nidcap FEDERATION INTERNATIONAL
voice of the newborn

Developmental Observer

The Official Publication of the NIDCAP® Federation International

2022 | VOL 15 | NO. 2

> "The key is zero separation."
>
> — Björn Westrup, MD

INSIDE

DOI: 10.14434/do.v15i1.33773

Profile

Björn Westrup, MD, PhD

DOI:10.14434/do.v15i2.34360

Interviewed by Pierre Kuhn, MD, PhD

Björn Westrup is a visionary and an influencer who, together with Agneta Kleberg and the Karolinska NIDCAP Team, has spread the philosophy of developmental care throughout Sweden and Scandinavia over the past 25 years. From my point of view, Björn has played an extraordinary role in the development of Infant and Family Centred Developmental Care (IFCDC) and NIDCAP across Europe and Worldwide. When I met him for the first time in 2009, I was very impressed by his strength of conviction and persuasion, the finesse of his understanding of NIDCAP and his involvement in research in IFCDC. I had the chance to be warmly welcomed for more than one year in Stockholm where I had the opportunity to "breathe" and "smell" NIDCAP and Mother Infant Couplet Care from the inside, especially at Danderyd, KI Hospital where Björn was the Head of Department for many years. I realized how resilient and skilled he was to carry system change and to succeed in the implementation of NIDCAP and parental involvement as primary caregivers. This experience contributed a lot to change my perception and vision of what perinatal care can be. Björn is a sensitive and endearing person, also very experienced in facilitating working groups. I learned a lot from his sense of consensus and balance while working with him as co-chair of the EFCNI Topic Expert Group on IFCDC. It has been a great privilege for me to collaborate with him in a very friendly and supportive atmosphere. Björn is also a great epicurean who knows at best how to enjoy great moments of friendship! We have many things to learn from your past and continuing journey, Björn. Thank you very much for sharing your story with us.

(continued on p. 2)

Profile – Bjorn Westrup PhD, continued from p. 1

Björn Westrup is a paediatrician and neonatologist with a PhD. He was a senior consultant in neonatology and the director of the Karolinska NIDCAP Training and Research Center at Astrid Lindgren Children's Hospital, Karolinska University Hospital since its start in 1999. It was the first NIDCAP Center in Europe and has played a leading role in the development of other European centers. Dr. Westrup was also a member of the NIDCAP Federation International's first Board of Directors. He has pioneered the development of Infant & Family Centered Developmental Care (IFCDC) and Mother-Newborn Couplet Care (MNCC) in Europe. Björn organised a unique meeting in Sweden with the Karolinska NIDCAP team. The Stockholm Conference on Ultra-Early Intervention is an internationally renowned and acknowledged meeting in Sweden dedicated to ultra-early intervention in IFCDC. He has been and is still very involved in research in that field and especially in immediate skin-to-skin contact in preterm infants after birth with the aim to avoid separation of infants from their mothers and fathers. Björn has also chaired the topic expert group dedicated to IFCDC of the European standard of care from the European Foundation of the Care of Newborn Infants (EFCNI).

PK: *When and how did you get interested in developmental care?*

BW: During my first rotation into neonatology in the paediatric residency program. The hospital was a small county hospital in Falun in the forest area of Sweden and was quite old fashioned and had just started allowing parents into the paediatric units. Parents were not allowed in the neonatal unit. I saw the importance of parents. A senior colleague and head of the Paediatric Public Health Program fought for parents to be allowed in the neonatal unit. He set me a challenge as a junior doctor to get parent's involved in their infant's care. I started to observe different infant behaviours when the parents were present. Towards the end of 1989 I attended a conference organised by Professor Hugo Lagercrantz at the Karolinska where Heidelise Als was an invited presenter. I was intrigued with the combination of natural science and behavioural science. This gave me some theoretical context to explain what I had seen.

On return to my unit, I mentioned this to a clever young neonatal nurse, Agneta Kleberg, who was enthusiastic about the concept. I arranged for funding and brought Agneta to Boston where we were both introduced to NIDCAP and APIB. Actually, we had just asked for a visit but were instead offered a four-day introduction of both NIDCAP and APIB – a surprising visit but that later proved be very instrumental for the development of NIDCAP in Sweden and Europe. Heidi was wise and strategically savvy as always.

PK. *Could you tell us more about your NIDCAP journey?*

BW: When we returned to Sweden, I realised that, at that point, there was not sufficient scientific evidence to a general recommendation for implementing NIDCAP and we needed more research before starting the program.

A prospective phase-lagged observational study was commenced during NIDCAP Training of myself and Agneta. Data was collected for the control infants during Agneta's and my training phase. After a wash-out period with staff training we prospectively recruited the NIDCAP infants and parents. The main findings of the three-year follow-up was a difference in behaviour in the NIDCAP cohort. There were fewer internalising problems and better parent child interactions in the NIDCAP group. We found no short-term benefits.

When Hugo Lagercrantz in 1994 heard about our study in Falun, he invited us to Stockholm to conduct a randomised controlled trial on NIDCAP as part of our PhD programs.

At the same time, we continued to consolidate the NIDCAP based care in Falun, which took a lot of energy. Agneta wrote the Swedish Handbook on NIDCAP which was also translated into Norwegian. She was a fantastic tutor and implementor.

Nevertheless, it was a great challenge to promote NIDCAP as it was quite controversial, and many professionals in the neonatal community in Sweden and internationally were quite sceptical. However, more parents were included in their infant's care and were very positive. In addition, we had important and continuous support of two professors Hugo Lagencrantz from Stockholm, and Nils Svenningson from Lund.

Despite the sceptic, we were not discouraged and continued. There was a gradual acceptance, however it is still not in all units in Sweden.

Today NIDCAP and/or FINE is practiced in 15 units across Sweden. FINE has been very well received and it led to more NIDCAP Training. I believe the development of FINE has been crucial for IFCDC and NIDCAP. We see more people interested in NIDCAP.

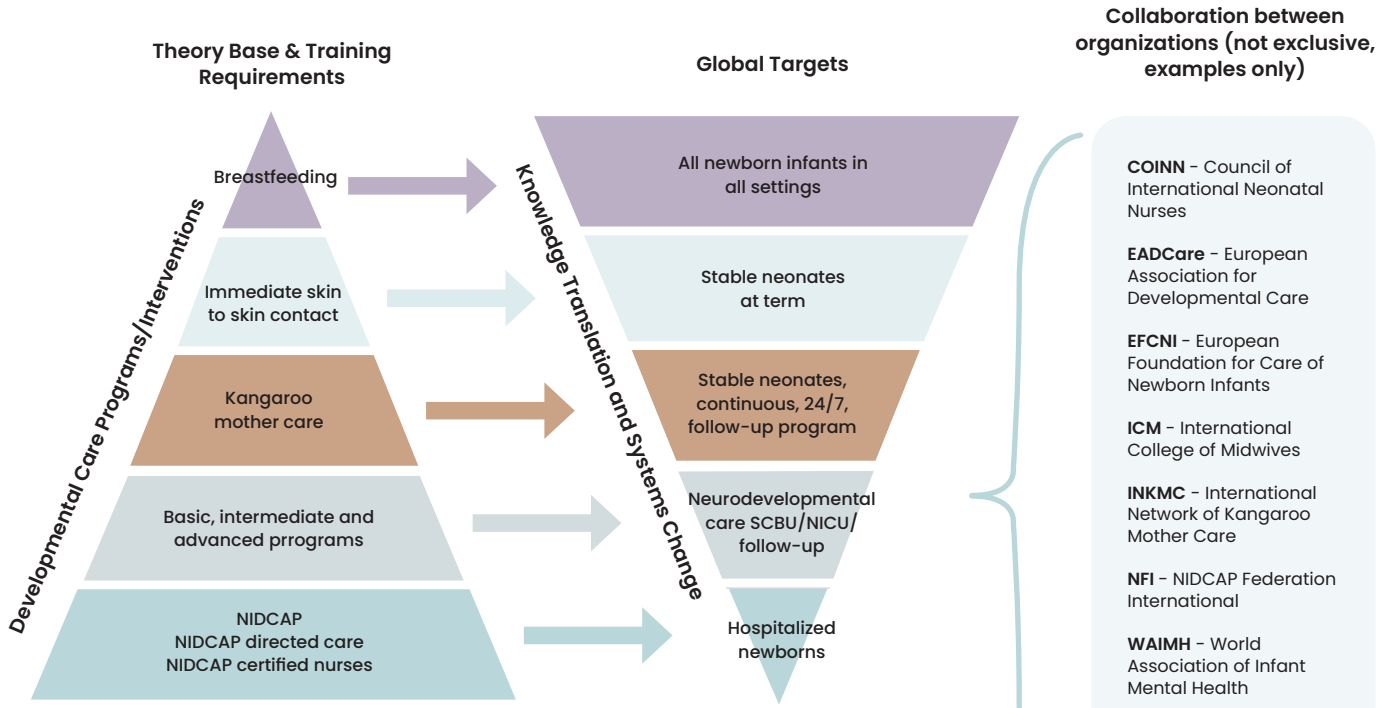
PK: *Can you summarise why NIDCAP is essential to you?*

BW: Firstly, it is very attractive to organise the care according to a framework that incorporates natural, behavioural sciences and theory of systems change. Secondly, the core pillars are ethical for sensitive care based on the infant's own voice and behaviours, and thirdly, the short- and long-term research results show positive effects on both child health and development and parents wellbeing and mental health.

PK: *Can you tell us how you see Infant Family Centred Developmental Care and NIDCAP – Are they the same?*

BW: IFCDC is a generic term for a framework of newborn care that incorporates the theories and concepts of neurodevelopment, neuro-behaviour, parent-infant interaction, parental involvement, breastfeeding promotion, environmental adaptation, and change of hospital systems. It is based on the leading-edge work of Als and her colleagues in the NIDCAP Federation International (NFI) and Brazelton and on the World Association for Infant Mental Health Declaration of

FIGURE: Global Perspective of Infant and Family Centered Developmental Care



Theories and Training taught by professional organizations (eg. NFI, Brazelton Touchpoint Center), higher education facilities, local health organization/services.

The programs vary in regards to comprehensiveness of training and support for systems change. Some programs include several or all interventions exemplified above.

Global refers to *all* babies born in - *high*, *middle* and *low* resource settings.

Developed by Bjorn Westrup and Kaye Spence for the NFI - work in progress

Infants' Rights. The core pillars of IFCDC are sensitive care based on infant behavioural communication and cues gives the infant a voice and is beneficial for brain growth, parent engagement supports parental wellbeing and infant development, and customised adaptations of the NICU environment and hospital system as a whole. IFDC is more descriptive and general in terms of ethics and legal benefits. Whereas NIDCAP is a philosophy and a caregiving approach that has a training program, so far, is the only program that includes all aspects of IFCDC. The work of Als and the NFI has greatly influenced on the concept of IFCDC and will surely continue to play a significant role in its future development.

PK: *Are there other programs that are part of IFCDC?*

BW: Yes, there are many and some quite specific. For example, breastfeeding, and skin-to-skin care are important components of IFCDC. There are also more specific programs. However, NIDCAP is the most developed and research based. [Figure 1] As far as I have understood, FiCare (Family Integrated care) is for example a program for parental involvement more, and in itself not a program that supports the whole idea of IFCDC. In contrast, the Close Collaboration with Parents program include most of the components of IFCDC, especially the behavioural part and parental involvement.

PK: *Can you tell us how you became involved in the EFCNI Standards and how important they are to you?*

BW: These standards are very important tools to initiate change and improve the quality of care in Europe and beyond. Most importantly they are multi-disciplinary. They are going to be revised regularly and the expert groups have started inviting comments and recommended changes. It is important to acknowledge that the initiative for the standards was taken by parent organisations under the broad umbrella of EFCNI. The standards were written in collaboration with parents and endorsed by professional and scientific societies in Europe. Standards are playing a role globally.

The US Design Standards and IDC Standards are complimentary to the European standards, and I strongly believe the collaboration between the two groups will continue.

PK: *What about the WHO study on immediate SSC with preterm infants: Could you summarize the scientific rationale for us?*

BW: The rationale is that 20 million babies are born worldwide annually with a need for neonatal care. We cannot only focus on high income countries. We need to turn to countries with high mortality in low-birth-weight infants globally. If we want to make a difference, then we need to consider the low- and middle-income countries. My experience at the Karolinska and through my lifelong experience with IFCDC and NIDCAP makes me realise it is beneficial with early skin-to-skin contact for small vulnerable infants. In collaboration with Nils Bergman from South Africa, we undertook observational studies to improve short term health outcomes in low- and middle-income countries to increase survival. One finding was better stabilisation at birth. It took eight years to convince the WHO and the Melinda and Bill Gates Foundation to fund the study in Nigeria, Malawi, Ghana, Tanzania, and India. The target group were infants born between 1000g and 1800g.

Used with permission Rachelle van der Meulen

NIDCAP Care in the Moment

A mother's presence - The Netherlands

We planned to recruit 4000 maternal/infant pairs. However, the data safety and monitoring board stopped the trial after 75% recruitment due to a statistical benefit in the intervention group, see:

WHO Immediate KMC Study Group et al. Immediate "Kangaroo Mother Care" and Survival of Infants with Low Birth Weight. The New England Journal of Medicine, 2021, 384, (21): 2028-2038. doi:10.1056/NEJMoa2026486

PK: *What do you see as the challenges and barriers for implementing early skin to skin for infants over 1000g?*

BW: There needs to be a lot of training and support for immediate skin-to-skin. The key is Zero separation – keeping infants and their mothers close both physically and psychologically. It necessitates a very strong collaboration with obstetrics in order to provide medical care for the mother while she stays in the NICU – Mother-Newborn Couplet Care (MNCC) in Mother-NICUs. However, you need to have strong leadership to set the goals and change professional attitudes through training and education. We also need changes in NICU design as well as ensuring quality care for mother /infant dyad.

PK: *Is immediate skin to skin challenging?*

BW: It is very challenging, and it will take decades before there is a general implementation across countries and globally. I would like to finish with a positive outcome. Following on from our and other studies, the government in India have issued a directive to re-build all the NICUs, that is over 1000 units. The goal is to accommodate mothers close to their infants as well as implementing developmentally supportive care. Moreover, WHO will in 2022 publish a general recommendation of immediate and continuous KMC for all sick or small newborn babies.

It will take many years to ensure Infant- and Family-Centered Developmental Care including Newborn Couplet Care for all – however we have made an important start.

PK: *Has NIDCAP affected your personal life?*

BW: It helped me enormously in my clinical work as a neonatologist, it makes it much easier to assess the condition of the newborn and its family and understand their needs. NIDCAP makes the work more interesting and rewarding. My NIDCAP work and involvement in training and research is the foundation of my engagement in WHO global research scale-up project of KMC. Also, it has been very important for my own scientific journey. On a personal level, I am not so sure that my own family members are convinced that I am successful in relationship-based and not task-oriented behaviour - but it hopefully has helped.

PK: *Thank you very much Björn for your time and kindness during this interview and also for all the incredible work you have done for the care of vulnerable preterm infants and their families.*