalize their knowledge of the infant’s behavior and subsystem integration in order to create an experience in the hospital that supports the infant’s strivings for development, the family’s and infant’s essential need for each other, and facilitates the transition from hospital to home. While the requirements and mentorship process are now formalized, the spirit of the AP remains as originally conceptualized by the Sahuaro NIDCAP group.

When the NIDCAP trainer is assured of the trainee’s skill in seeing and translating the story of the infant’s experience in the NICU (through the review of written reports of independent observations and of an observation done side by side with the trainer), the trainee is ready to embark on the AP.

The goals for the growth and learning of the professional through the AP include the following:

- Learn to support a team that is collaboratively engaged in caring for the infant’s parents to feel and be competent in the parenting of their infant and in supporting their infant’s development.
- Learn what makes NIDCAP implementation go smoothly, as well as ways to navigate the barriers for implementation, in a particular setting and/or with particular professionals.

In working toward and achieving these goals you learn about yourself as a professional and your strengths and needs to effectively implement developmental care. This can be addressed through the conscious use of the reflective process addressed

through the trainee’s journal writing. In addition, these goals offer opportunities for continued learning about the infant and family across time as the infant continues to grow and develop and becomes settled into his home environment after discharge.

The steps required for the implementation of the AP are: identification of the infant; meet the family; perform the first NIDCAP observation; meet with the family and staff; continue weekly or biweekly NIDCAP observations; provide the information from the reports to family and staff and identify processes to support the infant and family throughout the experience; create a binder or book as a family resource (including NIDCAP reports, family and staff journal, photographs, growth charts, etc.); and perform a final observation done in the family’s home after discharge.

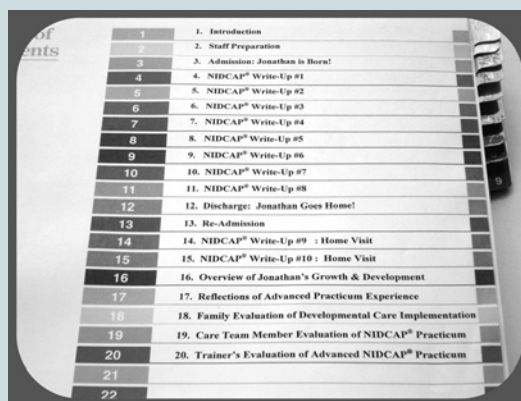
The trainee learns that through self-reflection and by reflecting with others, the successful AP is one which represents an effort by the trainee to hold for the team the ideals of nurturance, respect and empathy for the infant, the family and professional staff. The AP is a foray into the vastly complex life stories that the trainee will share with future infants and families.

Reflections

Jean Powlesland, RN, MS, is a NIDCAP trainer at the University of Illinois Medical Center in Chicago. As a staff nurse, she enjoyed the relative calm and quiet on the night shift for 10 years until she realized that most of the babies had fewer difficulties staying alert through the night than she did! For the last eight years, she has been a part-time developmental specialist in the NICU, working toward becoming a NIDCAP trainer, which she accomplished two years ago. “NIDCAP training has taught me not only to interpret the meaning of the baby’s behavior, but to consider carefully the behavior of the adults involved, and how I can use that information to help facilitate an environment conducive to the baby’s and family’s growth.”



This “Baby Book”, represents Rodd Hedlund’s Advanced Practicum (AP) with 20 weeks of documentation of the first weeks and months of Jonathan’s life with his family in the NICU to his home. This journal served to strengthen his understanding of premature infant behavior and strivings, family’s experiences, and nursery staff’s collaborations.



Inside, are the NIDCAP reports, photographs, growth charts and evaluations that Rodd has written, collected, and compiled.

Change is never easy. In the fast paced world of the complex medical, technological, multifaceted environment of the NICU, the process of change presents many challenges. Providing relationship based developmentally supportive care in the NICU is, of necessity, an evolving process.

—Hedlund, 2001*

This evolution occurs through the dynamic interchange between people: infant with family, infant with staff, staff with family, staff with staff, and the infant experiencing the human designed environment. As what we learn in NIDCAP enables us to see the infant's behavior in a different light, our values shift and we desire to provide care differently. This desire then leads us to problem solve the logistics of how this might look, and what barriers (policies, time, resources) may be in the way. The role of the developmental specialist, and of the AP trainee for whom this is an “internship” role, is to hold this vision of care, help problem solve these logistics, and determine ways around the barriers. This requires us to help others see what we are seeing, to learn what they value about the current practice and how to help them value the desired practice. During this process, conflict or unease may develop, as there is a growing consciousness that the care we should give is not the care that we actually provide. This is where the reflective process and a reflective process consultant are invaluable as a way to open ourselves to the possibilities of change. A reflective journal is a mandatory part of the AP, as communication of the thoughts and feelings that working through change may engender.

The AP provides the NIDCAP trainee with a chance to “put it all together.” It serves to integrate their knowledge of the infant gained through observation into components that will change the infant's and family's NICU experience with reports and guidance at the bedside that help caregivers see what the infant is communicating, as well as identifying where the

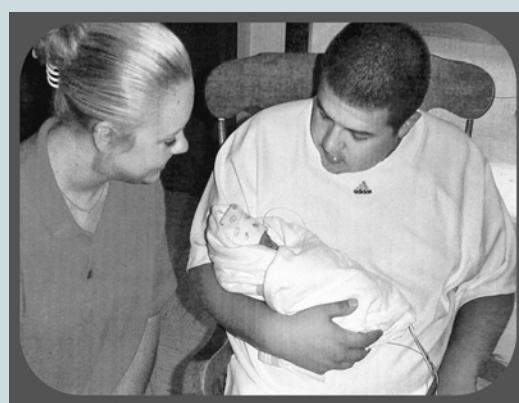
system is both helping and hindering this process. Much of the learning process takes place apart from the formal observations, and for this reason, the reflective journal is the most important component of the AP. Here, as the trainees think and write about what they are learning and struggling with, certain themes arise; themes that illuminate the particular strengths and challenges of the system and of the individuals participating in the process. The following are contributions from a number of trainees who have completed the AP over the years, revealing some of the challenges and insights that they have gained. These range from the challenge and disadvantage of being the first in a still evolving process, to taking advantage of moments when people are open to changing practice, to how new learning changes our perspective on our own and our co-worker's caregiving practice, to trying to negotiate and balance the requirements with the spirit of the work.

Jacqueline M. McGrath, PhD, RN, NNP, FNAP, FAAN, Associate Professor Virginia Commonwealth University School of Nursing, was one of the very first trainees to do the Advanced Practicum; in 1992 she worked with an infant born at 27 weeks after conception who developed lung disease (BPD) and was discharged 12 weeks later. Her reflections follow:

In 1992, I was a NIDCAP trainee in Arizona. It was during the course of my training that the experience of the Advanced Practicum was introduced. The AP provided an opportunity to gain insight into the relationship that was developing between the infant, family and newly trained developmental professional. This additional experience also provided the new professional with an opportunity to have continued support and feedback while a long term relationship was developing with an infant and his/her family in the NICU. However, it clearly lengthened the



Rodd's AP began in the NICU, five days after Jonathan's birth. Rodd noted in his journaling “Jonathan appeared to be quite sensitive to the sounds and activities within his area of the nursery and to the caregiving that he receives.” The entry went on to describe how Jonathan showed these sensitivities, his efforts to steady himself, and his apparent behavioral goals (including “maintaining his arms and legs tucked up close to his body to soothe and comfort himself”).



Rodd continued to observe Jonathan throughout his hospitalization, on a weekly basis, and regularly met with his family and caregiving team.

process. Although I valued the overall process I am not sure it was necessary. Don't gasp, I did appreciate the learning during the AP yet, I did not appreciate the additional step in the process that I had not previously agreed to, or the fact that the steps, guidelines or process were evolving during my training experience. I do realize that being the first trainee to have this experience had its distinct problems. I know these issues are clearer today and I am sure trainees do feel supported, encouraged and their commitment to this process is acknowledged by all involved. I believe praise and encouragement during the training process are important to the success of the NIDCAP trainee. Taking on this challenge is not for the faint of heart and these professionals really do want to make a difference in the lives of the infants they care for. I commend each of them for their commitment to excellence.

Jean Powlesland, RN, MS, NIDCAP trainer at University of Illinois, did her practicum in 2001 following Frances, born at 25 weeks after conception who was chronically vent dependent and was transferred to another institution for six weeks of her six month hospitalization. Jean writes:

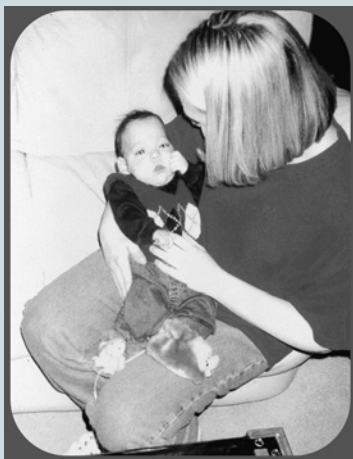
The AP really began to click for me when Frances returned from the other hospital. I felt my way as I began to define my role as developmental specialist as different from the therapists and nurses. Frances had a lot of behavioral challenges to work through and she suffered from severe withdrawal due to chronic narcotic use. In the early days of her life, the nursing staff appeared disinterested in my input; she was "just another 25 week preterm baby," and trying to convey why her nursing care should be "different" from the others, fell on deaf ears. But things were different now; the staff very much wanted my help with this very challenging baby. They now took the time to read the NIDCAP reports,

because they were eager for any resource that would help them to help her. More than once I have seen how important it is to take advantage of a situation where the information is greatly needed (i.e., if staff feel that they are getting by just fine with their current knowledge or experience, there is no incentive to change or to experiment with something novel).

Making the home visit to see Frances and her family was inspiring. Many staff had concerns about Frances' parents and whether they would quickly be overwhelmed by her needs and care. Our therapists felt that the mother was often distracted when they tried to teach her therapeutic techniques to use at home, and these techniques were going to be critical to help Frances become calm and relaxed. But Frances looked good as she sat in her mother's lap in her home. She was relaxed, breathing easily, much more so than when last in the hospital. Her parents said that at times she stayed awake and playful and they seemed realistic about the challenges of caring for her (e.g., not overly negative or optimistic). They had been aware that some of the unit staff doubted their ability to care for Frances and I was afraid that they would feel compelled to "prove" themselves to us during this visit, but instead I found them open and relaxed. I wish that the staff nurses could see how being in their own home environment has made such a positive difference. It was a rewarding closure to this long journey, and I felt that now I was beginning to have a clearer vision of what this role is all about.

Pam Kloska, PT, CIMI, a physical therapist at University of Illinois Medical Center, completed her Practicum in 2005. She worked with Angie, a twin girl born at 29 weeks after conception. Pam describes her experience:

By getting to know Angie and her family the entire AP process felt more special and meaningful. As I wrote the



Jonathan's progress was formally followed to 3 1/2 months corrected age in his home. At that time, Rodd noted that Jonathan "appears to be most interested in his environment and the people within it."



Though he completed the AP experience, Rodd has stayed in touch with Jonathan and his family continuing to appreciate the resilience of individuals and power of relationships within families.

reports, I could actually visualize the parents reading them. I know that the reports about Angie were written for the staff as well, but the fact that the parents were reading them took the importance of the observations and write-ups to another level for me. During the practice time prior to my NIDCAP workday, I would only meet an infant once through an initial observation followed by a write up. These one time encounters were challenging for me because I could not see any effect over time of the NIDCAP process.

However, with the AP, I got to know Angie over a period of multiple observations as well as through her parents' eyes; I felt more connected to her emotionally. This allowed me to go further in being able to understand her cues, what she was working toward in terms of goals, and what Angie needed in terms of people supporting her. The interesting thing was that before I even started NIDCAP training, I thought I was already doing this, but I realized through participating in NIDCAP, that I really was not. Now when I do something like change a diaper, I see care as an opportunity for learning about each infant and specifically how I can provide developmental support and nurturance.

Jeanine Klaus, IBCLC, a lactation consultant, accomplished her AP in 2007, working with Michael born at 29 weeks after conception. Jeanine reflects:

It is a rare opportunity to get to know one family so well as you share their journey with their newborn from birth, through the Intensive Care Unit stay, and finally to their own home. I cannot think of another way to grasp the magnitude of the "job" of providing individualized developmental care to one baby and family, given the myriad of hospital staff, the many family members and the multi-layered knowledge and expectations each brings to the infant's bedside. This form of focused, in-depth practice emphasized for me the importance of deciphering each care provider's personal appreciation for individualized developmental care in order to be able to translate the baby's behavior for them in a meaningful way.

From past experience I know that every family poses unique features that are accommodated in your relationship with them. In my AP, the mother was reserved and quiet, not always comfortable or fluid in articulating her feelings and concerns; she presented most of her worries in very concrete terms (e.g., Michael being able to do the things that other children do). It became important to point out Michael's competencies, especially those that might be easily overlooked when compared to a full term infant. I made sure to take time to just be with Michael and his mother without an agenda; to sit with the mother at her eye level; to be always first interested in her wellbeing; and to solicit her understanding of Michael's behavior and her plan for parenting. In retrospect, I wondered if I had been more directive, explicit

and didactic, whether the mother might have had less trouble breastfeeding and might have enjoyed more regular skin-to-skin care. But then I might also have lost opportunities to highlight how consistently and enthusiastically Michael responded to her and their relationship might have been fraught with "should do's" rather than filled with their mutual enjoyment of just relaxing with each other.

Though I never felt like I smoothly integrated all the parts of individualized care, I do see that I have come a far distance from where I started a year ago. I continue to work hard to pull the details of an observation together into a narrative whole, frequently getting lost in the minutiae of the scan sheets. I am just beginning to feel confident about how much more I can ask of the staff on behalf of the infant. I seek to validate what the caregiver sees consistent with developmentally supported care and to help scaffold their thinking to a different plane. As a result of this AP experience: I see what might be supportive at the infant's bedside; I have a keener sense of how to draw the parents into the care of their newborn baby; and I now have a vision of what developmental care of an infant should strive for at each point along the continuum, from birth to going home with their family.

Perhaps Angela Balensiefen, RN, BSN, a staff nurse at Children's Hospital of Wisconsin, Fox Valley, who completed her Advanced Practicum this year, said it most succinctly:

In the end...this has been quite a process. I have learned a lot!! Most of all, I have learned that the focus and primary purpose of developmental care is to foster the parent-infant relationship to the best of your ability. When I started this practicum, I was very keyed into the "write-ups," very nervous about working with the staff, and how to do so, while at the same time providing Jose with developmentally appropriate hands-on care. Now that I am finished, I realize that the write-ups were important for everyone's viewing and supported consistency in Jose's care. However, what seemed more important, and had a greater impact, were the few times I worked directly with his mother when she was caring for her son. My phone discussions with her during his stay and after were also crucial, I felt, in having her feel she had a consistent support person during this stressful time in her life. So, in the end, I would have done things differently. Perhaps by focusing more on the family, the staff could better appreciate Jose and his mother's experiences in the nursery; and Jose's mother could better ensure that her son received the care he deserved.

Reference:

- * Hedlund, R. The process of change. Unpublished presentation. Oklahoma Infant Transition Program, Oklahoma Children's Hospital, University of Oklahoma Health Sciences Center, Oklahoma City, Oklahoma. 2001.



Tammy Casper, MSN, RN and Linda Lacina, RN

This is a story of the birth of our NIDCAP Center. In 1997, the Maternal Child Nursing Division of the Ohio Department of Health funded introductory NIDCAP training for every NICU and SCN in the state. We were among the fewer than 5% of individuals who completed training to reliability. Our trainer, Dr. gretchen Lawhon, provided us with supportive guidance, establishing what is becoming a lifelong friendship as we moved from expert bedside nurses to novice NIDCAP students and eventually to NIDCAP trainers. We continue to be humbled as we look back to write our story for the Developmental Observer, acknowledging our accomplishments while realizing our challenges in becoming a NIDCAP Training Center.

We began at Cincinnati Children's Hospital Medical Center (CCHMC) as staff nurses working in the Regional Center for Newborn Intensive Care (RCNIC) in downtown Cincinnati, Ohio. Our unit is a 59 bed Level III C Neonatal Intensive Care Unit that provides services to infants and families transported from the surrounding area and from afar. This past year we had 724 admissions with an average length of stay of 23 days. About 33% of infants admitted into the RCNIC are <2500 grams and 46.3% are born before 37 weeks gestational age. Therefore, the majority of infants in our nursery are born around term with genetic, surgical, and/or complicated airway concerns. We opened the Fetal Care Center in 2005 for these infants requiring specialized services. Our interdisciplinary team includes a neonatologist, a neonatology fellow, medical residents, and advanced practice nurses along with our interdisciplinary bedside team. This distinctive population demands all members of the care team to have a wide set of skills at the bedside that support the direct care environment of the infants and families receiving our care.

In 2001, four years into our developmental care journey, many of the ingredients that make our nursery special began to come together. Our strong nursing leadership designed an individualized, developmentally supportive nursery environment. A stronger, unit-wide developmental care team emerged with three more staff (two registered nurses and one respiratory therapist) who accomplished NIDCAP reliability. And our team hired Pattie Bondurant, MN, RN, CNS as the Senior Clinical Director. She has been instrumental in empowering us to share our learned wealth of knowledge with the rest of our staff, our surrounding region and at statewide conferences. With all of this support and guidance, we committed to becoming a NIDCAP Training Center.

As the two of us independently worked to meet the necessary components of becoming NIDCAP trainers, we

developed ourselves and our professional roles. For Tammy, this meant further academic achievements through a graduate program that focused on adult education principles to identify strategies to help parents and instruct professionals in this work. For Linda, this meant enrolling in graduate nursing classes to

support her organization of the many training components and educational offerings for staff and the surrounding community. We worked together on the development of a NIDCAP budget and strategic plan to assist us in establishing our center.

Having met all of the NIDCAP training center development and trainer requirements, we proudly opened our NIDCAP Training and Research Center in 2007. Since then our focus has been on training

staff within our unit. At this time, we have three registered nurses, one occupational therapist and one speech pathologist as NIDCAP reliable staff. There are an additional five staff at various levels of NIDCAP training. We provide NIDCAP training for staff on a quarterly basis and plan to reevaluate this process at the end of this year. We provide NIDCAP observations monthly, with informal follow-up in between, for infants born at or less than 34 weeks gestation. The billing structure for these NIDCAP observations allows us to sustain and grow our NIDCAP program. Our goal is to increase the frequency of NIDCAP observations to every other week for those identified infants as the number of NIDCAP reliable staff increases.

In addition to training and increasing our capacity to provide NIDCAP observations, we are focusing on the assessment and planned interventions for infants who have difficulty with state organization. These infants have often endured multiple surgical procedures, long-term respiratory support, delayed enteral nutrition and chronic pain. This concentrated effort has led to the creation of what we have termed a "comfort bundle," with interventions



Tammy Casper and Linda Lacina

Continued on page 18

Understanding Developmentally Supportive Feeding with the Premature Infant

Erin Sundseth Ross, PhD, CCC-SLP

Erin Sundseth Ross, PhD, CCC-SLP received her MA in Speech and Language Pathology in 1988 from California State University, Stanislaus, California, and her PhD in Clinical Sciences, Health Services Research in 2007 from the University of Colorado Health Sciences Center in Denver, Colorado. She holds a Certificate of Clinical Competence from the American Speech/Language/Hearing Association. She has worked for 15 years in NICU settings and in pediatrics, with a specialty in feeding disturbances. Dr. Ross has supported Dr. Joy Browne during NIDCAP trainings in the United States and internationally. Currently she is completing a post-doctoral fellowship in nutrition, with a research focus on factors influencing growth and feeding in the NICU and post-discharge. She speaks internationally on the subject of feeding development and feeding problems in the medically fragile infant and child. Dr. Ross has been married to Alan for 23 years. They have three children, and in December became grandparents.



during feeding with the thought that it “will eventually get better,” rather than being used as a signal to provide additional supports for, or to diminish demands on, the infant. This simplistic viewpoint lacks an understanding or appreciation of the role of supportive care in facilitating feeding development.

The dichotomy between the philosophy of developmentally supportive care and the practice of feeding in many NICU’s may be attributed in part to both the pressure to reduce length of stay and the evolution of therapeutic intervention in the NICU setting. Feeding is typically the last milestone achieved prior to discharge from the NICU. In 2001, Eichenwald and colleagues¹ studied 15 NICU’s and found that infants who were discharged with a later post-conceptual age were reported to have later maturation in feeding behavior. Hospitals that used pulse oximetry for a longer duration reported later maturation of feeding behavior. The study concluded that there was a large variation in discharge results “in part from differences in monitoring for and documentation of apnea of prematurity and feeding behavior” (p 928). Some NICU cultures assume apneic episodes with feeding will be outgrown, and therefore saturation monitoring during feeding is not necessary. Instead,

caregiving is used to determine the ability of the premature infant to feed. However, Thoyre, et al.² found that preterm infants averaged 10.8 desaturation events per feeding when videotaped close to discharge, with severe ($SpO_2 \leq 80$) desaturation episodes observed in 21% of the feedings, and moderate (SpO_2 81 to 84%) desaturation episodes in an additional 20% of feedings. When Thoyre and Carlson³ sought to determine the behaviors that were associated with apnea or hypoxia during feeding, few observable behaviors were consistently associated with physiologic instability. The authors determined that attending to changes in breath sounds and the pauses in sucking may assist the feeder, in the absence of pulse oximetry. However, attunement to the infant and recognition of behavioral cues may be lacking without training in developmentally supportive care.

In addition to the pressure to decrease length of stay, feeding is often not recognized as a normal developmental process, but rather something to be taught. Preterm infants are known to be at risk for increased developmental problems and poor feeding behaviors, and therefore many therapists presume that all preterm infants need to be “habilitated” without appreciating individual developmental paths. Both therapists and medical professionals attempt to speed the process of feeding in premature infants. Gestational age has continued to be used as a marker for initiating breast and bottle feeding in some NICU’s. Others initiate feedings on all infants when they reach a physiological point such as tolerating all enteral feedings. Both of these approaches ignore the individuality of the infant, and indeed may be detrimental to the developmental process. Infants who are discharged from the NICU are at elevated risk of feeding and growth problems. There are data that indicate feeding problems (such as gagging, vomiting, and

food refusal) are seen in 50 – 75% of the premature infants discharged from the NICU, regardless of medical course of the infant.^{4,5} The role of learning must be appreciated, as feeding is supported by primitive reflexes only through the first six months of age, then moves into a completely volitional and learned task. Practice may be useless at best, and may even be harmful when it overwhelms the fragile balance of stability in the preterm infant. Feeding from a developmentally supportive care framework sets the stage for the infant and the family to have experiences that are positive and meaningful.

In 2001, Dr. Joy Browne and I developed the *Baby Regulated Organization of Systems and Sucking*, which was designed to provide a conceptual framework for caregivers to appreciate and facilitate the development of feeding. This conceptual framework integrates the concepts of supporting systems regulation with known developmental milestones in premature feeding to identify supportive interventions. We encourage staff members to consider the influence of the environment and the caregiver's decisions on the development of feeding, and to set the stage to support organization in all systems using the philosophy and the skills developed during NIDCAP training. Feeding needs to be an enjoyable, collaborative experience between the

infant and the primary caregiver, the parent.

Infants who are fed by nursery caregivers who lack developmentally supportive care training may be learning that feeding is not enjoyable, but testing this hypothesis presents challenges. Data exist that suggest infants may in fact be negatively influenced by early feeding experiences. In an article published by Fucile, et al.⁶ early aggressive oral stimulation was shown to decrease the transition time from start of oral feeding to attainment of full oral feeding. However, the difference in gestational age at full oral feedings was not significant. A later article by Fucile et al.⁷ reported no difference in maturation of feeding skills in infants treated with an oral stimulation program. In both of these articles, the control infants appeared to gain weight better than the experimental group. And yet, therapists and medical staff across the country do not appear to appreciate the possible negative learning with oral stimulation. Perhaps the oral stimulation that infants are subjected to is in fact contributing to the abysmal feeding outcomes.

Dr. Barbara Medoff-Cooper, Dr. Kathleen Philbin and I have been working over the last three years on research designed to examine feeding and growth outcomes for infants who begin nipple feeding at different gestational ages and who are fed by

caregivers with differing developmentally supportive care educational backgrounds. Additionally, I have been fortunate to have had numerous opportunities to teach professionals across the country to view feeding development within the context of developmentally supportive care. At these workshops and in particular at the Rocky Mountain Fragile Infant Feeding Institute, a multidisciplinary faculty specializing in therapy, nutrition, mental health, continuing education and nursing, train professionals on the intricacies of feeding and development. Comprehensive training in the NICU that includes a developmentally supportive feeding philosophy may be the key to improving long-term feeding outcomes.

References:

1. Eichenwald E, Blackwell M, Lloyd J, Tran T, Wilker R, Richardson D. Inter-neonatal intensive care unit variation in discharge timing: influence of apnea and feeding management. *Pediatrics*. 2001;108(4): 928-33.
2. Thoyre S, Carlson J. Occurrence of oxygen desaturation events during preterm infant bottle feeding near discharge. *Early Human Development*. 2003; 72(1): 25-36.
3. Thoyre S, Carlson J. Preterm infants' behavioural indicators of oxygen decline during bottle feeding. *Journal of Advanced Nursing*. 2003; 43(6): 631-41.
4. Cerro N, Zeunert S, Simmer K, Daniels L. Eating behaviour of children 1.5-3.5 years born preterm: parents' perceptions. *Journal of Paediatric and Child Health*. 2002; 38(1): 72-8.
5. Hawdon J, Beauregard N, Slattery J, Kennedy G. Identification of neonates at risk of developing feeding problems in infancy. *Developmental Medicine and Child Neurology*. 2000; 42(4): 235-9.
6. Fucile S, Gisel E, Lau C. Oral stimulation accelerates the transition from tube to oral feeding in preterm infants. *Journal of Pediatrics*. 2002; 141(2): 230-6.
7. Fucile S, Gisel E, Lau C. Effect of an oral stimulation program on sucking skill maturation of preterm infants. *Developmental Medicine and Child Neurology*. 2005; 47(3): 158-62.

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.



Interview by Deborah Buehler, PhD

Born in 1987, at 28 weeks after conception, Amara Selvitella weighed one pound and 14 ounces. During Amara's hospitalization, her mother, Linda, recounts that her prematurely born daughter had five blood transfusions, retinopathy of prematurity, apnea and hypertonia.

Also during that time, the Selvitella family participated in research, at the Brigham and Women's Hospital in Boston, studying the influence of the NIDCAP approach in the nursery with very early born infants who had received mechanical ventilation after birth. The US Department of Education, National Institute on Disability Rehabilitation and Research funded this investigation, led by Heidelise Als, PhD.

Now twenty years later, Amara is a college sophomore at Florida Atlantic University in Boca Raton and Linda is a physical education teacher in the Florida public school system. The following excerpts are from telephone interviews where Amara and Linda each shared remembrances, impressions and suggestions from their experiences and their relationship with one another.

What do you remember about the NICU?

LINDA: I visited Amara every day, twice a day. I never missed one day. Back then, the NICU was very different than I see it is today. We were only allowed to hold our baby once a day. I couldn't take her out in the afternoon because I wanted her father to also be able to hold her when he came to the NICU in the evening. I was allowed to touch her through the incubator windows. I believe that I had postpartum depression, but I didn't know it. I took videos of Amara every day. At least I was able to watch them when I was home, but it was very hard to leave my daughter. If I could have stayed with her, I would have stayed with her every single night. I would never have left her. I know that my being in the NICU with Amara every day definitely had a tremendous impact on my daughter doing as well as she has.

Can you describe some of your experiences over the years?

LINDA: I was a single parent, and at night I would sit on the bathroom floor and cry and just pray to God that I was I doing the right thing for Amara and that I had energy to keep up. I hoped I was giving her what she needed and teaching her the skills she needed in order for her to be independent and happy so she could have a normal life and grow up to enjoy the relationships and experiences that she desires.

I brought Amara to many different infant and child educational and therapy programs. In some of the programs,



Throughout Amara's hospital stay, she and her mother Linda were together everyday.

the children were normal and walked by themselves. But I had to carry my daughter everywhere because she didn't walk until 17 months. When she did walk it wasn't normal and she dragged her right leg so she wasn't able to get along by herself. Some of the other parents were a little abrasive and they would ask me "why can't your daughter walk and what's wrong with her?" And I said, "she's a preemie baby and she's not able to walk on her own yet so I have to carry her." I always made sure I was positive and told my daughter "yes this is what is happening right now but you are going to do fine." She would always smile at me.

AMARA: There are always struggles in life and the people you surround yourself with, they help, it's sort of a process. You should never try to do something alone because it's difficult. I think that with the right care, whether that be physical or emotional, and the right guidance everyone can get through whatever they are struggling with. Life is a constant struggle and as long as you look toward the positive of things, they tend to go by quicker and more easily.

LINDA: As her mother, I had to really get to know Amara and know when to push her and when to let go. I noticed when my daughter was very, very young that she would give up very easily if anything were challenging, except for sports. When she was out on that field, she loved the moving and the activity so much that she would push herself. But she had to love something that much and most things, like school work and chores, she didn't feel that way about. Amara did much better when I was supporting her and there for her so that's what I did. And from when she was a baby to a teenager she had to have choices and feel like she was the one making decisions. So I gave her choices that I could live with no matter which choice she made. As a

child, she really believed she was making the choices. Then when she got to be a teenager that is when it got tricky because she figured out what I was doing. I had to give her a lot of space. She was very, very opinionated and she knew exactly what she liked and what she didn't like and we got into some pretty tough spots there. I always stood my ground, and when I went too far, she would push more and then I would have to negotiate. Now that she's becoming an adult she has a better idea of why I was so tough with her.

AMARA: My mom was a disciplinarian. I was a little bit rebellious growing up especially more towards 15, 16, 17 years of age. I would assume this is normal, but she straightened me out and I always respected her and I think that was what made it easier for our relationship. Because I would never do anything that I thought she would disagree with or if I did it would never be bad. I was never into drugs. I would never sneak out. Because I knew there would be repercussions and I would never want to face them.

Do you think Amara being born early has shaped the people that you are today?

AMARA: I don't really give up on things that easily. So I think that has a lot to do with my development-- as my mom says, I kind of fought for my life for a while. I had tubes in every direction and it was just difficult to see me like that. I think that she is really proud of who I've become.

LINDA: I certainly think that it has made Amara a pretty strong person, that's for sure, because she had a lot of trials and tribulations. She doesn't remember all of them, but I know that she fought because I was with her. She had to fight to stay alive and to get to where she is today. I loved her from the moment she was born and I always thank God each day that things turned out the way they did.

I've become stronger and can see the growth in myself as well. When you have a premature baby your whole world gets turned upside down. You doubt everything in your life. You don't know how you're going to go on and how you are going to make it.

Can you describe your relationship with one another?

LINDA: I raised Amara to be independent, to know herself and to make decisions for herself and always know that I love her. She has grown into a very wonderful young lady and I'm very proud of her. I just feel that I'm always there for her and that's very rewarding to me that my daughter wants to talk to me, tells me how she feels, tells me her difficulties, asks me for advice sometimes and shares what she's going through. The most rewarding things are all the cards she sends me where she shares her feelings of what I mean to her. It reassures me as a parent that I've done the right thing even when I think I didn't do the right thing.

AMARA: Growing up I was always close to my mom. She has always done her best to support us and make a life for us. As a single parent, raising a daughter, she always struggles. The house that we live in, my mom did all on her own with her teaching salary. I really respect her a lot for doing those things because it's so easy to just say I can't do this and just to raise an okay family. She really did her best to be there for me. When she was at school, I was at school, and she would pick me up and we would go to soccer practice and she'd help with my homework and I got a knack for being responsible and for having a positive outlook on things from her. We had and have a great relationship. Now that I am away at school, I'm using what she taught me on a daily basis and she is proud of me. Our relationship just tends to get better as I get older because I am given more responsibilities as an adult.

What are your hopes for the future?

LINDA: I want my daughter to be excited about whatever it is that makes her excited. It's about her not me. I'm doing what I love and you've got to have passion about what you do because you are going to be doing it a long time. My wish for my daughter is that she finds a job that she has unbelievable passion for, that she finds someone that she can share her life with, and that she creates whatever it is that she wants to create.

AMARA: I plan to study occupational therapy in college and work with premature babies. I look forward to guiding them through their younger years and helping them. I want to try to be there for them when they need me because someone was there for me. I think that has a lot to do with my development, physically and emotionally, and my personality. I look forward to one day raising a family and maybe using a lot of the aspects of my mother to raise my kids. I look forward to living my life, wherever it takes me, because I'm a pretty positive person. I have a pretty good head on my shoulders.

Continued on page 18



Twenty years after her birth, Amara and her mother describe a closeness and mutual respect for one another.



Björn Westrup, MD, PhD



Björn Westrup, MD, PhD, is the Director of the Scandinavian NIDCAP Center at Astrid Lindgren Children's and Karolinska University Hospital, Stockholm, Sweden and Lund University Hospital, Lund, Sweden; as well as the Medical Director of Neonatology at Karolinska University Hospital, Danderyd, Sweden. Björn first became attracted to the medical field and the hospital setting when he was a parachute trooper in the Swedish military working part-time as a medic. He was fascinated with the discipline of pediatrics encompassing the holistic view of the family in context to the child. Throughout the years he has maintained a strong interest in philosophy and the social aspect of the family and its impact on health and healing for infants and children.

Björn first heard Dr. Heidelise Als present the Synactive Theory of infant behavior at the Karolinska University Hospital in 1989. He was fascinated by these concepts and developed a quest for knowledge and better understanding of this conceptual framework. Björn began his pursuit of individualized developmentally supportive care in a small, community-based non-academic hospital. Agneta Kleberg, RN, PhD, his collaborator of many years, shares one of their first “developmental moments” when they were learning about NIDCAP:

Having just returned from Boston, after our first NIDCAP and APIB introductory days (November, 1990), Björn and I entered the Karolinska University Hospital nursery in Stockholm to find a nurse attempting to help a mother and father bathe their son. The baby was fussing and stretching his arms and legs out away from his body. Björn quietly walked over to help the mother and nurse. He gently tucked the baby's arms and legs up close to his body. The baby became calm and relaxed into the warm comfort of his mother's arms as he softly looked up into his mother's face. Everyone was amazed. Björn and I were very happy that these new developmental supports that we had just learned about from Dr. Als, also worked here “at home” in Sweden. This event was the very first starting point for the implementation of NIDCAP in Sweden.

To address some of the challenges of the initial NIDCAP presentations to the larger academic university hospitals, Björn validated the approach through research. He has long been a strong advocate in the medical community, publishing many articles and lecturing on the efficacy of individualized developmentally supportive care. He speaks of the need for perseverance and stamina in implementing individualized developmentally supportive caregiving practices. He identifies the need for more research as he seeks to explain the physiological mechanisms of supporting improved

neurodevelopmental outcomes for premature and critically ill infants. Björn also recognizes the need for more randomized controlled trials and looks to continue to collaborate with research investigations in the areas of neuroimaging and kangaroo mother care with its influence on infants and their families.

Björn values the team process and has collaborated and supported many colleagues along his developmental journey. Colleague, Deborah Buehler, PhD recalls with a smile:

The ease with which Björn jumped up during a break in her introductory NIDCAP lecture in Falun, Sweden, and readily participated in a physical therapist-led rendition of the “Itsy Bitsy Spider” with the whole audience. The exercise pointed to the importance of adults using movement to support learning. At the time, I was thoroughly impressed with Björn's comfort with himself as a leader in his hospital and gained whole new appreciations of multi-disciplinary system-wide supportiveness and team spirit.

Björn's colleagues admire his investment and fortitude in supporting infants and their families. He is seen as valuing the physician's perspective as well as each member of the team's contribution to the success of the infant and family's experience.

In addition, Björn takes great pride and finds it incredibly rewarding to see the shift in support of developmentally supportive care over the past 10 years, first within the Swedish community and then throughout Europe's medical community. He has been actively involved at the international level with the creation of the NFI, including being a member of the Board of Directors from 2001 to 2007.

Families from diverse backgrounds often return to the hospital to share updates on the children he has cared for and the impact he has had on their lives. As Inga Warren, Dip COT, MSc, a colleague, reflects:

Continued on page 18



Family support is a primary goal of care guided by NIDCAP principles, and NIDCAP professionals use a variety of approaches to individualize their support of families. In her research and clinical practice, gretchen Lawhon, RN, PhD, NIDCAP Master Trainer and Director, Mid-Atlantic NIDCAP Center, shares some of her observations and research findings on a particularly valuable approach to helping families. Supporting families to find opportunities to reflect on and create memories of their NICU experience through written or pictorial journaling is the focus of this column.

Parent Journaling: Supporting Parents in Reflection

Effective process is an integral part of the NIDCAP approach to caring for infants and families. Finding an avenue for parents to reflect on who this new person in their family is and to express their hopes and dreams as well as anxieties and fears is a valuable adjunct to our clinical care in the newborn intensive care unit. Journal writing may be a therapeutic process that helps individuals clarify their thoughts and may be especially useful for those who have difficulty expressing feelings verbally. It is a safe and private way of confronting new challenges and processing both information and emotion. Having learned and come to value journal writing in my own work as a NIDCAP trainer, I incorporated it into my dissertation work facilitating parents in the newborn intensive care unit.¹ In a small exploratory study aimed to examine a therapeutic process of an individualized nursing intervention, seventeen parents responded through journal writing to a small set of questions on a weekly basis. The questions such as “*how are you feeling as a parent of this baby*” were designed to elicit the more elusive feelings and emotions that a parent has both regarding the infant and self. One response by a parent of a then 30 week infant was “*It’s getting harder and harder to leave her there night after night. She’s becoming less and less an event that’s been anticipated, and more of an actual person with a face that can stay in my memory, and be loved and missed.*” When the journal writing was analyzed with a constant comparative analysis several common themes became clear which demonstrated the parent’s integration of critical appraisal as a measure of parent competence. There was a positive trend in parents expressing their understanding of the infant as well as personal feelings. In writing about how they were able to provide care to their infant all parents wrote of physical aspects of care and fourteen wrote about emotional aspects of care. All parents expressed the issue of personal recognition and were confident that their infant knew who they were and responded to them in a unique way. In response to how the infant had changed in the past week,

all parents wrote in both physical and behavioral terms with a majority mentioning the most recent weight of their infant. Three of the ten mothers wrote about their infant’s developing personality over time. When offered the opportunity to share additional feelings, there were both positive and negative emotions expressed. Many parents expressed frustration in wanting to hold their infants more and in having limitations placed on their handling. More than half of the parents expressed a feeling of pride in their infant.

Since incorporating the journal writing in my dissertation study with parents, I have found support in the literature for journal writing as a therapeutic avenue to reduce stress in NICU parents. Macnab² demonstrated that 73% of the 23 mothers, who did journal writing while their infant was in the NICU, reported that it reduced their stress. In another study, Barry and Singer³ randomized 38 mothers of preterm infants, who were measured for psychological stress, into two groups. One of the groups was asked to journal about their most emotional and upsetting experiences in the NICU over four consecutive days. This intervention group, using journal writing, showed a significant decrease in symptoms of depression and post traumatic stress in comparison to the non-journaling control group.

Currently one of the most common ways that journal writing is incorporated in the newborn intensive care unit is with parent scrapbooking. The creation of scrapbooks combining photographs and journal writing often becomes a source of informal parent support in the NICU in addition to a method of clarifying the infant’s birth and place within the family. Regardless of whether parents express their integration of this new family member through photographs and/or brief journal entries, the creation of tangible evidence in a memory or scrapbook clearly represents reflection. Therefore this informal yet therapeutic vehicle for families in the newborn intensive care unit may be powerfully effective in facilitating parents’ understanding of their son or daughter.

References:

1. Lawhon g. Facilitation of parenting in the newborn intensive care unit. Unpublished Doctoral Dissertation, University of Washington; Seattle. 1994.
2. Macnab AJ, Beckett LY, Park CC, Sheckter L. Journal writing as a social support strategy for parents of premature infants: a pilot study. *Patient Education and Counseling*. 1998; 33:149-159.
3. Barry LM, Singer GHS. Reducing maternal psychological distress after the NICU experience through journal writing. *Journal of Early Intervention*. 2002; 24 (4):287-297.



The Physical and Sensory Environment of the NICU

The developmental impact of the physical environment attracts a lot of interest, not least from the Vermont Oxford Network (VON), which formed a physical environment exploratory group in 2005 nicknamed “Senses and Sensibilities.” This group, drawn from five centers (none of which have experienced NIDCAP) has published 16 evidence based recommendations for “Potentially Better Practices” (PBPs) that support newborn brain development (Liu et al.¹), and create “a NICU environment that optimizes the neurodevelopment of the infant while supporting the well being of family and staff” (Graven²). This work was also the subject of the most recent VON quality improvement internet seminar (iNICQ) on November 14, 2007. The report in the *Journal of Perinatology* begins with an overview of the processes of neurosensory development that underpin ensuing arguments for an environment that “protects and supports the developing newborn brain through gentler care practices and strategies that preserve sleep.” The clinical literature on tactile, chemosensory, auditory and visual systems and sleep were reviewed with PBPs. These were based on best available evidence using a five point classification system for evaluating strength and quality of evidence adapted from Gray-Muir³ in which one is the strongest and five the weakest level of evidence. Animal studies were included at level five. The PBPs related to chemosensory and acoustic development presented at the November 2007 VON iNICQ were based on evidence that rated level three on the evaluation scale.

Recommended practices are bundled into age groupings, thus there are 11 PBPs suitable for implementation from 23 weeks gestation to term, and five for implementation at 31-32 weeks to term and beyond in some cases. The multimodel nature of sensory stimulation is recognized and the recommendations do not exclude concurrent implementation. Some of the recommendations are quite general, for example strategies that preserve sleep are recommended for all NICU admissions, without specifying which strategies. While it is helpful to have such common sense reinforced with scientific evidence some of the other recommendations are worryingly prescriptive, particularly those that involve physical contact between infant and caregiver. The recommendation for daily massage “as tolerated” will set alarm bells ringing, especially as

the implication appears to be that this will be implemented by nurses and therapists until the infant shows signs of physiological instability. In the first place, there would surely be merit in regarding this kind of touch therapy as the province of parents, and secondly the concept of tolerance is likely to be subjective, depending on the subtlety of the caregiver’s observations skills.

In the concluding discussion, the authors make special reference to NIDCAP, in the context of stress reduction and self regulation, pointing out that “the potential benefit of diminishing stress during critical periods of development may reflect multiple strategies with overlapping beneficial pathways.” Stanley Graven brings the whole topic back into the territory of family centered care when he states, at the end of his address through the Vermont Oxford November internet seminar, “Bring the Family back to the NICU and the Mother closer to her baby! Family involvement will promote and facilitate all the PBPs.”

The VON project is closely linked to the Physical and Developmental Environment of the High Risk Infant Project which publishes its most recent update from the multidisciplinary consensus committee, chaired by Robert White⁴, in the same Supplement to the *Journal of Perinatology*. Some new ground is covered, including updated recommendations for single rooms, which are gaining popularity as a desirable option in the NICU. Although single rooms have many advantages, such as reduced infection and less environmental stress (Walsh et al.⁵), there are issues about managing care based on the infant’s behavioral cues. Even with one to one nursing it is likely that the infant will be alone some of the time and that electronic monitoring will take the place of direct observation.

It would be interesting to share ideas and thoughts about this in the context of implementing NIDCAP. Let us know what you think by writing to the editors at developmentalobserver@nidcap.org.

References:

1. Liu WF, Lauder S, Perkins B, MacMillan-York, E, Martin S, Graven S. The development of potentially better practices to support the neurodevelopment of infants in the NICU. *Journal of Perinatology*. 2007; 27: S48-74.
2. Graven, S. Vermont Oxford Network iNICQ Seminar. 2007.
3. Gray-Muir, JA. Evidence Based Healthcare: How to Make Health Policy and Management Decisions. New York: Churchill Livingstone; 1997, p. 61.
4. White, RD. Recommended standards for the newborn ICU. *Journal of Perinatology*. 2007; 27: S4-S19.
5. Walsh WF, McCullough KL, White RD. Room for improvement: Nurses’ perceptions of providing care in a single room newborn intensive care unit. *Advances in Neonatal Care*. 2006; 6 (5): 261-270.



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

Conferences

NIDCAP Congress in Aalesund

Place: Aalesund, Norway

Date: June 10-12, 2008

email: www.helse-sunnmore.no/default.asp?menu=3004

Neonatal Comfort: Analgesia, Sedation and Individualized Loving Care

Place: Madrid, Spain

Date: June 12-14, 2008

email: www.mkt.delipokrates/html/seminar.htm

Neonatal Pharmacology

Sponsored by Contemporary Forums

Place: Boston, Massachusetts, USA

Date: June 19-21, 2008

email: www.cforums.com

21st European Congress of Perinatal Medicine

Place: Istanbul, Turkey

Date: September 10-13, 2008

email: www.kenes.com/ecpm/

National Association of Neonatal Nurses 24th Annual Educational Conference

"Navigating Neonatal Care: A Safe Passage Home"

Place: Fort Lauderdale, Florida, USA

Date: September 24-27, 2008

email: www.nann.org/i4a/pages/index.cfm?pageid=803

Science Meets Our Hearts

"Attachment and the Early Years"

Place: British Columbia, Canada

Date: September 25-27, 2008

email: www.idpofbc.ca/calendar/view_entry.php?id=25&date=20080926

A World Wide View of Breastfeeding

Place: Vienna, Austria

Date: October 1-3, 2008

email: www.velb.org; www.ilca.org; or www.stillen.org

Developmental Interventions in Neonatal Care Annual Conference

Sponsored by Contemporary Forums

Place: Denver, Colorado, USA

Date: October 1-4, 2008

email: www.cforums.com

Academy of Neonatal Nurses

8th National Neonatal Nurses Meeting

Place: Washington, DC, USA

Date: October 8-12, 2008

email: www.neonatalnetwork.com/nn3/NNDC2008program.htm

Second Congress of European Academy of Paediatrics-EAP

European Society of Paediatric Research/ Neonatology/Neonatal Intensive Care

Place: Nice, France

Date: October 24-28, 2008

Call for Abstracts Now Open: EAP2008@mail.vresp.com

Infant Development in Neonatal Intensive Care (IDNIC):

"Closing the Gap Between Research and Practices"

Place: Paris, France

Date: December 11-12, 2008

email: www.info-congres.com

Publications

Early Development and the Brain

Linda Gilkerson and Rebecca Klein, Editors. Published by Zero to Three, National Center for Infants, Toddlers and Families. Cost: \$359.99

Early Development and the Brain is made up of several teaching units which include detailed lecture notes, learning goals, student handouts, PowerPoint slide presentations, reference lists and optional activities. This is a scientifically sound curriculum which utilizes the expertise of nationally recognized developmental and neuroscience professionals from over 23 institutions, including the Yale Child Study Center, Harvard Medical School and the Erikson Institute to bring the reader extensive information which provides a fresh approach to teaching and learning this material. Chapters include

prenatal development, neurobehavioral observation, brain basics, brain imaging, stress, sensory processing, maternal drug use, and language and the brain.

Understanding Newborn Behavior & Early Relationships

J. Kevin Nugent, Constance H. Keefer, Susan Minear, Lise C. Johnson, and Yvette Blanchard. Forward by T. Berry Brazelton.

This book is the handbook and manual for learning the Newborn Behavioral Observations (NBO), a complementary assessment to the Neonatal Behavioral Assessment Scale (NBAS) (Brazelton, 1973). The NBAS may be used as a diagnostic tool to assess newborn neurological and behavioral difficulties; the NBO was designed to enhance clinicians to share observations of their newborn with parents to begin the process of parent-infant interaction.

As Brazelton states:

"My dream is that all neonatal centers will train professionals in the use of the NBO to help them share observations of newborn infants with their parents. However, when professionals find unusual or deviant behavior in the neonate, they should also be able to turn to a trained NBAS observer to conduct the NBAS. I would like every center to have the NBO for relationship building, and the NBAS for a more detailed diagnostic assessment of neonatal behavior."

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 Kathleen VandenBerg's email: kavandenberg@yahoo.com

for modifying the environment, intervening behaviorally, and adding a pharmacologic component when other interventions are not successful. In addition, an interdisciplinary team rounds on these infants weekly, providing care recommendations that enhance communication with the family and healthcare team. This manner of conducting developmental rounds in our center is called “HANDS,” an acronym for Help for Any Neonatal Developmental Situation. On March 6, 2008 all members of our NIDCAP team, including hospital administration, our staff and our community interventionists celebrated the opening of our NIDCAP Training Center.

To complete the story of the birth of our NIDCAP center, we must mention the families that have enriched and guided



Nestled within his bed, Caleb holds onto his mother's finger.

us along the way. Families provide us with the rewarding energy that makes a difference in our work. A recent letter from one of the parents whom we had supported with NIDCAP wrote, “The developmental care Caleb received really made a difference. I feel like Caleb and I have a different “bond” than usual...it's kind of funny...he likes to hold onto my fingers when he is eating, and my holding him on my chest still soothes him just like it did with Kangaroo Care in the nursery.”

Clearly, we believe the NIDCAP model provides a framework to transform the way staff care for babies and their families. We are pleased to be part of an organization that helps us provide meaningful connections between parents and their babies since that is the most powerful relationship that makes a difference in the lives of infants and families.

FAMILY VOICES Continued from page 13

What would you like to share with parents who have infants in the NICU today?

LINDA: Just keep your baby close to you and touch her and massage her and talk to her and love her for exactly who she is. Be open to whatever happens. Get to know your child very well. Be there 100% for your child because what you put into it is what you are going to get out of it. Children need so much and babies born prematurely need even more. Stay connected to your child. I am connected to my daughter and I hope she always wants to be connected to me.

For parent energies, I suggest that you exercise and get a lot of sleep and you manage your life so that you can be there for your child who has special needs. I got eight hours of sleep a night, I exercised, and I ate healthy and had dinner every single night with my child. I participated in her life, 100%, in whatever she found interesting. I studied with my daughter every single night. You have to be emotionally and physically supportive of your child. Be around other children, both with disabilities as well as normal children. I've taught my daughter not to give up.

Now that she's on her own in college she knows what to do and what not to do. And the only way children are going to learn to internalize it is that when they fail you don't put them down. You tell them “don't worry you will get it better next time.” Stay totally positive with them. You have to know when to push and when not to push. That is important to understand between a mother and a father and a child. You have to get to know what works and what doesn't work with them.

AMARA: I visited the NICU this past summer and saw the babies lying in incubators. It's pretty amazing how they go from that, like how I went from that, to who I am now. There are a lot of technological developments that (the NICU occupational therapist) was telling me about that they didn't have when I was younger and so that's a positive. Parents could look at that increasing technology today and how it helps with development and helps aid certain needs of the baby and I just think that if you surround yourself with love and positivity that you can get through anything.

NIDCAP PROFILE Continued from page 14

With Björn what you see is what you get and what I see is all good. Most of us are always searching for the ultimate handbag, the perfect pair of shoes, the best book to take on holiday - with Björn you don't need to search any more - you have the ultimate NIDCAP neonatologist, the most enthusiastic organizer of Viking games, the most loyal of friends and colleagues, high moral standards, nifty on statistics, apparently low maintenance, provided he gets regular top ups from mother nature. What more could a baby want.

Björn cherishes the support and influence his wife, children, and now grandchild have made in his professional career. He is further rejuvenated by his closeness to nature, sailing on his boat and camping in the forest. He considers his dogs as among his co-regulators, often joining him on long walks through the woods. He utilizes this time for reflection and has grown to value the importance of reflective process and its impact on his thoughtfulness.

SUBSCRIBE TODAY!

Developmental Observer

The Official Newsletter of NIDCAP® Federation International

We invite you to subscribe by going to www.nidcap.org and selecting *Subscribe* on the NFI website.



Subscription Period: 1 Year (\$15) 2 Years (\$25) 3 Years (\$35)

NIDCAP Federation International Board Officers, Members and Staff

PRESIDENT

Heidelise Als, PhD

NIDCAP Senior Master Trainer
APIB Master Trainer
Director, National NIDCAP
Training Center
email: heidelise.als@childrens.harvard.edu

VICE PRESIDENT

gretchen Lawhon, RN, PhD

NIDCAP Master Trainer
Director, Mid-Atlantic NIDCAP
Center
email: Lawhon-gretchen@cooperhealth.edu

SECRETARY

Deborah Buehler, PhD

NIDCAP Master Trainer
APIB Trainer
West Coast NIDCAP and APIB
Training Center
email: deborahbuehler@comcast.net

TREASURER

Gloria McAnulty, PhD

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

ASSISTANT SECRETARY

Sandra Kosta, BA

National NIDCAP Training Center
email: sandra.kosta@childrens.harvard.edu

James M. Helm, PhD

NIDCAP Senior Trainer
Director, Carolina NIDCAP
Training Center
email: jimhelm@med.unc.edu

Tracy Price-Johnson, MA

Faculty at UCDHSC and
The Family Centered Care
Consultant at The Children's
Hospital in Colorado
email: Price-Johnson.Tracy@tchden.org

Roger Sheldon, MD

Co-Director, Sooner NIDCAP
Training Center
email: roger-sheldon@ouhsc.edu

Jacques Sizun, MD

Director, French NIDCAP Center
email: Jacques.sizun@chu-brest.fr

Karen Smith, RNC, MEd

NIDCAP Senior Trainer
St. Luke's Regional Medical Center
email: smithka@slrmc.org

Kathleen VandenBerg, PhD

NIDCAP Master Trainer
Director, West Coast NIDCAP and
APIB Training Center
email: kavandenber@yahoo.com

Victoria Youcha, EdD

Child Development Specialist
Children's Medical Associates
Alexandria, VA
email: vyoucha@gmail.com

David Wahl

Director of Development and
Administration
email: nfidirector@nidcap.org



NIDCAP TRAINING CENTERS

by order of establishment

National NIDCAP Training Center

Children's Hospital Boston,
Boston, Massachusetts USA
Contact: Sandra M. Kosta, BA
email: sandra.kosta@childrens.harvard.edu

Sooner NIDCAP Training Center

University of Oklahoma Health Sciences
Center, Oklahoma City, Oklahoma USA
Co-Director and Contact: Laurie
Mouradian, ScD, OTR/L
email: laurie-mouradian@ouhsc.edu

Carolina NIDCAP Training Center

WakeMed, Division of Neonatology,
Raleigh, North Carolina USA
Director and Contact: James M. Helm, PhD
email: jimhelm@med.unc.edu or
jhelm@wakemed.org

Colorado NIDCAP Center

The Children's Hospital,
Denver, Colorado USA
Director and Contact: Joy V. Browne,
PhD, RN
email: browne.joy@tchden.org

West Coast NIDCAP and APIB Training Center

Mills College, Department of Education,
Oakland, California USA
Director and Contact: Kathleen
VandenBerg, PhD
email: kvandenb@mills.edu

St. Luke's NIDCAP Training Center

St. Luke's Regional Medical Center,
Boise, Idaho USA
Contact: Karen M. Smith, RNC, BSN, MEd
email: smithka@slrmc.org

Mid-Atlantic NIDCAP Center

The Children's Regional Hospital at
Cooper University Hospital,
Camden, New Jersey USA
Director and Contact: gretchen Lawhon,
RN, PhD
email: lawhon-gretchen@cooperhealth.edu

Scandinavian NIDCAP Center

Astrid Lindgren Children's and Karolinska
University Hospital, Stockholm, Sweden
Contact: Ann-Sofie Gustafsson, RN, BSN
email: NIDCAP@karolinska.se

French NIDCAP Center

University Hospital,
Brest, France
Co-Director and Contact: Nathalie
Ratynski, MD
email: nathalie.ratynski@chu-brest.fr

The Dutch NIDCAP Training Center of Leiden

Leiden University Medical Center,
Leiden, The Netherlands
Director and Contact: Celeste Maguire,
RN, MS
email: NIDCAP@lumc.nl or C.M.Maguire@lumc.nl

Sophia NIDCAP Training Center

ErasmusMC-Sophia, Children's Hospital,
Rotterdam, The Netherlands
Co-Director and Contact: Monique Oude
Reimer, RN
email: m.oudereimer-vankilsdonk@erasmusmc.nl

Centro Latinoamericano NIDCAP Otamendi

Buenos Aires, Argentina
Director and Contact: Graciela Basso
MD, PhD
email: grace.basso@gmail.com

UK NIDCAP Training Centre at St. Mary's

St. Mary's NHS Trust, London, England
Director and Contact: Inga Warren, Dip
COT, MSc
email: inga.warren@st-marys.nhs.uk

University of Illinois Medical Center at Chicago (UIMCC) NIDCAP Training Center

University of Illinois Medical Center
at Chicago,
Chicago, Illinois USA
Contact: Jean Powlesland, RN, MS
email: jpowlesl@uic.edu

The NIDCAP Training Center at Connecticut Children's Medical Center

Connecticut Children's Medical Center
Hartford, Connecticut USA
Contact: Dorothy Vittner, RN, BS
email: vittner@sbcbglobal.net

NIDCAP Training and Research Center at Cincinnati Children's

Cincinnati Children's Hospital
Medical Center
Cincinnati, Ohio, USA
Contact: Tammy Casper, MSN, RN
email: NIDCAP@cchmc.org

The Brussels NIDCAP Training Center

Saint-Pierre University Hospital
Brussels, Belgium
Contact: Delphine Druart, RN
email: ddruart@hotmail.com

Become a Member of the NFI

The NFI has expanded opportunities
for membership to Certified NIDCAP
Professionals, NIDCAP Trainees, and
Families of Premature Infants.
Please join us! For more information
and the online application form,
visit our website at:
www.nidcap.org/become.html



NIDCAP Federation
International (NFI)
www.nidcap.org