



## Neurodevelopmental supportive care in a rainbow nation

South Africa, the rainbow country at the tip of the African continent, is home to a population of 65 million people. It is a country that is divided into nine provinces, with 11 official languages and cultural and ethnic diversity. Four major ethnic groups are evident in South Africa with various sub-groups (Department, 2019; SA-V; Statista, 2021). In addition, the country comprises urban, semi-urban and rural to deep rural areas.

The birth rate for South Africa in 2020 was 19.995 births per 1000 people (Macrotrends, 2021), (1,171,219 births in total for the year 2019) (Department, 2019). In South Africa the preterm birth rate was 12.4% in 2014 representing one out of every ten births (Chawanpaiboon et al., 2019). Premature babies are born and cared for in various economic areas, but care may differ dramatically due to the available human and other resources.

Neurodevelopmental supportive care (NDSC) is a widely known but fragmentally implemented care model in the South African context. A variety of researchers from different disciplines conducted studies on various components of NDSC over the last two decades and this article aims to provide an overview of the development and adoption of NDSC in the South African context.

The first training on developmental care was presented in 2001 in Pretoria by professional nurse, Sonja Willemse, to a small number of healthcare professionals, consisting primarily of nursing professionals. Thereafter some components were incorporated in neonatal care by individuals, however changing the culture to ensure that neurodevelopmental care became the underlying model of care in all neonatal units across the country, has proven to be challenging.

While working in the NICU, I (the author) realised that we, as hospital staff take on the 'ownership' of the babies in our care, and parents are not empowered for their parenting role. During 2003, I explored parental needs while their babies were admitted to the NICU in South Africa, with the aim to develop an early intervention program to restore the parenting role for parents while their babies were admitted to the NICU. After completing my master's degree, I developed the first South African, evidence-based website for parents with preterm infants in NICU: [www.littlesteps.co.za](http://www.littlesteps.co.za) (2004). The idea was that we can provide an information platform where information can be updated quickly, and that each unit could have a computer for



parents to access the information. This was before smartphones took over the world. The reality for both private and public sector was, that parents only had access to this information from private resources, such as a home computer or internet café. As a result, I started to present preterm parenting workshops for parents in my geographical area, in a format similar to that of ante-natal classes, but with the focus on preterm development and care. Parents' feedback was that they 'learned more in four hours than in 60 days in the NICU' and that 'staff do not know

this information'. I then realised that more must be done to ensure implementation of NDSC in all clinical facilities

During 2005, Little Steps, took over the professional 2-day training workshop, expanded it to a 3-day workshop to include preterm feeding, and in 2006 registered the Little Steps Premmies trademark and added an additional training: Little Steps Premmie Parenting Facilitators. I believed that parents in every hospital should have access to information about their preemie's development and care in a structured format, therefore training more presenters of the parenting workshop seemed like a



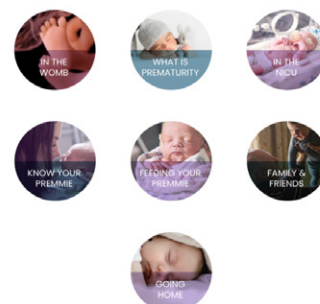
The guidelines in this website will help you to interpret your preterm baby's unique preemie language, support parent-infant bonding and attachment processes and return the parenting role to you, the parents of the preterm baby(s). It will further provide you with 'take-home' messages and tips for families and friends on how to support the preemie family. This website does not attempt to replace the doctors, nurses and therapists who are looking after your baby, but to help you to get to know your baby better and get involved in his or her care. This should help you being less afraid and more prepared when taking your preterm baby home and also enable you to care for yourself.

For more detailed information it is recommended that you also read 'Prematurity - Adjusting your Dream' by Welma Lubbe.

For the sake of simplicity, all babies will be referred to as her/his. This however does not exclude baby boys: they are just as important.

\*preemies are also referred to as preterm infants, preterm baby premature infants and preemies

WHICH SECTION WOULD YOU LIKE TO VISIT?



Little Steps Parenting Website: [www.littlesteps.co.za](http://www.littlesteps.co.za)

solution. Interestingly, enough parenting workshops were more evident in the public sector with the private sector taking much longer to adopt.

During my work in the NICU and with parent support and healthcare professional training, I realised that having a website (at that point in time) was not the most effective means of communication. Parents wanted to have something to read in their hands while sitting next to their baby in NICU. As a result, the full color illustrated book: *Prematurity – Adjusting your dream* (Lubbe, 2008), was born and published in 2008. It has since proven to be a valuable resource for parents and professionals working with preemies and got feedback that it really carried parents through their NICU journey – feedback for which I am very thankful. The second edition of the book is currently in pre-print format and should be available during 2021.

Awareness of developmental care grew during this time, with many healthcare professionals embarking on studies in this field but focusing on selected aspects of the care model - some focussed on sensory integration issues, while others focussed on kangaroo mother care or parental support. Developmental care was still not the underlying model used in the NICU, but rather a nice-to-have add on. However, in the process, some supporting products have been developed and manufactured within South Africa, such as the Little Steps Nest.



*Little Steps Nest*

I obtained my PhD in Nursing in Midwifery and Neonatal Nursing from the North-West University, in South Africa, and my dissertation was entitled the development of 'Best practice guidelines for neurodevelopmental supportive care of the preterm infant in South Africa (Lubbe, 2010). The first phase of the study was to identify the components of NDSC to determine how we could implement this in the South African context while programs such as NIDCAP were considered too expensive and time intensive for the South African context at this time. Some important publications followed from this research and are used in clinical practice, such as the 'Integrative literature review defining evidence-based neurodevelopmental supportive care of the preterm infant (Lubbe *et al.*, 2012) and more recently the publication of 'Best practice guidelines: Neurodevelopmental supportive care of the preterm infant – condensed guide for clinicians (Lubbe, 2019). Further research in the field of NDSC then funded by the National Research Fund (South Africa) from



*Public sector change*

2012-2015 and implementation became more evident with post-graduate students from various universities and a variety of professional disciplines working on this topic.

To highlight some work in this field, the following authors studied some component of NDSC.

- Hennessy (2006) obtained her PhD on 'Facilitation of developmental care for high-risk neonates: an intervention study'
- Nieder-Heitmman (2010) conducted her study on 'The impact of a sensory developmental care programme for very low birth weight preterm infants in the neonatal intensive care unit'.
- Lecuona (2012) completed her research on 'Sensory integration intervention and the development of the extremely low to very low birth weight premature infant.'
- Du Plessis-Faure (2019) obtained her PhD on 'A model for nurses to facilitate mothers' caring of their preterm infants in an informal settlement, Gauteng'.
- In 2020 Dr. Alet Rheeder obtained her PhD titled: 'Implementation strategy for neurodevelopmental supportive care best practice guidelines in South African context' (Rheeder, 2019) and successfully integrated NDSC in a private hospital group where NDSC is now part of the auditing structure of care.
- Dr. Lizelle Jacobs completed her PhD titled: 'The implementation of a multi-disciplinary, neurodevelopmental supportive care training program related to preterm infants in the South African public health sector (Jacobs, 2020)
- Dr. Susan Davis-Strauss her PhD titled: 'Developing a hospital-to-home transition programme to support South African parents of premature infants admitted into neonatal wards in public hospitals (Davis-Strauss, 2021).

Currently the aim is to support hospitals towards sustainable implementation of NDSC in their hospitals by means of a leadership program based on the Kouzes and Posner transformational leadership theory: The INDeSC study. This study has been funded by the South African Medical Research Council since 2018, with a pause in implementation in 2020 due to COVID-19.





*The hospital after the renovation*

Participants currently include both public and private hospitals across the country. The initial phase of the study was the identification of champions in the participating hospitals to act as project coordinators within their facilities. These champions were then provided with leadership training based on the Kouzes and Posner leadership theory and thereafter they are supported for a period of 10 months to implement the various components of NDSC in their facility: 1) Positioning, handling and KMC, 2) Pain management, 3) Neurosocial development, 4) Environment and sensory management, 5) Feeding and non-nutritive sucking, 6) Breastfeeding in the NICU, 7) Individualised, family-centered care, 8) Transport, 9) Procedures using NDSC, and 10) Hospital-to-home. Assessment of the status of NDSC is done before, midway and after the implementation of the various components, and champions experiences of the implementation is also determined to provide valuable information for scale-up of NDSC implementation. The INDeSC tool is used to determine the level of implementation of NDSC in participating units and provides a guideline on areas that require attention.



For parents in the South African context there are some FaceBook peer support groups available such as Neonatal Buddies, LittleLittlePrem, Parents of premature babies – Cape Town, to name a few. In addition, there is the Little Steps Online Parenting Workshop (Little Steps, 2021) as well as in-person premmie parenting workshops in selected hospitals.

Implementation of NDSC in a country such as South Africa that is so diverse in terms of resources and location, is a challenging undertaking. However, with healthcare professionals having the best interest of these tiny patients and their parents at heart, unexpected and impactful change can be seen across the country.

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