

Developmental Observer

The Official Publication of the NIDCAP® Federation International



In the NICU, where technology is at its most complex and densest and infants and families are at their most vulnerable, there is the greatest obligation for transformation and change. To be successful we must become fully present, attuned and accountable to each infant and each family, and effective in supporting optimal development of all infants, families and staff.

> - Heidelise Als, 2019 New Zealand

The Voice of Newborns, Infants, Children, Families and Care Partners All Around the World

Deborah Buehler, PhD. Presented at the 2022 Annual NIDCAP Trainers Meeting Bad Boll, Germany, October 9, 2022

ow did it come to be that one brilliant woman observed the hospital experience for the most vulnerable, fragile infants and became such an instrumental, invaluable, powerful positive force for change - transforming care with lasting positive influences, improving futures for young infants, families and health care partners?

Heidelise Als, or Heidi, had an immense intellectual curiosity about life - flowers and plants, music, literature... and most of all living beings (especially human). She brilliantly observed connections, articulated complex patterns and systems, translated visions into accessible clinical practice supports, and created and inspired a global community. And in doing so, Heidi made the world a better place. A life most definitely well-lived. A continuous thread throughout Heidi's life was the study of how people are shaped by their environments and the development and support for their health, regulation, well-being and potential.

On November 8th, 1940, Heidelise Als was born the middle child of Elizabeth



Heidelise Als, PhD

and Barrister Heinrich. Her family lived in the beautiful town of Krumbach in Bavaria Germany, between the Danube and the Alps. Yet, Heidi's early years were shaped by an unfathomably horrific time in world history, World War II in Germany. All around Heidi, there was death and destruction and suffering from the Nazis. Her home was invaded and confiscated, forcing her family to live in what she described as a "cramped

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Heidelise Als, continued from p. 1



attic apartment." During and following the war, their family experienced poverty and hunger. Her father, a well-respected judge, was forced to do hard labor.

Heidi's formal education had many layers. Heidi studied at the Universität Wurburg in Germany where she majored in education. She graduated Summa Cum Laude and became a third and fourth grade teacher in Nürnberg – Stein. After meeting her first and future husband, an American, Heidi was married in Nürnberg, Germany in 1964. They moved to Philadelphia, Pennsylvania in the United States where he was born and his family lived.

Heidi was accepted to study at the University of Pennsylvania and her studies led her to a master's degree and ultimately a doctorate in Education and Developmental Psychology. Her dissertation gave her the opportunity to collect one year outcome data from families, many of whom were facing very difficult challenges due to poverty. She described being "humbled by these families many strengths." Heidi's study documented that newborns respond to their mothers' social advances and remarkably also that newborn infants initiate and seek to elicit responses from their mothers.

There were many influential people, early in Heidi's life,

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Editorial



ovember 8, 1940 was the day our world was gifted with the birth of Heidelise Als. Unfortunately, since Dr. Als died on August 18, 2022, she will not celebrate her eighty-second birthday. The NFI community has chosen to commemorate Heidelise Als on this occasion with this special issue of our

Developmental Observer. To commemorate is to remember and to show respect for someone.

We provide the formal obituary written for Dr. Als as well as a more personal story of her life. In this issue we are bringing forward the important messages Dr. Als gave us in previous Developmental Observer editions. In our first volume Heidi shared with us in a very intimate manner how she learned to see another individual through her experience with her son Christopher. She told us that it was through learning her son's unique strengths and vulnerabilities and how they influenced their nurturing relationship that this was valuable and necessary for newborns. Dr. Als shared a great deal of her wisdom through the years and I was especially moved by her discussion on the importance of trust in ourselves, infants, families and health professionals. When reviewing Dr. Als' past contributions, I was reminded of her enthusiastic pursuit of science through research and feel so fortunate for having been able to be one of her collaborators in early developmental studies in newborn intensive care. Occasionally, Heidi's depth of

thinking and knowledge in areas not so familiar to me forced me to delve into unfamiliar territory as when she expounded on the similarities between Jazz, NIDCAP and the process of becoming. One of the most intriguing columns Heidi gave us was that of the value of silence in which she reminded us of the inherent cost of habituation. Sandra Kosta shares more about Heidi's love of silence.

Many of the amazing tributes written to and about Heidi are shared representing a true global perspective of her influence. As I shared at our 33rd Annual NIDCAP Trainers Meeting, just a few weeks ago in Germany, Heidi was my mentor, guide, colleague and friend for 42 years and I will attempt to honor her through my work with infants and families providing NIDCAP observations and APIB evaluations to support the emerging competence in both infants and parents. It is my sincere hope that this commemorative issue will remind each of you of your own special relationship with Dr. Als and lead you to reflect on what she inspired in you to pass on to others.

gretchen Lawhon, PhD, RN, FAAN

Associate Editor – Developmental Observer Clinical Nurse Scientist/ Newborn special care associates, pc/ Abington-Jefferson Health/PA/USA

Master NIDCAP Trainer/ West Coast NIDCAP and APIB Training Center/ UCSF/ CA/ USA

Cover photo of Heidi and Airi, Japan 2007 - used with permission

that led to her interest and understanding of premature infants and their families. Heidi's University of Pennsylvania advisor/mentor was the remarkable developmental psychologist, Sandra Scarr, PhD. She also studied with renowned Solomon Katz a physiological anthropologist. Heidi's graduate school studies occurred at a time when the field of neonatology was just developing. One of the earliest NICUs in the United States was within the Philadelphia General Hospital. It was there that Heidi's path to understand newborns and their families led her to meet and study with neonatologists Margaret Williams, MD and Maria Delivoria Papadopoulos, MD. These pioneers worked to improve prematurely born infants' survival as well their cognitive and emotional well-being and the well-being of their mothers. Heidi's exposure to this world and its possibilities lay the foundation for what became her career of understanding and supporting premature infants, their families and healthcare professionals and systems that care for them.

In June of 1965, after an uncomplicated pregnancy that went to term, Heidi's son Christopher was born. However, the labor and the delivery were difficult and led to Christopher developing cerebral palsy, epilepsy, and developmental disabilities. Christopher attended special schooling. Parenting of a



child with disabilities was joyful and challenging for Heidi. Her marriage did not survive this challenge.

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Editorial Board



Jeffrey R. Alberts, PhD, is Professor of Psychological and Brain Sciences at Indiana University -- Bloomington (USA). Jeff is also a NIDCAP Professional and blends his lab studies with similar research at Cincinnati Children's Hospital Medical Center.



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Deborαh Buehler, PhD, is a developmental psychologist with expertise in developmental care within newborn and infant intensive care nurseries. Her work has focused on NIDCAP research, education and mentorship, and awareness. Deborah has authored and co-authored papers and manuals pertaining to NIDCAP care.



Debra Paul, OTR/L, is an occupational therapist and NIDCAP Professional at Children's Hospital Colorado in Aurora, Colorado and the Column Editor for the Family Voices section for the *Developmental Observer*. Debra writes policies and guidelines which requires succinct writing and an eye for editing.



Sandra Kosta, BA, NFI Executive Director of Administration and Finance, has been an Associate Editor for the *Developmental Observer* since 2007. As a Research Specialist at Boston Children's Hospital, Sandra has co-authored several papers on the effectiveness and long-term outcomes of NIDCAP Care.



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Interested in learning all she could about newborn behavior, Heidi had the opportunity, as a graduate student, to be part of the "kitchen table" work group at Dr. Brazelton's home. This was when the Brazelton Neonatal Behavioral Assessment Scale was being developed. After Heidi graduated from University of Pennsylvania, in 1973, she held an inspiring Visiting Scholar and Scientist appointment. This offered Heidi further education and training in Human Ethology and Developmental Psychology at the Behavior Development Research Unit, directed by Anthony Ambrose, PhD, at St. Mary's Hospital in London. She then made the decision to move to Boston accepting a research position with T. Berry Brazelton and his team at Boston Children's Hospital. Heidi became the first trainer of this new Brazelton Neonatal Behavioral Assessment Scale. Heidi later stated "Berry shaped my thinking, my work and my personal and professional development. He had a major impact on me as I raised my son, a young child with disabilities. He defended undauntedly the competence of each newborn, each infant and each parent, of all human beings; he valued and brought out the strengths and talents in everyone, everyone's true goal for good."

After a serendipitous meeting over spilled coffee one day at work at Boston Children's Hospital, Heidi met Frank Hopkins Duffy, MD and their story became one of lifelong love. Frank a world-renowned neurosurgeon, pediatric neurologist, researcher, and engineer has deep understandings of the developing brain and environmental influences. Their work strongly influenced one another's and by 1978 Frank and Heidi married and became forever "collaborators on many levels." With their marriage, Heidi and Frank's family grew to include their children from their earlier marriages Christopher, Lisa, Brian and Victoria.

Heidi drew from her understandings of development, ethology and evolution, building on the Brazelton assessment. She added the conceptual Synactive Theory layer as a framework for understanding human, and especially young infant, development. Heidi described systems, and their interactions and their continuous environmental interplay. This new instrument, the Assessment of Preterm Infant Behavior (APIB) was published in 1982 (with co-authors, Berry Brazelton, Barry Lester, and Ed Tronick, her Child Development Unit colleagues). The APIB is a comprehensive neurobehavioral assessment of preterm, high-risk and healthy newborns and is used by clinicians and researchers around the world.

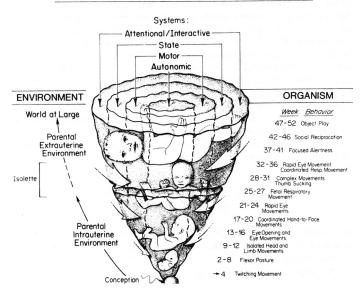
During this same time, Heidi was working very late each evening watching and learning from premature infants in the NICU at the Brigham and Women's Hospital in Boston. She was identifying very small babies' behaviors and patterns. She was studying the experiences of the families. And she was observing infants' and families' experiences of care and the nursery. She was developing a framework.

Heidi sought ways to support these vulnerable premature babies whom she described as being in a mismatched environment to their stage of fetal development. She partnered with



gretchen Lawhon, who began to translate her observations into caregiving strategies. As Heidi's research assistant, I supported Heidi's pilot research project's post-NICU outcome studies. From the Department of Neurology at Boston Children's Hospital, Frank and Gloria McAnulty were laying the groundwork for Heidi's understandings of brain/behavior relationships.

MODEL OF THE SYNACTIVE ORGANIZATION OF BEHAVIORAL DEVELOPMENT



Model of the Synactive Organization of Behavioral Development



The First NIDCAP Team (1982): Heidelise Als (not pictured), gretchen Lawhon, Frank Duffy, Gloria McNulty and Deborah Buehler

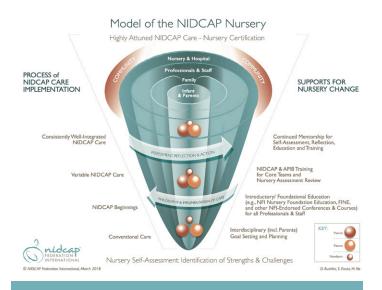
These early experimental supportive care changes showed that this approach was not harmful and instead, very promisingly, beneficial. And NIDCAP was born.

During the follow-up visits, I observed Heidi in what seemed like an exquisitely choreographed dance during each APIB assessment interaction. In those moments of assessment, Heidi became completely attuned to each baby, creating a supportive space for them to tell their story, their fragilities, their strengths, their thresholds to becoming disorganized. I observed her compassionate, reassuring, and thoughtful interactions with families... with masterful clinical skill, parents seemed to feel that she saw their child, really saw them and that they, the parents, were understood as well. Heidi's conversations with parents always acknowledged life and parenting realities and challenges though focused on strengths, supports and next steps. This is the same life affirming, life changing approach that Heidi's trainees and mentees describe experiencing as well.

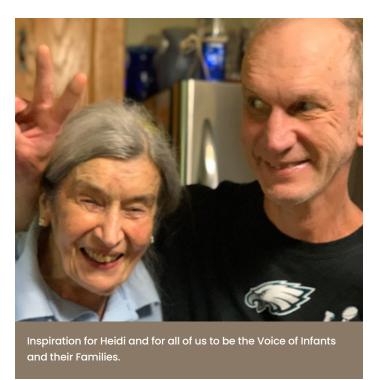
Every time that I have heard Heidi present, I learned something new. She continually reframed ideas in insightful ways. She brought ideas together from other fields of study. She kept growing understandings with new concepts, from big ideas like Synactive and NIDCAP Nurseries to more nuanced ones such as Co-regulation and NIDCAP as Humane Care. It was as if Heidi saw the full picture from the start and was guiding us to see it too. She described parenting as a "process of letting go". Perhaps that construct applies to her nurturance of the NFI, we certainly hope so. She created a tremendous foundation and scaffolding for our current work. We have been left with a model and program that has limitless potential to continue to make the world a better place.

Heidi was very intentional about everything in her life. And that included the way she dressed, with her blue or grey or beige blazer and the two pins she fastened on her lapel. She wore her pins everywhere she went. One was her NFI membership pin, as she was so very proud to be a member of this extraordinary community. The other was a pin of a swan. That one also held very special meaning to Heidi. The swan broach was given to her by her beloved husband Frank, decades ago. It was a symbol of her love for her son Christopher and the experience of riding the Boston Public Garden's swan boats together.

Fascinated by the beauty of swans, Heidi took lovely photographs of swans in Tübingen after a 2011 training session. Pulitzer Prize winning American Poet Mary Oliver wrote a poem entitled "Swan". This poem is about noticing what is happening



Model of the Synactive Organization of Behavioral Development



in the moment. Being present, observant, and thoughtful. For this is when she notes that growth and change occur.

Heidi was brilliant. She was compassionate. She was wise. She was thorough. She was astute. She was skillful. She was hardworking. She was dedicated. She was very many things. And in every way, Heidi had an extraordinary capacity for being completely present. Present in conversing, observing, assessing, training, mentoring, writing. Whatever Heidi was doing, she did it with her full attention, with heart, with skill and with conviction. And within each of these moments, she created change. Change for infants' and families' experiences, change for caregivers approaches and experiences, change for healthcare systems' provision of care and environments, and change for all of us directly or indirectly touched by her.

Heidi's love for Christopher was a source of enduring inspiration. She wrote, "Seeing Christopher and seeing the world, including myself, with his eyes, has opened my own eyes, and continues to make me more aware and conscious." In so many profound ways, Christopher and Heidi inform and inspire all of us. Opening ourselves to see and become changed in the process. And in doing so, we change the experiences and lives of others.

A Tribute to Heidelise Als

gretchen Lawhon, PhD

or years I looked forward to the time that we would have the NIDCAP Trainers meeting in Germany and that Heidi and I would be together in her native country and my birthplace. Alas, here I am in Germany with heartfelt thought and memories of Heidi, my guide, translator, mentor and friend.

Just as they say no one can step in the same stream twice – because of the ever-changing water – none of us experienced our relationship with Heidi in the same manner. We each have our own unique perspective, history, and memories. I would like to share a few of mine.

Heidi and I shared an interest and admiration for a woman named Sacajawea, an indigenous American who is most wellknown for guiding Lewis and Clark in their famous expedition across newly acquired western land. As was Sacajawea, Heidi was not only a guide but also my translator who taught me the behavioral language of our smallest most vulnerable infants in newborn intensive care.

In 1980 I courageously introduced myself to Heidi, a fascinating woman who observed, with great intensity, many of our tiny infants. She was at that time a nearly 40-year-old scientist who had conceptualized the Synactive Theory and was developing research that would attempt to minimize the iatrogenic damage to the preterm infant's brain and maximize their emerging competence within the context of their family and the NICU environment. I was a 25-year-old newly minted clinical nurse specialist recently transitioned from pediatrics to newborn intensive care. I was full of motivation and ambition and thrilled to be assigned as the

infant so we could strategize individualized recommendations for care. I then met with the primary nurse to discuss these recommendations and also ensure that the neonatologists were on board with our innovative ideas.

In many ways, I see an analogy of the beauty of how NIDCAP works similarly to the synactive theory with subsystems of function. Looking at the various perspectives and collaborative offerings of psychology, nursing and neonatology interacting in support of the infant within the context of family and physical environment. This multidisciplinary approach is what I believe has made NIDCAP so effective and powerful.

At the end of the first developmental research study, our nurse administrator suggested that Heidi and I might teach others how to observe infants and make recommendations for care. She even suggested the acronym NIDCAP and thus NIDCAP was born. I became the first NIDCAP Trainee and very soon thereafter the second NIDCAP Trainer.

Throughout the 1980's Heidi and I travelled extensively doing NIDCAP training together. We got to know one another extremely well, both our strengths and vulnerabilities. As we supported the developing relationships among infants, families and healthcare professionals, we became more than colleagues. We had amazing experiences together and even some fun times.

In Oklahoma we once spent a few hours playing in a pool together making up silly jumps off the diving board at the home of our host. We were both fairly anxious doing a hot air balloon ride at 5:00 on the morning of Heidi's Pediatric Grand Rounds presentation, not realizing the special ceremony after one's first hot air balloon ride, when you have to kneel and drink champagne from a cup on the ground before having some poured on your head. Everywhere Heidi and I went we were always on the lookout for infants and children we could interact with. Heidi taught me an appreciation of flowers.

For my fortieth birthday at the Oklahoma NIDCAP trainers meeting Heidi gave me an expensive Waterman pen. That evening, a few of us were feeling rather free and tipsy when we decided to roll down a hill. The next morning, I confessed to Heidi that I had lost my new pen. Two weeks later at the Contemporary Forums developmental conference Heidi handed me a small box wrapped in tissue paper with the note "Úbermut tut seltan gut, but it was fun and life is short, with love from Heidi" (Pride goes before the fall). We both loved hair barrettes and for years searched for unique ones to give to one another on special occasions.

Heidi continues to be my guide as I became a scientist in my own right, obtaining my doctorate. My dissertation built on the NIDCAP approach to facilitate parenting in newborn intensive care.

Through our work with some of you, in founding the NIDCAP Federation International, we worked very closely for another nearly 20 years. During that time as we were building the organization and creating numerous levels of training, we



had an ongoing joke that Heidi had become our Yoda.

I am so grateful that I had the opportunity at last year's NIDCAP Trainers meeting, with Heidi present virtually, to publicly acknowledge my appreciation for her as my mentor, colleague and friend.

Heidi was my guide, my translator, mentor, colleague, and my friend for 42 years. I am a far better clinician, scientist and person for having had the privilege of knowing her. In my family, the "Heidi factor", meant that if Heidi needed me then all else was less priority and I made myself available to Heidi.

We did not always agree and it took great courage to make a decision that was not what Heidi advised. Heidi's influence on me both professionally and personally is impossible to quantify.

In my opinion learning comes with a sense of duty. How can I ever express enough appreciation for what Heidi gave me? Through Heidi I learned the language of the newborn. As a NIDCAP Professional I hold the responsibility and obligation to be the voice of the newborn. With each NIDCAP observation and APIB evaluation I feel Heidi's presence. I interview the infant and discover both vulnerability and strength within emerging competence and development.

Communicating the infant's behavior to support parents in their understanding how best to nurture and support their son or daughter's comfort and development leads to greater confidence and competence in parenting. Research shows that greater competence in parenting, in turn, leads to improved infant and child development. This is how I will continue to honor Heidi – to live my tribute to her for as long as I am able.

A Few of the Global Tributes to Dr. Heidelise Als and her work

"They say you should never meet your hero. ...l did and she did not disappoint"

- Susan Vaughan, Cork, Ireland

"The NIDCAP concept changed and widened my mind and actions not only with premature babies but throughout my work and life"

– Qian Su, China

"Her work, as well as her spirit, have profoundly shaped so many of us and will continue to do so"

– Kelly and Bieke. On behalf of the UZ Leuven NIDCAP team, Belgium "She will be remembered by so many for helping the most fragile and their families"

> Dr. Christine Ganitsch – spouse of John Chappel in New York, USA

"Heidi changed me as a person through NIDCAP in my thinking, my actions, and my appreciation of each individual"

- Daniela Grafe, Germany

"I started out 30+ years ago with Heidi whose ripples have touched many hundreds of NIDCAP professionals and thousands of infants and their families"

– Elsa Sell, USA

"I treasure the endless hours of deep learning with her and the gifts she gave us of knowing what such small, fragile infants are telling us"

- Bette Flushman, USA

"We have lost a heroine who fought many a battle for babies and families"

– Inga Warren, UK

Silence By Sara Teasdale

We are anhungered after solitude,

Deep stillness pure of any speech or sound,

Soft quiet hovering over pools profound,

The silences that on the desert brood,

Above a windless hush of empty seas,

The broad unfurling banners of the dawn,

A faery forest where there sleeps a Faun;

Our souls are fain of solitudes like these.

O woman who divined our weariness,

And set the crown of silence on your art,

From what undreamed-of depth within your heart

Have you sent forth the hush that makes us free

To hear an instant, high above earth's stress,

The silent music of infinity?

Ode to Silence

Sandra Kosta (written for and read at Heidelise Als' funeral)

one, among many, of Heidi's goals for the NICU environment was to quiet the space. She had a deep respect for silence and believed that through quiet reflection one would heal, one would grow stronger, one would become more available mentally, emotionally, physically.

Upon hearing of Heidi's passing, I felt compelled to read her writings, to somehow conjure and feel her presence. I was drawn immediately to an eloquent piece she wrote many years ago entitled the Importance of Silence. When I found her "Silence" piece and read it again, it resonated with me, not only because I share her respect for silence, but because I felt that, upon the news of her death, there was a ripple of silence that enveloped the globe. I imagined that as people heard, and experienced the shock of the news, it caused them to retreat into themselves and reflect on the conversations they had with Heidi... what they may have learned from Heidi... the shared moments, the shared laughs, and oh what a laugh she had. This silent collective reflection that I imagined seemed the ultimate tribute to her.

Self-reflection was of course at the root of her philosophyit was the essence of her being and her teachings and trainings. Heidi wrote, "Hardly a place remains in the world that is truly silent, still, tranquil. This, almost spiritual quality, is necessary for silence of the mind, an inner peace and a clearing of our pressing thoughts and preoccupations. To 'hear silence,' brings openness, inner quietude, an attunement to nature's sounds, and to our inner selves."

She lived this philosophy and strived to improve

environments that seemed counter to tranquility, whether it was the cacophony that sometimes fills a newborn intensive care unit, or a patient waiting room with TVs blaring, or a parking lot rife with the sounds of beeping car locks and alarms. She aimed to quiet the world and succeeded in giving people the tools to quiet themselves in order to be their best selves.

She wrote, "The moment we pause in greeting a familiar bird, in watching a flower, observing a person, the pause of listening and tuning in, if only quite simply into our own breathing as meditation teaches us, this is well available to us all. And all of us have the power to cultivate actively an increased awareness of the intrusive noise that we create ourselves. In doing so we can help to reduce and eliminate it."

We are now faced with how to move forward without her force of nature, without her advice, without her insights. If for one moment we could break the silence to hear her laughter it would be pure joy.

In her own words, "The practice of silence will give us the strength and the joy to hold the moment, and hold the other in the moment and in silence. Being and becoming occurs in being held, being in the moment."

Heidi's quest for ultimate silence was reached on August 18 leaving us all with the opportunity to reflect on the meaning of silence. Heidi, I hope that you are indeed now resting in tranquility and I thank you for showing us how to quietly be our best selves. I will miss being quiet with you. We did that well together.



In Memoriam

Heidelise Als

November 8, 1940 - August 18, 2022

eidelise Als, PhD, Professor, Harvard Medical School, Boston Children's Hospital, Champion of Infants and Families Of Boston, MA and Tunbridge, VT, died suddenly on Thursday, August 18, 2022. She was Professor of Psychology, Department of Psychiatry, Emerita, Harvard Medical School, Director, Neurobehavioral Infant and Child Studies, Boston Children's Hospital. She is survived by her husband and research colleague of 44 years, Frank H. Duffy, MD, Neurologist at Boston Children's Hospital and Associate Professor of Neurology, Harvard Medical School and son Christopher Hopkins Als Duffy of Camphill Village (an anthroposophical community for adults with developmental disabilities). Heidelise (Heidi) was born in Krumbach, Germany in 1940, the daughter of Elizabeth Broicher and Heinrich Maria Als, a barrister. Heidi grew up in war-torn and post-World War II Germany. Her experiences during these formative years led her to question how people develop their emotions and inspired her to study how people are shaped by their environment.

Heidi received her BS (1963), Summa Cum Laude from the University of Würzburg, Germany and PhD in Developmental and Educational Psychology (1975) from the University of Pennsylvania.

During her graduate training, and married to her first husband, Heidi gave birth, in 1965, to her son, Christopher, a beautiful infant, whose neurological and developmental differences shaped Heidi's career by teaching her to understand that babies communicate and participate in their care if adults would only listen. This understanding led her to create a theoretical model, the Synactive Theory, which became the foundation for the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) in 1982. During this year, Dr. Als established the National NIDCAP Training Center, affiliated with both Boston Children's Hospital and Brigham and Women's Hospital, which provided a formal structure for NICU professionals to become certified in the use of NIDCAP.

In 2001, to coordinate and support NIDCAP training and training center development, Dr. Als founded the NIDCAP Federation International, Inc., a non-profit organization that ensures the quality of the NIDCAP model of developmental care education, training, and implementation and ultimately improves the future for infants in hospitals and their families around the world. Today there are 29 centers around the world training in individualized, developmental, family-centered, research-based NIDCAP care.

Over 49 years at Boston Children's Hospital, as Director of Neurobehavioral Infant and Child Studies, Heidi conducted many research projects on premature infants and how early experiences and care affect brain and emotional development from early infancy on to adolescence, publishing more than 150 research papers and giving countless presentations around the world. In addition, she disseminated an educational curriculum for hospital systems change for the education of professionals from many disciplines involved in the care of high-risk newborns in intensive medical care settings.

Over the last nine months, Dr. Als with her husband Dr. Duffy, transitioned to working remotely from their Vermont farm. During this time, she conducted remote training with professionals around the world and developed guidelines for online NIDCAP and APIB training and certification methods.

During this brief full-time Vermont life, Heidi found time to revive her garden and bird feeders, bake rhubarb pies for Frank and Duane Lawrence, their friend and farm caretaker on Monarch Hill, and reconnect with her farm life.

A visionary and a prominent scientist, Heidelise Als has left a legacy that will live on in those she mentored, worked with, and befriended; and in the lives of premature and ill infants and their families, made better by her vision and tireless advocacy.

Heidi is also survived by and will be held forever in the hearts of family from around the globe including:

Her brother, Heinzpeter Als (Rosemarie); nieces, Barbara, Astrid, Maria (Björn); great-niece and nephews, Konrad, Carlotta, Mathilda, Malte; her sister, Urselmarie Als (René Haas); niece, Joanna Ashworth (Glen); great-nephew and niece, Jonathan, Emily; stepdaughter, Victoria Duffy-Hopper; grand-daughter Galen Hopper; stepdaughter, Lisa Duffy; grandson, Brian Zagorski; great-granddaughter, River Fox; and stepson, Stephen; and her Farm family, Leigh Woods, Dakota Jensen and Duane Lawrence.

She will be forever missed by her Neurobehavioral Infant and Child Studies/National NIDCAP Training Center team,

Gloria McAnulty PhD, Sandra Kosta, Samantha Butler PhD, and Jack Connolly all of Boston Children's Hospital (BCH) and Deborah Buehler, PhD her student who currently serves as the NFI President, and by her entire international NIDCAP community.

In lieu of flowers, Heidi requested that donations be made to Camphill Village Copake, NY, www.camphillvillage.org

Obituary originally appeared in *The Boston Globe*, August 25, 2022

"Heidi's legacy of changing the future for premature infants and their families and all of us professionals will live forever"

> - Até sempre Heidi. Fátima and the Porto NIDCAP family, Portugal

"Despite her wonderful achievements, Dr Als remained the same down-toearth woman and role model"

> – Andrea Levy, Meir Hospital Nidcap group, Israel

"I'm thinking of her kind and sweet smile and smiling eyes"

Natascia and Modena
 NIDCAP Team, Italy

"She taught us that premature babies could communicate and how to support them by giving a prominent place to their parents"

- Sylvie, Céline, Nathalie, Jacques and Sandra on the behalf of the French NIDCAP team

"Heidi, we'll remember you with this image... Facing the challenges with a smile"

- Imma and the Turin NIDCAP team, Italy

"People like Heidi may pass physically but they stay with us forever"

– Lama Charafeddine, Lebanon

The Birth of NIDCAP: A Personal Journey

By Heidelise Als

s the NFI (NIDCAP Federation A International) launches its first blog, it seems appropriate to share how the seeds of NIDCAP (Newborn Individualized Developmental Care and Assessment Program) germinated. The purpose of the NFI's blog is to build awareness for our organization and its visionary and dedicated members, who, quite literally, change lives. This and future posts by NIDCAP Researchers, Trainers, NIDCAP Professionals, parents of preterm infants, members of our Board of Directors, and special guest bloggers will provide an opportunity to convey the NFI's perspective and to receive your comments and questions.

Life puts us in places that we may come to appreciate in their full significance only later. While a child in Germany during World War II, I saw again and again how overcoming extreme difficulties builds character. This, and all the other hardships around me, shaped me and it inspired me to study how people, from early on, are molded by their environment.

When I came to the United States as a graduate student at the University of Pennsylvania, I had the good fortune to visit the newborn intensive care unit (NICU) at Philadelphia General Hospital, one of the earliest NICUs in the U.S. at the time. Convinced that the dearth of appropriate experiences in the NICU was harmful for these immature human infants, Margaret (Peggy) Williams, MD, a pioneer neonatologist, collaborated with my advisor, Sandra Scarr, PhD, a developmental psychologist, to improve not only the infants' chances of survival but also their cognitive and emotional



Heidelise Als, PhD, Founder, NIDCAP Federation International

well-being and that of their inner city mothers. These insightful researchers innovated the first preterm infant developmental care program. Colorful mobile birds moved gently above the infants within the incubators. A group of specially trained nurses on this project was encouraged to speak to and gently stroke the infants as well as hold, feed, and rock them. Skilled guidance counselor social workers supported the mothers' well-being resulting in significant positive improvements for both infants and parents.¹⁻³

I had the opportunity to collect the infants' one-year outcome data, which meant home visits mainly in West Philadelphia's housing project neighborhoods where most taxis refused to go. I met amazing young women, strong grandmothers, and tough appearing young men, all proud of their tiny babies, who had 'made it'. I witnessed and was humbled by these families' many strengths. Just a year or so later, Maria Delivoria Papadopoulos, MD invited me into the NICU at the Hospital of the University of Pennsylvania, where I was studying the first interactions of fullterm newborn infants with their adolescent inner-city mothers. I jumped at the opportunity to have the chance to watch tiny preterm infants close-up. Never mind that I was the 'bagger' trying to help the infants breath, and the 'dabber' of the neonatologists' brows as they attempted to exchange fresh blood for the infants' poorly oxygenated blood in a valiant effort to combat dreaded lung disease.4 My fascination and awe was for the determination of these infants, who curled up, fought against the hands that tried to hold them down and keep them still, and swiped against anything that came towards them. They flailed, arched, and gave their all to get back to what they had been doing in the womb, sucking on their hands and fingers, tucking themselves up into little curled up balls, and cradling and hugging themselves into cozy comfortable positions. When Nilsson published his first incredible fiber-optic photographs of the fetus,⁵ I immediately saw how competent, yet misunderstood, these babies were, and how distinct and individual their different personalities expressed themselves in their behavior. This is when I resolved to figure out how to do justice to their competence, and to warrant and gain their trust.

When I gave birth to an infant son of my own, it turned out that he had a neurological problem. I drew from all

my life experiences, personal and professional, to understand better what my son was trying to tell me in his own way while he struggled to do his very best.

Though NIDCAP has grown over the past 40 years through the dedication of my many colleagues, who are all driven by the passion to care for preterm infants and their parents, it has been the infants themselves, believed in and supported by their parents, who have done the hardest work to reach their potentials. To them, I am ever grateful for the lessons of strengths, courage, and hope that they have taught me.

It behooves us to listen closely to the voices of all children, no matter how small at birth, and to their families,

Heidelise Als. PhD







Heidelise Als with son, Christopher

Notes

- 1. Williams ML, Scarr S. Effects of short-term intervention on performance in low-birthweight, disadvantaged children. Pediatrics 1971; 47:289-298.
- 2. Scarr-Salapatek S, Williams ML. A stimulation program for low birth weight infants. Am J Public Health 1972; 62:662-667.
- 3. Scarr-Salapatek S, Williams ML. The effect of early stimulation on low-birthweight infants. Child Dev 1973; 44:94-101.
- 4. Delivoria-Papadopoulos M, Morrow G, Oski FA. Exchange transfusion in the newborn infant with fresh and "old" blood: the role of storage on 2, 3-diphosphoglycerate, hemoglo-bin-oxygen affinity, and oxygen release. Peds 1971; 79: 898-903.
- 5. Nilsson L. Behold Man. Boston: Little, Brown and Company; 1973.



Mission

The NFI improves the future of all infants in hospitals and their families with individualized, developmental, family-centered, research-based NIDCAP care.

Adopted by the NFI Board, June 29, 2022

Vision

The NFI envisions a global society in which all hospitalized newborns and their families receive care in the evidence-based NIDCAP model. NIDCAP supports development, enhances strengths and minimizes stress for infants, family and staff who care for them. It is individualized and uses a relationship-based, family-integrated approach that yields measurable outcomes.

Adopted by the NFI Board, October 20, 2017

NIDCAP TRAINING CENTERS WORLDWIDE



National NIDCAP Training Center, Boston MA, USA

By Sandra Kosta and Samantha Butler

With much appreciation to Deborah Buehler, gretchen Lawhon and Gloria McAnulty for their editing for historical accuracy.

The National NIDCAP Training Center was established in 1982 in Boston, Massachusetts, USA by Heidelise Als, PhD. Here is our story...

The Beginnings

In the early 1980s, Heidelise Als, PhD was an independent researcher and clinician within the Department of Psychiatry at Boston Children's Hospital. She created her own sub-department, Neurobehavioral Infant and Child Studies Laboratory (Neurobehavioral Studies), where she would continue to pursue her scholarly and clinical interest in understanding and supporting prematurely born infants. She had just developed the Synactive Theory and the related neurobehavioral evaluation, the Assessment of Preterm Infants' Behavior (APIB). She was well on her way to conceptualizing what would become the Newborn Individualized Developmental Care and Assessment Program (NIDCAP).

A few years prior to the establishment of NIDCAP as an organized training program, Dr. Als and gretchen Lawhon, PhD (RN, MSN, Clinical Nurse Specialist at the time) met in the Newborn Intensive Care Unit (NICU) of the Boston Hospital for Women, Lying-in Division in Boston. This was where Dr. Als was observing infant behavior for one of her early research studies. Dr. Lawhon and the unit's nurse manager, Rita



Samantha Butler, Sandra Kosta, Heidelise Als, Frank Duffy and Gloria McAnulty

Gibes, BSN, MS, were curious about Dr. Als' data collection. They were eager to implement ways to help these vulnerable infants reach their potential based on her intensive observations and support from their caregivers. Between 1981 and 1983, with collaboration and support from Boston Children's Hospital and the NICU leadership at Brigham and Women's Hospital, the first research study of the NIDCAP approach was conducted. With evidence of this care being safe, as well as beneficial, this study launched what would become an international movement to change hospital care for infants and their families around the world.

The First Training Center

During this initial developmental care research study, Dr. Als became the first official NIDCAP Trainer as she trained Dr. Lawhon to NIDCAP reliability. Over the next few years, they collaborated in the development of NIDCAP (which got its

"The National NIDCAP
Training Center has the responsibility, charge and challenge of the timely and substantive training, consultation, and guidance of trainers and training centers around the world."

-Heidelise Als, PhD, Director of the National NIDCAP Training Center, 1982-2022

name from Ms. Gibes) and subsequently received requests from others to learn this approach. This was how the NIDCAP training program began. Shortly thereafter, the National NIDCAP Training Center (NNTC) was established at the Department of Psychiatry at Boston Children's Hospital and the Brigham and Women's Hospital NICU, Boston. Neurobehavioral Studies served as the academic umbrella for the training center.

Within the NNTC, Dr. Als served as the Center Director and Master NIDCAP Trainer. The first person she guided to become a NIDCAP Trainer was Dr. Lawhon. Dr. Lawhon became the Co-Director of the Center from 1982-1994. Deborah Buehler, PhD (Deborah Moir, BS at the time), a research assistant during this period, was trained by Dr. Als to be an

APIB Trainer and then a NIDCAP Trainer. The APIB became a complementary assessment tool in the NIDCAP training process and Dr. Buehler played an integral role in APIB and NIDCAP training at the training center.

During these first years, the Training Center focused its training on professionals from US-based Newborn Intensive Care Units (NICUs). Initially, professionals came to Boston for training. Between 1985 and 1989, students from the University of Washington Graduate School of Nursing came to the Brigham and Women's Hospital NICU for a clinical rotation to learn about NIDCAP and its implementation. By the mid to late 1980s, Dr. Lawhon and Dr. Als

began to travel to other states to train professionals in the NID-CAP approach. One of their first training experiences outside of Boston was at the Oklahoma Children's Hospital in Oklahoma City, Oklahoma. Martha Holmes, MSW had come to Boston to learn about NIDCAP. Upon her return to Oklahoma Children's, a neonatologist from her unit, Roger Sheldon, MD invited Drs. Als and Lawhon to train in their NICU. In 1986, their unit was the second in the US to become a training center and it was the training there that helped Dr. Als and Dr. Lawhon to better formulate a clear process, structure, materials and curriculum for NIDCAP training.

Between 1990 and 1995, a great deal of NIDCAP training was accomplished. This included across the Northwest of the US as well as Hawaii and Alaska through Dr. Lawhon's role as part of the NICU Transition Project and NICU Follow-Through Project. This initiative was funded by the U.S. Dept. Education and the University of Washington Child Development and Mental Retardation Center, with Rodd Hedlund, MEd as the Director. Dr. Als and Dr. Lawhon also trained in Oakland, California, Albuquerque, New Mexico, Madison, Wisconsin and Tucson, Arizona, laying the foundation for future NID-CAP training centers. The NNTC team introduced hundreds of NICU professionals to the NIDCAP approach in these early years and brought many of them to certification.

Reflective Processing

Reflective process consultation became an essential component of the NIDCAP Training process through the connection that Linda Gilkerson, PhD, of the Erikson Institute, had with Dr. Als and Dr. Lawhon in the late 1980s. At that time, Dr. Gilkerson became a co-investigator on Dr. Als' US Department of Education funded research study that focused on understanding NIDCAP's effectiveness in five different infant hospital settings (four NICUs: deliveries in inborn versus outlying



hospitals and primary versus conventionally scheduled nursing; and one special care nursery). Dr. Gilkerson consulted to Dr. Als' research team on a regular basis. Her reflective process approach was determined to be essential for developmental care due to the nature of the developmental care itself, which is theory-guided, systems-oriented and, as all of Dr. Als' work, relationship-based. Her collaboration and friendship with Dr. Als had a lasting impact on the NIDCAP training model. It shaped their thinking about the essential nature of relationships within hospital care and throughout life. Dr. Gilkerson became an essential collaborator and advisor to the NNTC.

Research and Dissemination

Dr. Als successfully secured government and foundation funding to conduct many research studies that would serve as further evidence for NIDCAP's effectiveness. The research that emanated from the NNTC via Neurobehavioral Studies inspired others across the globe to replicate and expand NIDCAP studies to support its integration into infant intensive and special care settings.

In the late 1970s and 1980s, Frank Duffy, MD, Neurologist, and Gloria McAnulty, PhD, Neuropsychologist, both of Boston Children's Hospital believed in Dr. Als' vision, approach and determination to improve the lives of fragile children and their families. This began a decades long collaboration on the effects of NIDCAP on brain development and function, deepening the evidence base for NIDCAP's effectiveness.

In 1986, the first NIDCAP study was published in Pediatrics. This was just the beginning of Dr. Als' decades long prolific scholarship at Boston Children's and the NNTC. Dr. Als, a proponent of documentation of the positive effects of NIDCAP on infants, children, families, their caregivers, and the health care system, instilled these values in her NNTC team. She and her colleagues went on to publish more than 30 original publications based on her research investigations of NIDCAP and APIB. These investigations were supported by, National Institutes of Health, the US Department of Education, the Charles H. Food Foundation, Merck Family Fund, the Irving Harris Foundation, and The John and Geraldine Rickard Weil Foundation. In addition, Dr. Als and her NNTC colleagues published more than 30 book chapters on understanding preterm infant behavior. Samantha Butler, PhD carries on this practice with publications regarding the implementation of NIDCAP in cardiology.

Dissemination of the NIDCAP program and its effectiveness was achieved through presentations as well. Dr. Als was an internationally recognized leader in the developmental assessment and care of preterm and high-risk infants and was world renowned for her inspiring presentations. Since the NNTC's inception, she delivered over 120 presentations to local institutions and organizations, such as Grand Rounds at Massachusetts hospitals and universities, as well as more

Dr. Als was an internationally recognized leader in the developmental assessment and care of preterm and high-risk infants and was world renowned for her inspiring presentations.

than 140 presentations, primarily keynote speaking engagements, throughout the United States. In addition, she gave more than 130 international presentations, including one or more presentations at nearly every one of the NIDCAP Trainers Meetings.

Most recently, Dr. Als presented at the Cardiac Neurode-velopmental Outcome Collaborative, opening the door to a new world of providers interested in developmentally supporting their patients and families. Drs. Als and Butler had the first opportunity to present together on the NNTC and NIDCAP efforts in Boston at the Translational Neuroscience Center at Boston Children's Hospital and Harvard Medical School in 2021. In November 2022, Dr. Butler will give Grand Rounds in Psychiatry in honor of Dr. Als.

Training and Certification

As dissemination of the research results increased, so did the demand for NIDCAP training. By 2001, Dr. Als had supported and trained many NIDCAP professionals and trainers that led to the establishment of 12 US training centers and one European center (Sweden).

Although the NNTC began as a "national" center for training in the United States, it expanded to international training in the late 1990s with Dr. Als' training of Agneta Kleberg, PhD in Sweden, which then allowed easier access to training for European nations. Over the course of her directorship at the NNTC, Dr. Als supported over 225 individuals to become NIDCAP Professionals, more than 25 Professionals to become NIDCAP Trainers, four NIDCAP Trainers to become NIDCAP Master Trainers and three NIDCAP Trainers to become Senior NIDCAP Master Trainers. The NNTC has supported the training of, if not directly trained, all of today's trainers and Dr. Als' consulted to each established NIDCAP Training Center. As of her passing, there were 28 active training centers.

Dr. Als' direct training focus became increasingly global, with training across six continents. Most recently, she hosted visiting professionals from countries including China, Korea and Taiwan and travelled to Iran. With the aid of UNICEF, Dr. Als conducted NIDCAP training in Iran and certified 10 NICU physicians and nurses as NIDCAP Professionals.

Over the last ten years, Dr. Als supported Dr. Samantha Butler in bringing NIDCAP to cardiology at Boston Children's Hospital with the training of professionals in the Cardiac Intensive Care Unit and the Acute Care Cardiology Unit, expanding the reach of NIDCAP outside of the Newborn Intensive Care Unit environment.

With the onset of the pandemic, Dr. Als led the effort to develop a formalized online training process. She began to transition to semi-retirement and transfer her direct training to other trainers while maintaining an advisory role. Despite this transition, she maintained a key role in the online training process of NICU professionals from Rwanda, as well as, Zambia. In addition, she was engaged in online APIB training of a physician from China.

The NNTC, under the authority of Dr. Als, aimed to provide advanced training for NIDCAP Trainers to move to NIDCAP and APIB Master Trainer status to enhance training availability for the development of additional trainers and training centers. This was a particular focus of hers over the last ten years. The NNTC team has maintained the importance to fulfill the critical role in safeguarding the excellence of the approach and of the various levels of professional training established and conducted by others.

The Establishment of the NIDCAP Federation International

Research, dissemination and training have always been at the core of the NNTC and its base Neurobehaviorial Studies. In addition to the direct training of professionals, the NNTC produced, updated and distributed the NIDCAP Training Program materials and assessed the need for updates, improvements and the assurance of its quality. Up until 2001, as Dr. Als wrote, "...the NNTC had the responsibility, charge and challenge of the timely and substantive training, consultation, and guidance of trainers and training centers around the world." Dr. Als consulted to each of the trainers and centers. Additionally, the NNTC organized the annual NIDCAP Trainers Meetings, from invitations to program planning, and developed and maintained the training database that documented training across the globe.

In the years leading up to 2001, it was evident that a structured organization was necessary to oversee the growing global demand for NIDCAP training. Therefore, the NIDCAP Federation International, Inc (NFI) was formed, and incorporated, as a non-profit (501c3) professional membership organization in Massachusetts in 2001. Several members of the NNTC,

past and present, are founding members of the organization including, Dr. Als, Dr. Lawhon, Dr. Buehler, Dr. Gilkerson and Dr. McAnulty. Dr. Als was the first President of the NFI from 2001 to 2012. She was also the Chair of the Quality Assurance Committee from 2001 to 2012, and the newly formed Program Committee Chair from 2012 to 2018, and the Co-Chair of the Program Committee from 2018 to her passing. Following Dr. Als' tenure as NFI President, Dr. Lawhon served as President for four years and now Dr. Buehler is the current NFI President, serving in her seventh year. Dr. McAnulty has been the Treasurer and Chair of the Finance Committee since 2001. Sandra Kosta has maintained a role in the NFI since its inception, as Secretary, Assistant Treasurer, Board Member and currently the Executive Director of Administration and Finance. The responsibilities that were once solely that of the NNTC were now spread under the authority of the NFI Board of Directors. As many members of the NNTC held key positions in the NFI, the work of the NNTC became more heavily focused on quality assurance, the development of policies, the NFI website, and the financial management and sustainability of the organization.

Since many of the programmatic and training responsibilities were the responsibility of the NNTC, it became important to recognize that a succession plan was necessary to sustain the level of oversight, development and quality of training. The last ten or more years were spent executing this succession plan. Dr. Als stepped away from the NFI Presidency making way for others to assume the organization's leadership. She prepared Dorothy Vittner, PhD to serve as the Chairperson of the Program Committee to assure the continuity of the training process. She finalized the Master Training status of several individuals who now train Trainers to guide and mentor others in the approach, thus securing the future of NIDCAP in newborn intensive care settings and beyond.

Members of the National NIDCAP Training Center Current

In addition to Dr. Als, who served as the NNTC Director from its inception until her death in August 2022, the NNTC has a small though dedicated group of individuals who maintain the operations of the center.

Gloria McAnulty, PhD, has collaborated with Dr. Als on infant behavior and brain studies since the mid- 1980s. In the 1990s, Dr. McAnulty became an integral part of the research studies as statistician and neuropsychologist and co-investigator disseminating the results. She served as the NNTC's Senior Developmental Care Educator.

Sandra Kosta, BA, joined Neurobehavioral Infant and Studies in 1990 as a Research Study Coordinator, and was engaged in all things related to the research process from scheduling studies to testing research patients to data analysis and grant



Former Members of the NNTC, left to right, Deborah Buehler, gretchen Lawhon, Deana DeMare, Laurie Mouradian, Christine Fischer, and Nikk Conneman

and publication writing. Simultaneously, under the NNTC, she managed Dr. Als' training efforts, as well as the training database as the Developmental Care Education and Training Facilitator. In addition, she managed the organizational aspects of the annual Trainers Meetings.

Frank Duffy, MD, Dr. Als' beloved husband, pediatric neurologist and research colleague has been instrumental in understandings of brain development. This knowledge has been integrated into NIDCAP's philosophy, caregiving approach and training program. Dr. Duffy has collaborated, since NIDCAP's inception, on the research documenting NIDCAP's effect on brain function. Most recently, has been developing a computerized program for digital scoring of the APIB.

Samantha Butler, PhD, began her career at Neurobehavioral Studies in 2001 as a Research Associate participating in the NIDCAP research studies. She is certified in the APIB and recently became a NIDCAP Trainer. She currently is the Director of Inpatient Neurodevelopment in the Cardiac Neurodevelopmental Program where she is working to implement NIDCAP into the Cardiac Intensive Care Unit and Acute Care Cardiology Unit at Boston Children's Hospital. Dr. Butler will assume the role of NNTC Director.

Former Members of the NNTC

Over the years, the NNTC has been host to many professionals who came for work, internships and fellowships. The following individuals became NIDCAP Trainers and/or Center Directors at training centers beyond the NNTC:

gretchen Lawhon, PhD, as described earlier, was integral to the early beginnings of the NNTC and remained a Trainer with the NNTC from 1984 through 1994 and was Co-Director of the Center from 1989-1994. She returned to the NNTC as Co-Director and Trainer from January 2003 through July 2005. Dr. Lawhon went on to have center directorships at two other training centers: the SAPTA NIDCAP Center at Toledo Children's Hospital in Toledo, Ohio from January 1995 through December 2002 and The Mid-Atlantic NIDCAP Center at The

Children's Regional Hospital at Cooper University Hospital in Camden, New Jersey from August 2005 through December 2013. Dr. Lawhon is currently a NIDCAP Master Trainer with the West Coast NIDCAP and APIB Training Center.

Deborch Buehler, PhD, also an early member of the NNTC, began as an APIB and NIDCAP Trainer. She remained at the NNTC from 1982-1995. Upon moving to California, she became affiliated with the West Coast NIDCAP Training Center, which at the time was in Palo Alto, CA. Dr. Buehler continues to do APIB training all over the world and is currently the Director of the West Coast NIDCAP and APIB Training Center at University of California San Francisco School of Medicine.

Deana DeMare, PT, worked at Neurobehavioral Studies as a Developmental Specialist and was an integral member of the research team from 1989 to 1993. Ms. DeMare went on to become a NIDCAP Training Center Director and NIDCAP Trainer with the Mid-Atlantic NIDCAP Center at The Children's Regional Hospital at Cooper University Hospital in Camden, New Jersey.

Laurie Mouradian, PhD, volunteered in the Neurobehavioral Studies in the late 1980s to the early 1990s while an occupational therapy doctoral student in Boston. During this time, she was mentored and trained in NIDCAP and APIB by Drs. Als and Buehler. She became a NIDCAP Trainer and she went on to become the Director of the Sooner NIDCAP Training Center at the University of Oklahoma Health Sciences Center in Oklahoma City, Oklahoma. Dr. Mouradian was instrumental in developing and expanding an extensive network of developmental care implementation for the State of Oklahoma and neighboring states.

Christine Fischer, MD, a physician from Heidelberg, Germany, came to NNTC in 1998 as a Research Associate and became a NIDCAP Trainer. Dr. Fischer's career path led her to become a doula and a lactation consultant supporting mothers, newborns and families.

Nikk Conneman, MD, a neonatologist from Leiden University at the time, was a member of the NNTC between 2001-2002. Already a NIDCAP Professional when he arrived, he wished to pursue the path to NIDCAP Trainer. During his stay, he mentored Samantha Butler, PhD as part of his NIDCAP Trainer training under the supervision of Dr. Als. He was also an integral part of Dr. Als' research studies. He is currently a NIDCAP Master Trainer and the Center Director of the Sophia NIDCAP Training Center, Rotterdam, The Netherlands.

The Future of the National NIDCAP Training Center

Dr. Heidelise Als will be sorely missed by the NNTC family. We will work to carry on her teaching through training, research and dissemination. We will continue to support training in our home hospital in both neonatology and cardiology. We are hopeful to begin training outside of our hospital in the next few years with the interest of several cardiac units. We will continue to advocate for NIDCAP care for all patients, including older infants and children. We will continue to provide documentation of the usefulness of NIDCAP through grant funded research and publications.

Dr. Duffy, Dr. McAnulty, and Ms. Kosta, continue to work on the development of a computerized automated reduction of the APIB's raw score variables to summary variables. Drs. Als and Buehler began to update the APIB manual and this work will continue with the support of Dr. Butler. Dr. Als and the NIDCAP Nursery Program Steering Committee were working to update the NIDCAP Nursery manual and this work will also continue to move forward.

The basis for the NIDCAP approach and the NFI has its roots within the NNTC. Forty years ago, Dr. Als planted the seeds for new growth in the area of understandings of infant development and support for infants who are hospitalized, for their families, for the healthcare professionals and staff members who care for them, as well for their hospital and community systems. Dr. Als' colleagues have worked with her for the last 40 years to foster the growth, to disseminate the knowledge, to support and expand training efforts. The National NIDCAP Training Center team is committed to fostering the legacy of Dr. Heidelise Als and improving the future of all infants in intensive care and their families.

Acknowledgements

The National NIDCAP Training Center Team has made and continues to make great strides in NIDCAP training, dissemination and preparations for the future. None of this work would be possible without the support of charitable donors inspired by the mission, most especially the Irving Harris Foundation. The NNTC team is grateful to the Harris Foundation for their decades long (1990) support of Dr. Heidelise Als, her research effort, her training center and our mission to secure the future of NIDCAP. We wish to further acknowledge and thank the *John Leopold and Geraldine Rickard Weil Memorial Charitable Trust* and the *John and Deborah Buehler Family Foundation*, both of whom have supported the National NIDCAP Training Center in their effort to secure the legacy of NIDCAP.



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The following articles are reproduced from the Developmental Observer as a testament to the breadth of the thinking and work of Dr Heidelise Als.

From the Developmental Observer 2007, Volume 1, Number 2

Preparing to See and Seeing

ne of the perhaps less visible threads of the NIDCAP journey is the life of my son Christopher Markoe Rivinus Duffy. Christopher, born fullterm, sustained brain injuries during the delivery process and has taught me the essence and importance of seeing a child, seeing the child's strengths, while being fully aware of and embracing his disabilities as part of him. Seeing him and seeing the world, including myself, with his eyes has opened my own eyes, and continues to make me more aware and conscious. It has shaped my life and career, and has offered me the gift to see infants and parents in a deeper way. Christopher informed my decision to study human behavior in greater depths. I learned that intuitive parenting¹ must become conscious parenting when the child's individuality portrays behaviors other than human expectation has prepared us for in the thousands of years of evolution to be good enough parents. I also learned from Christopher that each child actively shapes the adults and the environment around him or her, and that the adult, who becomes aware and has the emotional where-with-all to open earlier well-practiced ways, and see the child, becomes the better for it. This mindfulness and the attunement to grow oneself, shape the environment and all interaction to nurture, bring out the best in, and cherish the other person, is the mark of a trusting relationship. Children, who are unusual, help us better appreciate the dynamics of all children's development, and help us understand that all children are unusual, uniquely talented, and individual. We learn that what is good, and perhaps necessary to support the unusual child, is good for all children, and for all persons, and all relationships. Bowlby's volume on Attachment² partly validated my thinking. Yet I disagreed that the human newborn infant only keeps the mother close by crying, until

"I found it difficult to imagine that as a species, we would survive if no other infant stimulus but crying kept us engaged for the first six weeks."



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

at about 5 to 6 weeks. I found it difficult to imagine that as a species, we would survive if no other infant stimulus but crying kept us engaged for the first six weeks. Our ancestors likely would have discarded us a long time ago. As it turns out the newborn's eye opening and eye contact is the great reward that as adults we quite intuitively work and live for.³⁻⁵ When that eye contact is hard to come by, when its occurrence, characteristics, or frequency violate the adult's expectation, the interaction threatens to derail. However, when the parent becomes conscious of the infant's profile and the intuitive interaction's difference, the ensuing self-awareness and awareness of the child's individuality may help the parent right the relationship and interaction.

In order to understand these neuro-biologic-social-affective processes more fully, I spent a year rich in experience and learning at the Behavior Development Research Unit (BDRU) at St. Mary's Hospital in London, UK. Anthony (Toni) Ambrose, PhD,^{6,7} Director of the BDRU, studied the dynamic parameters of pregnant women's walking in order to test a gait-simulating moving cradle, in an effort to soothe unusually irritable newborns. Genevieve Carpenter, PhD,^{8,9,10} also at the BDRU, identified how very early newborn infants reliably distinguish their mother's face from another woman's face. Olga Maratos¹¹ then a Greek doctoral student at the BDRU in 1972, now Professor of Psychology at the University of Athens, discovered the newborn's capacity to imitate specific facial ex-

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

In an effort to deepen my knowledge and understanding, I then joined T. Berry Brazelton at his newly founded (1972) Child Development Unit, at Children's Hospital Boston. His generous mentorship and brilliant teaching convinced me of the importance of translation of clinical expertise into empirically testable questions. The opportunity to operationalize clinical skill and insight helped me focus my research on the fullterm infant's strengths and capacities, the openness of the parents¹⁸⁻²⁰ to hear and see, and to seek and accept support as at no other time in their lives. I learned about the infants' and parents' striving for connection and relationship from the first moments on. I learned that infants will struggle to connect with the parent, and vice versa, even in the face of an infant's intrinsic difference, 21-25 and in the face of experimentally imposed violation of expectation such as in the still-face mother paradigm.^{23, 26-29} Not least, my growing son Christopher helped me understand this striving manifold, and at times at more cost to him than I wished, he had to pay. These experiences prepared and motivated me to venture and attempt to see anew, with better skilled eyes, the preterm infant requiring intensive care.

In 1975, now at the Boston Hospital for Women, Lying-In Division, my goal had become to learn to read and understand the language of the preterm infant, to learn and document what the preterm infants experienced, how the NICU experience influenced and shaped and perhaps inadvertently changed and possibly damaged the infant. For the next year or so I observed, wrote, rewrote, and edited repeatedly the basic dictionary of the infants' communications in the face of various events and circumstances. I realized that the behavioral messages involved various subsystems and that depending

on the challenge and/or the immaturity or illness of the infant, even the most basic autonomic system functioning might be overtaxed and become overwhelmed.³⁰ The infant might simply stop. Often my own helplessness frightened me, yet the infants' and the caregivers' determination in turn assured me that they somehow tried their best to work together at this life too early outside the womb. I felt pressure to translate my observations into a coherent system that would be usable by others. I wanted to articulate the subsystems in their interplay and fluctuating relationship to one another and to the environment and events that occurred with, to, and around the infants, in order to support those who cared for the infants to see them as their collaborators and recognize their goals, determination, and their strengths, as well as their thresholds to stress. The Assessment of Preterm Infants' Behavior^{31, 32} took

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

shape together with its core, the systems sheet. I sketched and re-sketched the complex sub-systems in interaction, struggled with images and words, and wrote and re-wrote what became the Synactive Theory of Development.³³

In the effort to see and take seriously the support to the infant in helping the infant achieve his or her own goals, close communication and collaboration became essential with those who cared for the infants in the NICU, and who structured their environments. Pat Linton Thompson, and soon gretchen Lawhon, NICU nurses at the time, were the brave pioneers, who first removed the ties that held an infant's arms and legs in place; bedded an infant on the side; made soft nests for the infant to cuddle and tuck into; covered the infant to feel more secure, and the incubator to shield the infant from the bright lights; assured a comfortable chair for the parents at their infant's bedside; supported the parents to hold their tiny infant; and assured the neonatologists that all this was not only safe, but also supportive of the infants' and their parents' development. All the while, the detailed infant behavioral observations helped us stay true to each individual infant and assured us of the current appropriateness of the modifications and adaptations of care. Rita Gibes, RN, MSN, NICU Head-Nurse at the newly merged Brigham and Women's Hospital, quickly recog"We are all connected; we mutually support, teach, learn from, and enrich one another."

nized the great advantages this approach entailed, and became the first leadership professional to support the individualized developmental approach to care. She was a courageous change agent par excellence and insisted on the first ever installation of individual lights with dimmer switch capacity above each warming table, incubator and crib; an invitation to the parents to be with their infant at all times; and advocated for us and our observations and care modifications. She established the first ever "developmental care clinical nurse specialist" position for gretchen Lawhon. In addition, she insisted that the approach required its own name in order for others to adopt it. She coined the acronym "NIDCAP."

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

Around the same time, Christopher, now a young man, prompted my husband Frank Duffy and me to find an environment and life setting that built on similarly synactive principles as did the NICU work. After heart breaking searching, visits, and experiences at the traditional adult environments for persons with disabilities, we miraculously found Camphill Village Copake, an anthroposophical village, based on the principles of Rudolf Steiner, (1861-1925) an Austrian philosopher, who mainly worked and lived in Germany. His conceptualizations also underlie the Waldorf Schools. He inspired Karl König (1902-1964), the Austrian pediatrician and specialist in learning and developmental disabilities, who then founded the

Camphill Movement, an international movement of therapeutic "intentional" communities for those with special needs or disabilities, where all may thrive, as they live and work together. Just as in the NIDCAP work, the Camphill social and relationship-based fabric, and work and life environments aim to bring out, liberate, develop, and cultivate the competence, creativity, fulfillment, and mutual caring in every person, no matter their talent. While ending this essay, I continue to learn from Christopher, from my husband, all those who make Camphill the special place it is, from those engaged in the NIDCAP work and world with me, and from all the infants and families and the professionals who care for them. We are all connected; we mutually support, teach, learn from, and enrich one another.

To be continued.



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Message from the NFI President

The Courage to Trust



When recently visiting a relatively wealthy North African country, I had the opportunity to visit the capital city's University Children's Hospital NICU. Iron grey, factory-like open hall with cold fluorescent ceiling lights over metal cots and large, bulky milky-plastic incubators

lined up along a seemingly endless long wall. Shrill alarm, pager and telephone sounds incessantly pierced the air. I had come with high expectations. Suddenly I felt transported back to the NICU-world of the 70's in the United States. Despite the Internet and on-line worldwide access to many professional publications, and numerous international medical congresses, thousands of emaciated and limp infants, clad only in huge plastic diapers, still lie on their backs, depressed and alone in many countries and cities all over the world. Newly admitted infants, arching and protesting their treatments and abandonment quickly become subdued by relentless routine intensive care that emphasizes equipment and antiseptic procedures above all else.

It is difficult and painful to remember that just 30 years ago most NICU care was like that. Only professionals were admitted to the Unit. Loudspeakers overhead incessantly announced lectures and doctors' pages from anywhere in the entire hospital. Cleaning buckets and buffing machines, and those who operated them, merrily entered the NICU at any time. Staff members, well intentioned, called to one another from the entrance door to the farthest incubator's nurse and doctor.

The understanding we have gained over the past three decades in reading the infant's language has made it increasingly clear that the parents are quintessential and critically important to ease the infant's often abrupt and unexpected transition from the womb to the NICU. We have learned that

parents are the best medium for healing and development. Gradually parents' presence has become increasingly familiar to the technically trained NICU staff. Early on, parents were often relegated to standing at the incubator for short periods of time, as they gradually gained the trust of the staff that indeed they know and care deeply about their infant. Yet they also dutifully leave when the messages (whether spoken, in gesture, explicit in the emotional ambience, or the physical environment) tell them that they have outstayed their welcome. Often the parent booklet they receive states explicitly that they are invited to come at any time, 24 hours around the clock. Yet, still today in too many NICUs, even in those with individual family rooms for each infant and family, it's still a struggle for staff to live up to their own best proclamations. The mother or father who comes to be with their infant at seven o'clock in the morning and reluctantly leaves at eleven o'clock at night, may still today, in a modern NICU, be described as "controlling" and mistrustful of the staff's skill and caring. Much staff education, emotional support and guidance is still required to effectively enhance staff confidence and trust to truly value the parents as collaborators and their infants' foremost caregivers, nurturers, and life-long safe havens. Less psychologically demanding innovations over the last 30 years have become standard care by now in many US and European NICUs (e.g. all infants have nests and many incubators are covered; everyone appears to know about the importance of non-nutritive sucking, of support to midline positions, and of the values of skin-to-skin holding or kangaroo care). The bigger step is the astute appreciation of each infant's thresholds to stress and the conclusions to draw from this recognition for the individualization of care and experience for infant and family, including: the slow pacing of care; feeding only while holding the infant; support to falling and staying asleep while held for prolonged periods; and the many subtle aspects that truly enhance an

infant's competence and reduce stress. While everyone is concerned about brain growth and nutrition, the way the nutrition is delivered and received by infants still poses a challenge. The infant's active partnership in all care collaboration, the only way that care may become effective as intended, is a continued and active topic for staff education.

The situation becomes startling when all of the considerations are still below the threshold of conscious staff awareness: a NICU where mothers come reliably every morning to bring the milk that they have pumped at home for their infants and pass it through a small window to an anonymous hand on

"Each infant and each family count. Each infant and each family are valuable. But where to begin? Anywhere is better than not at all: one infant and one family at a time; one nurse and one doctor at a time; one NICU and one hospital at a time; one city and one country at a time. This is the only way to create the necessary change."

the other side; where parents come every day at a fixed hour in the afternoon for 10 minutes to stand in a dilapidated corridor and look into the NICU through a dirty, milky, scratched glass window, to see only the incubators and perhaps catch a glimpse of their infant's feet as they extend toward the foot end of the incubator; or hear an infant, maybe their own infant, cry with no one to attend to and comfort the upset child; where nurses with sad, yearning eyes wistfully care for their forlorn charges with little hope to find understanding from their leadership; and where money is spent on technical innovations yet is not available for pacifiers, blankets, chairs, and support and education to nurses and young doctors, who are still hopeful and seek to make a difference. Every day the staff cares for the

smallest and sickest infants, every day they sustain the pain of their forlorn charges, their emotions and creativity held down, restricted and bent to the rules that govern the system from the top. When death is almost hoped for and is the likely future of a preterm infant; when families are left to their own devices for rehabilitation and care should their infant survive the NICU; when even those with minor disabilities can expect a future fraught with difficulties; then NIDCAP and the NIDCAP stance and spirit are very much warranted as critical care components within the hospital system.

NIDCAP, a systems approach, helps bring about systemic change, not only NICU and hospital system change, but also societal and political system change. Each infant and each family count. Each infant and each family are valuable. But where to begin? Anywhere is better than not at all: one infant and one family at a time; one nurse and one doctor at a time; one NICU and one hospital at a time; one city and one country at a time. This is the only way to create the necessary change.

The medical visitors to this NICU were taken "on tour by the medical director," while the nurses stepped out of the way. As there were no explicit rules for psychologists, I took the liberty to look and smile at the nurses. They gathered quickly around me, and despite our language barrier, they clearly were eager to learn why I was there. In just a few minutes we stood together at a bedside and watched a little boy, who was severely growth restricted, lay flat on his back, flailing his arms, his shoulders retracted and pulled high up to his ears. He arched and screamed in utter despair with his mouth wide-open, ashen grey despite his arousal. I gestured that he might enjoy being tucked in and have something to suck on. The nurses shook their heads in sadness. He was not allowed to eat now. I tried to convey that sucking might help even without food. They looked at me, incredulous. They had never heard of pacifiers and the hospital had none. With gestures and mime, one nurse understood the concept and went to fetch a nursing bottle. We fashioned a pacifier out of the nipple and stuffed it with a piece of cotton cloth. "Now what?" they seemed to ask. When I then supported and guided one of the nurses to open the incubator and gradually place her hands around the infant's feet and legs and speak to him softly, then gather his hands in her hands, this helped his shoulders to relax, and he gradually looked at the nurse and calmed somewhat. When I now guided her to help him onto his side and to cradle him with her right arm, she spontaneously, with her left hand, supported his grasp, and all the while she spoke very softly to him, her eyes became shiny, her face soft and caring. The other nurses stood and watched, astounded and taken by the little boy's visible transformation in interaction. One nurse went to get some more of the cotton cloth and we made a soft cradle roll to support the little boy along his back. The nurse engaged with him, gently took the makeshift "pacifier" we had made, and held it close to the infant's lips. While still crying softly, he grasped the pacifier with both hands and pushed it into his

mouth, sucked like fury, and looked with wide eyes directly at his nurse. She in turn was glued to him and kept her eyes on him. Her hand cradled his body and she slowly covered him gently with another cloth that her colleague miraculously produced. The little boy gradually calmed and drowsed off to sleep, as the pacifier dropped out of his slightly parted, relaxed lips. Very gently the caregiving nurse pulled her hands one by one out of the incubator and softly closed its doors. Her face, her posture and her whole being had changed, becoming soft, fluid, and caring. The nurses crowded in on me. How can they learn more? How will they convince the doctors to help them learn more? How will they bring in the mothers and fathers? The bravest of the nurses, who had just helped the little boy, confided with tears in her eyes that she had smuggled the father of one of the infant's into the NICU several times in the evening, when she felt it was safe. She had observed what it meant to the infant to have his father talk to him and even briefly hold him. No wonder she was so open to try the next step under the guise of my visit.

This is but a tiny yet important seed in the beginning of a garden. I am convinced that with the courage to trust in ourselves, in the infants, in the parents and the staff of nurseries everywhere, we will multiply trust, courage, creativity, and generosity and the effectiveness to bring about change on behalf of infants, families and professionals in intensive care everywhere. Political agendas are made and carried by people. People all share in the same basic human heritage of empathy, caring, and responsibility for one another. NIDCAP must be a spark and an initiative that helps make the thousands of seeds of opportunities, to swell, sprout, and grow, even when seemingly buried deep in arid soils. Together we are strong and will continue to forge an agenda of national and international change and growth.

> Heidelise des Heidelise Als, PhD

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Message from the NFI President

In Pursuit of Scientific Knowledge: The Passion of Discovery

"You are capable of more than you know. Choose a goal that is right for you and strive to be the best, however hard the path. Aim high. Behave honorably. Prepare to be alone at times, and to endure failure. Persist! The world needs all you can give."1



he engagement in research is thought to be addictive; and indeed it shares many characteristics with other addictive agents and activities. Why else would a researcher forgo most of life's common comforts, a decent income, the small luxuries of evenings at home, free weekends, winter

vacations in the sun, and social events shared with friends just for the sake of having fun? The researcher is jealous of every minute frittered away in idleness when it might be spent in pursuit of the elusive goal, the Holy Grail, the finding of a momentary "truth," the discovery of yet another small aspect of the bigger mosaic of an emerging pattern, regularity, the all-consuming passion. The drive is great. Yet so is the simultaneous fear that must be contained, if one is not to succumb to self-doubt. Is the pattern really there? Is it too elusive to be captured; too trivial to be meaningful; too multi-dimensional; too variable, too dependent on too many uncontrollable aspects that blur its shape, or make it vanish all together? The seeds of doubt germinate unexpectedly at any time, sprout in

"Research is the cyclical and ultimate exercise and practice of year-and often decade-long delay in gratification."

the middle of the night; cause the poor scientist to wake up despondent, questioning the clarity of earlier thought, and the thought itself. The feeling of futility, of chasing an illusion, is familiar to everyone engaged in the pursuit of scientific discovery. Yet all it takes to overcome it, gain new hope, regain urgency and momentum, and the energy to press on, may be a validating comment, or a mere glimpse of evidence, a fleeting promise that the pattern, the heretofore elusive phenomenon,

is about to reveal itself. That brings with it elation, and the endorphin release, that makes the struggle all worthwhile and simultaneously launches the next push. "There is no better high than discovery."²

The verification of the dreamed for pattern, the good enough probability, the significant p-value, that emerges from a rigorous design and statistical test, will release a neuro-hormonal cascade that floods brain and psyche with that wonderful feeling and rush: "That's it! It fits! It's so! Eureka! How might anyone ever have doubted it?" No sooner does the brain experience that neuro-euphoria, likely evolved through the millennia, and species-specifically human, when the newly uncovered regularity already pushes to conquer and penetrate the next still amorphous state to reveal its underlying structure, its "truth." And so the cycle continues. As soon as results indicate that what began with a hunch discloses itself as indeed orderly, possesses a reproducible and meaningful pattern that may be articulated and communicated; as soon as the validation of one's intuition, one's best clinical judgment, takes the form of replicability, the researcher feels fulfilled, gratified, and happy, at least in the moment.

Research is the cyclical and ultimate exercise and practice of year-and often decade-long delay in gratification. Each many-year cycle begins with an intuition, an insight, a flash, associated with that pleasurable, scary, neurophysiological feeling of anticipation and promise. From there it evolves to fuller articulation. This is followed by the struggle to design an "airtight" trial to test the intuition's worthiness, and to think of and build in all the controls for all the possible (i.e., currently imaginable) factors that might invalidate the thought. It goes without saying that these factors always are more numerous than ever imagined. By the time they emerge in the process of the trial, it likely is too late to bring them under control. They may well force a redesign and restart. Once the variability within the sample is greater than the variability expected due to the phenomenon under study, the trial is jeopardized, perhaps doomed. The researcher must be brave enough to fail.

Assuming the trial is set to go, next follows the quest for the resources required to conduct the trial, which means to inspire those in possession of the means to share their resources with the dreamer, the applicant. "Normal science" may prefer to distribute resources and funding to those who validate the known, the status quo, well-accepted truths, rather than pursue novel thoughts that might raise uncertainty and discomfort.

And finally the time arrives for trial implementation. The hardest lesson the researcher learns, often painfully and at great cost, is that conducting a trial requires that the current design and methodology (i.e. the best knowledge at the time the trial goes forward), must be held constant until the trial's completion. Inevitably, in the course of any study, the researcher learns a great deal in how to improve on procedures and methodologies, avoid pitfalls not recognized in the beginning, add missing components, etc. Yet modification of any aspect

mid-stream may well invalidate the trial. It is better to do something reliably and systematically, if less than perfect, than to adapt and adjust, as one moves along the path of a trial. A systematically implemented study will yield interpretable results. A "moving feast" will yield regret and confusion and belongs in the development and pilot phase, instead of the trial itself.

"First they laugh at you, then they fight you, and then they say they knew it all along."

– Mahatma Gandhi

Most research trials require collaborators beyond the initiator with the burning question, the principle investigator. Unless the leader is compelled by an urgent mission to uncover the phenomenon under study, he or she may fail to convince the others of its merit, the worthwhile nature of the knowledge to be gained, and the benefit of participation. It behooves the researcher to identify that the benefit outweighs the cost for those important to the trial. Of all the collaborators, one's research subjects are one's most important, most valuable and most precious assets. Shared benefits secure successful research conduct.

To conduct research is often a lonely yet always an exhilarating path that prompts one to confirm and stand up again and again for what one holds most important in one's work and perhaps even one's life. It tasks others to poke holes, and raise questions, doubts and criticism, which in turn serves to sharpen the researcher's thinking and rigor in designing and conducting the next study. When the new discovery, or insight ultimately prevails, and brings about the inevitable sea change engendered by a worthwhile finding, the next status quo, the new "business as usual" is in the offing and thus paves the way for the next revolution.

Research conducted for the sake of insight and knowledge to better the state of humanity and the world will always be fulfilling, satisfying and enriching.²

Heidelise Als, PhD

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Message from the NFI President

Of Jazz, NIDCAP and the Process of Becoming

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

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



J azz has a spontaneity and vitality in which improvisation plays a role. The individuality of the performing jazz musician plays a key role. Travis Jackson states that jazz is music that includes qualities such as improvising, group interaction, developing an individual voice and being

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

set played is unique, new and different, developed each time in its dynamics and harmonies, solos and resolutions depending on the individuality and relationship of voices with one another of those playing together. Each player trusts the other; the interplay is the essence rather than the goal. The infants and families set the themes, as it were, that penetrate and are returned to over and over again, no matter the crescendo of surrounding voices and themes of the staff. Around the infant and family themes the contra-points surge and are resolved again and again yet differently each time. This makes it a challenge to move from a traditional to a NIDCAP nursery. It may be as difficult as moving from being an accomplished classical musician to becoming a jazz musician.

As NIDCAP Trainers teaching, guiding and helping nurseries, i.e. complex jazz ensembles, to come into their own, to trust themselves as partners, trust their interplay and continu-

"As NIDCAP Trainers teaching, guiding and helping nurseries, i.e. complex jazz ensembles, to come into their own, to trust themselves as partners, trust their interplay and continuously become anew, and create themselves, Trainers must have trust and confidence themselves as well as patience and vision."

ously become anew, and create themselves, Trainers must have trust and confidence themselves as well as patience and vision. Teaching the other the basic NIDCAP ingredients and tools is essential until these ingredients are mastered and have become second nature. Such ingredients include among others, astute observation of the interplay of the social and physical environments and the individual infants' behavior; tuning of writing to convey information that retains the emotional dimension of the interactions observed; deriving of specific and guiding interpretations that engender creativity in developing suggestions for next steps; and attunement and emotional presence to become astute in listening and proactive guidance. Once these are achieved and a sufficient core of such basic skills is available the transformation process from the traditional to the NIDCAP nursery is inevitable. Moving forward and creatively becoming is the emerging new theme. Much has been written about the process of change and the ways it may be facilitated. The NIDCAP Trainer's role becomes that of imparting the confidence that everyone counts and is accountable as individual for who he or she is. That presents the teacher's opportunity and yet also the main challenge. To paraphrase Sanford Meisner³: The NICU is "an arena where human personalities interlock in the reality of doing." The "elements in a person's training that will make him [or her] a distinctive... [NIDCAP professional] are... the most delicate factors that a teacher can impart.....One can use standard principles and textbooks in educating people for law, medicine, architecture, chemistry or almost any profession – but not for [NIDCAP]. For in most professions every practitioner uses the same tools and [techniques] while the [NIDCAP Professional's] chief instrument is himself [or herself] and since no two persons are alike, no [universal] rule is applicable to any two [persons] in specifically the same way."

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

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

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Heidelise Als, PhD

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Message from the NFI President

The Importance of Silence

"Eloquium est argentum; silentium est aurum." (Speech is silver, silence is gold.)

-Old Roman Saying

"Don't speak until you can improve on the silence."

-Attributed to Henry Simmons, MD, MPH, FACP, 1990



e all know the challenge of supporting nurseries to become calm and quiet places where an infant may hear the soft comforting murmur of the parents' voice speaking or singing. The deleterious effects of high levels of "noise" in nurseries, toxic to all, infants, families and staff alike,

are undisputed. It is all the more important, therefore, to meet the challenge we face in the nursery by first becoming steady and trustworthy sources of calm and quiet ourselves. Finding and maintaining the silence within so that we may assist others is a continuing process and often a real struggle. Our environment is polluted with sound, taxing and toxic to our well-being. What is it about humans that making noise is such a pervasive phenomenon? Our car doors beep when we open them and again when we close them; beeps remind us to take action with our seatbelts, washing machines and coffee maker alarms. Pedestrians walk about with ear buds that pipe music or podcasts, often loud enough for others to hear, directly into their ears and brains. Waiting rooms are pervasively equipped with television sets often set at high volume levels and non-adjustable. Airports, already oppressive with loudly rattling and clanking luggage carousels, provide travelers with continuous announcements and television newscasts set to increase in volume automatically when a plane arrives and passengers come through the gate into the waiting halls. We attempt to be heard in conversation by speaking at high volumes against this background din. Neighborhoods and whole towns complain about the noise pollution from commuter trains, truck and bus routes; some even must endure life beneath the flight paths of local airports. Communities insist on highway walls to gain at least a psychological protection.

Every so often when it becomes all too much, we attempt to regain our balance, "flee into nature," leaving our electronic devices behind to refresh ourselves, or so we hope, in the quiet and silence of a forest, the mountains, a lake or the ocean. Nature's sounds differ remarkably in their effects on us from the sounds we generate through our technological advances. We fail to recognize this disconnect and as a result our industries spend too little effort on designing and producing psychologically friendly, that is, quiet equipment. Too little aware of our deeply rooted biological vulnerability, we attempt to overcome our sub-cortical responses by cortical override. While our brains have developed impressive habituation mechanisms,

"Nature's sounds differ remarkably in their effects on us from the sounds we generate through our technological advances."

this habituation comes at a high cost and this cost often takes us unawares.

At the beginning of every summer my family and I take our first hike of the season up Little Deer Leap in Central Vermont. It is a grade-3 hike, which takes about an hour and a half up. It is well worth the beautiful view of Pico Peak, the north face of Mount Killington, the Coolidge Range, and the Sherburne Pass. While we walk, after leaving the car at the trail head, the woods become ever quieter; our steps stir up leaves and an occasional rabbit or partridge. The wind's rustle in the trees is soothing and familiar. Yet, finally at the top, looking forward to the rest and view, I am always disappointed, remembering the reason for my annual, yet quite ineffectual, resistance to this particular climb. A strange distant rumbling permeates the quiet. My husband and the children respond to my discomfort by asking: "What rumbling?" to which I reply "Can't you hear the traffic way down on Route 4." Edging to the ledge drop, we see it down in the valley, the ant trail of cars up and down the highway. In vain, I attempt to tune out the sound. Everyone else seems to delight in nature's peacefulness.

"One Square Inch of Silence"

Hardly a place remains in the world that is truly silent, still, tranquil. This, almost spiritual quality, is necessary for silence of the mind, an inner peace and a clearing of our pressing thoughts and preoccupations. To "hear silence," brings openness, inner quietude, an attunement to nature's sounds, and to our inner selves.

There are fewer than a dozen quiet places left in the US, places where natural silence reigns over several square miles. Quiet is now measured in minutes, the number of minutes of

the absence of noise encroachment. A silence of 15 minutes is extremely rare in the US and long gone in Europe, except in the northern most regions of Finland and Norway¹ (p 13). Our ever higher consumption of fossil fuels and the technologies they promote translates into more and more noise pollution. "Even far from paved roads in the Amazon rain forest the drone from distant outboard motors on dugout canoes and from the beep from a digital watch of the guide"¹ (p 13) intrudes on the sounds of nature.

In the US, the national government protected parks provide the hoped for places of escape from the noise and bustle of everyday lives. Gordon Hempton, one of the few acoustic ecologists, has mounted a national campaign to protect at least "One Square Inch of Silence" in the Hoh Valley in the Olympia National Park in Washington State. He quotes William H. Stewart, Surgeon General (1965-1969) under L. B. Johnson, "Calling noise a nuisance is like calling smog an inconvenience" (p 207).

Air-tourism is on the increase. Olympic National Park is the most likely area in the US to retain its natural quietude due to almost continuous rain or overcast skies, reducing air tourism. Yet even this pristine acoustic environment receives no special protection. Tours on demands such as those offered by Vashon Island Air advertise: "We fly past Mount Olympus and deep down into the Valley of the Hoh River, the only non-tropical rain forest in the World." And not a single person on the Park's staff is trained in acoustic ecology. Business and profits trump silence. How long will Hempton be successful in protecting his "One Square Inch of Silence?" By the time a single airplane's sound has travelled far enough to dissipate below audible levels, many square miles have been polluted. And anyone seeking solace will feel disappointed, "unbathed" by the cleansing power of quiet.

The Omnipresence of Anthropogenic Sound

Sound resulting from the influence humans have on the natural world is termed anthropogenic sound. This sound is for the most part noise, i.e. sound that is loud and/or unpleasant or that causes disturbance; it may have irregular fluctuations that accompany a signal but are not part of it and tend to obscure it; it may be confused, senseless and it is always undesired. Noise has become a modern plague found everywhere, at all times, and often at unsafe levels. It has become so prevalent that we take it for granted. It is so overlooked, and so systematically unmonitored that it is not included among the metrics that constitute more than 150 countries' rankings in the Environmental Performance Index (EPI)2 (Fig. 7, p. 18) annually issued by the Yale University Center of Law and Policy to monitor the protection of human health and the protection of ecosystems from environmental harm. Nine issues with a total of twenty indicators are addressed: Health Impacts (Child Mortality); Air Quality; Water and Sanitation; Water Resources; Agriculture (Pesticide); Forests (Change in Forest Cover); Fisheries (Fish Stock); Biodiversity and Habitat Protection; and Climate and Energy. But noise pollution is not among them. Meanwhile our cities grow more toxic with noise, and we "drift towards a nation of shouters. The sound of our footsteps has all but disappeared" (p. 322).

Archeo-Acoustics

This has not always been so. Our world used to be much quieter. So quiet in fact that until recently anthropologists paid little attention to the acoustics of ancient environments, thus overlooking the implications and impact of such quiet daily living conditions. Emergence of the novel fields of "acoustic anthropology" and "archeo-acoustics" reflects the increasing interest in this topic. Steven J. Waller, a biochemist and acoustic anthropologist by avocation, describes a natural occurring acoustic phenomenon appreciated by many early civilizations, which had been intentionally reproduced, to break the silence of earlier times, namely echoes. Echo myths are found in many cultures, often attributed to supernatural entities,3 such as the Native American tales of spirits who speak through portals in rock walls. These ancient myths show that echoes were widely worshipped as divine gods, were considered to be the "earliest of all existence" and were systematically sought out.

When not found naturally, they were created. Ancient builders designed subterranean soundscapes as stirring as any modern movie special effect. When priests at the temple complex of Chavín de Huántar in Central Peru sounded their conch-shell trumpets 2,500 years ago, tones magnified and echoed by stone surfaces seemed to come from everywhere, yet nowhere, supernatural and otherworldly. But there was nothing mysterious about their production. According to archaeologists at Stanford University, the temple's builders created galleries, ducts, and ventilation shafts to channel sound, displaying not only expert architectural skill but also acoustical engineering prowess. 4,5

The findings add to a growing body of research suggesting that controlled natural sound was more important to our ancestors than archaeologists once realized. Today we live in a less thoughtfully controlled sound-saturated society, full of iPods, thunderous special effects in movies, and thousand-watt boom car stereos. These modern acoustic environments result in sonic cacophony while our ancient ancestors may have sculpted their soundscapes in an attempt to reach the divine.

Until very recently, archaeology has been strictly visual.⁶ The acoustic studies at Chavín de Huántar and elsewhere show the value of broadening the field of archeology into acoustic archeology and helping us understand the roots of our manufactured sound world.

The Dangers of Modern Anthropogenic Noise

In stark contrast to the purposeful spiritual, even mystically intended sound phenomena, our modern day technology-generated pervasive sounds not only have little to do with the spiritual but are destructive. Here a few examples.

"Where have all the songbirds gone?" is a popular lamentation of today's bird watchers. The Audubon Watchlist in 2000 listed 25 species of US songbirds in decline; by 2007, 59 species were on the endangered list and an additional 119 species were listed as near endangered. Climate change is a big issue and noise pollution goes hand in hand with climate change. Increase in fossil fuel production underlies both. Our landscapes are losing their voice. Bird song-ranges are shrinking. Birds have been found to adapt their songs so as to be heard above the din of rural and urban noise pollution. And whole song repertoires already have been lost. Human activity has caused an, in evolutionary terms, sudden rise in, especially, low-pitched noise levels.^{7,8} These frequencies are detrimental to birds through direct stress, masking of predator or associated danger calls, and by general interference with acoustic signals, which serve mate selection, offspring protection, and territory defense. Significantly reduced reproductive success has been documented in noisy territories. 9, 13

"For humans noxious sounds and smells are impossible to ignore, processed by sense receptors which have evolved specifically to protect us from toxins."

Similarly toxic noise effects have been documented in oceans where they affect large mammals such as dolphins and whales. Oil industry's seismic explorations and drilling, the low rumble of the ever growing number of commercial ships and, likely most harmful, military sonar, have been implicated in the increasingly high number of dolphin and whale strandings and deaths. Despite these concerns all efforts to modify or eliminate, especially military sonar emissions, have been overruled by presidential decision claiming paramount security interests of the US.^{14, 16}

The word "noise" stems from Latin nausea, meaning disgust, annoyance discomfort, and literally seasickness. The later Old Provencal nauza refers to quarrel. For humans noxious sounds and smells are impossible to ignore, processed by sense receptors which have evolved specifically to protect us from toxins. While we have passed odor laws, we are slow to acknowledge the need for noise pollution laws.

William Stebbins¹⁷ points out that in the course of evolution mammals capitalized on the sense of hearing more than any other vertebrate or invertebrate group. The range of human hearing far surpasses the requirements to hear spoken

language or even to appreciate music. Human hearing graphed by frequency range and decibel level shows that human speech encompasses the center of the range. Sounds produced by musical instruments and appreciated by the human ear extend well beyond the human vocal range. Yet even beyond the sound range of our musical instruments there are many sounds, namely natural sounds that the human ear is capable of perceiving. Human hearing is exquisitely sensitive.

Moreover, the human hearing mechanism is always turned on.¹⁸ After humans have habituated to a sound, and even in sleep, the human body nevertheless responds to noise. The elicited nervous system, hormonal and vascular changes, the fight or flight response, has far reaching consequences. Noise, even at levels that are not harmful to hearing is perceived subconsciously as a danger signal, alerting epinephrine, nor-epinephrine and cortisol level secretions. 19 And loud enough noise leads to hearing loss: The World Health Organization (WHO) based on the work of Berglund and Lindvall20 among other research, recommends that unprotected exposure to sound levels greater than 100 dB, (jackhammers, snowmobiles), should be limited in duration (4 h) and frequency (four times/yr). The threshold for pain is usually given as 140 dB (boom-cars). Adults should avoid exposure to impulse noise (gunfire and other intense brief bursts e.g. from firecrackers, cap pistols, and other toys) above 140 dB with a limit of 120 dB for children. Exposure may result in sudden and permanent hearing loss. Levels greater than 165 dB, even for a few milliseconds, are likely to cause acute cochlear damage. As stated by the League for the Hard of Hearing: "Ears do not get used to loud noise - they get deaf."

Even when not leading to hearing loss, noise pollution interferes with spoken communication. By affecting language comprehension it may lead to a number of disabilities and behavioral changes such as problems with concentration, fatigue, uncertainty, lack of self-confidence, irritation, misunderstandings, decreased working capacity, disturbed interpersonal relationships, stress reactions and increased aggression. Some of these effects may lead to increase in the frequency of accidents, disruption in the classroom, and impaired academic performance. ²⁰⁻²² Particularly vulnerable groups include children, the elderly, and those not familiar with the spoken language. ²³

Despite the evidence of the medical, social, and economic effects of noise, including those incontrovertibly resulting from sleep disturbance, noise pollution is increasing in our cities. It impairs the ability to enjoy one's property and leisure time and increases the frequency of antisocial behavior.

Noise makers and the businesses that support them are as reluctant as smokers to give up their bad habits. It is clear from the statistics on reduction of smoking, that laws can change undesirable behavior; laws could also change noise reduction in ways that would benefit society as a whole.

The Urgent Importance of Chosen Silence

As a direct response to the continuous auditory assault, many are choosing to offset the toxic effects with chosen silence,

be it through yoga, retreats, meditation or other silent practices. Historically, chosen silence has been linked to religious practice such as the vows of silence taken by Christian monastic orders and also known as Mauna [the Silent One] in Hinduism, Jainism, and Buddhism. Examples from antiquity are Pythagoras of Samos (circa 570 – circa 495 BC), the Ionian philosopher and mathematician, who imposed a strict rule of silence on his disciples; in ancient Roman religion, the Vestals or Vestal Virgins (circa 720 – circa 380 BC), priestesses of Vesta, goddess of the hearth, also were bound to severe silence for long years. Prophets have gone into the wilderness for long periods of silence and meditation. Christian religious orders such as the Benedictines, Cistercians, Trappists, Carthusians, and Carmelites incorporate silence to this day as one of the essential rules of their communities. Other examples are Days of Silence such as Good Friday in the Catholic tradition or the Sabbath in Judaism, intended to promote better understanding of and dedication to a higher being, to achieve enlightenment. Often such religious or spiritual accounts accept "ineffability" i.e. the effects of such silence cannot be readily expressed in words. True mystics and hermits of both Western and Eastern traditions typically have little to say about their experience of silence. For instance, the biographer Vicky Mackenzie24 reports that Jetsunma Tenzin Palmo, a British Buddhist nun, who spent three years high in the Himalayas in radical silence, publically said only: "Well, it was not boring."

Since the 18th century there are more secular sources of silence stories. The Romantic Movement writers like William Wordsworth and Henry Thoreau, while theist in their understanding yet militantly non-religious, emphasized the value of nature and silence. Onward from the mid-nineteenth century many accounts speak of lone adventurers, explorers of remote areas, mountain climbers, solo sailors, hikers, even swimmers, solitary by choice, they seek silence and remove themselves from their social day to day environments. They also largely tend to be mute about their inner emotions as if it defeats the very nature of their experience. In "A Book of Silence" Sara Maitland²⁵ reports an extraordinary example referring to the Sunday Times sponsored, first "Golden Globe" race in 1968, of sailing single handedly nonstop around the globe (pp. 43-45). Two experienced solo-yachtsmen, Robin Knox Johnson and Bernard Moitessier independently from one another and the Times "Golden Globe" race had already decided and prepared to navigate the globe. The race therefore was framed such that it was impossible not to enter, by default making both participants. Moitessier announced that the very idea of such a "Race" made him nauseous. He had made a "pact with the gods" in reparation for what he considered an earlier "dishonest" book that he had written. Participation in the "Race" would sully the whole enterprise. Nine yachtsmen were entered in the race. Only one finished, Robin Knox Johnson. For all others it was not the sailing itself that proved the hurdle, no one was killed by the waves or the wind, but it was the

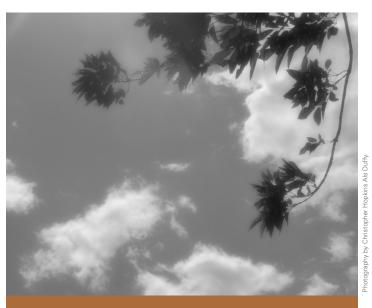
"Onward from the midnineteenth century many accounts speak of lone adventurers, explorers of remote areas, mountain climbers, solo sailors, hikers, even swimmers, solitary by choice, they seek silence and remove themselves from their social day to day environments."

emotional response to it. Their will was altered by the silence and isolation. For instance, Moitessier chose to round the Cape of Good Hope a second time, headed back across the Indian Ocean from whence he had just come; on into the Pacific, finally landing in Tahiti. In his diary he wrote: "I really felt sick at the thought of getting back to Europe...; does it make sense to head back for a place knowing that you will have to leave your peace behind?.... I feel a great strength in me. I am free, free as never before. Joined to all nonetheless, yet alone with my destiny." (p. 164), (pp. 56-57). This experience of strength and freedom is what Maitland considers a common effect of such chosen silence.

Maitland describes a recognizable sequence of emotional experiences of being in silence, based on her review of many accounts by others and on her own six-week period of planned silence living alone in a small cottage on the Isle of Skye, the most northerly island of the Inner Hebrides of Scotland. She recounts, that the first result is an extraordinary intensification of physical sensation, smells, taste, listening and hearing sounds such as the wind, the song of a bird, the experience of seeing color, the sensations of temperature, cold, wet, warm etc. Sensations become direct and total. As Maitland puts it: "It felt entirely NOW and physical"25 (p. 49). This then leads to an intensification of emotions, with crying, laughter, excitement, and anxiety quite disproportionate to the occasion, yet normal appearing at the time. Next is the experience of disinhibition. Those living in planned silence may abandon their daily routines of personal hygiene and customary dress codes as "banal vanities." The public self becomes stripped away "leaving the true self naked" as arctic explorer and geologist Augustine

Courtauld stated, having lived for five months in complete solitude in a tent on top of the Greenland ice-cap²⁷ in²⁵ (p. 54). A third experience Maitland²⁵ describes is that of hearing voices, often perceived as helpful and joyous rather than worrisome or pathological, and apparently serving communication of one's stressed self to one's more optimistic self. Additionally, natural sounds may become imbued with language-encoded meaning. The wind or ocean waves seem to be speaking or singing. Pinker²⁸ describes the "language instinct," as the instinct to make sense of what one does not understand, a translation into language of non-language phenomena. Our brain is an efficient interpreter of sound. As John Cage, 29 composer and music theorist, has said: "There is no such thing as 'real' silence. There is always some sound, even if it is only the sound that our body makes, our breathing, our heart beat." Finally, Maitland speaks of the feeling of being given an incredible gift which she terms "givenness" ²⁵ (p. 62). It engenders an indescribable joy, a bliss, intense happiness that moves into a feeling of "oneness" and an extraordinary sense of connectedness, a connectedness to the universe, to absolutely everything²⁵ (p.63), a feeling of communion and complete peace and certainty of being, without "pride or fear or surprise ...where each thing is simple... free to the right, free to the left, free everywhere"²⁶ (p. 164),²⁵ in (p. 65). This gift of connectedness is both integrative and connecting the self to something larger, the world, the other. Feelings of a loss of boundary between the self and the other, the self and the cosmos, even a sense of boundary confusion may occur at this stage. It may become harder to keep track of time, and track of danger. A certain exhilarating daring, almost a state of rapture may ensue, where everything appears feasible and delightful. Maitland interprets it as a shaking off of the rules, boundaries and safety codes of daily life, of the culturally instilled protection from and fear of risk taking. Such liberation seems freeing, induces joy and even giddiness, as a child might experience when taking a daring step. It engenders a "thrilling peril"; "a state of bliss that is simultaneously fiercely joyful" for which Maitland²⁵ (p. 74) uses the French term "jouissance," a joy that bypasses the moderating and mitigating influences of reason, an "over the top," unmitigated joy, as children experience quite naturally and that Wordsworth bemoans because of its fleeting nature in his "Ode: Intimations of Immortality from Recollections of Early Childhood."30 Prolonged silence appears to help us regain this state of "exhilarating consciousness of being at risk, in peril"25 (p. 78), this sublime daring, even if only for limited periods. The ineffability of experience ties in with the feeling of bliss.

The lasting benefits of planned silence experiences connect us back to ourselves and those around us, "without pride or fear or surprise" to use Moitessier's words. These are the personal attributes that our work as developmental professionals demands and expects of us. This is why the vulnerable infants and their families trust in us and our care. It is our professional responsibility to make room for such silence and its effects in



Every so often when it becomes all too much, we attempt to regain our balance, "flee into nature", leaving our electronic devices behind to refresh ourselves...in the quiet and silence of a forest, the mountains, a lake or the ocean.

ourselves, so that we can be ourselves fully.

Silence for years or months or even six weeks, as Maitland chose, is unrealistic for most of us. Yet the awareness of, and planned cultivation of the many moments of silence that offer themselves daily are feasible for all of us. The moment we pause in greeting a familiar bird, in watching a flower, observing a person, the pause of listening and tuning in, if only quite simply into our own breathing as meditation teaches us, this is well available to us all. And all of us have the power to cultivate actively an increased awareness of the intrusive, frequently gratuitous technology-based noise that we create ourselves. In doing so we can help to reduce and eliminate it; we have the power to educate, train and practice increased awareness of our often idle chatter, and our anxious over-talking to camouflage our fear of losing our public self, and "being naked", our true selves. The practice of silence will give us the strength and the joy to hold the moment, and hold the other in the moment and in silence. Being and becoming occurs in being held, being in the moment. Are we prepared?

Heidelise Als, PhD

Acknowledgement: Krista Tippett's interview with Gordon Hempton inspired me to write this column. The interview, entitled 'The Last Quiet Places - Silence and the Presence of Everything', was aired as part of her National Public Radio (NPR) Program Series 'On Being'.

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Interview with Heidelise Als by Kaye Spence, Senior Editor

In Conversation with Heidelise Als

n May this year I had the opportunity to have a conversation with Dr. Heidelise Als in Auckland, New Zealand as she was the invited keynote speaker at the Council of International Neonatal Nurses (COINN) 10th international conference. It was such an honour to have her speak and network with over 400 neonatal nurses from 23 countries.

In a quiet corner of the hotel café we had a most enjoyable conversation. As Heidelise sipped on her cappuccino she shared many stories, reflections and insights into NIDCAP and the impact it has on newborn infants and their families. I learned so much about this remarkable woman and the passion that has shaped her life. I would like to share parts of this conversation as I asked about her experience at the conference to trigger some thoughts about NIDCAP.

KS: After three intense days at the conference would you like to share your overall impressions?

HA: When I was invited and saw the conference theme, Enriched Family – Enhanced Care, I knew I wanted to attend. It was so in tune with the philosophy of NIDCAP. I was happy to see the concurrence of all strands of the presentations and the themes which were complimentary to NIDCAP. Each presentation was well thought out; the presenters were articulate with a certain seriousness and sincerity. I found the science presenters were diligent in their longitudinal research, the follow-up



Dr. Als giving her keynote address at the Council of International Neonatal Nurses (COINN) 10th international conference.

years and the large numbers of infants was impressive. Seeing the outcomes of our work causes us to pause and reflect. The nursery world is so different from the womb. It's like witnessing the evolution of our own species and looking at it from the outside. It was wonderful to hear the parents present; they have so much to teach us.

KS: Many of the delegates were impressed that you were in attendance for each session and you were taking notes.

HA: Why wouldn't I? I have so much to learn.

KS: What did you think of some of the futuristic presentations, for example the one on the artificial womb? I noticed you were quite absorbed.

HA: I found it a thoughtful and sensitive presentation and the intellectual drive of the neonatologists and physiologists is impressive; they haven't given up for nearly 50 years. This gives babies a chance, the more we learn the better we can make the experience for the newborn. You know I was present at some of those early trials in Philadelphia. It was early in my career, around 1968 and I had come to the USA and had just completed my master's degree. For my doctoral work I was in the nursery watching babies and doing pre-publication Brazelton observations. I remember one of the pediatricians asking me what I was doing and I explained I was observing the baby. She asked if I would like to see babies more fascinating than the full-term infants I was observing; of course I was curious, so she took me into a room on the side of the nursery. The room was full of various equipment, oxygenators, monitors and, in the middle, a table for the immature baby, who was about 28 weeks - pre-viable in those days. I was given the job of bagging the baby, who was flat on the table with the limbs restrained. I asked if we could help the baby tuck and place the hands to face and arms midline. As she spoke Heidi took on the flexed position demonstrating the ideal position for the baby's limbs and hands. She was demonstrating what she wanted to happen. I was told this was not possible as it could interfere with the tubes and wires!

KS: Did this influence you in any way on your early concept of NIDCAP?

HA: Yes, this was my first encounter with preemies. It made me think about their experiences and how they are looking for support and nurturing when surrounded by all the technology. Developmental care and NIDCAP started. There were many challenges to getting these concepts into practice at the bedside and if you want to overcome those barriers you have to have the right persons. The Psychologists have the ideas, but the doctors and nurses actually do it in practice. Early on there were some real nursing champions (Pat Linton and gretchen Lawhon) who were given the opportunity when developmental specialist positions were created. These were the early adopters, who helped make it happen, who made NIDCAP happen.

KS: What to do you see as the impact of NIDCAP? At this conference as well as globally.

HA: The number of nurses who spoke of their knowledge and awareness of my work surprised me. People seem hungry for

information and they appear dedicated in using this for their interactions. You know this is only the second nursing conference to which I have been invited. The amount of research that has been accomplished is fantastic and there is an appreciation of the impact on the brain and the changes that occur. However, there remains a lack of recognition in one's own local environment. This manifests in lack of support for development or research. In order for early intervention work to succeed, there must be support and this includes financial support. Ultimately there are costs to the community, supporting families with babies who, early on, experienced less than optimal care and now require life-long support.

KS: As one of the neonatologists said on the opening day – the nurses at the conference have a once in a lifetime opportunity at the conference to hear you speak. You received a standing ovation following your last presentation at the conference. How did this make you feel?

HA: Very humble. Maria Maestro's beautiful video had a lot to do with it.

KS: I think you gave many hundreds of nurses a glimpse of what NIDCAP is and the work and research that have gone into making it the model of choice. You also showed them that you are also prepared to have fun. Did you enjoy the Gatsby dinner?

HA: Yes, it was fun, but I can't dance the way I used to. I enjoy watching the young people enjoy themselves.

KS: What would you say is your 'pearl' of NIDCAP?

HA: Everything matters, for what we experience once we can't do it over or change what has happened. We always make the best of what we experience, and nothing is without cost. We all make mistakes and if we reflect and think about it we will figure it out so it won't happen again. I have learned a lot from being the mother to a child who was different from birth. There is a consciousness that makes life enjoyable, happy and good. A baby has no way to pretend, so you must consider how you touch a baby, work with a baby, and the voice you use, as these all have an effect on the baby and potentially cost the baby. You must be aware and keep your focus on the baby.

KS: NIDCAP was born 40 years ago - what do you see as the biggest change that has occurred for NIDCAP over the past 40 years?

HA: Awareness of NIDCAP varies greatly and depends on where you come from. There must be more articulation and communication about the detail required. For example, the reports cannot be condensed, as you want the detail that describes the core of the baby, the observations and the recommendations. The baby's goals are essential for the report. There have been many changes and more are required. A psychologist developed NIDCAP and is free of the burden of keeping the baby alive. It is the doctors and nurses who implement

NIDCAP in partnership with the parent. If NIDCAP is embraced by nurses the direction can quickly change, the nurses drive the change. We have the unifying umbrella of the NIDCAP Nursery Program (NNP) to help with the system change. This together with programs such as FINE and NIDCAP will ultimately benefit the baby and the family. Of course if we are going to have programs to support the baby and family we also must support the staff. They have to have time away from the bedside for time out, self-awareness and reflection; this is very important and has to be part of the implementation plan. Globally, we are expanding and we must engage those drivers who are interested and prepared to embrace NIDCAP and respond to requests for training. I think we are still figuring it out.

KS: Thank you, Heidi, this has been very enlightening for me. I must say the video you showed in your presentation really had an impact on the audience. To see all those interventions being

done, eye exam, cardiac echo while the baby was skin-to-skin with little reaction was truly NIDCAP.

HA: Yes, Maria Maestro from Spain allowed me to share this video. It shows how a neonatologist, who is a NIDCAP Trainer together with a NIDCAP Professional nurse, can provide these opportunities that embrace NIDCAP and ultimately benefit the baby and mother.

KS: On that note, thank you for your generosity of time for this conversation.

We said our farewells and I watched this diminutive and powerful woman walk towards the elevator. As she did so, a group of nurses walking by turned and chatted amongst themselves and I overheard 'that was Heidelise Als, wasn't she inspirational'.

Photo of H.Als presenting courtesy of COINN.

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Heidelise Als, PhD

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Additional Global Tributes to Dr. Heidelise Als and her work

"Your way of being will always be in our thoughts"

– Natascia, Gina, Sandra, and all the NIDCAP Professionals and staff from Rimini, Italy "We rejoice in Heidi's amazing life achievements and the love and connection in the NIDCAP community"

> – Stina, Agneta, Ann-Sofi, Björn, Elisabeth and the Swedish NIDCAP Teams

"Her legacy of changing the futures of premature infants, and their families will live forever"

- Grace, Laura and the Latinamerican NIDCAP
Training Center, Argentina

"Such an amazing woman, teacher, and mentor"

– Dr. Jeanne Watson Driscoll in Boston, USA

"I feel so privileged to have met her when she took the time to look around the NICU and congratulate us on the small achievements we had made"

- Aroha nui, Dale Garton, New Zealand

"Heidi will be sorely missed but will live on in all that we do for the tiniest babies and their families"

> – Juzer and the Edmonton NIDCAP Team, Canada

"We are better people and clinicians from knowing her"

- Nadine and the Australasian NIDCAP Training Centre, NIDCAP Australia "Her work and those early developmental conferences reshaped my nursing practice"

– Claire Panke, NICU Nurse and filmmaker in NYC, USA

Heidelise Als Bibliography

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Although times might be rough and difficult, with upheavals and waves to manage...hold on to your enthusiasm. Hold on to your sunny and optimistic personhood. Stay steady as much as possible and be tough. Every child and family deserve it.

Natalie Wetzel

Heidi has taught us the importance of observing and interpreting nonverbal language of preterm infants in a unique way. The opportunity we have every single time we interact with a newborn baby, to make things different, perhaps improving things for them in their relations with their family and caregivers.

Sant Joan de Déu Hospital Barcelona, Spain We leaned our heads close to the incubator wall, saw a tiny baby resting in a nest and started looking for behavioral cues. Heidi was whispering – explaining what the baby was "telling us". I was amazed and felt –it was possible to see and understand the baby.

Agneta Kleberg

I was inspired by her always present curiosity and chase for knowledge. My very first live image of her is her sitting humbly in the first rows in a scientific meeting, taking notes and paying attention to each word pronounced. She... who mastered so much knowledge and had such deep insights...

Dalia Silberstein

I learned love and kindness from her and whatever compassion and kindness I had in me, I mixed with her teachings and gave to babies who were defenseless in my hands and I knew for sure that my hands were created to be a safe place for those small miracles of God, so I did my best. Heidi made me a more patient and kinder person.

Azadeh Ranjbar

Heidi was and always will be my hero; she taught me how to help people and systems to change the outcomes for our tiniest citizens, and I have spent my career teaching and supporting developmental care and NIDCAP.

I will be forever grateful.

Linda Lacina

Her kindness, her time management, her compassion and sympathy, the way she cared to every single detail, and the way she articulated the words to make sure that the message was clearly understood, all will remain in my memory and will be a lifelong teacher along the way.

Patrick Manibaho

Her kindness, her way of being, speaking, her words and research inspire me... With Heidelise I learned to be more sensitive to babies and families as well to my colleagues. So, if I would share a pearl that I learned with Heidelise I think this summarizes all: Trust babies and trust parents!

Elsa Silva

Heidi has touched my life, making me a better person and a better professional. Heidi has engaged me in a lifetime process of collaborative care with parents and professionals, safeguarding a quiet soothing environment for infants and family...changing the future for infants and families everywhere!

Fatima Clemente

...the excitement and pure awe that I was actually going to be working with Heidi, was incredible. Too much to even put into words. Completely surreal. She changed my life... LITERALLY. The complete trajectory of my path was changed by Heidi, and I will forever be grateful and continue every day to be inspired by the incredible human being she was.

Bonni Moyer

You planted the seeds and a community has grown and flourished! Thank you Heidi for the support, teaching and guidance that made us better professionals.

São João NIDCAP Training Center, Porto, Portugal She entered each room of our unit and spoke with parents as if she had been in touch with them from the very first days of their baby. The parents didn't understand a word because they didn't speak English, but they understood Heidi's smile, her huge empathy, and her emotional touch. Heidi taught me the perfect interaction...

Natascia Bertoncelli

I have only met Heidi once – in Porto 2019 and I was lucky to have a little talk with her. I have never looked into a person's eyes and felt I could read a story of that person. Her eyes were full of power, so strong and at the same time so humble, supportive, respectful, full of joy and hope.

Jannie Haaber

It was a very special experience to have Dr. Als as a Trainer, she "saw" us all, and spread inspiration and joy in those she met. Her unique knowledge and guidance changed me as a professional, my mind and thoughts, my heart and hands in interaction with and care for the very tiniest babies, their families and my colleagues.

Unni Tomren

Heidi and her way of transmitting her knowledge with her warmth and magnetism, made me know who I really am as a Neonatologist and what motivated my actions the most when I work with little patients.

In my whole life she always occupied a privileged place.

Graciela Basso

Dr. Heidelise Als inspires me in many ways...her smile brings you comfort... a Leader with humility, Great Educator, Strong Woman...A mother of thousands of babies, her work and research, her patience and untiring nurturance to each and everyone...her humbleness...her intelligence and her strong stamina to nurture others and the newborns and their families.

Buenafe Cala

She taught me not to just do my medical works, but be with the babies and families during each interaction, through observation of those subtle behaviors and reflection of those moments.

Chao-Huei Chen

Heidi... said something like "well, hopefully the baby isn't recovering from care, but instead looks better later BECAUSE of the care." That was an ah-ha moment for me. Up to that point I had assumed that NICU care was stressful by nature and our goal was to lessen that stress. Heidi opened my eyes that the care can be a nurturing, positive experience for all involved.

Jean Powlesland

Heidi will always be alive in our practices and we will always work to protect the mental and physical development of newborn and we will be the heard voice of newborn.

Samia Ali Mubarak

Professor Heidi changed my eyes and view that premature babies should be treated as a human being and care should be taken individually and based on the baby's behavioral cues observation in order to avoid impairment and prevent subsequent disabilities.

Marzieh Hasanpour

A baby's behavior is always honest and available to be observed and is therefore our anchor. If we are skilled enough to understand this behavior and open enough to believe and respond to what the baby is telling us, it is our guide to shape the baby's relationships, environment, and care.

Bieke Bollen

Heidi inspired me to always strive to widen and deepen my lens of perception, and to always find the strengths in any situation or person.

Jennifer J. Hofherr

Heidi wrote an inspirational note that I will always cherish. She encouraged me to continue with "...gentle thoughtful persistence, empathy and discipline...and unshakable conviction...to keep moving mountains... [even if] it may appear those mountains shift ever so slightly."

Diane Ballweg

I will do my best to continue to acquire APIB accreditation and spread NIDCAP throughout Japan as a way to appreciate her.

Noriko Moriguchi

Heidi was one of the warmest people I ever knew. She was concerned that I was struggling alone in Korea without being able to be with her in one space, and she became a compass for me to move forward.

Jungyoon Lee

Listening to her lectures allowed me to see the babies in a different way. She gave me tools to work with babies and their families, always thinking about achieving the best neurodevelopment.

Rossanna Figueredo

Heidi taught me that what is taken for granted should be questioned the most.

Birgit Holzhüter

Opportunities and change doesn't just happen, you have to work to create it.

The likelihood that you might struggle should not deter you from continuing to support a cause you believe in.

Samantha Butler

We need to find a balance between that lifesaving action and individualized, supportive and protective developmental care.

Stina Klemming

Heidi inspired me a lot because of her way of being, her simplicity, her empathy with people, her great sensitivity towards babies and parents of premature babies.

Mónica Virchez

I can still see her leaning over a fragile infant in the incubator, putting her hand around her tiny body. So much tender, love, respect, and knowledge in one touch. So much freedom in this restrictive action.

Ita Litmanovitz

With Heidi, the relationship was everywhere even in the sharing of a cheese platter!

Nathalie Ratynski

The discussions with Heidi and Frank about newborns, families, society and the whole world... were always exciting and enriching.

Jacques Sizun

"Always find the next place of balance"... Thank you Heidi, for always guiding us towards that place of balanced regulation, while nudging us ever forward on our developmental journey.

Juzer Tyebkhan, Andrea Nykipilo and The Edmonton NIDCAP Training Centre Canada Heidi was truly a champion for us clinicians. She encouraged me. She helped me change lives. And I loved her for that.

Kathi Frankel

She said to me... "Kaye, sometimes you just have to act old." I have used this wise advice on several occasions while traveling. For me it showed the character of Heidi.

Kaye Spence

I heard Heidi say to a room full of hundreds of nurses from all around the globe "it doesn't matter what your unit, what those four walls look like, it is what you do within them that matters."

Nadine Griffiths

My biggest inspiration is "the babies voice" that they have something to say, that I can hear their voice and see that I've understood and helped the baby always bring a smile to my face.

Eva Jørgensen

Through the years I've known she always inspired me to be happy with every small change I could accomplish to make a better world for the newborn and his family. Her inspiration and her ability to be happy with small changes will stay with me forever.

Ingrid Hankes Drielsma

'Remember that you don't have to be the one who reaches the top of the ladder when endeavouring to change things: it's enough to have put your foot on the first rung'

Gillian Kennedy

The very first time I met Heidi, I was captured by the kindness reflected through her eyes. She talked about the babies with such genuine warmth and expressed herself so precisely that suddenly everything made sense. Being ...exposed to her ideas made me feel that I have found my place, both as an occupational therapist and as a person.

Adi Freund-Azaria

Heidi inspired me to reflect on a person's needs to take the next steps

Kelly Janssens

Someone who not only changed my professional life but also helped me to be a better human being... to be a better mother, wife, friend, teacher, and nurse. She has many trainees all around the world, however, she spends time on each one of them separately. She had an individualized approach to each one of us.

Jila Mirlashari

"You can always do more than you think"

To find the strength in a fellow human being and build from there has changed my thinking and thus my life.

Nikk Conneman

Heidi as a person that, beyond everything, will stand for the babies and their families. I learned that there is no compromise possible on what is best for the babies...if you see the baby uncomfortable or overwhelmed, you have to speak up, even to people you work with everyday and it sometimes feels uncomfortable. But the higher goal, is their future!

Angeline Parez

Heidi was inclusive and appreciated the importance of parents because we work with the healthcare team to provide the most individualized and nurturing care for our babies.

Yamile Jackson

I learned [from Heidi] that everyone is important, different, useful, and capable of integrating teams. Everyone should be given the opportunity to choose their role in each project... Advice that slowly but continuously shaped my "know how".

Hercília Guimarães

Learning and teaching to listen to babies and families is the most important thing that we have to do when we take care of them. Heidi's work helps us to realize that and has impacted the way to take care of vulnerable babies everywhere in the world!

Delphine Druart

"I understand that my presence can be a stimulus for the team to show its best image, but...if they are now working in this way, they are showing us that they know it and that they can do it, that a change in the model is already taking place." At that moment we were aware that...things had really changed.

Fátima Camba, Estrella Gargallo, Josep Perapoch Heidi taught me that every change, how small it seemed, is important, she taught me to be patient and try again.

"Always hold on to your passion" she said, "convince people with facts from your research".

Joke Wielenga

Her warmth when she spoke about preterm babies, the wisdom to understand what happened to them, the dedication to stay near the bed, day after day, observing their behavior, trying to find the way to help them... that was amazing and totally encouraging. That inspired me to help families in the NICU.

Laura Goldberg

I followed Heidi for many years and at first I couldn't understand NIDCAP. After her careful and detailed demonstration, I was moved and began to understand the preemies. I could read them after that.

Xiaojing Hu

Our most sincere gratitude to Heidi for helping us "see" the newborn infant's strengths and sensitivities, for casting the light on the importance of involving the family from start in the infant's care... her extraordinary way of "holding us" throughout this ever-continuing process.

Neonatal Units at Karolinska University Hospital and Karolinska NIDCAP Training and Research Center, Stockholm, Sweden



NIDCAP Training Centers - Facebook Pages

The promotion of NIDCAP on Facebook continues with new pages being added. Over the past few months, we have seen these pages promote conferences, seminars and support sessions, helpful information, new publications, achievements, and celebrations of NIDCAP. Please visit these sites and explore other information and achievements to help you celebrate NIDCAP.



















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NIDCAP TRAINING CENTERS

AMERICAS

North America

CANADA

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GERMANY

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