

# Developmental Observer

The Official Newsletter of the NIDCAP® Federation International

## NIDCAP Federation International (NFI)

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

“Our bodies have five senses: touch, smell, taste, sight, hearing. But not to be overlooked are the senses of our souls: intuition, peace, foresight, trust, empathy.”

JOY BELL

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## Chappel's Utopia

Written by Mary Stanford, PhD(c), MS, CCC-SLP, an NFI Professional Member, colleague and dear friend of John Chappel. Her passion to assist infants and families, sparked by John, will enable her to carry on his legacy of healing and teaching in the NICU

*“There is no utopia. There never will be. There is only the valiant attempts of each person to live spiritually in a world where spirituality is almost impossible.”*

—Deng Ming-Dao

He certainly was valiant in his attempts to live spiritually. In fact, John Chappel lived and healed others though his deep connection to his spirituality. His religion was kindness. His craft was compassion. He could see, hear, and feel lots of things that we can not. No matter how big or how small his patient, his intuition always guided

him toward those in need of healing. He often knew when a fellow human being was facing a problem before they themselves knew. I believe this is why he was such an effective healer, educator, friend, and servant-as he often referred to himself.

In his presence, it was as if the environment instantly became technicolored when he entered it. There was an energy that surrounded John, almost as if there was a force field wrapped around him. Amazingly, you could feel the magnetism the minute he entered. You somehow recognized almost immediately that you would never be the same after meeting him. Never the same, but better.

After an interaction with John Chappel, no matter the length of time, you felt better. He helped us all to breathe. He would always relieve us of our discomfort. It was his second nature. Those who knew him felt calm and often relieved in his presence. This was observed most in the eyes and body language of every single parent he ever worked with. They would often look at him with amazement as he dazzled them with his endearing smile, confident yet comforting voice, and his kindness. He would often walk into the newborn intensive care unit and somehow knew where the infant and family were that needed his support. He gravitated to those bedspaces and never left their side until they were better. Minutes, hours, days, weeks, months, years; it didn't matter. Whatever the patient and family needed to heal, he gave his everything, willingly and without complaint.

John Chappel was born to be a neonatal physical therapist. It's impossible to determine if his 35 week premature birth in 1953 predestined him to become the impeccable clinician he was, however it's hard to believe that there was not some sort



Mary Stanford and John Chappel during earlier times.

of connection. His brilliant mind, compassion, and healing hands were his tools. Without question, his role in the NICU went beyond the confines of the job description. He was a healer, visionary, inventor, student, and pioneer who assisted in developing modern neonatal therapy.

One afternoon in September 2001, I sat typing a speech and language evaluation on a three year old patient who could not produce the consonant cluster “tr”. Although his speech development was typical for his age, this was a problem for his family. He substituted ‘f’ for this consonant cluster in every position of every word. A significant problem since several times a day, the child would talk about his favorite things, like “fire trucks”. Having received a well-rounded educational and clinical training in speech pathology, my most recent work had been at a sub-acute pediatric facility in a borough of New York City where the sickest infants and children are cared for. As I typed this patient’s evaluation, my mind was reviewing how exactly and in what creative way I was going to help this sweet boy and his family. At that moment, a physical therapist who had been working with a young child outside my door walked into the office and said “Hi. I heard that you know how to feed babies who have been trached”. This was true. In fact, this was a population that I felt compelled to know more about so I’d recently taken a three day course on infants with tracheostomy. I desperately missed treating infants and working with their families and it had only been a few weeks since I had left that facility. She then said “Do you know John Chappel? You need to call him, he needs to meet you. Call him tonight. He will be expecting your call at 7:30 p.m. He is the greatest clinician you will ever meet. He cares for of all of the babies here.”

I believe fate intervened that day. For the next 12 years, John and I worked closely together in a Level III NICU, as well as with patients on other acute care units, in pediatric subspecialty clinics, and in other outpatient settings. John had an unbelievable command of human anatomy and physiology, a profound knowledge of embryological development, coupled with the power of healing infants through his hands. I often watched in awe as he healed the most fragile infants and their parents through his gentle, almost untraceable touch. One morning as we prepared for interdisciplinary NICU rounds, John and I stopped off at one of the NICU’s small nursing

stations. There was a very small scale that nurses mainly utilized to weigh an infant’s diaper. John looked over at me and smiled. He said ‘close your eyes and touch the scale as if you would touch an infant.’ He then said, ‘don’t worry, there’s no wrong answer here.’ We both did this three times each. He looked at me afterward and said, ‘Impressive!’ I looked at him puzzled. He replied ‘a healing touch can be accomplished with about a gram’s worth of pressure, no more. Babies should never have more than that and they don’t *need* more than that. That day, we calibrated our hands together using the scale. After that day, whenever I walk into a patient care area, I always find the scale and calibrate.

When John healed infants, he healed their families, and the staff caring for that infant and family, literally. John was motivated by his passion to heal the sickest infants and their families, to assist neonatal practice professionals to understand how important it is for them to know the best ways to provide this care, every day, with each patient and family we served, with no exceptions. John taught others often by presenting quotes from other famous philosophers, educators, inventors, and visionaries. He himself was famous for his own quotes such as “*when I’m working with a baby, my mind is in my hands*”. In looking back, the unit we worked in together for so many years was our own utopia, perfect. We had all that we needed to provide the highest level of individually supportive care.

John was a devout NIDCAP professional for over 30 years. He lived and breathed the synactive theory, incorporating it into each interaction with infants and families, and in his developing of ideas for the world to better understand it. All in a valiant effort to support all human kind. He would often say that as clinicians and practicing humans, we must listen more than we speak and act *only* when we can be supportive, compassionate, and intentional so that we can heal others with kindness and medicine. In a letter he sent me years ago, he wrote “Let compassion and idealism be at the root of everything that you do. Keep your ideals in clear focus, and never compromise those ideals.” I know for certain this is a mantra he had for himself as well. It continues to be mine.

John instilled in me that bringing your intentions to the bedside was critical. “Leave your ego at the door and set your intentions for the day.” John brought his intentions to infants and their families each day. He prepared for each work day by

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### Contributions

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



Mary Stanford and John Chappel

reading his daily meditation, setting his intention, and always had a 'word of the day.' Often, he would write down that word on the smallest piece of paper, then place it into his shirt pocket to carry it with him as he interacted with the world. Ironically, his last meditation and word of the day was "utopia."

It was a great honor to have worked with John Chappel but an even greater honor to have had him as a friend. He did not just teach me the therapeutic theory of synactive caregiving, or how to handle, position, or touch an infant to facilitate improved gross motor development or respiratory function; or how to feed infants; he showed me what was possible. He held expectations of greatness from all who take on the incredible responsibility caring for infants and their families.

On the front of every notebook he carried with him into the NICU each day, he wrote his name and a phrase often stated by Dr. Als, his hero, "Everything Matters". Because he would use a soft whisper to speak while in the NICU, often when he observed excellent caregiving being offered to an infant at a bedside, he would just pick up his notebook for the bedside nurse to see, underline that phrase with his pointer finger and mouth those two words. By doing this, he gently reminded us every day that in fact, everything the infant and family experience in our care, matters.

September in New York is beautiful. You can feel the summer slip away on Labor Day weekend and Fall enters with crisp cool evenings and bright blue cloudless skies. September has always been John's favorite month to spend in East Hampton, NY. This was his sanctuary, his place of healing, his heaven on earth, his personal utopia. It was here, in one of his many 'thinking notebooks', this passage was found shortly after he passed.

*Life is a series of ever deepening dedications.*

*If we are fortunate when we are born, our parents dedicate their unconditional love and lives to us- and we*

*to them. Brothers and sisters, aunts and uncles. Then our community and religion ask us to dedicate ourselves to them each week in services, each day in behaviors.*

*Friends demand the same, and hopefully receive the same- all our lives. Somewhere in the process, we are gifted if we learn to love. The gift comes in being able to put our tears aside to share that love with all and those closest to us.*

*Then if you are really fortunate you become an empath and dedicate yourself to using this gift each moment for others. To be able to sustain this through a profession that allows the practice of true empathy by touching others with your hands, or voice or deeds can "easily" fulfill your human destiny and dedicate your life to others.*

*I was this lucky.*

—JOHN CHAPPEL

## NIDCAP Care in the Moment



UCSF Benioff Children's Hospital Oakland

*Family intimacy*





Niklas Hauswald

## Lessons learned from life's unexpected turns

*It is human nature to assume the worst when life events throw us a curve ball. Our minds can play tricks on us and in the moment, we are scared and can be driven by fear. When we come through on the other side, we realize that unexpected circumstances can teach us valuable lessons, and when we are surrounded by the right resources and support systems, we thrive.*

—Debra Paul. OTRL

*“The power of the mind is often more scary than the actual situation”*

—Niklas Hauswald

I think back to the first ultrasound when we found out we were expecting twin girls. My wife Beatrice and I were told that her pregnancy was considered a “high risk pregnancy” which meant we would need to check on the girls every month to monitor their health as they were growing.

I was getting ready to eat my daily lunch with the students I teach, at the school where I work. My lunch was suddenly interrupted by an urgent phone call from Beatrice who was at the hospital getting one of her routine check-ups on our daughters. I answered the phone and the first thing she said was “it does not look good.” I could tell from the tone of her voice that she was very worried. Something had gone wrong, terribly wrong. The doctor told us the twins had Twin to Twin Syndrome or TTTS. Little did we know what lay in store for us. This was the beginning of a journey that we could have never imagined or thought possible.

My wife was forced to give birth to our baby girls a few weeks later, even though it was clearly too early for them to be born. They each only weighed about one kilogram and were in incubators hooked up to many wires and cables. We longed to touch them and were not able to hug or hold them as parents do with a new baby. The following week after the girls were born was like being on a rollercoaster. We were filled with so many emotions. The ups and downs were intense as we held on tight during the rollercoaster ride of having girls in the newborn intensive care unit (NICU). We were overwhelmed by love and fear. This was the beginning of a new chapter in our lives. We learned to appreciate the small gains that these wonderful little babies made as they became bigger and stronger.

One day a few weeks later, the doctor discussed a method of care with us called NIDCAP. My wife and I were so excited! We were told that we could do “skin-to-skin or kangaroo” with our babies, even though they were both still in an incubator hooked



Beatrice and Agnes

up to monitors. What a fantastic way to get to know our girls! I remember the very first time we held our precious daughters. The nurse opened the side of the incubator and gently moved each of them to our laps. What an amazing experience to feel our tiny babies on our chests. It was such a drastic difference, from not being able to have that much physical contact with our little ones, to actually holding them in our laps for hours...and believe me, we did! As we became more comfortable holding our girls, not only did we become more comfortable with the monitors, but we also learned what the girls were telling us by their signals or behaviors.

As the weeks (a total of nine) went by it felt like we really came to know the doctors and nurses well as they provided us with education on how to help our babies. Hand hygiene was very important. We learned we needed to be very quiet due to the girls' sensitivity to sounds because of their prematurity. I remember we had a small blanket that we gave to each of our girls every night. We had placed these blankets inside our shirts to let them smell the fragrance of our bodies as they fell asleep. All of the things we were taught helped our girls “get to know us” in a comfortable way. We learned to hold them gently against our chests so that they could feel our hearts beat and feel more secure and calm. It was a very thorough education in being a parent. The doctors and nurses were very good “teachers,” and my wife and I were, of course, eager to learn every single bit that there was to learn! The nursery staffs' aim was to involve us in as many parts of our girls' lives as possible. We became experts of our own children!

One day a scary thing came up. One of our girls needed to be intubated because the CPAP (a mask that provides oxygen) was not enough. My wife was ready to run out of the nursery

and cry out in fear at the sight of being intubated. The nurses encouraged her to stay and provide support to our daughter. To this day she does not regret doing so. The staff were there to help her face her fear which allowed her to be there for our daughters, and in doing so, she came to realize that *“The power of the mind is often more scary than the actual situation.”*

The NIDCAP method itself does not only focus on the babies themselves, but also focuses on the parents. We were encouraged to take on more and more responsibility for the girls' caregiving such as changing their diapers, bathing them, and taking care of their other needs. It almost became another job. We used to say to each other “our ordinary work and lives are on hold.” The idea of involving the father in every aspect of care made me, as the father to my twin girls, feel really important from the very beginning. The NIDCAP method focused so much on the whole family and also helped us with the recovery process.

As parents that lived through the experience of having our babies in the NICU, we came to an understanding of the importance of our role as parents. Spending almost every waking hour with your premature infant is a gift. As our girls grew, it was exciting to see them become healthier and stronger. I still remember that day when we were able to take them out on a walk with our stroller while they were still in the nursery. It was a relief to finally take them outside and to feel and experience what other families do with their baby. As the girls became more stable they were finally able to go home. To this day I still remember all the tears that fell from my cheeks when I drove home with

our daughters after they were discharged from the hospital. I felt very well treated by the doctors and nurses and thankful to the beloved NIDCAP method.

Love,

Niklas Hauswald & Beatrice Hauswald



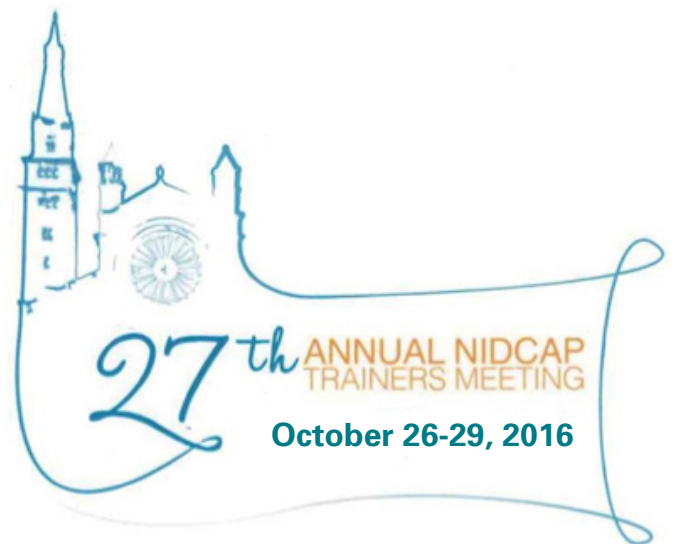
*From Left to Right Agnes and Siri, 2 years and 5 months, Linköping, Östergötland, Sweden*

## **Annual NFI Membership Meeting**

**Wednesday, October 26, 2016**

**3:45PM – 5:45PM**

Royal Hotel Carlton  
Via Montebello 8  
Bologna, Italy, 40121



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*Hosted by the Italian Modena NIDCAP  
Training Center  
(By Invitation Only)*

# NIDCAP Federation International Family Advisory Council

Samantha Butler, PhD, NIDCAP & APIB Professional  
Mandy Daly, Dip. H Diet & Nutrition, Dip. Ki Massage, AclI, DIDU

The NIDCAP Federation International (NFI) Family Advisory Council (FAC) was formed in 2016 to increase alliances and support the growth of the NFI. The council will work to build relationships with premature and ill newborn parent organizations, create world-wide ambassadors for the NFI, explore partnering opportunities with parent organizations to support shared goals, advise on ways to integrate NIDCAP into hospital settings and broaden the NFI's reach. The council includes board appointed individuals, with a prematurely born or ill newborn in their family, as well as individuals who represent parent organizations. The council members are from around the world and are overseen and facilitated by the NFI Advancement Committee.

The council members include Co-Chairs Mandy Daly and Samantha Butler and 11 members: Jennifer Degl, Deb Discenza, Yamile Jackson, Nina Nikolova, Marni Panas, Debra Paul, Keira LevitSorrrells, Asta Radzeviciene, Susan Tomaro, Mark DeLucchi and Lelis Vernon. Please see descriptions of each member below.



**Mandy Daly, Dip. H Diet & Nutrition, Dip. Ki Massage, ACII, DLDU** is a par-ent of a preterm infant born in 2006 and is one of the founding members and the Director of Advocacy and Policy Making of the Irish Neonatal Health Alliance. Mandy sits on the Parents Advisory Board of the European

Foundation for the Care of Newborn Infants (EFCNI) and is a member of the NFI Board of Directors. Mandy is a regular contributor to the [NIDCAP Blog](#) where she has shared the story of her daughter's premature birth. Mandy currently resides in Ireland with her family.



**Samantha Butler, PhD, NIDCAP and APIB Professional** is a mother of twin boys, Elliot and Nathaniel, born late preterm and now thriving in first grade. She is a developmental and clinical psychologist at Boston Children's Hospital (BCH) and an Assistant Professor at Harvard Medical School,

Boston, Massachusetts, USA. She is a NIDCAP Professional, a member of the NFI and a contributor to the [NIDCAP Blog](#). At BCH she is a member of Dr. Heidelise Als' research team in Neurobehavioral Infant and Child Studies Laboratory. She is a member of the Cardiac Neurodevelopmental Program at BCH where she provides education on NIDCAP Care and is the inpatient attending psychologist in Cardiology. Dr. Butler is also a member of the Cardiac Neurodevelopmental Outcome Collaborative. Samantha currently resides in Boston, USA with her family.



**Jennifer Degl, MS** is the mother of four, including a 23 week micro preemie. She is also the author of *From Hope to Joy: A Memoir of a Mother's Determination and Her Micro Preemie's Struggle to Beat the Odds*, and a writer for *Huffington Post Parents* and *The Mighty*. Jennifer currently resides in New York, USA with her family.



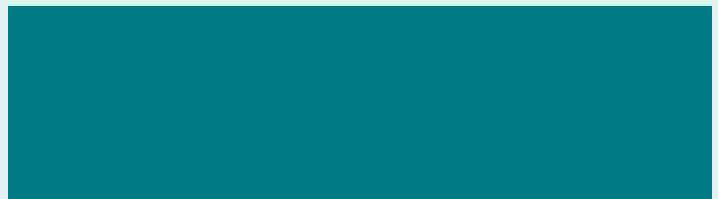
**Deb Discenza, MA** is the mother of Becky born at 30 weeks gestational age. She is also the founder and former Publisher of *Preemieworld*, co-author of *The Premie Parent's Survival Guide to the NICU* and she has a tenure with the award-winning *Premie Magazine*. She is the founding member and

steering committee member of the National Premature Infant Health Coalition and a founding member and Leadership team member of the Premie Parent Alliance. She is a regular Column Editor for the Neonatal Network's *Neonatal Network Journal*, and a columnist for both the quarterly newsletter for the Council of International Neonatal Nurses (COINN) and for *Neonatal Intensive Care* magazine. Deb received an award from the National Perinatal Association for her work in supporting families during the NICU journey. Deb is also a contributor to the [NIDCAP Blog](#). She currently resides in Washington DC, USA with her family.



**Yamile Jackson, PhD, PE, PMP** is the mother of four children, including Zachary who was born prematurely at 28 weeks. Her son is the inspiration behind the development of the Nurturing Technology™ from Nurtured by Design® [The Zaky™ and Kangaroo Zak®]. Yamile has a PhD in ergonomics and human

factors engineering, is a licensed Professional Engineer in Texas, and holds certifications as a Project Management Professional and as Professional Kangaroo Caregiver. Zachary is in high school, learning to drive, and is Nurtured by Design's CIO (Chief Inspirational Officer). Yamile currently lives in Houston, Texas, USA with her family.







**Nina Nikolova, BS** is the happy mother of twins born premature at 29 weeks, Martin and Joana. She is Chairwoman and a Co-Founder of the Bulgarian Foundation “Our premature children”, the first Bulgarian non-profit organization which supports premature babies and their families. She founded the organization following the

difficult birth and loss of twins. She shared her emotional journey on the [NIDCAP Blog](#). Nina currently resides in Sofia, Bulgaria with her family.



**Marni Panas, BS** is a proud parent to two special boys, Alex & Andrew. It was her sons’ birth at 24 weeks gestation, five months of experiences in the Neonatal Intensive Care Unit (NICU) that followed and the passing of Andrew that introduced Marni to the world of health care, Patient & Family Centred Care and NIDCAP.

She served as one of the first Co-Chairs of the Stollery Children’s Hospital, Canada, Family Centred Care Council and as the Coordinator of Family Centred Care. She is currently a Senior Employee Relations Advisor with Alberta Health Services, family and staff participant on the Stollery Children’s Hospital NIDCAP working group, and an active member of the NFI. Marni is also an engaged member of her community where she received the Human Rights award from the John Humphrey Centre for Peace and Human Rights, has recently been nominated as an Edmonton YWCA Woman of Distinction and named a Camrose Composite High School Alumnus of Distinction for her commitment to creating a community where diversity is not only accepted, but celebrated. Marni currently lives in Alberta, Canada with her family.



**Debra Paul, OTR/L, NIDCAP Professional**, is the proud parent of twins who were born late preterm. One of her twins has graduated from college and the other twin is set to graduate from college this coming winter. She is an occupational therapist and the Quality & Safety/Clinical Effectiveness Program

Coordinator for the Division of Occupational and Physical Therapy at Children’s Hospital Colorado. She is also a NIDCAP Professional and practices in the neonatal intensive care unit (NICU) at Children’s Hospital. Debra is an active member of the NFI. Debra lives in Colorado, USA with her family.



**Asta Radzeviciene, MBA** is the mother to Margarita born preterm at 26 weeks. She is also the Founder and President of the Lithuanian Premature baby association, NEISNESIOTUKAS, an international organization in conjunction with the EFCNI and creator of “Fairy of Hope”. Asta lives in Vilnius, Lithuania with her family.



**Keira Levit Sorrells, BSFACS** is the mother of triplets, Avery, Lily, and Zoe, born at 25 weeks. Avery and Lily spent four months in the NICU and Zoe was there for 9.5 months. After coming home, Zoe was rehospitalized at 14 months and died suddenly from a secondary infection. As a result of those

experiences, Keira founded the Zoe Rose Memorial Foundation which offers support to parents of premature infants and those who have lost an infant; as well as the Preemie Parent Alliance (PPA), where she now serves as President. PPA is a national network of 33 NICU parent support organizations that collaborate to share best practices and work together with professional provider associations to improve support for NICU families. She also serves on steering committees for the National Coalition for Infant Health, the Mississippi Perinatal Quality Collaborative and the National Network of Perinatal Quality Collaboratives. Keira resides in Mississippi, USA with her family.



**Susan Tomaro, MSJ and Mark DeLucchi, PhD** are the proud parents of three children, one born preterm at 31 weeks. Susan is a Special Education Teacher and Mark is a Clinical Psychologist. They experienced the NIDCAP Program with the birth of their son. Once through the NIDCAP Program, they became involved

in helping many other parents who had premature infants and they contributed to the NFI’s film, *NIDCAP Three Decades of Training and Support* highlighting how this program can support the family, the infant and the entire staff. Susan and Mark live in California, USA with their family.



**Lelis Vernon, BA** is mother of a premature infant born at 25 weeks. She is the first volunteer NICU parent to work with the NICU team at Baptist Children’s Hospital, Miami, Florida and since then she has worked to create, grow, and coordinate all activities of the Parent Advisory Council (PAC). She is on the

Clinical Guidelines Committee as a Public Member at American College of Physicians. She actively participates and collaborates in specific study groups and unit committees of the NICU (Baptist Children’s NICU FCC Committee, Vermont Oxford Network Team, QI teams). She is an active member of the NFI. Lelis lives in Florida, USA with her family.

*Currently, the FAC is working with the NFI Board in support of a more international and family accessible NIDCAP website and Facebook page. The FAC has enlisted several families of preterm infants to contribute towards the NIDCAP Blog over the coming months. They are also collaborating with the NFI Board on their World Prematurity Day plans. Please contact Mandy Daly or Samantha Butler to learn more about about the opportunities of the FAC.*



# Siblings in the NICU

## A New Challenge for Family-Focused Developmental Care

Families face a long list of challenges when their infant or infants are hospitalized in an intensive care nursery. One challenge that is not often discussed is the care of older brothers and sisters. As with so many issues in the nursery, this challenge can also be a gift, as the urgent needs of siblings may, with the right support, help parents to stay in touch with healthy family routines. While parents who are experienced with breastfeeding, swaddling, diapering and other baby care skills may have more confidence. However, spending the optimal amount of time caring for the preterm or sick infant in the hospital, while still caring for siblings at home, may feel overwhelming in settings that do not provide care for the family together. Many parents have shared with me, that no matter where they are, they feel guilty or torn because they aren't somewhere else.

Hospital policies vary both in the United States and internationally, but it is not uncommon for there to be rules that limit sibling access to the nursery (some rules are based on the age of a sibling, especially during times of the year when viral illnesses are more common). When siblings are not allowed to experience the joy of being with their baby brother or sister, parents may face the challenge of helping their older children to see the baby as a real person, rather than an abstract figure that lives far away in a hospital, and keeps mother and father away from them. As young children are welcomed into the nursery, families often benefit from professional guidance on how to best support the siblings for this experience, (guided by the age and maturity level of the sibling). With the use of pictures and video preparation, along with simple and concrete explanations, even very young children can experience the sight of their quietly nested sibling in a positive way. After all, young children don't necessarily have expectations about what a new baby should look like, and can be guided to admire tiny fingers and fuzzy hair.

Parents, who are going through periods of major stress, as they cope with their newborn's hospitalization, may struggle to create an emotionally calm and safe space for the sibling, whose little world has also been turned upside down. Toddlers, preschoolers or school-age children may act out their own worries and stresses during the enormous changes happening in their family. Parents need access to information about how young children respond to stress, including behaviors such as regression in toileting, sleep, language and general cooperation.

While there is surprisingly little literature on this topic, there are a number of clinically tested strategies that clinicians have developed over the years in conjunction with wise parents. Some of these strategies include:

- Providing siblings with the opportunity to play out their perceptions and feelings about their new baby brother or sister with a small doll, a premie diaper, small baby bottle, and swaddle blanket, etc. In addition, a large clear plastic food storage container can serve as an incubator;
- Offering photos of the real baby, and of the well cared-for baby doll, could be mounted together for the child, to reinforce the reality of his new baby brother or sister;
- Using smartphone technology for the opportunity to share frequent photos and short video clips of the infant with the sibling. This can be especially powerful. In addition to watching videos of the baby, siblings could also record their own message of love for their new sibling;
- Creating videos in situations where siblings can be with their new brother or sister, these videos of them together will become family treasures;
- Drawing pictures for the new baby, and seeing photos of the picture hung up in the baby's hospital space, can help children of all ages feel included and valued;
- Reading the several books written specifically for siblings of infants in the nursery can be informative and supportive. However, many parents find success in creating a simple, custom-made book for the sibling by incorporating photos of the family, the home, the future nursery, and the infant, with the appropriately simple, matter-of-fact language and names of all family members; and
- Scrapbooking, which has been successful in a number of nurseries, may translate well into books that siblings can treasure.

One nursery (recently awarded the NIDCAP Nursery Assessment and Certification Award ) provides a large, home-like kitchen and dining area, in which the family can cook and share meals together with their growing and developing infant. A mother emphasized over and over again that during this time the family really was TOGETHER!

In nurseries with sufficient numbers, evening "sibling club" meetings can provide peer support and a chance to learn more about their baby brother or sister. Some nurseries have volunteers who provide recreational evenings for siblings. In one successful group, siblings were given baby dolls to take home. They practiced washing their hands before kissing the doll on the back of the head and on their toes, (with the hope of limiting viral transfer in the future). The brothers and sisters took pride in



showing their parents that they knew the safe way to give their babies kisses.

This issue was discussed with a parent whose child had a complex surgical problem and was hospitalized for many months. She shared with me a wonderful idea for a baby going home with a gastrostomy tube. She sewed an old tube onto the appropriate spot on a baby doll with a fabric tummy. This helped to educate the siblings about what to expect, and then became the infants favorite doll! This mother also emphasized the importance of giving the siblings a chance to ask about their worries, some of which were unanticipated. For example, one of her children asked her one day “are you coming home from the hospital?” After all, the baby had stayed there for months, so this child did not assume that people always came home from the hospital. This family also found it helpful to select a few routines

that were sacred and were continued over time, such as picking her older child up from school which provided a special one-on-one time for the mother and child.

Over time, with increasingly supportive NICU design and policy, there will be fewer periods of separation and more periods when families can be together. Families benefit from and appreciate the support of peers and professionals to figure out what works best for their unique situations.

*The author would like to thank (with her permission) Kimberly Poling, RN, mother of three, for her wisdom, insights and ideas.*

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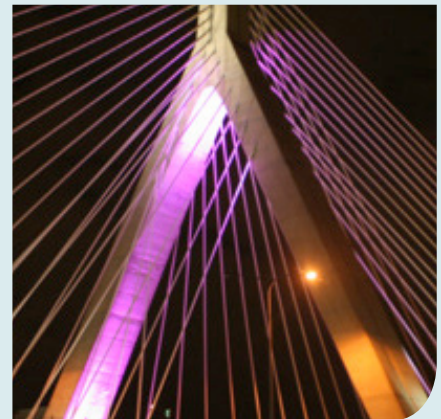
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## NFI Celebrates World Prematurity Day November 17, 2016

### About World Prematurity Day

Celebrated internationally on November 17th, World Prematurity Day (WPD) acknowledges the journeys of preterm infants and their families as well as raises awareness of the challenges faced by children born preterm and their families.

Purple is the symbolic color of WPD representing sensitivity and individuality, two of the characteristics of the premature infant.



### Please Join Us

In honor of World Prematurity Day 2016 the NIDCAP Federation International (NFI) invites you to pay tribute to newborns, and to their families, nursery staff and hospitals around the world who provide essential NIDCAP care.

A popular way to spread the word is through the purple illumination of landmarks in your communities and the purple illumination of hospital websites. The National NIDCAP Training Center in Boston, Massachusetts has arranged for the lighting of the Zakim Bridge which is traversed by tens of thousands of people every day, and the NFI hopes that each training center will arrange for a similar marking of the day whether it be the lighting of a bridge, a government building, your hospital's website, your NICU's webpage, or your community's local newspaper (print or electronic version). Please consider contacting the programs in your communities that can execute such "illuminations".

### Other suggestions for celebrating the day:

- Send the NFI's WPD [information sheet](#) to your local news agencies to inspire a story about preterm birth;
- Sponsor activities for the parents of preemies in your newborn intensive care units and/or your communities;
- Coordinate an educational workshop for your NICU staff on the sensitivities and individuality of preterm infants;
- Promote your activities using the [NFI's poster template](#) found on the NFI's WPD page.
- Share your WPD activities via your own social media and share on the NFI's social media:

We encourage you to mark World Prematurity Day in your own special way and to [share](#) these ideas with us so that we may help broaden NIDCAP's global reach.

# The Infant Behavioral Assessment and Intervention Program, LLC, (IBAIP®)

Rodd Hedlund, MEd

*“What happens during the first months and years of life matters a lot, not because this period of development provides an indelible blue print for adult well-being, but because it sets either a sturdy or fragile stage for what follows.”<sup>1 p.5</sup>*

## Neurobehavioral Characteristics of the Preterm Infant

Many infants born prematurely or with disabilities, once discharged from the hospital newborn intensive care nursery (NICU), continue to lack a well-organized central nervous system which results in: less control of sleep, arousal, alerting;<sup>3,4,5</sup> less attentiveness;<sup>6,7</sup> less smiling and positive affect;<sup>8</sup> greater fussiness and irritability;<sup>9,10</sup> and gaze aversion during early social interactions.<sup>6,7,11,12</sup> Because many of these infants lack the physiological control to respond to stimuli appropriately or predictably, their overall behavior is highly disorganized.<sup>7,13</sup> They are often unable to effectively utilize self-regulatory behaviors that normally support the typically developing infant to progress on to higher developmental tasks.<sup>14,15</sup> These infants also fail to provide predictable, clear behavioral cues that assist parents to respond in a manner that will produce organized responses in their baby and support their infant's self-regulatory efforts and emerging neurobehavioral and developmental competence.<sup>3,14,15,16</sup>

## Parental Response to the Infant

Caregivers are naturally imbued with a desire for reciprocal, responsive interactions and seem to be biologically programmed for normal newborn behavior.<sup>17</sup> A substantial body of research, however, suggests that parents of infants born prematurely and/or with disabilities show continuing anxiety and low confidence in their caregiving competence, at least during the first year of their infant's life.<sup>18</sup> Parents may be frustrated or feel tremendous guilt in response to the infant's disorganized behavior;<sup>24</sup> may be frightened by the neurophysiological sensitivity of their infant;<sup>25</sup> may be hesitant to interact with their fragile baby;<sup>26</sup> or may experience emotional, physical, and financial stresses which place the disorganized infant at high risk for child abuse and neglect.<sup>27,28,29</sup>

Researchers have observed that parents worked harder to generate smiles, attention, and contented vocalizations.<sup>30,31</sup> However, the parents' efforts were often counterproductive and frequently elicited stress in their babies. Parents should be supported to learn to sublimate the natural tendency to “try harder” when the infant demonstrates a hypoactive or stress related response to their stimulation.<sup>32-33</sup> *An infant's poor responsiveness, difficult temperament and diminished adaptability have been found to contribute to parental levels of stress even more so than an altered rate of development.*<sup>12,23</sup>

The impact of the infant's behaviors upon the parent, as well as the parent's sensitivity to reading the infant's cues, has received increasing attention in the literature. Research over the past thirty years has revealed the central role of the parent's responsiveness to the infant's signals in mediating infant cognitive and linguistic development, as well as infant sociability.<sup>36-42</sup> With the recognition of the critical role social interactions play in the development of the child, as well as the impact that the infant's characteristics have on the caregiver, a new approach in supporting mutually satisfying parent-infant interactions is most desperately warranted. Parents often times need guided support to: 1) observe their infant and trust their own observations,<sup>22,24</sup> 2) recognize and interpret the often unpredictable behavioral cues expressed by their baby,<sup>42</sup> 3) provide the neurobehavioral support to their infant that is suggested by the expression of their baby's cues<sup>43,44</sup> and 4) experience pride and joy in their infant while trusting their own importance and effectiveness in parenting their child.<sup>3,14</sup>

## Traditional Early Intervention Programs

Infants who are born prematurely, or at-risk for failures in developmental outcome, require an array of early intervention services throughout their first two to three years of life. There has been an explosion in the creation of “infant stimulation” programs offered via schools and community-based intervention programs.<sup>45</sup> The past three decades have seen an increase in both the number of early intervention professionals involved, and the number of programs aimed at optimizing developmental recovery, following newborn hospitalization.<sup>17</sup>

Early intervention services, whether they be home- or center-based community programs, continue to take a stimulus/environmental deprivation approach to intervention, helping the child to “catch up” by introducing her to various modes of sensory stimulation and instruction in age-appropriate developmental skills; often guided by the developmental assessment that is currently utilized at their agency.<sup>45-48</sup> This “catch-up” approach is inappropriate or possibly harmful for these infants, as they may not be stabilized, at a neurophysiological level, that would allow them to effectively process the sensory input offered to them.<sup>5,6,8</sup> As Blackburn states: *“Stimulation that is too complex or intense or inappropriately timed in terms of infant state threshold, maturity, or physiologic status can be as harmful as the lack of stimulation”*<sup>11p.78</sup> Obviously, infants must be provided with opportunities to be engaged by, and engaged in social/environmental interactions to continue their growth and development. These interactions, however, must be graded to each individual infant's neurophysiological, behavioral and developmental agenda, as well as her regulatory competence.<sup>5,13,14,15,17</sup>

Campbell,<sup>49</sup> as well as others,<sup>43,44</sup> have described the general insensitivity of early interventionists to the bio-behavioral state of children with disabilities. Campbell observed that early intervention professionals involved with classroom programming are often inattentive to the child's readiness for interaction. Further, when the child is presented with a developmental task, the effect is more often a response of disengagement or stress (e.g., turning away; arching; turning pale; and/or moving from an alert state to fussing or crying) than of engagement or approach behaviors (e.g., looking at, or reaching for the presented stimulus).<sup>14,43,44</sup> This in turn, leads to a program environment that does nothing to enhance parent-infant interactions or the infant's feeling of competence. Nor does it provide opportunities for the infant to positively experience her effects upon the environment and learn from these experiences.<sup>50-52</sup>

### Rethinking Traditional Early Intervention

Guralnick<sup>53</sup> and others<sup>54-56</sup> have concluded that early intervention programs that were initiated within the first 12 months, following the birth of a premature infant, with the goals of fostering sensitive parent-infant interactions and infant neurobehavioral development and organization, have the greatest impact on improvement in developmental outcomes.

Early intervention and health care professionals in the community and/or in hospital-based infant follow-up programs, infant pediatric chronic care settings, and/or their equivalents, need additional training to support the infant's neurobehavioral and physiological capacity within the context of developmental assessment, intervention, caregiving and social interaction.<sup>42-44</sup> This means training these professionals to learn to: 1) recognize and interpret the unpredictable behavioral cues expressed by these infants; 2) facilitate and validate parental perceptions of the behavioral cues of their baby; 3) present and modulate stimulation in response to the infant's individual neurobehavioral and physiologic status; 4) provide the infant with neurobehavioral support that is attuned to the infant's request for such; and 5) translate the infant's behavioral communication system into the development of a supportive neurobehavioral assessment, intervention, and caregiving plan.<sup>42,44,50,54</sup>

As Als states: "Support and neurobehavioral intervention cannot end when the infant is discharged from the hospital NICU, but must systematically link families and infants to sound models of community-based supports that build on the neurobehavioral care and intervention that was provided in the NICU."<sup>17, p. 353</sup>

### Integrating Theory into Practice: Neurobehavioral Assessment and Intervention

New assessment and intervention approaches for infants born with very low/extremely low birth weight or disabilities should incorporate the new directions in service content and delivery that have been called for by those who have been developing and studying direct services over the past years.<sup>53-59</sup> These researchers have refocused our attention upon:

#### 1. The Synactive Theory of Newborn Behavioral Organization and Development<sup>60-62</sup> (Synaction n., or Synactive adj. [from

the Greek **syn** "together" and the Latin **actio** "action," resulting in "together in action"]) is the foundation of the Assessment of Preterm Infants' Behavior (APIB),<sup>63,64</sup> and the Newborn Individualized Developmental Care and Assessment Program (NIDCAP®).<sup>57</sup> The Synactive Theory "proposes that development proceeds through the continuous balancing of approach and avoidance behaviors, yielding a spiral potentiation of continuous intra-organism subsystem interaction and differentiation and organism-environment interaction, aimed at bringing about the increasingly well-differentiated realization of a species-unique developmental agenda."<sup>60, p. 129</sup>

This theory focuses upon the infant's intra-organism, subsystems of functioning and their continuous interaction with each other and with the environment across time. The four subsystems include the: 1) Autonomic, 2) Motor, 3) State and Attention/Interaction, and 4) Regulatory.

"The infant actively shapes her own environment by selecting information and initiating and eliciting action in others. The environment, in turn constantly provides opportunities and challenges either to be taken or avoided. If the level of input and information is currently appropriate for the infant—so that she maintains balanced and well-regulated behavioral modulation—the infant may effectively take in the information and make it useful for her next developmental step. If on the other hand, the level and/or intensity of the environmental input is currently inappropriate or poorly timed, the infant has strategies available to defend herself against such input."<sup>60, p.129</sup>

"The Synactive Theory is not a temporally hierarchical model, but emphasizes the simultaneity of system differentiation and interplay, and sees this differentiation always in interplay with the environment."<sup>118, p. 6</sup> Through the direct observation of the behavioral repertoire of an infant, one can infer: a) what goals the infant seeks to accomplish; b) what self-regulatory strategies are being employed by the infant to accomplish these goals; c) how effective these strategies are; and d) what co-regulatory supports might be useful to facilitate the infant's overall development and neurobehavioral organization;<sup>3,14,17</sup> As Als and Duffy postulate "the infant's behavior provides the best information base from which to be continuously attuned to the infant."<sup>64 p.154</sup>

**2. A Brain-Environment Interaction Perspective.** The White House Conference on Early Childhood Development and Learning: What New Research on the Brain Tells us About Our Youngest Children,<sup>65</sup> has dramatically underscored the critical role that early experience plays in the organization and growth of the evolving brain.<sup>66</sup> Early interactions have a decisive impact on the architecture of the brain, the nature and extent of adult capacities, and directly effects the formation of dendritic-axonal interconnections.<sup>67-69</sup> Each of the estimated one trillion total human neurons, once migrated to their respective locations, develop dendritic and axonal interconnections with an average of 100 other cells, yielding a total of about one quintillion synapses.<sup>70</sup> Although the first synaptic contacts are established as early as seven weeks of age,<sup>71</sup> new cortical cells are generated at a low rate up until and beyond 40 weeks, and synapses continue to be established richly until five years of age and, more slowly, at least until 18 years of age.<sup>72</sup> Support for infants born prematurely and/or with disabilities must



combine knowledge of the evolving dynamic brain with knowledge of neurobehavioral developmental progression.<sup>3,14,17</sup>

**3. A Parent-Infant Interaction Perspective.** The formation of an enduring attachment relationship between parent and infant appears to be directly affected by the mutual social regulation between the partners in the dyad.<sup>73,74</sup> *“The infant’s sense of security may result from adequate homeostatic regulation within the caregiving relationship, with the earliest form of “security of attachment” encoded physiologically in the experience of non-disruptive and need-satisfying neurobehavioral regulation of early states.”*<sup>75</sup> p.20 It is imperative that parents are supported as they provide the life sustaining nurturance and cherishing of their infant as she progresses along her individual developmental trajectory. The infant “speaks” to them through her behavioral communication system, and they in turn, quite naturally, even intuitively, attempt to respond to her needs and requests for support.<sup>74-78</sup> Parents of infants born prematurely or with disabilities need help in recognizing and interpreting the unpredictable behavioral cues expressed by their infant as well as guidance in modulating stimulation in response to their infant’s physiological and neurodevelopmental status.<sup>79-81</sup>

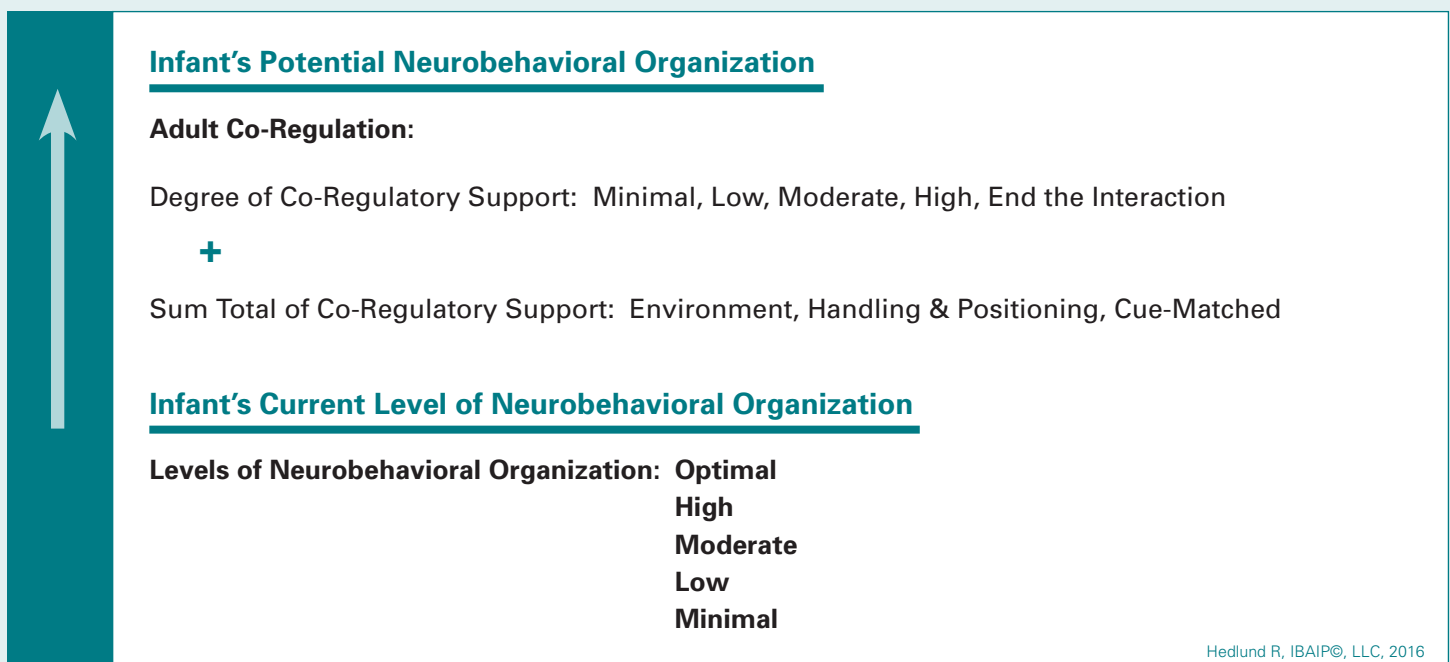
**4. A Social-Interactionist Perspective.**<sup>82,83</sup> Dynamic assessment and intervention is based upon Vygotsky’s conceptualization of the “zone of proximal development.” (ZPD)<sup>71</sup> The process of dynamic assessment and intervention<sup>82</sup> has been applied to the neurobehavioral approach offered by the Synactive Model.<sup>60-62</sup> Vygotsky defined ZPD as “the distance between the actual developmental level as determined by independent problem solving, and the level of potential development as determined through problem solving under adult guidance or mediation.”<sup>82, p. 86</sup> Simply stated, the “floor” of the ZPD is what the infant can do on her own; the ceiling is what she can do given a “reasonable” amount of restructuring or

facilitation by the adult.<sup>85</sup> The ZPD is different for each child, varies as a function of context and task, and changes constantly as the child learns new skills.<sup>86,87</sup> Some infants may require high support and make small gains, whereas other children will learn quickly with minimal assistance. The same child may respond differently to various types of assistance and in various areas of development. The process of dynamic assessment and intervention requires the professional to identify how the infant independently attempts to achieve mastery on a task, and how the infant’s performance can best be facilitated<sup>88</sup> through the use of *scaffolding* techniques;<sup>89</sup> the process where the adult continuously adjusts her interactions as a function of the infant’s changing needs for support.

The principles of dynamic assessment and intervention can be elegantly applied to supporting the neurobehavioral organization of the infant. From this perspective the ZPD is the distance between what the infant can do to stabilize herself or self-regulate (e.g., bringing her hand-to-mouth) when presented with a task during an assessment, intervention, caregiving or social interaction; and what further co-regulatory supports are needed from an adult, to support the infant to accomplish the task (see Figure 1). The **degree** of co-regulatory support may range from low support (e.g., graded positional adjustments to facilitate a tucked midline position) with minimal adult assistance, to high support (e.g., the use of swaddling to maintain this position). The **sum total** of co-regulatory supports that are offered to the infant may include: conducting an intervention session in a separate room, where light and/or sound levels can be controlled (an Environmental consideration), positional adjustments to facilitate a tucked midline position (Handling & Positioning consideration) *and* providing a pacifier for the infant to suck on (a Cue-Matched consideration). In this example, the **sum total** of co-regulatory support offered to the infant would be three.

## FIGURE 1. Zone of Neurobehavioral Organization

Adapted from Vygotsky’s “Zone of Proximal Development.”<sup>82</sup>



Hedlund R, IBAIP©, LLC, 2016

Thus, the task of the professional is to: 1) identify how the infant independently attempts to achieve the “next step” along her developmental and neurobehavioral trajectory; 2) determine what specific self-regulatory strategies the infant currently attempts to employ; 3) ascertain how successful the infant’s self-regulatory efforts are; and 4) discover how the infant’s performance can best be facilitated through the sensitive application (**degree** and **sum total**) of co-regulatory support; support that is offered to facilitate the neurobehavioral and developmental competence of the infant.<sup>43,44</sup>

## The Infant Behavioral Assessment and Intervention Program (IBAIP)<sup>43</sup>

### A Training and Education Program for Health Care and Early Intervention Professionals in the Community and/or in Hospital-Based Infant Follow-Up Programs, Infant Pediatric Chronic Care Settings, and/or their Equivalents.

*“The capacity of the infant to learn requires an alert state, a graded presentation of stimuli, and a sensitivity to feedback signals indicating limits of tolerance”*<sup>2 p. 38</sup>

**The IBAIP trains health care and early intervention professionals: To read and interpret the infant’s behavioral communication system.**

**The Infant Behavioral Assessment (IBA).**<sup>90</sup> The IBA (Figure 2) is a time sampling of 113 communicative behaviors. The behaviors are categorized according to the four subsystems: 26 autonomic/visceral cues, 44 motor responses, 9 state categories, and 34 attention/interaction behaviors. These are organized along a continuum of behavioral responses from approach, to self-regulation, to the expression of stress or disorganization. Each of the four subsystems is further divided into a total of 14 sub-categories. The IBA and *IBA Training Manual*<sup>91</sup> assists professionals to read and interpret the infant’s individual “behavioral story,” and to evaluate the infant’s neurobehavioral organization, self-regulatory competence, and needs for co-regulatory support. From this information base, a neurobehavioral narrative is developed (i.e., *IBA Observational Report*<sup>91</sup>) that paints the neurobehavioral and developmental story of the infant, and identifies specific neurobehavioral and developmental goals that the infant is working towards.

Drawing upon Als<sup>60-62</sup> conceptualization of the Synactive Model, Hedlund and Tatarka<sup>44,90,91</sup> have further articulated this theoretical construct. The IBA identifies four intra-organism subsystems: 1) autonomic, 2) motor, 3) state, and 4) attention/interaction. The infant may utilize behaviors within each of these four subsystems to: a) engage in the exploration and processing of cognitive and social-emotional information; b) stabilize herself during this process of engagement c) defend herself by momentarily breaking the intensity of the interaction; or d) remove herself from over challenging environmental/social input, by ending the interaction (via behaviors of varying degree of disorganization expressed through one or all four subsystems). Three categories of communicative behaviors have been identified as:

**1. Approach Behaviors.** These may be interpreted to indicate that the sensory input that is being received by the infant matches her readiness to process and to make sense of the presented information. The infant may be saying “I am actively engaged by, and engaged in, this interaction.”

**2. Self-Regulatory Behaviors.** These may be interpreted to be behavioral supports that the infant uses to maintain a balanced, relatively stable state across and among all four subsystems or to return to such a state of balance. The infant uses self-regulatory behaviors as a means:

a) **To Concentrate**, process, and learn from the stimuli offered to her. For example, the infant is presented with a toy to visually explore. She may call upon a self-regulatory behavior (*Hand to Mouth*, or *Bracing* into a supporting surface) to assist her to concentrate on the toy, process the information, and learn from this experience.

b) **To Strive** for and interact with a stimulus that may now offer new or increased challenges. “Infants are understood as actively striving for their next steps in development, while depending upon “good enough” environments and care to assure progress on their developmental trajectory.”<sup>118</sup> Self-regulation, utilized to strive for the next developmental step, assists the infant to continue to maintain a balanced, relatively stable state across and among all four subsystems while simultaneously attending to a more challenging task. For example, the infant is now encouraged to visually track a toy as it is moved from side to side, across her horizontal visual field (a more difficult task). The infant may call upon several self-regulatory strategies within her behavioral repertoire (e.g., she may bring her to *Hand to Mouth* to suck on [*Sucking*], *Brace* with her feet into a supporting surface, **and** *Hold On* to her own clothing with her other hand). She may also seek additional co-regulatory support from the adult in her strivings to interact with a stimulus that may test her current state of neurobehavioral organization and functioning. This should suggest to the intervening professional that the task at hand is challenging and any additional input may cause upset and lead to neurobehavioral disorganization in one or all four subsystems.

An additional parameter of the regulatory behaviors is observable in the neurobehavioral efforts, or behavioral “requests,” that are made by the infant to assist her to engage in assessment, intervention, caregiving or social interactions. For example, the infant is placed in supine and the adult presents a colorful toy for her to visually explore and possibly reach for. The infant attempts to bring her hand to her mouth to suck on, as a self-regulatory support. However, after several attempts, it appears that she lacks the necessary energy to maintain her hand in this position; or her efforts to move her hand to her mouth are ineffective, and her efforts may eventually tire her.

In the above scenario, the infant appears to be behaviorally “requesting” assistance from the adult to engage in visually exploring the toy. The adult “answers” these requests as she reflects upon what actions to take that will best facilitate the infants desire to look at the toy, paired with the “requested”

**FIGURE 2. The Infant Behavioral Assessment (IBA)**

### Infant Behavioral Assessment (IBA)

Observer: \_\_\_\_\_ Child: \_\_\_\_\_

Birthdate: \_\_\_\_\_

Gestational Age: \_\_\_\_\_

Observation #: 1 2 3 4

Dates: / / / /

AUTONOMIC / VISCERAL						MOTOR						STATE					
<b>Color</b>	Pink					<b>Arms</b>	Reach					<b>Active Alert</b>					
	Mottled						Well-Regulated Tone						<b>Hyperalert</b>				
	Pale						Smooth Movement						<b>Cry</b>				
	Red						Arm Over Face					<b>ATTENTION / INTERACTION</b>					
	Dusky						ATNR					<b>Eyes</b>	<b>Facing Gaze</b>				
<b>Respiration</b>	*Stable					Stop					<b>Directed Gaze</b>						
	Yawn					Bow					<b>Brow Raising</b>						
	Sigh					Airplane					<b>Animate Locking</b>						
	Irregular					Flaccid					<b>Inanimate Locking</b>						
	Sneeze					Straighten w/Tension					<b>Hand Gaze</b>						
	Cough					Shoulder Retraction					<b>Gaze Aversion</b>						
	Hiccough					<b>Hands</b>	Grasp						<b>Brow Lowering</b>				
	Gasp						Resting						<b>Blink</b>				
	Pause						Holding On						<b>Clench</b>				
	<b>Visceral</b>	*Stable						Hand to Midline					<b>Upward Gaze</b>				
Burp							Hand to Mouth					<b>Expression</b>	<b>Smile</b>				
Spit Up						Groping					<b>Ooh Face</b>						
BM Grunt						Hand on Stomach					<b>Facial Brightening</b>						
Gag						Self-Clasp					<b>Sober</b>						
Elimination						Hand on Head					<b>Lip Compression</b>						
Vomit						Finger Extension					<b>Wary</b>						
<b>Neurophysiological</b>		*Stable					Finger Splay						<b>Frown</b>				
		Tremor					Fisting						<b>Pout</b>				
		Twitch					<b>Legs</b>	Well-Regulated Tone						<b>Grimace</b>			
	Startle					Smooth Movement							<b>Ugh Face</b>				
	Seizure					Bracing						<b>Gape Face</b>					
<b>MOTOR</b>	<b>Head</b>	Orients				Toe Grasp						<b>Oral</b>	*Neutral				
		Lowering				Foot Clasp							<b>Sucking</b>				
		Headshake				Toe Splay					<b>Mouthing</b>						
		Maximal Head Turn				Flaccid					<b>Tongue Show</b>						
		<b>Trunk/Extremities</b>		Well-Regulated Tone				Sitting on Air						<b>Suck Search</b>			
Stilling						Straighten w/Tension					<b>Droping</b>						
Tuck						<b>STATE</b>	Deep Sleep					<b>Tongue Extension</b>					
Immobility							Light Sleep					<b>Jaw Extension</b>					
Squirm							Drowsy					<b>Vocal</b>	<b>Pleasurable</b>				
Pull Away							Diffuse Alert						<b>Undifferentiated</b>				
Flaccid							Alert						<b>Protest</b>				
Arching						Interactive Alert											



co-regulatory support. Several options may be considered based upon the behavioral observation of the infant during the course of this interaction. These may include: 1) gently supporting the infant's forearm to guide her hand to her mouth to suck upon (Cue-Matched neurobehavioral consideration); 2) softly holding the infant's wrist and gently placing and maintaining the infant's hand to her mouth to suck on; or 3) tenderly rolling the infant from her back, to her side. This may support the midline flexion of the infant's arms, with her hands now positioned up close to her upper chest and mouth. It may also provide the infant with the opportunity to "discover" that she may use this positional change to grasp and *Hold On* to her own clothing or both of her hands (Handling & Positioning neurobehavioral consideration). Given that the infant has unsuccessfully attempted to bring her hand to her mouth, and it appears that she may be tiring from these efforts, a positional change (3 above) would seem to be in order. Gently rolling the infant to her side, decreases the effects of the pull gravity upon her arms and affords her the opportunity to "discover" and practice another self-regulatory support ( *Holding On* to her own clothing or hands). These examples of co-regulatory supports may facilitate the infant's engagement in this social interaction, when her own self-regulatory efforts are not successful or are unsustainable.

Co-regulation is not the intervening goal; it's a means to the desired end (the infant's acquisition or refinement of self-regulation). The trained professional, understanding this qualification, gradually reduces the proffered co-regulatory supports, as the infant learns to integrate these into her own self-regulatory repertoire. This transitional process, from the infant's acceptance and use of co-regulatory supports, to the integration of self-regulation, provides the infant with the early sensations and experiences of success in her beginning attempts to open up, take in, and process the world around her...and gradually, over time (drawing upon her integrated self-regulatory repertoire), reach out and actively participate in what life has to offer her.

c) **To Console** herself, if pushed beyond her sensory threshold, in an attempt to regain a state of neurophysiological subsystem balance and functioning. For example, the intervening adult speaks to the infant, encouraging her, as she visually tracks the toy across her horizontal visual field. This new auditory input (e.g., speaking to the infant) may be offered as a support to encourage the infant to continue with the task. However, it may be too much for her to process, while simultaneously attempting to visually track the toy, and may lead to the expression of stress behaviors or disorganization. The infant may now use self-regulatory strategies (e.g., *Hand to Mouth*, *Sucking*, *Bracing* and/or attempts of the *Tucking* of her extremities up close to her body) as a means of consoling or comforting herself, in an effort to bring herself down from an agitated state of fussing or crying.

**3. Stress Behaviors.** These behaviors indicate that the sensory input the child is receiving is too intense, too frequent, too long, or too complex. The infant seems to be saying "I need some time

*out from this interaction,"* or "I'm not currently ready for this level of information, at this point in time."

These three categories of behavioral cues reflect both the infant's response to sensory input and the integrity of the four subsystems. Although behaviors are categorized as approach, self-regulatory or stress, their interpretation may vary depending upon the manner in which the infant utilizes them. Each behavior may be viewed as part of a continuum. For example, what commonly may be interpreted as a stress or disorganized behavior (e.g., *Shoulder Retraction*) may be used as a self-regulatory mechanism by some infants; while other infants may persistently utilize a self-regulatory behavior (e.g., *Foot Bracing*) in an increasingly ineffective, frantic manner, and thus may be interpreted as an indicator of stress and disorganization. These postures or patterns of movement may lead to greater disorganization, affecting other subsystems. Alternative co-regulatory supports should be considered, (e.g., the intervening professional offers co-regulatory support to assist the infant to move her arms/hands into a flexed, midline position, up close to her body; and supports the infant's feet with a hand or firm and supple surface to brace up against).

In the discussion of the infant's communication system above, it seems apt to share Als' eloquent description of the "necessary occurrence of stress in all development."<sup>118, p.6</sup>

*"An important point in the context of the discussion of stress or disorganization [as well as self- and co-regulation] of the infant is the necessary occurrence of stress in all development. The organism is only transiently in a steady state of balance and self-regulation, since as soon as such a state is achieved, the next developmental agenda becomes possible and, driven by internal neurobehavioral fueling, the balance is opened up... The neurobiological experience of satisfaction and pleasure, when reorganization at a next level of differentiation comes about, appears to be at least part of the driving energy of the developmental process, supporting the sense of integration and balance while providing the base from which the next phase of disequilibrium opens up... The goal appears to be further differentiation and the above-mentioned pleasure and satisfaction that comes about with the accomplishment of differentiation, and thus constitutes another step in the lifelong process of constructing the sense of self... A process-based proposition, requiring confidence in the competence of the developmentally self-constructing infant, as well as the parents and the professionals in the setting."*<sup>118, p.6</sup>

For infants to learn about the world around them and the important people in it, they must be provided with opportunities to interact with environmental input that are novel and may be initially challenging for them. The keen, trained eye of the intervening professional will guide her to offer graded experiences that "support the sense of integration and balance while providing the base from which the next phase of disequilibrium opens up... The goal appears to be further differentiation and constitutes another step in the lifelong process of constructing the sense of self."<sup>118, p.6</sup> During the course of an interaction, the professional continuously adjusts her interactions as a function of the infant's changing needs for facilitation,<sup>82,83</sup> while simultaneously supporting the infant along her individualized neurobehavioral and developmental trajectory.

**The IBAIP trains health care and early intervention professionals: To provide graded levels of co-regulatory support, to facilitate infant self-regulation during assessment, intervention, caregiving and/or social interactions.**

*“The growth of self-regulation is a corner-stone of early childhood development that cuts across all domains of behaviors.”*<sup>1 p.3</sup> Researchers have come to recognize the critical role that self-regulatory behaviors play in the infant’s development.<sup>35,55,57</sup> *These self-regulatory behaviors assist infants to acquire the behavioral, emotional, and cognitive self-control that is essential to competent functioning throughout life.*<sup>13-15, 76</sup> Infants born prematurely and/or with disabilities are often unable to effectively utilize self-regulatory behaviors that normally support the typically developing infant to progress to higher developmental tasks.<sup>13,55,76,90</sup>

**The Neurobehavioral Curriculum for Early Intervention (NCEI)**,<sup>44</sup> identifies five levels of infant neurobehavioral organization (i.e., Optimal, High, Moderate, Low and Minimal) and five corresponding **degrees** of co-regulatory support (i.e., Minimal, Low, Moderate, High Support, and *End the Interaction* [removing the infant from an interaction in which the intensity of the environmental input is currently inappropriate, too complex or poorly timed. In effect, *ending the interaction* is a co-regulatory support, in situations where the infant becomes disorganized as a result of her introduction to inappropriate sensory input. In this scenario, the adult would end the interaction, and the infant would be comforted and consoled to assist the child to return to a more organized state of functioning]. The five degrees of co-regulatory supports are applied to the following categories: Environmental, Handling and Positioning, and Cue-Matched neurobehavioral considerations. If the infant’s level of neurobehavioral organization was determined to be **High** then the degree of co-regulatory support required by the infant would be **Low**; if, on the other hand, the infant’s neurobehavioral organization is **Low** then one would expect the degree of co-regulatory support to be **High**.

Another parameter of functioning to be considered, is the **sum total** of co-regulatory supports that are offered to the infant from one or all three categories of neurobehavioral considerations (e.g., Environmental, Handling and Positioning and Cue-Matched). The **sum total** and **degree** of co-regulatory support that facilitates the neurobehavioral organization of the infant, serves as the best information base for assessing the complexity of the infant’s self-regulatory abilities and co-regulatory needs. For example, the infant may appear to be well organized but may require one neurobehavioral strategy (**sum total**) offered at a **minimal degree** of co-regulatory support (e.g., the dimming of overhead lights [an Environmental consideration]; or gently supporting the infant’s hand to mouth to suck upon [a Cue-Matched consideration]) to best facilitate the infant’s Interactive Alert state and support her engagement with a presented toy; supporting the infant to “open up,” take in, process, and learn from this experience. Thus, the **sum total** and **degree** of co-regulatory support offered to the infant helps to determine at what neurobehavioral level (i.e., Optimal, High, Moderate, Low, Minimal) the infant is currently functioning at (See Figure 1, p. 12).

In addition, the **Individualized Record of Neurobehavioral Facilitation (IRNF)**<sup>95,96</sup> was developed to chart the **sum total** and

**degree** of neurobehavioral strategies requested by the infant over time. *Over the course of assessment and intervention, the sum total and degree of neurobehavioral facilitation is expected to decrease as the infant learns to take on more of a self-regulatory role; with decreasing needs of co-regulatory support.*<sup>44,90-92</sup> In this way, the IRNF opens another window of infant progress that can be measured, articulated and recorded as a neurobehavioral developmental domain, along with the domains of mental, motor and psychological development.

The **IBA**, **NCEI**, and **IRNF** provide a curriculum-based and linked approach to neurobehavioral assessment and intervention by: 1) reading the “*behavioral story*” of the infant; 2) discovering the developmental and neurobehavioral goals that the infant is working towards; and 3) developing specific recommendations that are guided by the sum total and degree of neurobehavioral strategies to be applied in supporting the infant’s own developmental and neurobehavioral agenda.<sup>44,90-92</sup> The curriculum components, described above, assists early intervention and health care professionals to offer an individualized neurobehavioral plan to support infants during assessment, intervention, caregiving and social interactions.

Figure 3 provides an example of a highly skilled IBAIP trained physical therapist as she offers co-regulatory support to facilitate the infant’s attempts to interact with the interventionist and proffered toy, while enjoying this interaction and learning from these experiences.

As the interaction proceeds, the therapist, intuitively grades the sum total and degree of support that she offers the infant. This sensitive grading of co-regulatory support provides the infant with opportunities to “take-over” this process, as she begins to self-regulate. This transition from co-regulation to self-regulation is thus integrated, over time, into the infant’s behavioral repertoire, as she is engaged by, and engages in, interactions with the environment at large and the people within it.

**The IBAIP trains health care and early intervention professionals: To facilitate and validate parental perceptions of the behavioral cues of their infant.**

*“Virtually every aspect of early human development, from the brain’s evolving circuitry to the child’s capacity for empathy, is affected by the environments and experiences that are encountered in a cumulative fashion, beginning early in the prenatal period and extending throughout the early childhood years.”*<sup>1 p.6</sup> These early experiences take place in the context of supportive and nurturing relationships between the infant and her parent, and are formed through a process of mutual social regulation between partners in the infant-parent dyad.<sup>97-99</sup> Parental responsiveness to infant communication signals, plays a central role in mediating infant cognitive and linguistic development, as well as infant sociability, and a sense of “security of attachment.”<sup>75,100</sup>

***“The mother’s aliveness and physical management provide an essential psychological and emotional milieu, essential for the baby’s early emotional growth.”***<sup>101, p.89</sup>

The *parent’s aliveness* is presented to the infant through their own body. It is from the parent’s arms that the infant experiences their warm body, their breathing in and out, the sound of their

FIGURE 3. Application of Neurobehavioral Supports



1

Jane is laid down upon a blanket that has been placed on the floor. Jane's arms are positioned out away from her body (*Airplane*). Her legs/feet frequently kick up into midair (*Sitting on Air*). She moves from alert to diffuse alert states as her gaze briefly alternates between two adults, one sitting off to her left side and a physical therapist sitting directly in front of her.



2

The physical therapist supports *Foot Clasping, Bracing and Tucking* of the lower trunk and extremities, by gently holding Jane's feet together in a flexed position (co-regulation). This in turn, appears to facilitate an *Interactive Alert State (an Approach behavior)* as Jane looks up at the therapist's face as she softly speaks to Jane. Jane's arms, however, continue to lie out away from her body.



3

The therapist continues to support *Foot Clasping, Bracing and Tucking* by gently holding Jane's feet (co-regulation) **and** brings Jane's *Hands to Midline* (co-regulation); as Jane *Holds On* to the Interventionist's finger (self-regulation). An *Interactive Alert State* is maintained, as she continues to look up at the therapist who softly speaks to her.



4

Co-regulatory support of *Hands to Midline* continues, however, support of Jane's feet has been discontinued, as Jane is now able to *Foot Clasp and Brace* with her feet against the supporting surface of the floor (self-regulation). An *Interactive Alert State* is maintained as Jane continues to focus her attention upon the therapist.



5

Jane is now introduced to a toy, as the physical therapist continues to support Jane's *Hands to Midline* (co-regulation). Jane continues *Holding On* to the therapist's finger (self-regulation) and continues to support her own feet in *Foot Clasp and Bracing* against the floor (self-regulation). This appears to assist Jane to *concentrate* on the presented toy. An *Interactive Alert* state is maintained.



6

The therapist releases support of Jane's right hand, while offering gentle support to Jane's left hand (*Hands to Midline*). Jane continues to *Hold On* to the therapist's finger (self-regulation) and supports her own feet in *Foot Clasp and Bracing* (self-regulation). This appears to assist Jane to *concentrate* on the presented toy and reach up and grasp it. An *Interactive Alert* state is maintained.



7

All co-regulatory support has been removed. Jane is now able to effectively utilize self-regulatory strategies to visually explore the toy (i.e., *Hands to Midline, Holding On* to her own clothing, *Tucking* in of her upper and lower trunk and extremities, and foot *Bracing*). These self-regulatory strategies appear to assist her to *concentrate* on the task at hand. An *Interactive Alert* state is maintained.



heartbeat, and the assurance that she is safe and loved within the warm comfort of their arms. It is from the arms of the parents that the baby is cared for, and introduced to the important people in her life, and the outside world.

*“Parents and professionals are seen as co-regulators of infants... In the Synactive Theory’s framework, the mutual co-regulation conceptualization is comprehensive to overall functioning and is seen as biologically based and species specific to humans.”*<sup>118, p. 7</sup>

Heeding the critical importance of the developing parent-infant relationship,  *Holding Parents Holding Their Baby*<sup>95</sup> was developed to assist professionals to support parents as they continue to explore ways to adjust their interactions to the neurobehavioral, psychological, and developmental needs of their ever changing and growing infant.  *Holding Parents Holding Their Baby* recognizes and respects the parent’s natural capacity to love and care for their baby,<sup>86-97</sup> while simultaneously assisting early intervention and health care professionals in supporting the parent’s engrossment with their child and the child’s neurobiological based expectations for nurturance from the family.<sup>3,4,22,102</sup> Given the process-oriented perspective of neurobehavioral co-regulation, parent support, and promoting parental confidence in being with, and caring for the infant, is one of the most important goals of the IBAIP.

### Organization of the IBAIP Training and Education Program

Training in the Infant Behavioral Assessment and Intervention Program is offered to special education teachers, physical and occupational therapists, communication disorder specialists, visiting home nurses, pediatricians, psychologists, social workers, infant developmental specialists, or staff in hospital-based infant follow-up programs, infant pediatric chronic care settings, and/or their equivalents.

These professionals first receive instruction in the administration of the Infant Behavioral Assessment to ensure the successful implementation of the Neurobehavioral Curriculum for Early Intervention. As the applications of neurobehavioral co-regulatory support are based upon the clinical observational skills of the adult, it is imperative that training in all neurobehavioral components of the IBAIP have been successfully completed. In addition, clinical experience with newborns or young infants and knowledge of infant development and standardized testing is required. Training in the application of co-regulatory supports and related materials is best suited for clinicians who are already skilled in their own pediatric specialty and who are currently providing intervention services to the infant populations identified below.

### Infant Populations

The IBAIP may be implemented with infants from birth through twelve months of age who are medically fragile, high risk, developmentally delayed, neurologically impaired, or drug-/alcohol-exposed. In the case of infants who were born prematurely, the observation is based upon the infant’s corrected or adjusted age (one month corrected age). The IBAIP may also be useful with older infants whose neurological impairment or developmental

delay suggests associated CNS functioning within the birth-to-twelve month age range,<sup>55,56</sup> due to the mediating influence of the central nervous system in human behavioral responses.<sup>57</sup>

### IBAIP Training Format

Training in the IBAIP combines instruction in the reliable use of the Infant Behavioral Assessment (IBA), the Neurobehavioral Curriculum for Early Intervention (NCEI), the Individualized Record of Neurobehavioral Facilitation (IRNF) and Holding Parents Holding Their Baby. Organization of the IBAIP Training<sup>98</sup> is described in Table 1.

### Evaluation Effects

A pilot study<sup>103</sup> demonstrated the efficacy of IBAIP training in Amsterdam, The Netherlands.<sup>99</sup> Significant gains ( $p < .05$ ) were found for both mental (MDI) and psychomotor (PDI) developmental indices on the BSID-II as well as demonstrating clinically significant differences in neurobehavioral competence in favor of the intervention group.

More recently Koldewijn and Wolf, Academic Medical Center, University of Amsterdam, conducted a randomized controlled trial of 176 very low birth weight infants (2004-2007). This study compared the effect of IBAIP to standard follow-up care, with respect to infants’ neurobehavioral regulation, psychomotor and cognitive development, the well-being of the parents, and parent-infant interaction.<sup>100,101</sup> The children were examined at six, 12 and 24 months of CA (10–12). Two tertiary-level hospitals with neonatal or newborn intensive care unit facilities and five general hospitals in Amsterdam, The Netherlands, participated in the study. All the physical therapists that provided IBAIP intervention to infants and families in the experimental group for both the pilot study, and the studies reviewed below, were trained and certified in the IBAIP by Hedlund. Between 2009 and 2011, a follow-up study was performed to evaluate the effects of the IBAIP at six months to five and a half years, CA (see IBAIP Follow-Up Results, Table 2).

### Reliability, Sensitivity & Responsiveness of the Infant Behavioral Assessment (IBA)<sup>113</sup>

Koldewijn and her colleagues<sup>113</sup> investigated the reliability, sensitivity and responsiveness of the IBA to evaluate neurobehavioral organization in very preterm infants. Videotaped assessments of very preterm infants participating in a recent trial served to evaluate a standardized IBA observation. Inter-rater reliability was based on 40 videos scored by two independent observers, using percentage agreement and weighted Kappa’s. Sensitivity was evaluated by comparing the IBA results of 169 infants at 35–38 weeks postmenstrual age, dichotomized according to two developmental risk factors. The effect size (ES) was calculated between 0 and 6 months corrected age in all intervention and control infants and in subgroups of high-risk intervention and control infants with oxygen dependency > 28 days. Results indicated:

1. Inter-rater agreement was 93% in the total assessment;
2. Kappa agreement was moderate to good in the behavioral categories; and

**TABLE 1. Organization of IBAIP Training**

### **IBAIP Pre-Conference Workshop**

Prior to IBAIP Workshop I, the IBAIP Curriculum, training materials and required readings are sent to the IBAIP Site Coordinator for distribution to the IBAIP Trainees, approximately four months before IBAIP Workshop I. The IBAIP Trainer meets with the Trainees via a scheduled phone conference, to discuss the Trainees' homework assignments as outlined in the *IBAIP Program Guide*.

### **IBAIP Workshop I: Five-Day IBAIP Training Course**

The first day of this workshop consists of a half-day lecture followed by a half-day introduction to the *IBA* and the *IBA Operational Definitions*. During Days Two-Five the Trainees are instructed in the administration and implementation of the: *Infant Behavioral Assessment (IBA)*, *Neurobehavioral Curriculum for Early Intervention (NCEI)*, and *Holding Parents Holding Their Baby*.

### **Written Critique of the IBA Observational Report**

Approximately three-months from the completion of Workshop I, each Trainee sends one *IBA*, and *IBA Observational Report* to the Trainer. The Trainer reviews and comments on these submitted materials. A written critique is then sent back to each Trainee (usually consisting of six-eight type-written pages). After each Trainee has received their written critique, the Trainer follows up with a conference call to answer the Trainees' questions with regards to their critique.

### **IBAIP Workshop II: Four-Day IBAIP Follow-Up Workshop**

Approximately six months following Workshop I, the Trainer returns to conduct a follow-up workshop with the Trainees. Trainees participate in a four-day workshop to check Trainee IBA inter-rater agreement reliability, the development of the *IBA Observational Report*, as well as the implementation of the *NCEI*, and *Holding Parents Holding Their Baby*. On the fourth day, the Trainer reviews the requirements involved in the development of the *IBAIP Case Study*.

### **IBAIP Workshop III: Four-Day IBAIP Certification Workshop**

The IBAIP Trainer returns approximately six months after IBAIP Workshop II, to conduct *IBA* inter-rater agreement reliability sessions with the Trainees and assess the implementation of the *NCEI* and *Holding Parents Holding Their Baby* via review and discussion of their *IBA Observational Report*. This occurs during the first three days of this workshop. On the fourth day, the Trainees meet together with the IBAIP Trainer to present their *IBAIP Case Study*.

**IBAIP Certification:** Upon successful completion of all of the IBAIP Workshops (I-III and all IBAIP homework assignments) the IBAIP Trainee is certified as an IBAIP Professional and is granted the right to implement all IBAIP assessments, curriculum, and associated training materials in his or her professional practice.

Hedlund R, IBAIP®, LLC, 2016

3. Significant differences were found between groups with or without risk factors. Larger differences between ESs in the randomized groups with oxygen dependency >28 days than in the total randomized groups reflect the responsiveness of the IBA.

The authors concluded that the Infant Behavioral Assessment (IBA) is a reliable and valid tool to evaluate and support neurobehavioral organization in very preterm infants. Satisfactory to good clinical metric characteristics of the IBA were found in very preterm born infants. Additional validation of the IBA in different infant populations, and at different ages is warranted.

### **Summary**

The IBAIP is a proven<sup>103-113</sup> comprehensive assessment and intervention model which supports the developmental and neurobehavioral integrity of premature infants born with low to extremely low birth weight, or with disabilities. The focus of the IBAIP is not “what to teach” (content curricula) but “how to teach and support the infant during assessment, intervention, caregiving or social interactions;” a process oriented approach. By focusing on how to facilitate learning and social interaction, the IBAIP adds a critical individualized,<sup>78-80</sup> relationship-based,<sup>114-117</sup> family-cen-

tered,<sup>90-92,101,102</sup> and neurobehavioral dimension<sup>3,14,60-62</sup> to early intervention, often lacking in traditional early intervention models.

From 1989-1995 over 500 early intervention professionals from 48 Early Intervention Programs, across 24 states were trained in the IBAIP. IBAIP Training and/or training in components of the IBAIP have also been conducted in Victoria, Canada, Riyadh, Saudi Arabia, London, England, throughout The Netherlands, and Tehran, Iran over the course of the past fifteen years. Recently, the IBAIP has been endorsed by the NIDCAP Federation International (October, 2016).

## Future Plans

Pr Jacques Sizun, MD, Service de Néonatalogie et Réanimation Pédiatrique, Pôle de la Femme, de la Mère et de l'Enfant, CHRU Brest, France will conduct a multicenter, cluster randomized study with eight NICU Follow-Up Clinics and 340 infants to evaluate the effectiveness of the IBAIP. IBAIP Training of ten physical therapist will begin in the Spring of 2017, in Brest, France.

IBAIP Training is also scheduled for Tehran, Iran with eight early intervention and health care professionals to commence in the Fall of 2017.

**TABLE 2. IBAIP Follow-Up Results**

<b>6 Months</b>	At six months corrected age (CA) the IBAIP improved the infant's motor development (PDI, BSID), mental development (MDI, BSID), behavioral development (BRS, BSID), self-regulatory competence (IBA), <sup>106</sup> and mother-infant interaction. <sup>107</sup>
<b>24 Months</b>	At 24 months CA, the IBAIP improved the infant's motor (PDI, BSID) development. <sup>108</sup> Additional positive effects of the IBAIP intervention included: <ul style="list-style-type: none"> <li>• The most vulnerable infants profited most from intervention, affecting interactive, behavioral, mental and motor aspects of development: infants with BPD, GA &lt; 28 weeks, abnormal cranial ultrasound, a combination of social and biological risks, male sex, and infants with low educated mother.<sup>108</sup></li> <li>• Children that received IBAIP intervention needed significantly less paramedical support once discharged home.<sup>108</sup></li> </ul>
<b>44 Months</b>	At 44 months CA, the IBAIP improved independency in mobility (PEDI) and sensory processing (oral/tone; SP-NL), <sup>109,110</sup> At 44 months CA, the most vulnerable infants (i.e., infants with: BPD, GA < 28 weeks, abnormal cranial ultrasound, a combination of social and biological risks, male sex, and infants with low educated mothers) profited most from IBAIP intervention, effecting interactive, behavioral, mental and motor aspects of development: <ul style="list-style-type: none"> <li>• Children with BPD in the IBAIP group showed better modulation relating to body position/movement, better social functioning and less withdrawn behavior;</li> <li>• Children born extremely preterm (EPT) with a gestational age of &lt; 28 weeks, in the IBAIP group had better executive functioning, better modulation of visual input on emotions and activity level, and were less emotionally reactive;</li> <li>• Boys profited extra from the IBAIP in relation to self-care and social functioning;</li> <li>• VLBW children in the IBAIP group born to a low educated mother demonstrated better word comprehension; and</li> <li>• For children with abnormal neonatal cerebral ultrasound findings, the IBAIP group was found to be particularly effective with respect to modulation relating to body position/movement.</li> </ul>
<b>5.5 Years</b>	At 5.5 years CA, the IBAIP leads to improvement in intelligence, ball skills and visual motor integration. <sup>111</sup>
<b>5.5 Years</b>	At 5.5 years CA, the IBAIP leads to long-term developmental improvements in very preterm infants, especially infants with bronchopulmonary dysplasia. Infants with bronchopulmonary dysplasia showed significant longitudinal intervention effects for cognitive (0.7 SD; p = 0.019) and motor (0.9 SD; p = 0.026) outcomes. <sup>112</sup>



For additional information on the IBAIP please visit:  
[www.ibaip.org](http://www.ibaip.org) or contact: [rhedlund@ibaip.org](mailto:rhedlund@ibaip.org).

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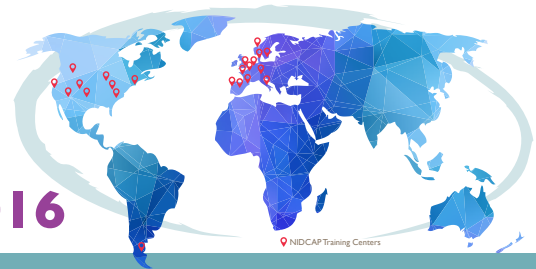


# In Appreciation



The NFI wishes to express sincere appreciation to Kathleen Vandenberg, PhD for her steadfast support and participation as a Director of the Board since its incorporation in 2001. Kathy was a very early adopter of the NIDCAP approach to care having been APIB certified in 1980 before becoming a NIDCAP Professional in 1986, a NIDCAP Trainer in 1988 and a Master NIDCAP Trainer in 2004. Dr. Vandenberg has demonstrated her dedication to infants, families and staff through over forty years as a clinician, researcher and educator. She was co-investigator for a number of the seminal NIDCAP studies and has been the Director and Trainer/ Master Trainer in three different Centers in California. She has authored *Individualized Developmental Care for High Risk Newborns in the NICU: a Practice Guideline* and *Coming Home: Transitions from NICU to Home*

in addition to nearly 50 peer reviewed publications. Currently Kathy is at University of California San Francisco directing the West Coast NIDCAP and APIB Training Center. Kathy exemplifies her definition of a Newborn Developmental Specialist performing neurodevelopmental/behavioral assessments, providing developmental interventions and developing a continuously evolving plan of individualized developmental support for each NICU family and infant as well as consulting with professional staff and supporting the caregiving relationship with staff, parents and extended family. We sincerely thank Kathy for her many years of service to the NFI Board and look forward to her continued dedication as an active member of our professional organization.



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## Video/Movies

Video and movie (fragment) in English  
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The NFI thanks its first corporate sponsor, Sonicu, as well as its second corporate sponsor, Dr. Brown's. The generous support of these sponsors helps the NFI raise global awareness of the need for NIDCAP care and enhances opportunities to develop educational programs to broaden the reach of this care to more and more NICU professionals and the 'preterm families' they serve.



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The Newborn Individualized Developmental Care and Assessment Program (NIDCAP), originated in 1984 by Heidelise Als, PhD, is the only comprehensive, family centered, evidence-based approach to newborn developmental care. NIDCAP focuses on adapting the newborn intensive care nursery to the unique neurodevelopmental strengths and goals of each newborn cared for in this medical setting. These adaptations encompass the physical environment and its components, as well as, the care and treatment provided for the infant and his or her family, their life-long nurturers and supporters.

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The NIDCAP Nursery Assessment and Certification Program (NNACP) provides a comprehensive resource for the self-evaluation by a nursery system of its strengths and goals for integration of NIDCAP principles into all aspects of their functioning. External review and validation by the NFI may be sought when a nursery feels it has achieved this goal. Successful NIDCAP Nursery Certification, the ultimate goal, denotes distinction in the provision of a consistently high level of NIDCAP care for infants and their families, as well as for the staff, in a developmentally supportive environment. Nurseries that have achieved this recognition serve as a model and an inspiration to others. For information on eligibility requirements and the certification process please see: [www.nidcap.org](http://www.nidcap.org); and/or contact Rodd E. Hedlund, MEd, NNACP Director at: [nnacpdirector@nidcap.org](mailto:nnacpdirector@nidcap.org) or 785-841-5440.



## **Mission**

The NFI's mission is to promote the advancement of the philosophy and science of NIDCAP care and to assure the quality of NIDCAP education, training and certification for professionals and hospital systems.

*Adopted by the NFI Board, May 1, 2015*

## **Vision**

The NFI envisions a global society in which all hospitalized newborns and their families receive care and assessment in the evidence based NIDCAP model, which supports development, minimizes stress, is individualized and uses a relationship-based, family-integrated approach.

*Adopted by the NFI Board, May 1, 2015*

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National NIDCAP Training Center  
email: [gloria.mcanulty@childrens.harvard.edu](mailto:gloria.mcanulty@childrens.harvard.edu)

### SECRETARY

**Kaye Spence**  
Children's Hospital at Westmead  
Westmead, Sydney, Australia  
email: [kaye.spence@health.nsw.gov.au](mailto:kaye.spence@health.nsw.gov.au)

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email: [alberts@indiana.edu](mailto:alberts@indiana.edu)

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email: [heidlise.als@childrens.harvard.edu](mailto:heidlise.als@childrens.harvard.edu)

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Family Representative, Dublin, Ireland  
email: [mandy.daly@yahoo.co.uk](mailto:mandy.daly@yahoo.co.uk)

### Kathleen VandenBerg, PhD

NIDCAP Master Trainer  
Director, West Coast NIDCAP and  
APIB Training Center  
email: [kathy.vandenberg@ucsf.edu](mailto:kathy.vandenberg@ucsf.edu)

### Rodd E. Hedlund, MEd

Director  
NIDCAP Nursery Assessment and  
Certification Program  
NIDCAP Trainer  
email: [nnacpdirector@nidcap.org](mailto:nnacpdirector@nidcap.org)

### Sandra Kosta, BA

Financial Operations and  
Administration Director  
email: [sandra.kosta@childrens.harvard.edu](mailto:sandra.kosta@childrens.harvard.edu)



# NIDCAP On the Web

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The NFI [NIDCAP Blog](#) offers observations from many different perspectives on NIDCAP and its implementation, such as NIDCAP and APIB training, Nursery Certification, the science behind the approach, the family experience with NIDCAP, the NFI, and much more. We encourage you to visit the *NIDCAP Blog* and to leave comments for our bloggers and our NIDCAP community in general. If interested in becoming a guest blogger please contact Sandra Kosta at [sandra.kosta@nidcap.org](mailto:sandra.kosta@nidcap.org).

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# NIDCAP TRAINING CENTERS

by order of establishment

## National NIDCAP Training Center

Boston Children's Hospital and Brigham and Women's Hospital  
Boston, Massachusetts, USA  
**Director:** Heidelise Als, PhD  
**Contact:** Sandra M. Kosta, BA  
**email:** [nidcap@childrens.harvard.edu](mailto:nidcap@childrens.harvard.edu)

## Sooner NIDCAP Training Center

(inactive)  
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**Director:** Andrea Willeitner, MD

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**Director and Contact:** Kathleen VandenBerg, PhD  
**Associate Director:** Deborah Buehler, PhD  
**email:** [kathy.vandenbergl@ucsf.edu](mailto:kathy.vandenbergl@ucsf.edu)

## Carolina NIDCAP Training Center

WakeMed, Division of Neonatology  
Raleigh, North Carolina, USA  
**Director and Contact:** James M. Helm, PhD  
**email:** [jhelm@wakemed.org](mailto:jhelm@wakemed.org)

## Colorado NIDCAP Center

University of Colorado Denver  
School of Medicine and The Children's Hospital  
Aurora, Colorado, USA  
**Director and Contact:** Joy V. Browne, PhD,  
PCNS-BC, IMH (IV) Mentor  
**email:** [joy.browne@childrenscolorado.org](mailto:joy.browne@childrenscolorado.org)

## St. Luke's NIDCAP Training Center

St. Luke's Children's Hospital  
Boise, Idaho, USA  
**Co-Director:** Marcy Weber MBA, MSN, RN  
**Co-Director and Contact:** Karen M. Smith, RNC,  
BSN, MEd  
**email:** [smithka@slhs.org](mailto:smithka@slhs.org)

## Karolinska NIDCAP Training and Research Center

Astrid Lindgren Children's Hospital at  
Karolinska University Hospital  
Stockholm, Sweden  
**Director:** Björn Westrup, MD, PhD  
**Contact:** Ann-Sofie Ingman, RN, BSN  
**email:** [nidcap@karolinska.se](mailto:nidcap@karolinska.se)

## French NIDCAP Center

Medical School, Université de Bretagne Occidentale and University Hospital  
Brest, France  
**Director:** Jacques Sizun, MD  
**Co-Director and Contact:** Nathalie Ratynski, MD  
**email:** [nathalie.ratynski@chu-brest.fr](mailto:nathalie.ratynski@chu-brest.fr)

## Sophia NIDCAP Training Center

Erasmus MC-Sophia Children's Hospital  
Rotterdam, The Netherlands  
**Director:** Nikk Conneman, MD  
**Co-Director and Contact:** Monique Oude Reimer, RN  
**email:** [nidcap@erasmusmc.nl](mailto:nidcap@erasmusmc.nl)

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Fernández Hospital  
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Buenos Aires, Argentina  
**Director and Contact:** Graciela Basso, MD, PhD  
**email:** [basso.grace@gmail.com](mailto:basso.grace@gmail.com)

## UK NIDCAP Centre

Department of Neonatology, University College  
Hospital, London, UK  
**Director:** Neil Marlow, DM FMedSci  
**Contact:** Gillian Kennedy, MSc, OBE  
**email:** [gillian.kennedy@uclh.nhs.uk](mailto:gillian.kennedy@uclh.nhs.uk)

## Children's Hospital of University of Illinois (CHUI) NIDCAP Training Center

University of Illinois Medical Center  
at Chicago  
Chicago, Illinois, USA  
**Director:** Beena Peters, RN, MS  
**Contact:** Jean Powlesland, RN, MS  
**email:** [jpowlesl@uic.edu](mailto:jpowlesl@uic.edu)

## NIDCAP Training and Research Center at Cincinnati Children's

Cincinnati Children's Hospital Medical Center  
Cincinnati, Ohio, USA  
**Director:** Whitney Brady, MSN, RN  
**Contact:** Linda Lacina, MSN  
**email:** [nidcap@cchmc.org](mailto:nidcap@cchmc.org)

## The Brussels NIDCAP Training Center

Saint-Pierre University Hospital  
Free University of Brussels  
Brussels, Belgium  
**Director:** Inge Van Herreweghe, MD  
**Co-Director:** Dominique Haumont, MD  
**Contact:** Delphine Druart, RN  
**email:** [delphine\\_druart@stpierre-bru.be](mailto:delphine_druart@stpierre-bru.be)

## NIDCAP Norway, Ålesund Training Center

Ålesund Hospital, Ålesund, Norway  
**Director:** Lutz Nietsch, MD  
**Contact:** Liv Ellen Helseth, RN  
**email:** [nidcap@helse-mr.no](mailto:nidcap@helse-mr.no)

## The Barcelona-Vall d'Hebron NIDCAP Training Center Spain

Hospital Universitari Vall d'Hebron  
Barcelona, Spain  
**Director and Contact:** Josep Perapoch, MD, PhD  
**email:** [jperapoc@vhebron.net](mailto:jperapoc@vhebron.net)

## Hospital Universitario 12 de Octubre NIDCAP Training Center

Hospital Universitario 12 de Octubre  
Madrid, Spain  
**Director:** Carmen Martínez de Pancorbo, MD  
**Contact:** María López Maestro, MD  
**email:** [nidcap.hdod@salud.madrid.org](mailto:nidcap.hdod@salud.madrid.org)

## St. Joseph's Hospital NIDCAP Training Center

St. Joseph's Hospital and Medical Center  
Phoenix, Arizona, USA  
**Co-Directors:** Bonni Moyer, MSPT and Marla Wood, RN, MEd  
**Contact:** Windy Crow  
**email:** [stjosephnidcap@dignityhealth.org](mailto:stjosephnidcap@dignityhealth.org)

## Italian Modena NIDCAP Training Center

Modena University Hospital, Modena, Italy  
**Director:** Fabrizio Ferrari, MD  
**Contact:** Natascia Bertoncelli, PT  
**email:** [natafili@yahoo.com](mailto:natafili@yahoo.com)

## Danish NIDCAP Training and Research Center

Aarhus University Hospital  
Aarhus N, Denmark  
**Director and Contact:** Hanne Aagaard, RN,  
MScN, PhD  
**Co-Director:** Eva Jörgensen, RN Newborn and  
**email:** [hanne.aagaard@skejby.rm.dk](mailto:hanne.aagaard@skejby.rm.dk)

## São João NIDCAP Training Center

Pediatric Hospital at São João Hospital  
Porto, Portugal  
**Director:** Hercília Guimarães, MD, PhD  
**Co-Director and Contact:** Fátima Clemente  
**email:** [saojoaonidcap@chs.j.min-saude.pt](mailto:saojoaonidcap@chs.j.min-saude.pt)

## NIDCAP Germany, NIDCAP Training Center

Tübingen, Tübingen, Germany  
Universitätsklinik für Kinder- und Jugendmedizin  
**Director:** Christian Poets, MD PhD  
**Contact:** Natalie Broghammer, RN  
**email:** [Natalie.Broghammer@med.uni-tuebingen.de](mailto:Natalie.Broghammer@med.uni-tuebingen.de)

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