



## Individualized Developmental Care for Preterm Infants

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### **Topic**

*Prematurity*

### **Introduction**

Individualized developmental care in the Newborn Intensive Care Unit (NICU), originated in the 1980s. Based in theory<sup>1</sup> and supported by scientific evidence, it is referred to as NIDCAP (Newborn Individualized Developmental Care and Assessment Program).<sup>2</sup> The approach focuses on a detailed reading of each individual infant's behavioural cues. Environment and care are adapted to enhance each infant's strengths and self-regulation collaboratively with the infant and parents, who play the primary role in providing daily nurturance and helping their infant develop trust.

### **Subject**

Of the 4.03 million infants born annually in the United States, 12% are born prematurely; for African-Americans, the figure is 18 percent.<sup>3</sup> Up to 52% of children born preterm develop school problems and emotional disabilities.<sup>4,5</sup> Premature birth places the brain at significant risk for adverse outcome. The intensive care technology and treatments necessary to save these babies' lives disrupt the fetal brain's development. The dual stress of being isolated from the mother and experiencing daily pain and discomfort leads to neurotoxic brain-altering events.<sup>6</sup> The NICU's challenge, therefore, is not only to ensure survival, but also to optimize developmental outcome. NIDCAP's goal is to prevent unexpected sensory overload and pain, and enhance strengths and competence. It adapts intensive medical care and environments to the neurodevelopmental individuality of each infant, thus meeting the infant's medical *and* developmental needs. NIDCAP fundamentally changes traditional care from task-orientation to relationships. The infant's behavioural communications form the basis for individualized developmental environment and care planning for infant and family. This means all medical and nursing interventions are timed and adjusted to the sensitivity of each infant. The approach simultaneously provides support for the parents and key members of the care team. This requires an understanding of infant, parent and family development, the interplay of medical and developmental processes, and of oneself as a person and a caregiver. NIDCAP makes it possible to experience NICU environments and care from the baby's perspective and recognizes the baby's complete dependence and trust.

### Problems

Some neonatologists still criticize the scientific evidence for NIDCAP.<sup>7,8</sup> NIDCAP cannot be studied in double blind fashion, as subject numbers are small; control infant care is contaminated with the study treatment; and NIDCAP is varyingly employed.<sup>8</sup> It is challenging to study NIDCAP, which is theory-driven and relationship-based and requires systems integration. Its hardware and technology free nature makes measurement difficult.<sup>1,9-11</sup> Its essence is continuous resourceful modification of care to the infant's competence and vulnerabilities,<sup>2,12,13</sup> and open minds for “doing, learning and coming to know.”<sup>9,14</sup> Common misunderstandings of developmental care include “minimal stimulation” (fully covered incubators, protection from all visual and auditory contact, and “clustered care” of rapid routines at set intervals) and “developmental decoration approach” (pretty nests and incubator covers, indirect lighting, whispering zones; yet routinized care as before).<sup>15</sup> The change required is internal, a shift in mind, attitude and seeing anew. Further challenges exist for cultures and systems where reflection and relationship processes are unfamiliar,<sup>10,12,16,17</sup> and medical professionals have the ultimate authority for making all decisions.<sup>18</sup> Nurseries may differ in financial and leadership stability, staff relationships, patient census, staff/patient ratios, family characteristics, history, traditions and culture, organizational, communication and conflict resolution styles and their distinctive competences.<sup>9,19</sup> Yet the hopes and expectations of infants and families remain the same worldwide.<sup>17</sup> Combining best technology and intensive care with the most sensitively individualized developmental care is the responsibility.<sup>10,13</sup> The NIDCAP training program ([www.NIDCAP.org](http://www.NIDCAP.org)) focuses on education and training of multidisciplinary developmental specialist teams in NICUs. These in turn support, educate and mentor the bedside professionals in individualizing care and fully integrating the parents.

### Research Context

NIDCAP has been studied in several historical phase-lag trials and criticized for likelihood of contamination by uncontrolled intervening variables. The preferred design is the randomized controlled trial. NIDCAP trials require large NICUs to provide control and experimental group subjects. Staff requires understanding in behavioural research. Cross contamination of caregiver implemented interventions is unavoidable; experimental effects have to exceed contamination effects. NIDCAP research requires experienced developmental specialists, superb nursing and neonatology leadership, and extensive research expertise for the supervision of intervention integrity, acquisition of complex databases and analysis of large data sets. These all are highly labour-intensive. Result generalizability is limited by population and NICU characteristics.

### Key Research Questions

The main research questions concern NIDCAP's effectiveness in terms of medical, neurobehavioural, neurophysiological and brain structural outcome; effects on parents; long- term outcomes; and effects on staff and systems. Some studies investigate change processes and differential effectiveness for infant subgroups. A European multi-centre trial is planned and a U.S. trial appears indicated. Criteria and qualifications for NIDCAP nurseries and adoption by different health-care systems and insurance companies are the

next steps. Applicability to other health-care areas includes geriatrics, psychosomatic medicine and medical intensive care.

### **Recent Research Results**

Four historical<sup>20-23</sup> and six randomized controlled trials<sup>24-29</sup> have investigated the effectiveness of NIDCAP. One recent negative review<sup>8</sup> aside, the results provide consistent evidence of improved lung function, feeding behaviour and growth, reduced length of hospitalization, improved neurobehavioral and neurophysiological functioning, and recently<sup>29</sup> enhanced brain fibre tract development in the frontal lobe and internal capsule. A three-centre trial<sup>28</sup> involving two transport and one internal NICU showed positive results, including lowered parental stress, enhanced parental competence and higher infant individualization. Several studies have demonstrated significantly better Bayley<sup>30,31</sup> mental and psychomotor developmental scores at three, five<sup>22</sup> and nine months<sup>20,24,29</sup> corrected age, as well as improved attention, interaction, cognitive planning, affect regulation, fine and gross motor modulation and communication (Kangaroo-Box paradigm).<sup>20,24</sup> At three years corrected age, a Swedish study<sup>32</sup> documented better auditory processing and speech (Griffith Developmental Scales<sup>33</sup>), fewer behaviour symptoms (Höök-Cedarblad Child Behaviour Interview, in Kleberg,<sup>32</sup>) and better mother-child communication (Parent-Child Early Relational Assessment Scale-ERA<sup>34</sup>); at six years corrected age,<sup>35</sup> higher survival rates without developmental disabilities, specifically mental retardation and attention deficits.

### **Conclusions**

The NIDCAP model is based on scientific evidence and likely leads to savings in NICU and educational costs. NIDCAP training, while requiring financial and time investment, is cost-effective, with documented care cost reductions of U.S. \$4,000 to \$120,000 per infant.<sup>23,24,26</sup> A team consisting of at least two NIDCAP-certified developmental specialists, a medical and a developmental professional, guides the care as tested in the various studies. Detailed weekly bedside observations are followed by written documentation, discussion and guidance to families and caregivers in support of the infants' strengths and reduction of stress. Daily problem-solving leads to environmental and care modification geared to enhance infants' and families' unique strengths and reduce vulnerabilities. The main ingredient of the intervention's success lies in the reliable developmental specialist support. It ensures small, steady increments of progress in emerging strengths and guards against even minor setbacks, often due to misinformation regarding current sensitivities and reaction.

### **Implications**

Given the encouraging results of the NIDCAP studies, it behooves those responsible for NICU care to be knowledgeable and educated in the NIDCAP model. The introduction of NIDCAP into a system involves considerable investments at all levels of organization. It may require physical changes and adaptations. First and foremost, it requires substantive educational efforts and changes in the practice of care. Since NIDCAP is also highly compelling from an ethical perspective and in direct keeping with family-centred care, it promises to become the standard of care for future NICUs. The individualized approach requires leadership support<sup>10</sup> aside from staff training, education and role redefinition.<sup>10</sup>

## PREMATURITY

A formally established international teaching program focuses on such education and provides on-site consultation towards institutional change, leadership and reflective process capacity. NIDCAP requires development in professional self-awareness and capacity to be present in the moment, to “hold” complex relationships and interactions. The developmentally skilled NICU professional combines highest technical skill embedded in highest relationship skill. All NICU work involves human interaction at many levels and in the complex interface of physical and emotional vulnerability. At its core are the tiny, immature, fully dependent, highly sensitive and rapidly developing fetal infant and the infant’s hopeful, open and vulnerable parents, trusting and counting on the caregivers’ attention and investment. Here lies the challenge and the opportunity of developmental NICU care.

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