



Developmental Observer

The Official Newsletter of the NIDCAP® Federation International

NIDCAP Federation International (NFI)

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

“When work, commitment, and pleasure all become one and you reach that deep well where passion lives, nothing is impossible.”

NANCY COEY

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Discovering Collaborative Pleasure and Pride Through the NIDCAP Nursery Certification Process

gretchen Lawhon, RN, PhD

Several years ago, the Newborn Intensive Care Nursery at the Children’s Regional Hospital at Cooper University Hospital in Camden, New Jersey accepted the opportunity to be a pilot site for the NIDCAP Nursery Certification Program. In the beginning, we entered this process in order to provide the NFI with the experience of working with a nursery that would likely require remedial work in order to attain



certification. From the NFI’s perspective, Cooper represented a NICU with a diverse population within an academic setting in an economically challenged city. From Cooper’s perspective, this opportunity to go through the certification experience within the structure and support of the pilot process was a chance of a lifetime regardless of the less than optimal timing.

Lest you think that this is the beginning of Cooper’s journey let me set the record straight. In 1994, Sonia Imaizumi, MD came to Cooper and discussed the NIDCAP program with her new colleague Gary Stahl, MD and within a year the Mid-Atlantic NIDCAP Center was established (1995) under the direction of Deana DeMare, PT. Cooper’s NICU has been committed to the provision of NIDCAP care for the past fifteen years. This philosophy of care would not be possible without the full support of both the nursing and physician leadership which began with Charlotte Tobiason, RN and Frank Briglia, MD. Over the years our NICU has continued to strive toward excellence in practice and to demonstrate the implementation of the NIDCAP philosophy of care through multidisciplinary collaborative care.

As with many examples in life it turns out that the process is in many ways more important than the outcome due to the power of relationships. This was very evident at Cooper during our thorough site self assessment utilizing the nearly 120 five point descriptive *NIDCAP Nursery Certification Criterion Scales (NNCCS)*. To enlist the participation of as many individuals as possible, the decision to participate in the NIDCAP Nursery Certification Program had been made by the NICU clinical council. A small multidisciplinary group then met to assign various portions of the site assessment with the charge to go into the unit on both day and night shifts and facilitate the staff in coming to consensus on each of the NNCCS descriptive ratings. There were many very heart warming stories brought up in the small staff group

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discussions that exemplified excellence in care such as when we discussed how we met the criteria for “caregiver’s understanding and sensitivity to parents and families.” One nurse shared her experience of having transferred a severely ill infant requiring high frequency ventilation to a large stretcher in order to facilitate the mother’s dream of being able to sleep with her son.

Our actual NNCP site visit included four members of the NIDCAP Federation representing medicine, psychology, education and nursing. Sessions were held with the administration of the hospital, department of pediatrics and neonatology in addition to all disciplines involved in the NICU. The reviewers spent time in the unit and spoke with staff and family members. The review team’s feedback acknowledged our significant level of NIDCAP care implementation with an offer for an extension for further integration and subsequent review within a year. Despite our inability to obtain the certification, the staff felt such a boost of energy and encouragement from the process that we gathered momentum. For the next ten months, we accumulated photos and stories demonstrating exemplary developmental care to contribute to our compilation of “evidence” to present to our review team within the year. One of the areas we realized needed improvement was in our care of one another as staff. Upon reflection we decided it was time to take ownership of caring for one another and in the process we renovated our small staff lounge. The staff mailboxes were moved to another location and a group volunteered and managed to get the room painted in a color that was soothing while one nurse made a curtain for the window. Decisions were made to create areas designed to meet the social needs of the staff rather than to be inundated with professional notices and messages.

The most significant result of this process has been the value of our working together and carefully assessing our clinical practice in a reflective manner. There is tremendous value in taking the time to include as many individuals as possible in a process of self assessment especially when it includes necessary reflection on the manner in which we approach infants, families, and one another in the NICU. It is clear that our individual and collective attitude can compensate for the less controllable limitations in our physical environment. The most significant lesson has been the appreciation of the value of relationship-based care not only with our infants and families but with one another.

Cooper’s Newborn Intensive Care Unit achieved NIDCAP Nursery Certification culminating in a huge celebration last July 28th with Heidelise Als, PhD presenting the award in our beautiful new lobby with many staff and families present.

Having been successful in our quest for NIDCAP Nursery Certification, we have a sense that we have reached a new level in our relationship-based caregiving. We are now committed as an entire staff to work toward developing the strategies to sustain our momentum and commitment to infants, families and one another. We will continue to further integrate the NIDCAP approach into our policies and procedures and in our evaluation process as well. It is essential that we have an ongoing assessment and re-evaluation process to maintain the level of quality in our practice. The journey toward NIDCAP Nursery Certification has been extremely gratifying as we worked together in carefully assessing our clinical practice in a reflective manner. It has been amazing to realize just how invested each staff member is to the quality of care provided. This process clearly enhanced our collaboration with one another as professionals as well as with our infants and their families. We have gained a clear sense of pleasure and pride in the work being done in our NICU and have greater sensitivity and awareness of our own words and actions on a daily and nightly basis.



Developmental Observer

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The Growth of NFI Membership

Jim Helm, PhD

In 2001, the NIDCAP Federation International (NFI) was founded with twenty-six members. At that time, only NIDCAP Trainers, Training Center Directors, and Members of the NFI Board of Directors were members. One of the goals of the NFI was to oversee NIDCAP-related work and create an organization that could eventually support advancement of developmental care in all nurseries. NIDCAP training had expanded to hundreds of health care professionals and it required an organizational structure to help support these professionals and support the further development of NIDCAP. The NFI was developed to provide this structure and infrastructure around which training could grow while maintaining the standards of a small group. The following provides a brief overview of the growth and evolution of the NFI Membership.

As the NFI organizational structure developed over the first several years, membership issues were discussed and debated. NIDCAP has always been multidisciplinary and it is recognized that a wide variety of roles are necessary for successful implementation of this process. The NFI Board wished to offer membership to those individuals at Training Centers who currently supported the work of the NFI in addition to Trainers and Training Center Directors. In October 2005, the NFI By-Laws were amended to allow the NFI Board of Directors to expand membership and to create special categories and other official associations to the NFI. The Board invited all professionals who were NIDCAP certified, now designated as NIDCAP Professionals, to join as well. Further, it was determined that Trainers-in-Training should be offered membership. The Board also felt that it was important to bring all NIDCAP Trainees into the process, so Student Membership was created. Professionals training in the NIDCAP approach to care could thus become Student Members for up to three years as they trained. By April 2006, membership categories were agreed upon and as of June 2006 the NFI was

open for nominations and applications for new members. There were various edits and clarifications to this process through October 2006 as the membership continued to grow.

More milestones occurred during January 2007 when the Board discussed the creation of another new category of members—Family Members. First the Board approved the creation of two additional Directors for the Board. These included two seats for family representatives. Family Memberships were officially approved in May 2007. Family Membership is open to any parent or extended family member who supports the mission and goals of the NFI and who has an infant who is currently or was previously cared for in a newborn intensive or special care nursery. NICU graduates may, themselves, also apply for membership

The NFI has recognized Emeritus Members for several years and the definition and process for this special category was formally clarified during the April 2009 meeting. At that time the Board also created and defined an Honorary Membership category. Emeritus Members are nominated from the membership, and Honorary Members are nominated from outside the membership. Both of these categories were formulated to recognize special individual contributions to NFI and/or NIDCAP. Currently there are four Emeritus Members and one Honorary Member. These special members are described below.

Emeritus Members

Martha Holmes, MSW, LCSW, Director of the Oklahoma Infant Transition Program, was introduced to NIDCAP, through a suggestion from Linda Gilkerson, PhD. She met Heide-lise Als, PhD and gretchen Lawhon, RN, PhD and started NIDCAP training after a week-long workshop with Linda and Project Welcome, a federally funded grant that addressed the needs of NICU graduates and was administered at Wheelock College, Boston, Massachusetts. When

Martha returned to Oklahoma City, her visionary leadership along with major support and contributions from Roger Sheldon, MD and Joy Browne, PhD, PCNS-BC, IMH (IV) Mentor led to the first NIDCAP Training Center outside of Boston. The Sooner NIDCAP Training Center was established in 1986.

Elsa Sell, MD, a neonatologist from Tucson, Arizona was also involved in developmentally supportive care from the earliest days. She was the first physician to become a NIDCAP Trainer. Elsa also became the second APIB Trainer, and was instrumental in guiding Arizona to require professionals in developmental care to be part of nurseries across their state. As an attending neonatologist at Arizona University Medical Center, in Tucson, Arizona, Elsa directed the Sahuaro NIDCAP and APIB Training Center for many years.

Susann Hill-Mangan MA, LPC was a NIDCAP Trainer with Elsa Sell, MD. Initially Susan was Elsa's research assistant, and administered Dr. T. Berry Brazelton's Neonatal Behavioral Assessment Scale (NBAS)¹ evaluations. Her understanding of the challenges in implementing NIDCAP led to the development of the Advanced Practicum.² In addition, Susann's behind-the-scenes expertise contributed greatly to and facilitated Arizona's statewide support of developmentally supportive care requirements in newborn intensive care nurseries.

Jean Gardner Cole, MS also became interested in NIDCAP through work with the NBAS. She was trained by Kevin Nugent, PhD, then worked with Linda Gilkerson, PhD and Project Welcome. Jean later became an NBAS Trainer traveling the world with Dr. Brazelton and his team. She met Dr. Als when they both became NBAS Trainers. During that time Deborah Buehler, PhD was an undergraduate assistant to Dr. Als. Drs. Als and Buehler supported Jean to become a NIDCAP Trainer in 1993. Jean trained out of Boston City Hospital (now Boston Medical Center). She is known for her

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Karen Smith, RNC, MEd

St. Luke's NIDCAP Training Center

"The voyage of real discovery consists not in seeking new landscapes but in having new eyes." —Marcel Proust

St. Luke's began its NIDCAP voyage when it was selected to participate in the NICU Transition Project. This federally funded grant (US Department of Education) provided training to hospital NICU staff in the NIDCAP approach to care. It also provided training to community early intervention staff in the administration of the Infant Behavioral Assessment (IBA).¹ Both Rodd Hedlund, MEd, and gretchen Lawhon, RN, PhD came to Boise, Idaho in October of 1989 to train health care and community early intervention professionals in these two neurobehavioral assessment and intervention programs.

The day our group met gretchen and Rodd was an exciting one. There were four individuals from the NICU that were to take NIDCAP Training and three persons from our hospital who were to take IBA Training. This training provided concentrated study; individual observations and reports were required by each Trainee. By the time I received my NIDCAP reliability, I knew I wanted to become a NIDCAP Trainer. I assumed that anyone who was exposed to the NIDCAP program and took care of sensitive infants would be interested in becoming NIDCAP reliable. I asked gretchen what I would need to do to become a Trainer. She calmly took a very small piece of paper (a "Post-it" note) and wrote down that I would need to become reliable in the APiB;² develop my own NIDCAP lecture and bedside demonstration; and bring Trainees to reliability. She explained to me that I needed to talk with Dr. Als for more details about the training process. I carried that Post-it note in my day planner for the next six years. Actually I still have it. Even after we became a Training Center, it remains my lucky note.

When I spoke with Dr Als, she made it clear I needed the support from my hospital administration in pursuing this process. I spoke with the Medical Director of the NICU, who was supportive of increasing developmental awareness and care in the NICU. Cheryl Weedon, BSN, MS, another nurse who also was interested in becoming a Trainer, and I then made an appointment to meet with the Vice President of Nursing, Sharon Lee, BSN, MSN at our hospital. After we presented the NIDCAP program, she expressed her belief that this program was certainly in line with our hospital's philosophy and she expected that there would be support from hospital administration to pursue becoming a NIDCAP Training Center. The Vice President of Nursing stated that we would need to develop a five year plan and provide more information on the costs involved, as well as a



Karen Smith, RNC, MEd, and Julie Swanson, RN, BSN

budget for the program. She wanted us to present the plan to the Executive Board of the hospital.

Cheryl and I worked on a proposal describing NIDCAP and a plan for the development of a Training Center to present to the hospital's Executive Board for funding. We rehearsed our presentation by practicing with the Medical Director and the Vice President of Nursing as our audience. They coached us on our presentation and then went with us to the meeting with the Board. The executive and financial officers of the hospital were very supportive of the plan to develop a NIDCAP Training Center at St. Luke's. Though the financial director rubbed his head and said that we had underestimated the cost of the venture, he smiled and volunteered to work with us to revise the budget.

Cheryl and I worked with Vera Fink BSN, MSN, the administrator for Women's and Children's Services at St. Luke's, to clarify the organizational plan for the development of the NIDCAP Training Center. Together we formulated a three year plan. Cheryl and I began our APiB Training a few months later and attended our first NIDCAP Trainers Meeting in Estes Park, Colorado in 1992. During that first year Cheryl decided that the path to becoming a NIDCAP Trainer was not for her and withdrew from the process. Cheryl continues to provide NIDCAP observations in our NICU and to make significant contributions to our Developmental Interventions Group. I continued on with my studies; working in the NICU; developing my NIDCAP lecture; and working with the NICU manager and administrator

to select the first Trainees for the NIDCAP Training Center in the process of development.

The first NIDCAP lecture I presented at St. Luke's NICU was well attended. My Trainees, a nurse and occupational therapist, were in the first row eagerly soaking up the lecture information. This day was followed by an equally successful demonstration day. Other staff interested in NIDCAP Training took part in bedside days over the following months. NIDCAP lectures and small workshops on developmentally sensitive caregiving were also presented. The NIDCAP Trainees practiced their observations diligently. Work day sessions were long though invigorating. We all managed to keep our energy up and directed towards our goal of becoming a NIDCAP Training Center. This training continued over twenty months. In the summer of 1995, with the successful completion of my Trainees' reliability, St. Luke's became a NIDCAP Training Center. We came in on our "due date" as our administrator Vera Fink liked to say. The three year time line for the Training Center's development had worked. Our hospital and NICU were thrilled.

Our voyage as a new NIDCAP Training Center continued as we expanded our training to areas outside of our own center, not only to units in the US, but to some in Europe as well. The interest in developmental care and NIDCAP began to increase in many NICUs around the world. Our commitment as a Training Center to demonstrating the highest level of developmentally supportive care was now stronger than ever in our own setting.

As developmentally sensitive care providers we began in earnest to contribute ideas to the design plan of our new fifty bed semi-private room NICU. Prior to construction we attended the Graven conference with our architects. Our new NICU, which was to be part of a ten story addition to the hospital, was completed in 2002. We moved into the unit in March of that year, and soon thereafter, we realized the bed number was still inadequate for the number of infants that needed our care. Fortunately a number of rooms had been built to allow for expansion, so eleven more beds were added to the unit.

We have added two more hospitals with NICUs to the St. Luke's system: 1) St. Luke's Meridian Medical Center; and 2) St. Luke's Magic Valley Medical Center. The NIDCAP Training Center, here at St. Luke's, has made, and continues to make strong efforts to be supportive to professionals in providing developmentally sensitive family centered care. At St. Luke's Magic Valley Medical Center we are building a new hospital which will include an eighteen bed NICU with private rooms. We have provided NIDCAP Training at this site and are working with four new Trainees. Since the demand for training has increased, we have entered the process of training another NIDCAP Professional to become a NIDCAP Trainer, Julie Swanson, RN, BSN. Julie has been developing her lecture and beginning bedside work and will be starting with her two Trainees in 2010. Julie has been working with our Meridian Medical Center NICU with developmental rounds, educational offerings and

NIDCAP observations. Her Trainees will come from this site and will have opportunities to study at our Boise campus as well.

Providing the highest level of developmentally sensitive family centered care has been a priority for us from the beginning of our exposure to NIDCAP Training. St. Luke's has consistently been committed to improving care and practice in our center. It has also been fortunate over the years to have the support of family volunteers in our NICU. The relationship with and support from these graduate families have also inspired and assisted us in improving our nursery, and designing our NICUs and services with families' input in mind. Our Family Advisory Board, comprised of 20 families, contributes their special insight into what families need in the NICU and beyond.

As a Training Center, we have hosted the NIDCAP Trainers meeting twice in Idaho. We are surrounded by a beautiful environment which we envisioned sharing with other Trainers, even before we were a Training Center. Both Trainers Meetings, in McCall and Sun Valley, allowed us to share the places that give us our energy and determination. It is the West after all, where anything is possible.

In 2007, we volunteered to be a pilot site for the NIDCAP Nursery Certification Program.³ Our NIDCAP Nursery Certification (NNC) Site Visit was a great experience for us. We were able to reminisce about how we have developed over the years and work toward our goals that we are determined to attain. The visit provided a burst of energy for our nursery and our staff. Over the years of being a NIDCAP Training Center, our staff has enjoyed visitors to our nursery. We like sharing what we do and always feel we are learners in those experiences as well. We know that those professionals caring for infants in our setting are special and wanted to share that with them through the NNC Site Review experience. Through this process, St. Luke's was the first NICU to be recognized as a NIDCAP Certified Nursery.

We have been a NIDCAP Training Center for almost fifteen years now. We feel that each day provides an opportunity to make a difference to infants and families in our NICU. The phrase "changing the future for infants in intensive care" rings true for us. We know that NIDCAP changed our nursery and many of our lives. We want that change for every family we provide care for in our NICU.

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A Message from the Director of the NIDCAP Nursery Certification Program



Rodd E. Hedlund, MEd has been an active participant in NIDCAP over the past twenty years. He is a certified NIDCAP Trainer, affiliated with the Mid-Atlantic NIDCAP Center; currently serves as the Senior Editor for the Developmental Observer, serves on the Washington Research Institute's Human Subjects Review Board, Seattle, WA; and is the Director and Master Trainer of the Infant Behavioral Assessment and Intervention Program (IBAIP).¹ He received his undergraduate degree in Special Education from Washington State University (1976), and Masters Degree in Early Childhood Special Education, Specialization in Infant Development, from the University of Washington (1984). Most of his funded research has been in social and neurobehavioral development of infants and young children with disabilities. Rodd has served as the Project Director on five major federally funded grants and one foundation grant (leading to the development and further refinement of the IBAIP). Each of these grants involved neurobehavioral training components which addressed the needs of hospital NICU professionals, community early intervention professionals, paraprofessionals, and infants born prematurely and/or with disabilities and their families. Rodd currently lives in Lawrence, Kansas with his partner of 17 years, Thomas Tuozzo, PhD, Professor of Philosophy, University of Kansas.

As the recently appointed Director of the NIDCAP Nursery Certification Program (NNCP),² I have been asked to introduce myself to the NFI family and say a few words about the NNCP. Since December of 2009, I have begun to immerse myself in the work of the NNCP Steering Committee and the NFI Board as they have, in the last few years, been involved in the development of the NNCP. Two pilot nurseries have completed the process, resulting in NIDCAP Nursery Certification (NNC) of the newborn intensive care nurseries at: 1) St. Luke's Regional Medical Center, Boise, Idaho (please see *Developmental Observer*, 2009, 3(1):1-4);² and more recently at 2) The Children's Regional Hospital at Cooper University Hospital, Camden, New Jersey (please see this issue of the *Developmental Observer*, p. 1). In June of this year, an NNC Site Visit to a newborn intensive care nursery in the United States is scheduled as the third and last pilot site visit. In addition, two international sites are in the process of preparing materials for review by the NNCP.

Final revisions are being made on many of the supporting materials of the NNCP application process, evaluative tools, and modes of dissemination. These include:

1. NIDCAP Nursery Certification Program (NNCP): A Guide to Preparation, Application, and Implementation of NIDCAP Nursery Certification³

This guide provides a general introductory overview of NIDCAP and the supporting research to date, as well as specifically addressing: a) a detailed overview of NNCP; b) NNCP eligibility requirements; and the c) NNCP application process with an illustrative flow chart. Additional training documents pertinent to NIDCAP and NNCP are also listed (e.g., NNCP cost analysis, NNCP Participant Roles, Responsibilities and Duties, etc.).

2. NNCP Application: Part I⁴

This application includes:

- The identification of the nursery applicant's contact professional, administrative leadership, NICU NIDCAP leaders, and NICU interdisciplinary care team.
- A description of the applicant's hospital and NICU, including hospital accreditation and licensure; a description of the infant population served; and a report on NIDCAP Training that the NICU staff may have received.

- The assurance that the NICU leadership and staff are formally committed, across all disciplines, to practice the NIDCAP approach to care; and the assurance that financial resources are available for staff seeking further training in NIDCAP.
- A description of the strengths and challenges of the applicant's nursery regarding individualized, developmentally supportive family-centered care.
- Supporting Evidence:
 - A copy of the hospital and nursery's mission statement(s), as well as goals and objectives;
 - Two examples of developmental care plans (e.g., NIDCAP write-up, developmental report); and
 - Six Letters of Support (i.e., Nursing Hospital Leadership, Financial Hospital Leadership, Administrative Hospital Leadership for NICU, Neonatology Leadership, NICU Nursing Leadership, and Family Leader Representative).

3. NNCP Application: Part II

This application consists of two distinct evaluative tools, the *Nursery Self-Assess-*

ment Questionnaire,⁵ and the *NIDCAP Nursery Certification Criterion Scales (NNCCS)*.⁶ The *Nursery Self-Assessment Questionnaire* asks the nursery applicant for detailed information with regard to:

- Hospital and nursery environmental characteristics;
- Specific leadership structures;
- Hospital/NICU structural and organizational characteristics;
- Developmental care support characteristics;
- Developmental care history and goals; and
- Descriptions of the dynamics of the relationships that currently exist between the NICU staff (e.g., nurse-to-nurse relationships, nurse-to-doctor relationships), as well as staff and administration relationships, and relationships that develop between staff and the families and infants that they care for.

The nursery applicants rate their nursery using the *NIDCAP Nursery Certification Criterion Scales* (please see Smith, Buehler, and Als⁶ for detailed description of the organization and administration of these scales). This tool assists an applicant nursery to assess itself on the level of quality and the degree of adherence to the key NIDCAP concepts of: individualization of all care and environmental aspects; family centeredness; developmental support for all infants and families cared for in the nursery; and developmental support for the staff involved in delivering such care. This process of self-evaluation serves to identify the nursery's readiness for NIDCAP Nursery Certification.

The NNC Site Review Team scores the scales on the written materials submitted by the nursery applicant, and during the actual on-site visit (e.g., the Review Team's observations and interviews with infants, families, hospital and nursery staff). The NNCCS are also used for: training and mentoring; documentation of change in the course of a nursery's adoption of developmental care as framework of care delivery; documentation of the standard of care within a nursery; and examination of the relationship of environmental and caregiving parameters to infant, family, and staff functioning and satisfaction.

4. Updated NNCP description/materials on NFI website. These include: a revised description of the NNCP, the *NNCP Guide*, *NNCP Application: Part I*, *NNCP Application: Part II* (includes the *Nursery Self-Assessment Questionnaire* and the *NIDCAP Nursery Certification Criterion Scales*), and the *NNCP Cost Analysis Document*. These materials will be posted on the NFI website on or before the next NIDCAP Trainers Meeting, September, 2010.

5. Outreach and Dissemination of the NIDCAP Nursery Certification Program via Workshop Presentations/Poster Sessions. Slide and video presentations, for the purpose of NNCP outreach and dissemination, are in development. Workshop presentations are being planned.

Future NNCP projects include the development of NNCP Site Reviewer Trainers, NNCP Site Reviewers' Training Program and a NNCP Site Reviewers' Training Manual with the goal of increasing the number of site reviewers available to conduct site visits.

"NIDCAP Nursery Certification is both a goal and a process. Nurseries that apply for this certification will, by the process of the application and by their self evaluation, define the areas of their current strengths and areas for future growth. Successful NIDCAP Nursery Certification represents distinction in the provision of a

consistently high level of NIDCAP care for infants and their families, as well as for the staff, and as such is to be commended and celebrated as an inspiration for all."² (p. 4)

I'm very happy to assume the role of the Director of the NNCP, and I look forward to working with the NNCP Steering Committee, NFI Board and all current and future NNCP applicant nurseries.

--- Rodd E. Hedlund

For further information on the NIDCAP Nursery Certification Program, please visit the NIDCAP website (www.nidcap.org) and/or contact:

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Developmental Care in the Moment

Holding and holding on to.



Linda Gilkerson, PhD



Linda Gilkerson, PhD has a long association with NIDCAP and has made a significant impact on the research and integration of its philosophy into practice. She is the Director of both the Irving B. Harris Infant Studies Program and the Faculty Development Project on the Brain at the Erikson Institute in Chicago.

Her area of specialization is early intervention with infants and families, with special emphasis on high-risk children in hospital settings. Dr. Gilkerson's research addresses the needs of infants and families in a wide range of settings including newborn intensive care units, Early Head Start, childcare and teacher and caregiver's education about brain development.

Linda directs the Fussy Baby Network, Erickson's first clinical initiative. This network provides support to families who may have concerns about their infant's development, health, crying, feeding, sleeping, or temperament. The Fussy Baby network provides several services including a call in line for parents, a home visiting program, a Fussy Baby Clinic at the University of Chicago, as well as parent support groups (for more information on this program please see: www.erikson.edu/fbn.aspx). Linda is also conducting research on infant crying in collaboration with several of her colleagues at the University of Illinois at Chicago, the Erikson Institute, and the University of Chicago. This research, entitled the "Fussy Baby Study," is examining the causes of excessive infant crying and how infant crying may relate to behavior and development (www.fussybabystudy@yahoo.com).

Linda directs Project Connect, an initiative that provides parent-child therapeutic services to young children in the foster care services and their families, with the goal of strengthening and reuniting families. She has served on the Illinois Interagency Council for Early Intervention and has chaired the Early Care and Education Committee of the Futures for Kids Initiative. As a Board Member of Zero to Three, she also chairs their Infant Mental Health Task Force.

Linda has been instrumental in introducing, supporting and sustaining the integration of the reflective process within our

work of providing relationship-based, family-centered, developmental care. As Linda states, "Developmental care is inherently reflective. There are no protocols that tell you exactly what to do. Instead, ongoing observations and continuous feedback from the baby [as well as the family] guide care [and your interactions with them]."¹

I had the opportunity and pleasure to interview Linda during the 20th Annual Trainers Meeting, "Reflection: Our Vision for Individualized Developmental Care," that was held in Chicago in October, 2009.

KS: Linda it is great to have this opportunity to learn more about you and how you see NIDCAP. May I start by finding out more about your professional background?

LG: I started my career in education and then went back to school for three years to train as a social worker. I felt I needed to fill a gap and wanted to make the world a better place.

KS: How did you become interested in early intervention?

LG: I identify with people who are different. I was a fussy baby who was small for gestational age – I took my parents for a loop! I felt I wanted to reach out to those who are different – an individualized approach.

KS: What is your motivation for the work that you are currently doing?

LG: Supporting people and providing mentorship. I have two doctoral students at the Erikson Institute and their work is really exciting. I try to support them through the system.

KS: I noticed that your Fussy Baby Network is on Twitter – how do you find this new communication medium?

LG: I need to figure out how it works! I see that it has potential to work for the parents. It seems easily accessible and I see it as contributing to discussions by the families.

KS: What do you see as most exciting about NIDCAP?

LG: It gives confidence to people – it gives me confidence. I see this as the standard of care in the NICU. I find the expansion into Europe exciting and progressive. We do not seem as progressive here in the US.

KS: What do you see as the future for NIDCAP?

LG: I see a bright future ahead – NIDCAP is here to stay. We are now in our third generation with Trainers and Master Trainers. Institutions are using it as a standard of care, whether it is called

NIDCAP or not. I also see it as a movement coming from the parents; they are real collaborators in their baby's care.

KS: Now I would like to ask you some questions that can give the reader an insight into Linda and what makes you "tick." How do you relax?

LG: I have discovered yoga – it is simply the best. The last ten minutes are the best when you reach Nirvana – my husband goes with me. I also find gardening meditative. I have a very messy garden which is a challenge. I like to call it my friendship garden – many of the plants were given to me by friends – when I am in my garden it makes me smile.

KS: What a lovely picture you have created. Is there a book which has left an impression on you?

LG: The one that comes to mind is 'Learning from the Patient'² written by Casement, a psychoanalyst. It made me think about how to be with others, also how to play with ideas.

KS: What are some of your favorite places?

LG: Out west in Colorado and New Mexico. I learned to enjoy watching the world go by from a train. I was in a sleeper in a hammock, gently swinging – I felt so contained.

KS: How do you like people to remember you?

LG: As someone who is safe and someone to share with. I am also very persistent – I see this trait in my son. When I settle on something I usually get it.

KS: Thank you Linda for sharing yourself with me and the readers. I have gained a lot from meeting you. Is there anything else you would like to say?

LG: Yes, I will never forget sharing my life with Heidi – a gift I treasure with all my heart.

KS: Thanks again – I can see why NIDCAP has such a solid foundation with people like you being the pioneers and supporting others in their accomplishments.

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Assessment of Preterm Infants' Behavior (APIB)

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

Newborn Individualized Developmental Care and Assessment Program (NIDCAP)

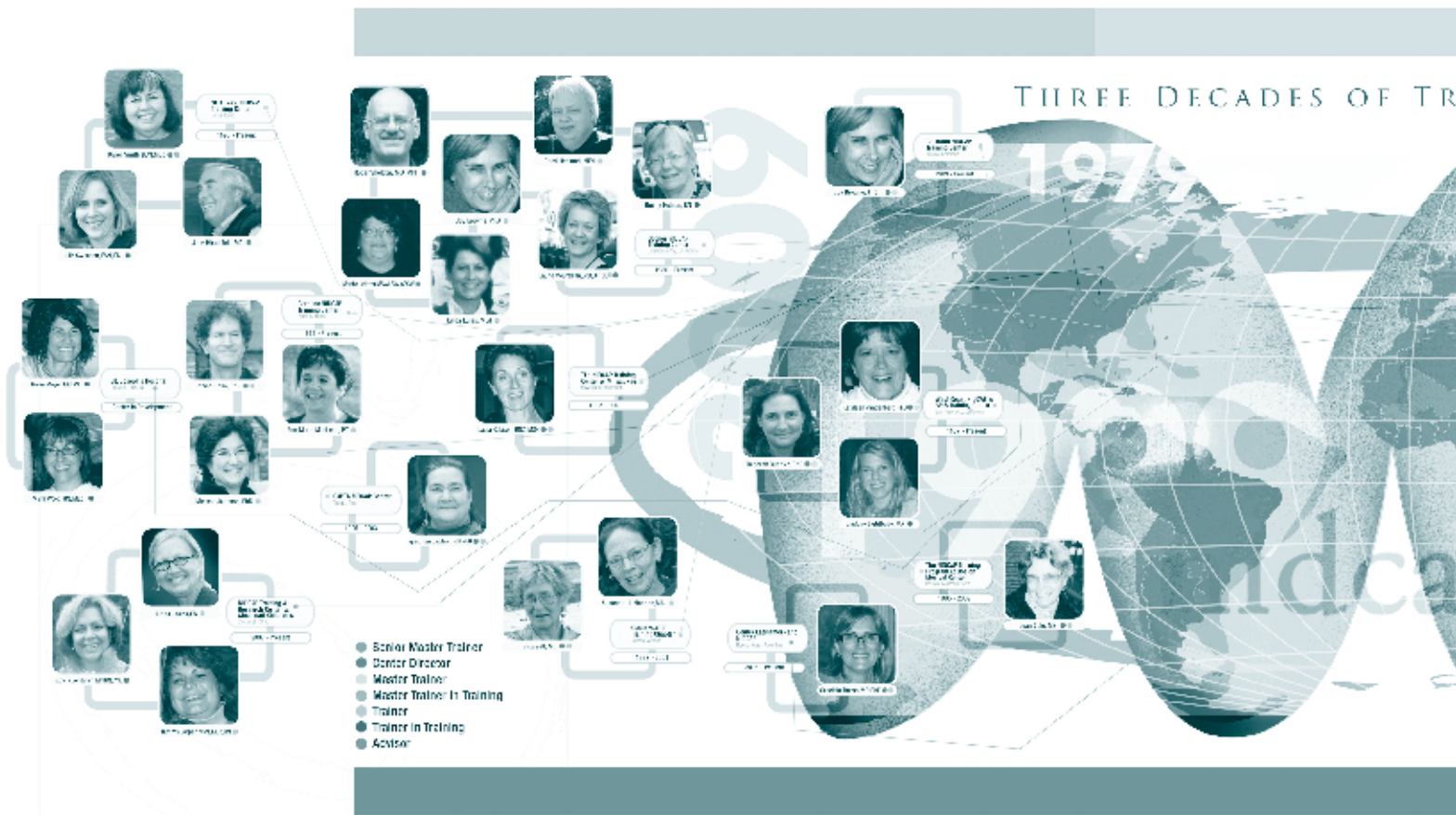
The Newborn Individualized Developmental Care and Assessment Program (NIDCAP), originated in 1984 by Heidelise Als, PhD, is a developmental, family centered, and evidence-based care approach. NIDCAP focuses on adapting the newborn intensive care nursery, including all care and treatment and the physical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

NIDCAP Nursery Certification Program (NNCP)

The NIDCAP Nursery Certification Program (NNCP) under the auspices of the NIDCAP Federation International (NFI) recognizes the excellence of a hospital nursery's commitment to and integration of the principles of the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) for infants and their families. NIDCAP Nursery Certification is both a goal and a process. Nurseries that apply for this certification will, by the process of the application and by their self evaluation, define the areas of their current strengths and areas for future growth. Successful NIDCAP Nursery Certification represents distinction in the provision of a consistently high level of NIDCAP care for infants and their families, as well as for the staff, and as such is to be commended and celebrated as an inspiration for all. For information on eligibility requirements and the certification process please see: www.nidcap.org; and/or contact NNCP Director at: www.nncpdirector@nidcap.org or 785-856-NNCP (6627).

2009 Marks Major Milestones for NIDCAP

Deborah Buehler, PhD



30 YEARS AGO, the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) was conceived. Heidelise Als, PhD began studying premature infants by standing near their incubators and observing their behaviors and sensitivities. She made careful observations before, during and after caregiving, documenting subtle and not-so-subtle changes in posture, muscle tone, coloring, movement, breathing and more. The simplicity (yet detail!), straightforwardness and integrity of these observations led a number of nursery professionals to participate in the development of and training with NIDCAP. **30 years** of research have documented improved outcomes for these infants and their families cared for with NIDCAP.

25 YEARS AGO, the first NIDCAP certification was bestowed on gretchen Lawhon, RN, PhD, from the original NIDCAP Training Center in Boston. One NIDCAP Trainer has led to the current total of 22 NIDCAP Trainers, one Certified NIDCAP Professional has led to many Certified NIDCAP Professionals, and one Training Center has led to the present 16 Training Centers. NIDCAP training continues to provide education and support to health care practitioners to facilitate the integration of NIDCAP at consistently high levels of implementation.

TRAINING & SUPPORTING



20 YEARS AGO, the first NIDCAP Trainers Meeting was held outside Washington, D.C. From this meeting the NIDCAP Federation International (NFI) formed, and in only eight years its membership has grown from 26 to 158 members. The NFI and these annual meetings continue to support a worldwide collaborative community of NIDCAP Trainers, Training Center Directors, Professionals, Families, and other Partners to strive to assure the highest quality of individualized, developmentally supportive, family centered care for newborns and their families in intensive and special care nurseries.

1 YEAR AGO, the first NIDCAP Nursery Certification was conferred on St. Luke's Children's Hospital in Idaho. And recently another certification has been achieved by Children's Regional Hospital, Cooper University Hospital in Camden, New Jersey, with the certification program's official launch planned for 2010. The NFI and its members envision a day when NIDCAP represents the standard for the delivery of care in newborn intensive and special care nurseries around the world.

The graphic above was designed by William Rieser of the Agency Orange, as a commemorative poster to mark the evolution of the Training Centers and their Directors and Trainers over the past thirty years.



Tracy Price-Johnson, MA



The Anderson Family

Life for parents who have a baby in the newborn intensive care unit is daunting and uncomfortable at best, and may be fraught with repeated challenges, seemingly insurmountable hurdles, and terror when their baby is very sick. Parents' efforts to manage themselves, remain emotionally intact and available for their baby, interact with many medical staff, and make sense of 'medical speak' can be a huge and exhausting task. Taryn and Brent Anderson and their son Bryden are highlighted in this column. Taryn shares her NICU story, speaking to the challenges her family faced, and how they dealt with those challenges.

Bryden was the Christmas present Taryn and Brent had wanted. However, shortly after he was born on December 18th, Bryden began having difficulty breathing and was transferred to Children's Hospital in Oklahoma City for life saving medical care.

As Taryn reports, "My husband and I were very upset, after all this is not how it was supposed to be. We had no idea that the next weeks would be the worst of our lives." CPR was required to sustain Bryden en route to the Newborn Intensive Care Unit. Upon arrival at Children's Hospital, his condition worsened. "The first time we saw him he was in the surgery room and the nurse was bagging him in order to keep him alive. I left the room so that he could have the surgery to place him on the heart-lung bypass machine, and I just sank. I only thought that was as low as a person could feel."

During surgery, Bryden's heart stopped beating, and as he was resuscitated, he received a laceration to his liver and experienced massive bleeding. "When we got to see him after the surgery, the nurse told us to prepare ourselves. Well, I am not sure that you can prepare yourself." After receiving many blood transfusions Bryden's body was swollen and the incision in his chest and abdomen was open. Taryn and Brent stayed at his bedside all night.

Ultrasound pictures of Bryden's brain were taken the next morning which showed multiple strokes and bleeding in his brain. Bryden was removed from the heart-lung bypass machine and his breathing efforts were supported by a ventilator. "...they explained to us that this was not likely to keep him alive. Everyone got ready for the end." For a third time, the priest was called to Bryden's bedside. "I remember my husband's breaking point was when the priest was called into the room. He yelled out 'GET OUT NOW' and then, after further reflection, he said to the priest, 'I am sorry but you cannot be here.'" Twenty to thirty medical staff and family were in the room when he was taken off the heart-lung machine; the room was silent. "My own personal

fight for Bryden's life drove me. I guess inside I thought that if I fought as hard as I could it would somehow help him survive."

Bryden did not die. He continued to slowly recover with assistance from his parents and the entire medical team. Bryden's parents went home for the first time in four days to be with their two older children. They explained Bryden's condition to his ten year old brother. "This was the hardest conversation that I have ever had to have. He cried on and off for weeks. It was nearly impossible for him to understand why he could lose his brother."

During the next six weeks, Bryden began to breathe on his own and no longer needed the ventilator. "He had at least seven surgeries, and multiple blood transfusions. Bryden experienced many challenges including feeding, regaining muscle strength, keeping his joints pliable, and stopping muscle contractures. Sometimes I felt like we lost...and found our baby all in six weeks."

The Andersons were supported by Wanda Felty, the Family Advocate with the Oklahoma Infant Transition Program (OITP) at Oklahoma's Children's Hospital. Wanda's interaction with families under stress gives them a sense that someone understands what they are experiencing and that they are not alone. Her support continues after infants are discharged as parents need her. As Taryn reflects, "Wanda is my right hand woman, my go to person. If I have any questions, she is the first person I call; she helps me in all aspects from how to weave through the system to simple pep-talks when I am having a down day."

As Bryden got ready to go home, Bunny Hutson, RN, Infant Development Specialist with OITP and the Sooner NIDCAP Training Center, received a referral for a behavioral observation to help Bryden's parents understand his unique ways of expressing himself. As Taryn reflects with Bunny, "I remember being so scared when you did your evaluation and you talked about bathing Bryden. After I talked to you, I knew that I was capable of taking care of him at home. You totally put me at peace with my decision to take Bryden home and know that I was not doing him a disservice."

Continued on page 18

Post Traumatic Stress Disorder in the NICU and Beyond

“The relatively high levels of psychological distress experienced by parents, coupled with the potential negative outcomes on the parent and infant, suggest that it is important to try to prepare parents, [whenever] possible, for the expected psychological reactions that may occur in the event of a NICU hospitalization and also to support parents during the transition to home care.”^{1(p 136)}

“Psychiatric help may be important for some parents, if they want it, and it should be widely available. But the fact is, for many of us, a “minor” medical issue in our surviving preemie really needs “major” attention because our children really “are” vulnerable.”²

The two quotations above, one from a recent article published in *Psychosomatics*¹ and the other included in a commentary from Helen Harrison,² a long-time advocate for NICU parents, both provide important words of wisdom. They also hint at the complexity of the issue of drawing on psychiatric diagnostic descriptors to conceptualize parental responses to the NICU experience. The article by Shaw¹ and colleagues, cited above, was widely reported in the general press,³ reminding us that it is important for NIDCAP practitioners to be aware of this work and how it might best be used. The idea that acute stress disorder (ASD) and/or post-traumatic stress disorder (PTSD) may be appropriate diagnostic categories for parents with a baby in or graduated from the NICU is not new.⁴ However, parent advocates, as represented by Harrison,² note that it is important to avoid the potential error of labeling legitimate parental reactions to crisis, or observations of potentially significant problems, as part of a psychological reaction. How can developmental and medical professionals address both of these important and legitimate issues in their care of families?

In evaluating this literature in terms of its value in our care of families of newborn intensive care infants and graduates, several issues need clarification. One of these issues is the distinction between ASD and PTSD, which is described by Shaw¹ and colleagues as follows: “ASD is thought to represent an early manifestation of the trauma response and is characterized by symptoms similar to those of PTSD. It has been shown that ASD characteristics of dissociation (i.e., a sense of feeling disconnected from one’s body or usual sense of self), startle

reaction, fear or avoidance of the trauma, and social withdrawal are powerful predictors of subsequent PTSD symptoms.”^(p 131) Thus, the major difference between ASD and PTSD is timing and persistence. The authors go on to report on responses reported by parents immediately after the birth of their infants, and again four months later. Clearly, interpretations of these reports must take into account the likelihood that during the first reporting period, parents were in fact in the middle of a true crisis, and the possibility that four months later, many reality-based threats to the survival of their infants may still have been present. The question remains, for those working to support these parents, of what responses are in fact appropriate and expected in the face of daily stresses of a level unique in parental experience?

What are the actual data on the frequency and severity of ASD and PTSD as reported in the existing literature? The paper by Holditch-Davis⁴ and colleagues reported on data gathered in semi-structured interviews of 30 ethnically diverse, primarily married mothers when the infant was six months corrected age. This paper focused on the symptoms of re-experiencing past traumatic events, avoidance, and increased arousal. The authors found that all thirty mothers reported at least one symptom, twelve had two, and sixteen three, independent of the severity of the infant’s illness. The authors were careful to note that they were assessing specific symptoms, not diagnosing PTSD, and thus were not providing evidence about the actual incidence of PTSD as defined in the Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition-Text Revision.⁵

The paper by Shaw¹ and colleagues was based on extensive questionnaire data obtained from eighteen parents, both mothers and fathers, who were all married, primarily well-educated and higher-income; assisted reproduction played a role in many of the pregnancies. They had originally approached approximately 120 parents, of whom forty filled out the self-report shortly after birth, and the eighteen parents, who were the subjects of their paper, completed the four month follow-up. Thus, as the authors note, the “representativeness” of this group may be of a significant concern. They found an initial rate of ASD, according to the self-report, of thirty-three percent, all in mothers. At four months, fifty-nine percent of the parents (10 individuals) had elevated PTSD indicators, though only three parents met the most definitive diagnostic criteria. Interestingly, the fathers’ distress appeared to increase over time, while the mothers reported symptoms decreased. Later PTSD symptoms were associated more with early ASD symptoms than with measures of the severity of the infant’s condition. Keeping in mind the small and homogeneous nature of this sample, it is open for several interpretations. It actually is quite impressive that in a group with a mean length of hospital stay of almost fifty-six days, only nine percent of the

mothers at four months met the “likely diagnosis” criteria for PTSD. It is also interesting to note that Beck Depression Inventory⁶ scores placed fourteen parents in the minimal, one in the mild, and one in the moderate range of depression (these scores reflect the severity of the depression, not the number of episodes). Perhaps another indicator of the rather robust coping in a group of parents who had recently experienced a tremendous reality stress.

Neither of the above papers included a control group, making an article by Vanderbilt⁷ and colleagues of special interest. This research evaluated “the prevalence of acute posttraumatic stress symptoms among low-income mothers of infants admitted to the NICU compared with similar mothers with infants in the well baby nursery (WBN)”^{7(p 50)} in a much larger sample size of fifty-nine mothers caring for their infants on the NICU and sixty mothers caring for their infants on the WBN. The researchers used several questionnaires, administered in person by a registered nurse, within a few days of the birth of the infant. Only about a third of the mothers were married, most were members of ethnic minorities, and over eighty percent were covered by public insurance. In this group of mothers who were experiencing both social stresses and the birth of a newborn, twenty-four percent of the mothers caring for their infants on the NICU and three percent of the mothers caring for their infants on the WBN “met screening criteria on the Perinatal Posttraumatic Stress Disorder Questionnaire⁸ for risk of a diagnosis of acute stress disorder.”^{7(p 53)} As the data was collected while the mothers were essentially in the throes of the crisis/trauma experience, it is difficult to compare them to data collected months afterward, and especially to consider responses as “posttraumatic” when the trauma was still very much active. Yet, it is very interesting to note the similarity in the frequency of ASD symptoms reported in the two groups of mothers caring for their infants in the NICU, whose other life experiences were so very different. Again, one is struck by the resilience evidenced by 76% of the mothers of babies in the NICU, with limited social and economic resources, not meeting criteria for ASD, and also by the generosity of the mothers; of the seventy-six mothers caring for their infants in the NICU, only ten refused to be interviewed (with seven found ineligible).

What do these complex data suggest for clinicians? Should we be suggesting psychiatric support for parents who meet specific criteria, educate all parents about the risk of PTSD, or neither? Helen Harrison² cautions us that if we offer psychiatric services, we need to “consider the damage you may be inadvertently inflicting by implying that the mothers have psychological disorders that they are somehow imposing on their children.” Harrison² suggests: advocating for excellent medical care for the sequelae of prematurity, high-quality respite, parent-to-parent support, and improved education about the aftermath of prematurity. Vanderbilt⁷ and colleagues suggest that screening for both postpartum depression and acute posttraumatic stress symptoms

may be valuable (some states, such as New Jersey, have mandates for post partum depression screening), and they note that NIDCAP is one approach that has been found effective in reducing family stress and enhancing maternal function. Holditch-Davis⁴ and colleagues advocate that nurses and other health providers provide support and education around these issues, and note that “education about normative reactions to the trauma of having a sick infant in the NICU could be useful for many NICU families. Opportunities to enhance maternal feelings of self-efficacy, such as partnering in providing care to her infant in the NICU, might counter feelings of helplessness and use of avoidance.”^(p 169) They also suggest early identification and referral of mothers with PTSD symptoms, as do Shaw¹ and associates. Based on their failure to find an association of PTSD symptoms with infant medical variables, Shaw and colleagues also suggest that “treatment interventions that target parental psychological variables may have the potential to limit the development of future trauma symptoms;”^(p 135) advice that should be considered in the context of the caveats raised by Harrison.²

In summary, the research discussed above, as well as other studies in the literature, vary along dimensions of time, social factors, parental gender, method of data collection, and many other factors. The research suggests that acute and chronic traumatic stress is an important issue for a significant minority of parents, and yet also points out the strength and resilience that many parents demonstrate in the face of overwhelming experiences. It challenges us to provide a range of choices for support services, including, though not limited to formal psychiatric and psychological therapies, and also to remember to listen carefully to what each parent has to tell us about their own experience and the experience of their infant.

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This column provides our readers with current information regarding resources of interest.

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Books/DVD

NDC: Neonatal Developmental Care
This recently revised, self-paced program is designed to promote introductory understanding of developmental care and application to NICU practice (www.neonataldevelopmentalcare.com). An interdisciplinary team, led by Terri Daniels, MEd, and affiliated with The Institute

for Disability Studies at the University of Southern Mississippi, Forrest General Hospital, and Southern Mississippi Neonatology developed the program. Updates include the new DVD format, expanded reference lists, updated content, additional photos and videos, a new segment regarding supporting newborns during intubation following delivery, and was recently reviewed in the *Developmental Observer*, 2009; 3(1):15-16.

Internet

The Hera Project

This multidisciplinary initiative created for parents and care providers of prematurely born infants includes 43 hospitals throughout Spain and is extending into the community. The program serves to foster optimal development through advancing family centered, individualized developmental care. For information please visit www.proyectohera.com/in_index.html.

99NICU

This website, founded by staff at the Karolinska University Hospital in Stockholm, Sweden, provides a forum to explore and discuss newborn care and resources. For information please visit www.99nicu.org.

The European Foundation for the Care of Newborn Infants

Created by health care professionals and scientists from across Europe, this internet site strives to combine the strengths of parents and professionals and facilitate mutual understanding by enhancing public awareness, supporting research and training, and encouraging discussion. For information please visit www.efcni.org.

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



Inga Warren, Dip COT, MSc

Research Review: Fathers of Preterm Infants

Understanding and supporting parents through the difficult, and usually unexpected, journey of becoming mothers and fathers in a newborn intensive care nursery is an important part of our work. Much has been written about the mothers of preterm infants, however, there is relatively little that specifically addresses fathers' experiences. Most studies have used qualitative methods based on interviews and, although limited by small sample sizes, they reveal interesting insights into fathers' experiences, and provide ideas for support tailored to their needs.

The interview method in and of itself can be a positive experience for fathers. Pohlman¹ reported that a series of interviews conducted over several months built a strong rapport that supported fathers to become comfortable discussing their feelings candidly. Arockiasamy² and colleagues offered fathers a choice of a male or female physician or a female therapist. All the fathers chose the male physician and reported that they found the interviews beneficial, suggesting that men may prefer to get their information and support from male members of the care team. Others have reported that fathers may feel like outsiders in the "feminine" environment of the newborn intensive care unit.³

Family centered practice and policy varies from country to country, and unit to unit.⁴ Swedish researchers^{3,5} describe generous paternity leave, and financial compensation when a father needs to take time off work to look after a sick child. In contrast, none of the fathers interviewed in the American Midwest¹ had any paternity leave benefits and they were also often put under financial pressure by the cost of medical care; it is not surprising that "work" was the primary topic in their conversations with the interviewer. Other cultural and environmental factors that could have an impact on fathers such as family participation policies, space to be present in the newborn unit, and implementation of developmental care, are not described in relation to fathers' experience. However a study in the Netherlands⁶ looked at mothers' and fathers' stress in the context of a randomized trial of NIDCAP and did find some evidence that fathers who participated in NIDCAP care appeared to be less stressed than those that did not. Perhaps this was because of the fathers' increased involvement with their infants care in the NIDCAP group.

Loss of control is a common theme in interviews with fathers and provides a context for other themes.² Fathers may have to juggle multiple roles at this time including being overseers, fathers, husbands, primary wage earners, and protectors. Fathers for whom work is the primary method of contributing to support of the family report that they feel in control. However, these fathers may lose out on information, creating a need to

monitor the infant's progress more carefully, by adopting high levels of vigilance and the monitoring of staff actions.² Fathers seem to invest much energy in observing the staff³ in their efforts to achieve some sense of control. Some fathers feel so stressed by the loss of control that they have to remove themselves from the situation.²

Fathers find that information is important for their sense of control and they value communication with health care professionals who treat them as equals.² Pohlman¹ describes fathers' feelings of being demoted in the newborn unit compared to feelings of competence and control at work. Not all fathers require the same amount of information (it may be helpful to ask them if they would prefer detailed information or an overview). However, consistency is important, as is the communication style of professionals.^{1,2}

Fathers' initial concerns appear to be mostly for the mother's wellbeing, more so than needing to be involved with the infant's caregiving.^{1,2,3} Providing opportunities for the father to concentrate on his partner's needs may be one way to help him establish a sense of control.³

Providing timely information helps fathers to focus on their infant. Their sense of being a father is strengthened once they have more contact with their infant, whether this be eye contact or physical holding.^{2,3} Providing information and guidance on how father-infant interaction can promote the infant's development may be helpful.²

Although there are many common themes in these studies there are also wide variations in fathers' experiences and reactions.² Some fathers use external activities such as exercise or religion as coping strategies, some find work a comfort, while others find it overwhelming. Some fathers prefer to depend on their own resources or their partner while others appear to seek strength from friends, family and health care professionals. Interestingly they do not seem to view contact with other parents on the newborn unit or fathers' groups as particularly beneficial.²

Fathers' stressors and reactions appear to be different to those of mothers. Mothers of preterm infants are likely to report more symptoms of acute stress disorder than fathers during the infant's sojourn in the newborn unit. However four months after the birth, fathers have been reported to be more vulnerable to post traumatic stress disorder; with thirty-three percent reporting symptoms compared to nine percent of mothers.⁷ Severity of symptoms does not appear to correlate with severity of the infant's illness or length of hospital stay.⁷ Perhaps fathers' energies are so directed toward being guardians of their family that they have no time to deal with their own feelings and this catches up with them once the crisis has passed. Sensitivity to the fathers' protective role³ may ameliorate their experiences of stress and perhaps prepare them for potential psychological after effects of becoming the father of a preterm infant.⁷

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A [Personal] View from the East

Newborn Intensive Care Units in our country of Israel are not defined as such by our health system, but rather as units for the Special Care of the Newborn. They are not officially considered as intensive care, in spite of their providing care to extremely premature, sick and complex infants. They are hence staffed and financed accordingly. A direct consequence of this fact is our nurse to infant ratio, probably one of the poorest among developed countries.

I am not especially interested, nor skilled, in ratios, numbers and policy making. I just know that it is an all too common situation, in my unit, for a single nurse with no other auxiliary professional around, to take care of four to five intensive and intermediate care infants, some of whom might be on ventilator or CPAP; some of whom might be post-operative. Complex infants, by all standards. In the minimal care area of our unit, a single nurse usually takes care of eight to ten stable growing babies. No doubt, we nurses here are capable of managing huge masses of work.

In our milieu, complex and stable are terms mostly used and understood strictly by their medical connotations. Superimposed on these already quantitatively overwhelming medical, biological and technical complexities, there is a whole constellation of parental, social, developmental and psychological needs to be addressed

and taken care of, at least in part, by the assigned nurse.

Our unit's circumstances are not different, in this regard, from others across the whole country. It is just that we embraced, purposely and reflectively, a neurodevelopmental approach to care a few years ago, even amidst the harsh reality described above. We had the dream, courage and generosity to envision that such an approach was possible for the babies and families we take care of. We made certain to gather sound, up to date knowledge to guide our actions and to situate us as valid interlocutors in the "developmental dialogue" taking place internationally. We studied, changed, implemented, made enormous steps forward. We improved ourselves as health care professionals and as human beings in a mesh of never ending relationships.

Yet, I wonder today if we are lacking the astuteness and creativity to make further and bigger steps forward.

Is staffing a real and crucial element in developmental care and NIDCAP promotion within a unit? Should we let staffing difficulties become a major barrier in our efforts to provide a type of care that is more attuned to infants' and parents' needs? Is the NIDCAP approach plausible only for units which have conquered other basic and essential needs?

In trying to face this conflict two different lines of thought come to my mind. The first is my conviction

that when I give hands-on care, the moment I enter that infant's incubator, it is – as in a love crush – only between him/her and me; I must make every effort to bring myself to believe that for those even brief moments (because I am, after all, a 1:5 ratio nurse) the world outside can wait. I will take care of you as gently and contingently as I know and can.

The second is my belief that professionals working under conditions similar to the ones I have succinctly described, should find creative and efficient pathways to more actively and purposely involve parents in care. In units with staffing circumstances as ours, parent advocacy for and involvement with their infant's care should not be an approach, a luxury, nor a wished goal. It is a first necessity.

The professionalism, eagerness and creativeness of the NIDCAP community worldwide can make a significant contribution in transforming these and additional lines of thought into viable strategies to support endeavors to overcome staffing difficulties as well as other barriers to sensitive preterm infant care. We can strengthen each other and assist others not to desist from the dream of a more professional, updated and humane care for preterm infants and their families.

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From the Editors

We invite you to write us with your comments regarding the content of any of the columns presented in this newsletter. We are also interested in any suggestions that you have with regard to future topics that you would like to see addressed in the Developmental Observer. Please contact us at: developmentalobserver@nidcap.org.

Developmentally yours,

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generous spirit, wonderfully gentle guidance and a long career in supporting babies and their families and supporting other professionals to do so as well.

Honorary Member

Kathrine Leigh Peters, PhD, RN became the first Honorary Member of the NFI this past October at the Board of Directors' meeting in Chicago. She is the lead author and a guiding light for the recently published NIDCAP study: "Improvement of Short- and Long-Term Outcomes for Very Low Birth Weight Infants: Edmonton NIDCAP Trial."³ Her published work and research in supporting infants during necessary medical/nursing procedures has been long-standing, and she has been recognized as a leader

in nursing with multiple awards since the mid-1990's.

The NFI's growth continues. As of November 1, 2009 there were 158 members on the roster: One hundred and eighteen Professional Members, thirty Student Members, five Family Members, four Emeritus Members, and one Honorary Member.

One of the goals of the NFI is the creation of a standard for developmental care leaders in nurseries worldwide as well as supporting the growing number of professionals who are NIDCAP certified. In October 2009 the NFI Board announced that, as a part of training, all new NIDCAP Trainees must become Student Members, and that all newly Certified

NIDCAP Professionals must become Professional Members of the NFI. The NFI welcomes them all and continues to invite those formerly trained to join our organization.

For a complete description of the NFI membership and its categories discussed above, please visit the NIDCAP website at: www.nidcap.org.

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FAMILY VOICES

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The NIDCAP certified Infant Development Specialist in the NICU provides essential support for families who strive to understand their infant. The behavioral observation, which interprets the infant's behavior and responses to the lived NICU experience, environment, and caregiving interaction, opens the door to a deeper understanding and promotes the emerging relationship between the infant and family. Parents become more confident in their parenting role when their own observations and understanding of their baby are confirmed and supported. Suggestions for caregiving, made in collaboration with the parents, provide additional support to the parents' self-assurance as well as strengthen the infant's care during the infant's hospitalization and as they prepare to take their infant home.

With the help and support of the Oklahoma Infant Transition Program (OITP) and the Sooner NIDCAP Training Center at Children's Hospital, family centered care continues after discharge. The OITP staff meets the family in the hospital and continues to provide services to them when their child is transitioned home. OITP is one of the few programs in the nation that has a paid family advocate position. This position is held by

a parent who has lived the NICU experience and has navigated the service system and community supports. The interaction that the OITP family advocate has with families offers them hope for the future.

Bryden went home with his parents on January 22nd; his parents often return to the NICU to visit those who cared for him. As Taryn reports, "Everyone else in the world looks at him as if he is his Magnetic Resonance Image (i.e., brain image). Our NICU family sees what he has come from and says, 'You know what? We all know what he is supposed to be and do but look what he has already done. Only God knows what he will accomplish.'" Bryden's family works together and with the community to help him achieve his goals. "As long as Bryden is fighting, we as a family are fighting for him. We have a very different normal to our life now," said Taryn. "We have different passions for rehabilitation and unconditional love."

Article contributors: Taryn Anderson, Bunny Hutson, RN, Wanda Felty, OITP Family Advocate, and Laurie Mouradian, ScD, OTR/L.

CURRENT DEVELOPMENTAL RESEARCH

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