# **Premature Infants: A Later Look**

by the staff of the NYU Child Study Center

## Introduction

Every year approximately 400,000 babies are born prematurely, defined by some according to birth weight under approximately 5.5 pounds <sup>1</sup> or age, being born before 37 weeks of gestation. <sup>2</sup>Modern medical technology has improved the chances of survival for the smallest of these premature infants. In the first days and weeks of a premature infant's life, attention is appropriately focused on supporting and enhancing vital organ development. Intense intervention is often related to immediate needs such as lung functioning and brain growth. In addition to physical survival, professionals and parents are concerned with improving the odds for the child's developmental and intellectual progress. Given the greater number of premature infants who have reached toddlerhood and school age, researchers have begun to evaluate and understand more about how early birth and life saving measures affect later life.

### What are the risks of later problems for premature infants?

Premature infants are at risk for problems in a variety of areas. The later the infant is born, the lower the risk of later problems. Results of the largest long-term study of babies born extremely prematurely at the age of 25 weeks or fewer were published in the New England Journal of Medicine in 2005. When the children were assessed at age 2 1/2 results showed that 50% had no disabilities, 25% had some level of disability and 25% had severe disability. Results of follow-up at age 6 ½ showed a high rate of disability; 22% had a severe disability such as inability to walk caused be cerebral palsy, very low cognitive ability, blindness or deafness. A further 24% were moderately disabled with cerebral palsy (but walking), IQ in the special needs range and lesser problems with hearing and vision. Milder problems such as wearing glasses, a squint or low/normal cognitive scores were shown by 34% of children. Twenty percent of the very premature babies had no problems. According to Neil Marlow, joint author of the paper "These results show that the majority of children do not have a serious physical disability, i.e., do not have cerebral palsy, blindness or deafness, and despite the high incidence of learning difficulties, half are doing reasonably well and keeping up with their classmates."

Events that influence genetic composition or the structure and function of the brain can affect later development. The most significant risk factors include:

- 1. the prenatal environment: e.g. cigarette smoking, substance abuse, infection
- 2. neonatal complications: e.g. loss of oxygen, intraventricular hemorrhage, types of Neonatal Intensive Care Unit (NICU) experiences
- 3. chronic factors: e.g. mother-infant interaction, post natal nutrition, hydrocephalus, blindness, deafness

The areas that have been shown to be most likely affected include:

- 1. cognitive and academic ability e.g. math or reading disability, intellectual ability)
- 2. language (e.g. delays)
- 3. fine and gross motor (e.g. poor coordination)
- 4. vision, hearing (e.g. visual impairment)
- 5. mental illness (e.g. attention-deficit/hyperactivity disorder)

The disabilities can range from relatively minor, such as difficulty catching a ball due to poor eye hand coordination, to more significant or global disabilities such as blindness, with the type and severity dictating future intervention.

# **Recent trends in neonatal care to prevent/minimize negative long term effects\***

"Individualized Developmentally Supportive Care (IDSC)"  $\frac{1}{2}$  is the most recent trend in the care of premature infants. In general, IDSC is based on the belief that

- 1. different subsystems within the infant are interrelated, develop differently and provide feedback to one another
  - autonomic (e.g. heart rate, breathing)
  - motor (e.g. movement, posture)
  - o state of consciousness (e.g. level of sleepiness and wakefulness)
  - attention (e.g. ability to attend to sound)
  - self regulation (e.g. ability to calm self)
- 2. the physical environment of the typical neonatal nursery is in stark contrast to the prenatal womb environment and not conducive for optimal care.

In order to create the most beneficial environment for each particular infant, parents and professionals look for signs of stress and comfort in the infant in the different system areas. For example, what is the heart rate, is he arching his back, does he seem fretful? By accurately evaluating and recognizing the infant's stress, adjustments can be made to increase comfort and minimize risk.

One key element of the IDSC approach involves learning the infant's own personal style of needs and wants. It is believed that infants, even at this young age, have particular preferences for comfort and can communicate these desires and needs. Thus the adults must discover the clues and respond to the communications appropriately. For example, an infant whose mother was drug addicted may be most responsive and comforted by some stimulation due to his being most familiar with such an environment in utero.

Ideally, in the IDSC model, structuring the infant's day around quiet times and touch times minimizes stress to the baby's developing internal systems. Necessary medical procedures would be conducted during the sanctioned touch times, while other soothing interactions are done during the quiet times when the infant may also be encouraged and helped to sleep.

#### The effect of neonatal care on later development

The type of care required by the infant in the NICU to improve physical functioning may impact later development. For example, the infant who has difficulty breathing may need frequent placement of a breathing tube. The infant who receives this repeated unpleasant touch in the area of the mouth may develop oral motor sensitivity or oral motor muscle problems that can affect later speech and language development. Further, if the infant isn't appropriately supported during these stressful medical procedures with positive touch, pressure in the brain may increase causing the fragile blood vessels in the brain to burst. This can lead to intraventricular hemorrhage (IVH), resulting in neurodevelopment problems in the future.

Positioning the preemie can also influence future development. For example, preemies may be routinely left to lie on their backs, a position that differs from the natural curved fetal position they would maintain in utero. This can result in a shortening of the scapula muscles between the shoulder blades, causing a restricted range of motion and later motor problems. Thus, the older infant may be unable to appropriately reach for objects in front of him.

Researchers believe the different physiological systems are affected both positively and negatively by early NICU experiences. Imagine the seemingly simple and common NICU experience of giving a preemie a heel stick (for a blood test). People may be talking over the infant who is under bright lights. Different internal systems are stimulated simultaneously causing the infant to become overwhelmed. Typically, due to the overload, the infant is unable to soothe himself and restore a calm state. As a result of overload, the infant may (a) dissociate (tune out the painful or confusing situation), (b) become defensive in one area (be hypervigilant and on guard when stimulated) or (c) become distractible (trying desperately to switch from one stimulated area to another in an effort to manage the assault on the different areas of the system). Therefore later in life, when faced with multiple tasks or input, seemingly simple tasks such as listening to the teacher while she is writing on the board or putting on a jacket amongst a group of young children, can overwhelm the child's coping ability.

New understanding of the impact of the physical environment on later development has led to new interventions and devices.

- 1. Correctly sized diapers is one such simple invention. For example, it was found that preemies who are put in diapers that are too large must keep their legs spread apart in order to accommodate the extra fabric. This resulted in incorrect turn out of the hips and thus later motor problems.
- 2. A form of holding called Kangaroo Care is being practiced and taught to parents in many NICUs. This special holding has parents hold the infant on their chest allowing for skin-to-skin contact. Results have shown that "the parent's body temperature adjusts to keep the baby's temperature at the right level. The baby's breathing also becomes more even, and the heart rate and blood oxygen levels stay steady." 7

### What can/should parents do?

- If you are concerned about the possibility of having a premature infant, you should investigate the type of care offered in your hospital. IDSC is becoming the standard of care at more hospital NICUs. You should find out if/where it is practiced in your community. You should be aware that even if the ideal is not offered, hopefully certain aspects of this type of care are practiced or the attitude and philosophy of the health team reflect this new thinking.
- If you are a parent with a newborn in an NICU, you should be trained by the health care team in the correct approach to use with your infant once at home. Parents and infant do best when involved in and continuing developmentally appropriate care beyond the hospital setting.
- If you have a child at home who was a premature infant it is important to continually monitor his developmental progress. It is currently impossible to accurately predict who will have later problems. Rather, over time, different deficits may become apparent when the child reaches different expected milestones for walking, talking, and reading. Certain difficulties may not become apparent until the school years when some premature infants will need special education services. <sup>2</sup>, <sup>10</sup> If difficulty is noted, it then becomes necessary to seek guidance on the proper intervention.
- Parents should consult their health care team to become educated about the types of services available in their state for premature infants. For example in NY state, Early Intervention Programs are provided for eligible children birth through age 3.
- The more parents know about their own child's individual style and the earlier intervention begins, the better the outcome.

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