New Perspectives on Premature Infants and Their Parents

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Babies born before their expected due dates have always been in our consciousness, particularly if family or friends have delivered a premature infant. Infants born too early are at higher risk than full-term babies for medical and developmental complications, which can affect the growing baby and family well into childhood. The earlier the birth, the more risk of complications. These range from chronic lung disease to feeding problems, speech and language difficulties, and socio-emotional challenges.

Intensive care for premature infants is a fairly recent phenomenon. An explosion of technological, pharmacological, and specialty hospital care for tiny preemies began only in the 1960s. As a result, smaller and earlier-born infants not only survive, but thrive. High-tech neonatal intensive care units (NICUs) provide increasingly family-centered and environmentally supportive care to parents and siblings of preemies. As changes in care and rates of survival among premature babies advance — rapidly and remarkably — infant–family professionals must continually reexamine, in the light of new research and clinical findings, our beliefs about appropriate intervention for these vulnerable infants. What we used to think becomes enhanced — and frequently altered — by what we now know.

This article will compare what we used to think with what we have learned in the past 2 decades in several aspects of caring for premature infants and their babies. Taken together, advances in research and evidence-based practice are providing us with a genuinely new perspective on premature infants and their parents.

Preventing Prematurity

We used to think that prevention and intervention before and during pregnancy could dramatically reduce prematurity. But between 1990 and 2002, the incidence of preterm births

at a glance

- More than 485,000 low-birth-weight, premature babies are born in the U.S. each year.
- The increase in preterm births since 1990 may be due to assisted pregnancies and births to older mothers.
- Although their survival rates are improving, many preemies experience long-lasting developmental and behavorial problems.
- Individualized, relationship-based developmental intervention in the NICU should focus not only on medical and nursing care, but also on safety, privacy, confidentiality, comfort, and togetherness for the whole family.

in the United States actually *increased* by 14% and the low birth weight rate is at the highest level it has been in three decades (Martin et al., 2003). Currently, more than 485,000 low-birth-weight (less than 5.5 pounds), premature (less than 37 weeks' gestation) infants are born each year in the United States (see Table 1 for a list of premature and low birth weight terms and Table 2 for numbers of babies born prematurely in the United States). Approximately one out of every eight babies (12%) is born prematurely. African Americans have the highest rate of preterm birth in the US (17.4% of all births to this group), are 2 times as likely to have babies with a low birth weight, and are 3 times as likely to have very low birth weight babies as are white mothers. They are followed in rates of preterm births by Native Americans (12.8%), Hispanics (11.2%), Whites (10.4%) and Asians (10.2%; Martin, Hamilton, Ventura, Menacker, & Park, 2002). Of these preterm infants, approximately 60,000 (approximately 1.4% of all births) weigh less than 1500 grams, or 3 pounds, 4 ounces, and are born at 32 weeks or earlier (Martin et al., 2002; Martin et al., 2003).

Rates of preterm birth are higher in women under 20 and over 35 years of age. The American College of Obstetrics and Gynecology (ACOG, 1999) attributes the increase in prematurity over the last decade in part to an increase in the number of women in the US who are postponing pregnancy and in part to increased use of fertility therapies. Fertility therapy often results in multiple fetuses, who tend to be born premature (ACOG, 1999; Martin et al., 2003).

Poor nutrition during pregnancy, smoking, multiple-birth pregnancies, and infections are also associated with prematurity (March of Dimes, 2003a). Premature births have become the focus of national campaigns to increase public awareness about the difficulties associated with preterm birth, and about the signs of early labor (March of Dimes, 2003b).

Multiple Births, Older Mothers, More Risks

We used to think that couples who were infertile could never conceive and deliver babies. But technological and pharmacological advances in reproductive medicine now make it possible for older women to conceive, and for couples who were thought to be infertile to become pregnant and have babies. Many assisted pregnancies result in twins, triplets, or higher order multiples (ACOG, 1999). Any increase in the number of fetuses sharing a uterus also increases the rate of premature birth, which has led to NICUs around the world experiencing an increasing rate of premature, multiple-birth admissions. From 1980 to 1997, pregnancies resulting in multiple births increased by 52% overall, triplets and higher-order births increased by 404%. Only recently have the rates for triplets and higher order multiples shown a slight decline, while the twin birth rate continues to climb (Martin et al., 2002; Martin, et al., 2003). Rates of prematurity and death for twins and higher-order multiples are from 4 to 33 times higher than those for singleton babies (Martin & Park, 1999).

Most mothers of multiples conceived through fertility therapy are 35 or older. The age of these mothers poses additional risk of prematurity and death to their infants (Martin & Park, 1999). A baby who is a triplet or of higher birth order and who is born prematurely faces a substantial risk of medical and developmental difficulties (ACOG, 1999). The challenges parents experience in caring for multiple-birth preemies also affect their developmental outcomes (Nidus Information Services, 2001).

Surviving and Thriving

We used to think that babies born weighing less than 2 pounds or earlier than 27 weeks' gestation had a dismal chance of survival. In fact, babies are now surviving who were in the supportive environment of the uterus for little more than half of the typical 40 weeks of pregnancy. However, the younger the infant, the smaller the chance of survival. Thanks to improvements in medical and technological intervention, infants born at 23–26 weeks, who usually weigh between 500 and 750 grams, have a 40%–60% chance of survival. Babies born at 27–28 weeks (about 750–1000 grams), have approximately an 85% chance of survival (for an excellent review of outcome data, see Bennett, in press). As the pregnancy goes on, survival rates increase dramatically, so that almost all infants born at 34 weeks or later survive.

Unfortunately, survival alone does not ensure a premature

Table 1: A Vocabulary of Prematurity

Premature	Any baby born before 37 weeks of gestation, with 40 weeks being considered "full term"
Very premature	Any baby born before 32 weeks of gestation
Low birth weight	Under 2,500 g or 5 1/2 pounds
Very low birth weight (VLBW)	Under 1,500 g or 3 1/3 pounds
Extremely low birth weight (ELBW)	Under 1,000 g or 2 1/4 pounds

baby's health or typical development. Premature infants continue to face a significant risk of severe neurodevelopmental problems, including major, permanent neurosensory impairments; cognitive and language delays; motor deficits; neurobehavioral and socioemotional problems; and learning disabilities. Many of these underlying deficits lead to challenges in school for children who began their lives in the NICU. Rates among preemies of permanent neurosensory deficits such as cerebral palsy, mental retardation, and hearing or visual impairments have not decreased substantially in recent years. Again, major impairments are most likely among younger and smaller preemies. The youngest babies who survive (those born at 28 weeks' gestation or earlier) and who are less than 2 pounds (about 1,000 g) at birth face a 25% chance of permanent impairment in one or more areas of functioning. In contrast, babies born at 32 to 36 weeks have less than a 1 in 10 chance (8%) of irreversible impairment (Bennett, in press).

We have become increasingly aware that preemies may experience subtle but substantial neurodevelopmental and socioemotional deficits, including cognitive delays, speech and language disorders, persistent neuromotor problems, and perceptual problems (Bennett, 1988, in press). These difficulties may not be identified until school age, when prematurely born children must use more differentiated language, visual–spatial skills, and social competencies in order to succeed. In the classroom environment, preemies' developmental and behavioral challenges become increasingly apparent. Typically, they do not subside as prematurely born children grow; rather, these difficulties may persist into adolescence and even young adulthood (Hack et al., 2002; Ment et al., 2003; Rickards, Kelly, Doyle, Lex, & Callanan., 2001), although many have adapted well and report a good quality of life.

The Impact of the Physical Environment

We used to think that a premature baby's physical environment — for example, the NICU where they may spend days, weeks, or months — didn't have much effect on development. However, studies of animals and of adults in the work environment have documented the impact of environmental sound and light on the emergence of circadian rhythms, sleep, early relationships, and the developing brain itself (Bendersky & Lewis, 1994; Bremmer, Byers, and Kiehl, 2003; Morris, Philbin, & Bose, 2000; Philbin, 1996, 2000). Until recently, noise and light in most NICUs were constant and invasive. Babies could not count on darkness and light occurring with rhythmic predictability, nor did they have opportunities for quiet, calm, and restful interactions with their parents. Recent environmental and staff modifications have proven somewhat successful in reducing the impact on fragile babies and their families (Philbin & Gray, 2002).

We know now that the infant's brain is sensitive to incoming sensory stimuli very early in gestation. The fetal brain grows dramatically from the size of a tangerine at about 25–26 weeks to the size of a grapefruit at term. During gestation, the migration, connection, and communication of neurons begin a process of organization in the brain that continues after birth (Monk, Webb, & Nelson, 2001; Volpe, 1991, 2001). The environment can have a powerful effect on this process, and thereby a major effect on later development (Webb, Monk, & Nelson, 2001). When fragile preemies spend their first weeks and months in the NICU instead of in the uterus, protection of the developing brain from environmentally initiated insults is essential.

Sound affects both the growing fetus and the developing child. What the baby hears influences not only the development of the structure of the auditory system but also the organization of behavior, sound sleep, and communication with parents. Comprehensive studies have revealed that the loud, unpredictable sounds that are typical of the NICU disturb babies' physiologic and behavioral organization (Morris et al., 2000; Philbin, 2000). Consider, for example, that the full-term newborn prefers the sounds of the mother's body and voice, and typically respond to their mother's language rather than another (DeCasper & Fifer, 1980; Mastropieri and Turkewitz, 1999). Because the auditory system develops early, even the most premature infants have had some exposure to their mother's voice. However, preemies may not be able to distinguish their mother's voice amidst the cacophony of a noisy NICU.

In the 24-hour darkness of the uterus, the full development of the visual system develops relatively late in gestation. The anatomic structures of the eye and the behavioral capaci-

Table 2: Prematurity Facts

Babies born prematurely in the US

1998	1999	2000	2001	2002
452,275	460,853	467,201	476,250	486,628

One in eight babies is born prematurely in the US

1,305 premature babies are born every day in the US

Adapted from Martin et al., 2003.

ties of the premature newborn are not ready to defend against bright light (Fielder & Moseley, 2000). Because inappropriately timed visual input can harm the developing structure of the brain (Weisel, 1982), it is important to protect the preemie's eyes from direct light, especially during procedures that are already stressful for the baby (Glass, 1999). Cautious presentation of visual stimulation in the incubator or during social interaction protects the infant's developing sleep state organization and availability for interaction with parents. Before the infant is born, the mother provides hormonal and activity cycles that are consistent with her daily routines and that prepare the infant for day/night cycles (Hao & Rivkees, 1999). We now believe that cycled dim lighting in the NICU not only provides a restful, calm environment, but also offers the infant rhythmic, predictable cycles which he or she does not experience once outside the uterine conditions of pregnancy (Brandon, Holditch-Davis, & Beylea, 1999, 2002; Mann, Haddow, Stokes, Goodley, & Rutter, 1986).

Available evidence suggests that the best environment for the stable preemie is his or her parents' faces, voices, and bodies.

Odor may provide some of the most important organizing and learning environments available to the baby. To survive, it is as important for an infant to be able to identify and turn to their mother as their source of nourishment as it is for a mother to identify, support, and protect her newborn (Schaal & Marlier, 1998). However, the early odor environment for fragile newborns receives scant attention. Providing a scarf or clothing with the mother's breast milk odor might be one way to support the continuity of sensory recognition from uterine to extrauterine life.

Fragile babies typically use their own emerging movement and touch capabilities to calm themselves with the use of many motor maneuvers. These might be bracing their feet on the mattress or blanket; grasping their clothing, tubing, or a caregiver's finger; putting their hands to their face; getting their hands to their mouths; and clasping their hands or feet together. Without appropriate positioning and bedding, preemies have a hard time achieving these behaviors. Empirical research suggests that supportive bedding which nestles a baby in a comfortable position with blankets or other soft materials to support the shoulders, legs, trunk, and head should be standard in all NICUs in order to prevent deformities caused by lying on the back for extended periods, and to reduce behavioral disorganization and long-term disabilities (Als, 1998; Als, Duffy, & McAnulty, 1988; Mouradian & Als, 1994; Sweeney and Gutierrez, 2002).

Research findings have directed practitioners' attention not only to the types and quantities of sensory stimulation that reach preemies in the NICU, but also to the timing of sensory input and the question of whether a stimulus is presented alone (unimodally) or as part of a multimodal experience (including, for example, touch, sound, and the visual experience of looking at a human face [Lickliter, 2000; Turkewitz and Mellon, 1989]). From animal studies we are learning that in the fetal and newborn period, optimal organization and behavioral responses to stimulation depend on the availability or unavailability of sensory input at different ages. If incoming stimuli are not timed appropriately, there may be effects on later-developing sensory systems and behavior such as attachment (Lickliter, 2000). For example, overwhelming sensory stimulation when the fetus is very young may affect their behavioral and physiologic organization in ways that may alter their responsiveness during later multimodal social interaction with their parents. Similarly, the impact of unimodal incoming stimuli is quite different from stimuli presented multimodally (Gotlieb, Tomlinson, & Radell, 1989; Lewkowitz & Turkewitz, 1991; Lickliter & Bahrick, 2000). For example, sensitive infants may be able to listen to a mother's soft voice, but when, in addition, they are offered her face and rocked, they may become overwhelmed and disorganized.

We are just now beginning to understand how environmental sensory input affects the developing premature infant. Available evidence suggests that the best environment for the stable preemie is his or her parents' faces, voices, and bodies (Als, 1998; Als & Gilkerson, 1997; Glass, 1999). They are familiar, appropriately complex, multimodal, specific to the infant's individual expectations and needs, and can readily modify themselves according to the baby's responses.

Preemies and Pain

We used to think that premature infants did not experience pain. But over the past decade we have become aware that preemies do respond to painful and noxious stimuli in the NICU. Additionally, some evidence suggests that repeated painful procedures cause preemies to experience more intense pain than the same procedure experienced for the first time (Anand, 2000; Bhutta & Anand, 2002). Researchers suspect that unless premature babies are given medication or other forms of support, repeated painful interventions in the NICU may have long-term adverse behavioral and physiological effects (Anand, Coskun, Thrivikraman, Nemeroff, & Plotsky, 1999; Bhutta, Cleves, Casey, Cradock, & Anand, 2002; Porter, Grunau, & Anand, 1999).

As a consequence of recent research, invasive procedures and surgeries should no longer be performed in the NICU without appropriate analgesia (American Academy of Pediatrics. Committee on Psychosocial Aspects of Child and Family Health & American Pain Society, 2001; American Academy of Pediatrics. Committee on Fetus and Newborn. Committee on Drugs. Section on Anesthesiology. Section on Surgery. Canadian Pediatric Society, Fetus and

Newborn Committee, 2000). Additionally, NICU staff now use supportive techniques to reduce the discomfort of intravenous sticks, heel sticks, intubations, and dressing changes. Swaddling, positioning to encourage self-regulation, and provision of pacifiers and sucrose are additional evidence-based, nonpharmacological interventions that may be used to reduce the physiological and behavioral disorganization commonly associated with pain responses (Franck & Gilbert, 2002; Franck and Lawhon, 1998; Stevens et al., 1999; Stevens, Yamada, & Ohlsson, 2001).

Design of the Modern NICU

We used to think that NICUs should be designed primarily to accommodate new technology and complex lifesaving procedures. New technology has brought more people to manage the equipment, alarms to alert the staff of changes in the baby's stability, more light in order to see the equipment, and more activity around the baby's bedside. Two new areas of research have increased our understanding of the impact of these disturbances on the infant's and family's comfort, sleep, and physiologic stability.

First, findings from basic science, adult environmental impact studies, and applied clinical research show that high levels of sound and light have an influence on physiologic responses and developmental outcomes (Gottfried, 1985; Graven, 2000; Graven et al., 1992). Research on fetal and newborn sensory development suggests the importance of introducing appropriate sensory input carefully during the sequence-specific development of a premature baby's central nervous system (Lecanuet & Schaal, 1996; Lickliter, 2000; Philbin, Lickliter, & Graven, 2000).

Second, the movement toward family-centered care throughout hospitals has encouraged NICU designs that promote comfortable family interaction and reduce environmental harm to the developing baby (Johnson, 1995; Lawhon, 2002; Van Riper, 2001). Parents are no longer required to wear gowns in the NICU. Siblings are typically welcome. NICU designers and staff recognize that because preemies may be hospitalized for weeks or even months, the NICU has become the baby's bedroom. To afford families privacy, confidentiality in encounters with staff, and comfort, many NICUs now include private rooms, in which families are able to spend extended time with their babies while supported by medical and nursing staff. Some newly constructed NICUs provide parents with a bedroom adjacent to the infant's room, with a full-sized bed, refrigerator, CD player, and a private bathroom — all of the amenities needed to live as a 24-hour-a-day family.

In response to these two emerging areas of study, a consensus group of scientists and architects have developed standards for NICU design, which provide guidelines for space, family support resources, and allowable environmental levels of light and sound (White, 2003).

Skin-to-Skin Contact

We used to think that mothers and fathers shouldn't hold their very sick or very tiny babies. However, we now know that babies and mothers benefit from close contact. Most premature infants who are snuggled upright on the mother's or father's bare chest experience more organized sleep patterns, better oxygenation, adequate temperature regulation, and more positive attachment relationships later on (Anderson, Dombrowski, & Swinth, 2001; Conde-Agudelo, Diaz-Rossello, & Belizan, 2003; Feldman, Eidelman, Sirota, & Weller, 2002; Feldman, Weller, Sirota, & Eidelman, 2002; Kambarami, Chidede, & Pereira, 2003; Ramanathan, Paul, Deorari, Taneja, & George, 2001). Mothers who provide their preemies with skin-to-skin ("kangaroo") care produce more milk and experience less psychological and physiological stress (Dombrowski, Anderson, Santori, & Burkhammer, 2001; Furman & Kennell, 2000; Hill, Aldag, & Chatterton, 1999; Tornhage, Serenius, Uvnas-Moberg, & Lindberg, 1998; Uvnas-Moberg, 1998; Uvnas-Moberg, Johansson, Lupoli, & Svennersten-Sjaunja, 2001; Wheeler, Johnson, Collie, Sutherland, & Chapman, 1999). Although extremely preterm infants who are on ventilators have some adverse physiologic reactions to the move from the bed to the parent's body, the benefits to both parents and babies seem to outweigh them (Anderson et al., 2001; Neu, Browne, & Vojir, 2000).

With kangaroo care, NICU staff no longer see parents as visitors, but as essential providers of physiological stability for the growing baby.

As its name suggests, kangaroo care turns the parent's body into the baby's immediate "natural environment" — in essence, the baby's world. The infant experiences the parent's body as his or her 24-hour diner, transportation module, automatic heating and cooling device, playpen, massage therapist, entertainment coordinator, and comfortable reclining bed. With kangaroo care, NICU staff no longer see parents as visitors, but as essential providers of physiologic stability for the growing baby.

How Preemies Develop in the Context of Relationships

We used to think that relationships and development were low-priority concerns in the care of sick and premature newborns. We now know that premature babies are at significant risk for later developmental and relationship difficulties as consequences of their early birth, the impact of hospitalization, and the altered relationship patterns that they and their families experience (Talmi & Harmon, this issue, p. 13).

When health care professionals first designed intensive care for premature infants, they focused on protecting these

fragile babies. Believing that sensory input could overwhelm preemies' physiologic stability, NICU staff protected babies from most "stressful" interactions — including those with parents. Next came a period in which researchers hypothesized that premature infants in NICUs *lacked* the tactile, kinesthetic, auditory, and visual stimulation they needed for adequate brain growth. Researchers studied the effects of sheepskin mattresses, rocking beds, visual targets, and sound in NICU incubators. Currently, researchers are studying sensory enhancement interventions such as massage and music therapy (Dieter, Field, Hernandez-Reif, Emory, & Redzepi, 2003; Ferber et al., 2002; Field, 2002; Standley, 2002). Although positive outcomes for groups of babies, such as weight gain and early discharge, have been documented as a result of these sensory enhancement interventions, they do not typically address the individual strengths and challenges of either the baby or the baby's relationship with his parents. Given the fragility of most premature newborns, care should be taken in introducing sensory input over and above the NICU environmental stimulation. Identification of the effects of additional stimulation on fragile infants is essential so as to not overwhelm the infant's precarious behavioral or physiologic capability. Provision of gentle touch, massage, or music should be individualized with sensitivity to the infant's needs and capacities, and should be provided primarily by the parents (Browne, 2000).

As described earlier, recent studies have revealed that ill-timed and intense stimulation can have detrimental effects on the emerging organization of infants, and ultimately on brain development. Additionally, the ability of the newborn to communicate through behavior has been described and used as the basis for providing developmental care dependent on the baby's behavioral cues (Als, 1977). Researchers and clinicians began to focus attention on developmentally supportive caregiving for premature babies. Most NICUs now embrace an organized approach to developmentally appropriate caregiving as a matter of course (Byers, 2003; Robison, 2003). These efforts vary from nursery to nursery, but typically include protection from light and sound, altered bedding that provides boundaries for sleeping infants, timing caregiving and medical interventions to minimize stress, and including family members in babies' care.

The most influential and best studied of the comprehensive intervention programs is the Newborn Individualized Developmental Care and Assessment Program (NIDCAP), which was developed to meet the individualized needs of each infant and family (Als, 1982, 1986, 1991). Seeing infants as able to communicate their own strengths and needs and to participate in their own developmental goal striving, the NIDCAP approach provides assessment, attention to the infant's developmental goals, and recommendations for ongoing, comprehensive support for the infant in the context of the family. Additionally, NIDCAP works with the NICU and hospital system to incorporate and enhance developmentally supportive principles (Als & Gilkerson, 1997). Since 1985, national and international studies have documented NIDCAP's promise for reducing medical complications and developmental delay in premature infants, promoting organized brain functioning, and enhancing early parent–infant relationships (Als, in press; Als et al., 1986; Als et al., 1994; Becker, Grunwald, & Brazy, 1999; Becker, Grunwald, Moorman, & Stuhr, 1991, 1993; Buehler, Als, Duffy, McAnulty, & Liederman, 1995; Fleisher et al., 1995; Westrup, 2003; Westrup, Kleberg, von Eichwald, Stjernqvist, & Lagercrantz, 2000). Thus the NIDCAP approach is emerging as the most cohesive, evidence based, individualized, relationship supportive intervention program to optimize outcomes for preterm infants in NICUs.

Current parental leave policies offer no good solutions for parents of prematures.

We have known for many decades that premature infants have difficulties in communicating clearly through their behavior. Parents often have difficulties in understanding how to interact with their fragile newborns. During the weeks and even months that many preemies spend in the hospital, physical and emotional concerns take a toll on parents' abilities to be available to their infant (see Talmi & Harmon, this issue, p. 13). Mothers who work outside the home are faced with many challenges over and above recovery from birth. Many mothers and fathers must decide between using parental leave to be with their very young, fragile infant in the NICU, and returning to work in order to save leave until the baby is discharged. These decisions take an emotional, physical, and financial toll on the infant's as well as the family's outcomes. Current parental leave policies offer no good solutions for parents of prematures.

Not surprisingly, relationships between preterm infants and their parents are often difficult. Families in crisis because of the premature birth or from ongoing medical, social, or economic distress have a hard time relating to their babies. Many report relationship problems throughout the childhood years (Taylor, Klein, Minich, & Hack, 2001). Prematurely born children are at higher risk for abuse and/or neglect, reflecting early relationship difficulties (Sullivan & Knutson, 2000).

Long-Term Challenges

We used to think that if premature infants reached school age without showing evidence of developmental problems, they would not experience further difficulties related to their prematurity. Unfortunately, the more we understand the impact of early birth on the later differentiation of the child's

abilities, the more we realize that children born prematurely may have long-term, significant physical, cognitive, and socio-emotional challenges that contribute to difficulties in school (Bennett, 1988, in press). Children born prematurely often have deficits in visual–spatial skills and receptive and expressive language problems (Hubatch, Johnson, Kistler, Burns, & Moneka, 1985; Hunt, Cooper, & Tooley, 1988; Michelsson & Noronen, 1983). They may have a hard time coloring within the lines, doing arithmetic, or sitting still and paying attention to the teacher. Although systematic studies are lacking, parents and professionals frequently report regulatory disorders, anxiety, and problems with peer relationships among prematurely born children. As infants progress through toddlerhood and preschool to the school years, neurodevelopmental issues become evident. Many prematurely born children need special education services (Klebanov, Brooks-Gunn, & McCormick, 1994).

Prematurity and the NICU experience have long-term effects on parents as well as on children. Parents may overprotect children or treat them as vulnerable even if their health is robust and their development typical (Estroff, Yando, Burke, & Snyder, 1994). Like some of the symptoms of post-traumatic stress disorder, intrusive memories, dreams, and sadness, resulting from their experience in the NICU, continue to be part of the lives of parents of prematures (Hynan, 1998).

What Do We Do With What We Now Know?

We now know that although prevention of premature births has been a goal for several years, the incidence of preterm births appears to be still rising (March of Dimes, 2003a; Martin et al., 2003). Prematurity prevention is now the focus of national campaigns (March of Dimes, 2003b). Further efforts at public education and research are necessary to lessen the short- and long-term impact on early-born infants and their families.

We now know that greatly expanding technology and information are available to support the medical and developmental needs of prematurely born infants. NICU technological and pharmaceutical interventions have improved the outcomes of infants, particularly for the earliest-born infants, and should continue to be supported through research and evidence-based practice. Additionally, the promise of better developmental and health outcomes provided by individualized, relationship-based developmental intervention using the NIDCAP model points to the need for developmental care standards within all NICUs. Environmental design, caregiving, and systems change in the NICU should focus not only on excellent medical and nursing care, but also on safety, privacy, confidentiality, comfort, and togetherness for the growing family.

Because *we now know* that even infants who are at low risk for significant ongoing developmental and physical problems may have long-term sequelae, close monitoring of these infants is called for by their medical home health provider, as well as assessment and supports such as Part C of the Individuals with Disabilities Education Act (IDEA). Many states now have systems to identify infants who are automatically eligible for Part C services while they are still in the NICU. Similarly, some states have begun the process of developing an individualized family service plan (IFSP) for infants in the NICU, thus providing seamless assessment, referral, and intervention services (Browne, Langlois, Sundseth Ross, & Smith-Sharp, 2001).

We now know that we will continue to have early-born infants, with all of the complexities that prematurity brings to their medical and developmental outcomes, as well as to the continuing impact on their families. We also know that the vulnerability of these babies consists of much more than the physiological challenges they experience in the NICU; prematurity can affect their cognitive and socioemotional development well into the school years. Therefore, up-to-date medical care; early, individualized developmental intervention; and supportive parental relationships can and must begin in the NICU and continue into preemies' early years in order for them to experience the best outcomes possible. These tiny babies will continue to challenge our thinking about how we provide support to infants and families in hospitals, communities, and in the larger social context.

REFERENCES

Als, H. (1977). The newborn communicates. *Journal of Communication*, *27*(2), 66–73.

Als, H. (1982). Toward a synactive theory of development: Promise for the assessment and support of infant individuality. *Infant Mental Health Journal*, *3*(4), 229–243.

Als, H. (1986). A synactive model of neonatal behavioral organization: Framework for the assessment of neurobehavioral development in the premature infant and for support of infants and parents in the neonatal intensive care environment. In J.K. Sweeney (Ed.) *The high-risk neonate: Developmental therapy perspectives* (pp. 3–53). New York: The Haworth Press.

Als, H. (1991). Neurobehavioral organization of the newborn: Opportunity for assessment and intervention. *National Institue on Drug Abuse Research Monograph*, *114*, 106–116.

Als, H. (1998). Developmental care in the newborn intensive care unit. *Current Opinion in Pediatrics*, *10*(2), 138–142.

Als, H. (in press). A three-center randomized controlled trial of individualized developmental care for very low birth weight preterm infants: Medical, neurodevelopmental, parent and care giving effects. *Journal of Developmental & Behavioral Pediatrics*.

Als, H., Duffy, F. H., & McAnulty, G. (1988). Behavioral differences between preterm and full-term newborns as measured with the APIB system scores: 1. *Infant Behavior and Development*, *11*, 305–318.

Als, H., & Gilkerson, L. (1997). The role of relationship-based developmentally supportive newborn intensive care in strengthening outcome of preterm infants. *Seminars in Perinatology*, *21*(3), 178–189.

Als, H., Lawhon, G., Brown, E., Gibes, R., Duffy, F. H., McAnulty, G., & Blickman, J. G. (1986). Individualized behavioral and environmental care for the very low birth weight preterm infant at high risk for bronchopulmonary dysplasia: Neonatal intensive care unit and developmental outcome. *Pediatrics*, *78*, 1123–1132.

Als, H., Lawhon, G., Duffy, F. H., McAnulty, G. B., Gibes-Grossman, R., & Blickman, J. G. (1994). Individualized developmental care for the very low-birth-weight preterm infant. Medical and neurofunctional effects. *Journal of the American Medical Assocation 272*(11), 853–858.

American Academy of Pediatrics, Committee on Psychosocial Aspects of Child and Family Health, & American Pain Society, Task Force on Pain in Infants, Children, & Adolescents. (2001). The assessment and man-

agement of acute pain in infants, children, and adolescents. *Pediatrics, 108*, 793–797.
American Academy of Pediatrics. Committee on Fetus and Newborn. Committee on Drugs. Section on Anesthesiology. Section on Surgery. Canadian Pediatric Society, Fetus and Newborn Committee (2000). *Journal of Pediatrics, 105*(2), 454–461.
American College of Obstetrics and Gynecology. (1999). Special problems of multiple gestation. *Educational Bulletin, 64*, 323–333.
Anand, K. J. (2000). Pain, plasticity, and premature birth: A prescription for permanent suffering? *Nature Medicine, 6*, 971–973.
Anand, K. J., Coskun, V., Thrivikraman, K. V., Nemeroff, C. B., & Plotsky, P. M. (1999). Long-term behavioral effects of repetitive pain in neonatal rat pups. *Physiology & Behavior, 66*(4), 627–637.
Anderson, G. C., Dombrowski, M. A., & Swinth, J. Y. (2001). Kangaroo care: Not just for stable preemies anymore. *Reflections on Nursing Leadership, 27*(2), 32–34, 45.
Becker, P. T., Grunwald, P. C., & Brazy, J. E. (1999). Motor organization in very low birth weight infants during caregiving: effects of a developmental intervention. *Journal of Developmental and Behavioral Pediatrics, 20*(5), 344–354.
Becker, P. T., Grunwald, P. C., Moorman, J., & Stuhr, S. (1991). Outcomes of developmentally supportive nursing care for very low birth weight infants. *Nursing Research, 40*(3), 150–155.
Becker, P. T., Grunwald, P. C., Moorman, J., & Stuhr, S. (1993). Effects of developmental care on behavioral organization in very-low-birth-weight infants. *Nursing Research, 42*(4), 214–220.
Bendersky, M., & Lewis, M. (1994). Environmental risk, biological risk and developmental outcome. *Developmental Psychology, 30*, 484–494.
Bennett, F. C. (1988). Neurodevelopmental outcome in low birthweight infants: The role of developmental interventions. *Clinics in Critical Care Medicine, 13*, 221.
Bennett, F. C. (in press). Developmental outcome. In M. G. MacDonald, M. M. K. Seshia & M. D. Mullett (Eds.), *Neonatology: Pathophysiology and management of the newborn*. Philadelphia: Lippincott, Williams and Wilkins.
Bhutta, A. T., & Anand, K. J. (2002). Vulnerability of the developing brain. Neuronal mechanisms. *Clinics in Perinatology, 29*(3), 357–372.
Bhutta, A. T., Cleves, M. A., Casey, P. H., Cradock, M. M., & Anand, K. J. (2002). Cognitive and behavioral outcomes of school-aged children who were born preterm: A meta-analysis.[comment]. *Journal of the American Medical Association, 288*(6), 728–737.
Brandon, D. H., Holditch-Davis, D., & Beylea, M. (1999). Nursing care and the development of sleeping and waking behaviors in preterm infants. *Research in Nursing & Health, 22*(3), 217–229.
Brandon, D. H., Holditch-Davis, D., & Beylea, M. (2002). Preterm infants born at less than 31 weeks' gestation have improved growth in cycled light compared with continuous near darkness. *Journal of Pediatrics, 140*(2), 192–199.
Bremmer, P., Byers, J. F., Kiehl, E. (2003). Noise and the premature infant: Physiological effects and practice implications. *Journal of Obstetric, Gynecologic, and Neonatal Nursing, 32*(4), 447-454.
Browne, J. V. (2000). Considerations for touch and massage in the neonatal intensive care unit. *Neonatal Network, 19*(1), 61–64.
Browne, J. V., Langlois, A., Sundseth Ross, E., & Smith-Sharp, S. (2001). BEGINNINGS: An individualized family service plan for use in the intensive care nursery. *Infants and Young Children, 14*(2), 19–32.
Buehler, D. M., Als, H., Duffy, F. H., McAnulty, G. B., & Liederman, J. (1995). Effectiveness of individualized developmental care for low-risk preterm infants: Behavioral and electrophysiologic evidence. *Pediatrics, 96*(5 Pt 1), 923–932.
Byers, J. F. (2003). Components of developmental care and the evidence for their use in the NICU. MCN: *American Journal of Maternal Child Nursing, 28*(3), 174–180; quiz 181–182.
Conde-Agudelo, A., Diaz-Rossello, J. L., & Belizan, J. M. (2003). Kangaroo mother care to reduce morbidity and mortality in low birthweight infants.[update of Cochrane Database Syst Rev. 2000;(4):CD002771; PMID: 11034759]. *Cochrane Database of Systematic Reviews*.(2), CD002771.
DeCasper, A. J., & Fifer, W. P. (1980). Of human bonding: Newborns prefer their mothers' voices. *Science, 208*(4448), 1174–1176.
Dieter, J. N., Field, T., Hernandez-Reif, M., Emory, E. K., & Redzepi, M. (2003). Stable preterm infants gain more weight and sleep less after five days of massage therapy. *Journal of Pediatric Psychology, 28*(6), 403–411.
Dombrowski, M. A., Anderson, G. C., Santori, C., & Burkhammer, M. (2001). Kangaroo (skin-to-skin) care with a postpartum woman who felt depressed. MCN: *American Journal of Maternal Child Nursing, 26*(4), 214–216.
Estroff, D. B., Yando, R., Burke, K., & Snyder, D. (1994). Perceptions of preschoolers' vulnerability by mothers who had delivered preterm. *Journal of Pediatric Psychology, 19*(6), 709–721.
Feldman, R., Eidelman, A. I., Sirota, L., & Weller, A. (2002). Comparison of skin-to-skin (kangaroo) and traditional care: Parenting outcomes and preterm infant development. *Pediatrics, 110*(1 Pt 1), 16–26.
Feldman, R., Weller, A., Sirota, L., & Eidelman, A. I. (2002). Skin-to-skin contact (kangaroo care) promotes self-regulation in premature infants: Sleep-wake cyclicity, arousal modulation, and sustained exploration. *Developmental Psychology, 38*(2), 194–207.
Ferber, S. G., Kuint, J., Weller, A., Feldman, R., Dollberg, S., Arbel, E., & Kohelet, D. (2002). Massage therapy by mothers and trained professionals enhances weight gain in preterm infants. *Early Human Development, 67*(1–2), 37–45.
Field, T. (2002). Preterm infant massage therapy studies: An American approach. *Seminars in Neonatology, 7*(6), 487–494.
Fielder, A. R., & Moseley, M. J. (2000). Environmental light and the preterm infant. *Seminars in Perinatology, 24*(4), 291–298.
Fleisher, B. E., VandenBerg, K., Constantinou, J., Heller, C., Benitz, W. E., Johnson, A., et al. (1995). Individualized developmental care for very-low-birth-weight premature infants. *Clinical Pediatrics, 34*(10), 523–529. [erratum appears in *Clinincal Pediatrics*, 1996 Mar;35(3):172]
Franck, L., & Gilbert, R. (2002). Reducing pain during blood sampling in infants. *Clinical Evidence*, (7), 352–366.
Franck, L. S., & Lawhon, G. (1998). Environmental and behavioral strategies to prevent and manage neonatal pain. *Seminars in Perinatology, 22*(5), 434–443.
Furman, L., & Kennell, J. (2000). Breastmilk and skin-to-skin kangaroo care for premature infants. Avoiding bonding failure.[comment]. *Acta Paediatrica, 89*(11), 1280–1283.
Glass, P. (1999). The vulnerable neonate in the NICU environment. In M. A. Fletcher (Ed.), *Neonatology: Pathophysiology and management* (5th ed.). Philadelphia: Lippincott.
Gotlieb, G., Tomlinson, W. T., & Radell, P. L. (1989). Developmental intersensory interference: premature visual experience suppresses auditory learning in ducklings. *Infant Behavioral Development, 12*, 1–12.
Gottfried, A. (1985). *Environmental neonatology*. Baltimore: University Park Press.
Graven, S. N. (2000). Sound and the developing infant in the NICU: Conclusions and recommendations for care. *Journal of Perinatology, 20*(8 Pt 2), S88–93.
Graven, S. N., Bowen, F. W., Jr., Brooten, D., Eaton, A., Graven, M. N., Hack, M., et al. (1992). The high-risk infant environment. Part 1. The role of the neonatal intensive care unit in the outcome of high-risk infants. *Journal of Perinatology, 12*(2), 164–172.
Hack, M., Flannery, D. J., Schluchter, M., Cartar, L., Borawski, E., & Klein, N. (2002). Outcomes in young adulthood for very low birth weight infants. *New England Journal of Medicine, 2002*, 149–157.
Hao, H., & Rivkees, S. A. (1999). The biological clock of very premature primate infants is responsive to light. *Proceedings of the National Academy of Sciences of the United States of America, 96*(5), 2426–2429.
Hill, P. D., Aldag, J. C., & Chatterton, R. T., Jr. (1999). Breastfeeding experience and milk weight in lactating mothers pumping for preterm infants. *Birth, 26*(4), 233–238.
Hubatch, L. M., Johnson, C. J., Kistler, D. J., Burns, W. J., & Moneka, W. (1985). Early language abilities of high-risk infants. *Journal of Speech & Hearing Disorders, 50*(2), 195–207.
Hunt, J. V., Cooper, B. A., & Tooley, W. H. (1988). Very low birth weight infants at 8 and 11 years of age: Role of neonatal illness and family status. *Pediatrics, 82*, 596–603.
Hynan, M. T. (1998). The Perinatal Posttraumatic Stress Disorder (PTSD) Questionnaire (PPQ). In C. P. Zalaquett & R. J. Wood (Eds.), *Evaluating stress: A book of resources, Vol. 2* (pp. 199–220). Lanham, MD: The Scarecrow Press, Inc.
Johnson, B. H. (1995). Newborn intensive care units pioneer family centered change in hospitals across the country. *Zero to Three, 15*(6), 11–17.
Kambarami, R. A., Chidede, O., & Pereira, N. (2003). Long-term outcome of preterm infants discharged home on kangaroo care in a developing country. *Annals of Tropical Paediatrics, 23*(1), 55–59.
Klebanov, P. K., Brooks-Gunn, J., & McCormick, M. C. (1994). School achievement and failure in very low birth weight children. *Journal of Developmental & Behavioral Pediatrics, 15*(4), 248-256.

Lawhon, G. (2002). Facilitation of parenting the premature infant within the newborn intensive care unit. *Journal of Perinatal and Neonatal Nursing, 16*(1), 71-82.
Lecanuet, J. P., & Schaal, B. (1996). Fetal sensory competencies. *European Journal of Obstetrics, Gynecoloy, & Reproductive Biology, 68*(1–2), 1–23.
Lewkowitz, D. J. & Turkewitz, G. (1991). Intersensory interactgion in newborns: Modification of visual preference following exposure to sound. *Child Development, 52*(3), 827–832.
Lickliter, R. (2000). Atypical perinatal sensory stimulation and early perceptual development: insights from developmental psychobiology. *Journal of Perinatology, 20*(8 Pt 2), S45–54.
Lickliter, R., & Bahrick, L. E. (2000). The development of infant intersensory perception: Advantages of a comparative convergent-operations approach. *Psychological Bulletin, 126*(2), 260–280.
Mann, N. P., Haddow, R., Stokes, L., Goodley, S., & Rutter, N. (1986). Effect of night and day on preterm infants in a newborn nursery: Randomised trial. *British Medical Journal Clinical Research Ed, 293*(6557), 1265–1267.
March of Dimes (2003a). *Perinatal Profiles: Statistics for monitoring state maternal and infant health U.S. 2003 edition*. www.peristats.modimes.org/ataglance/us.pdf.retrieved on December 1, 2003.
March of Dimes (2003b). Prematurity Campaign Retrieved on December 1, 2003 from www.modimes.org/prematurity/5126.asp
Martin, J. A., Hamilton, B. E., Sutton, P. D., Ventura, S. J., Menacker, F., & Munson, M. L. (2003). Births: Final data for 2002. *National Vital Statistics Reports, 52*(10).
Martin, J. A., Hamilton, B. E., Ventura, B. J., Menacker, F., & Park, M. M. (2002). Births: Final Data for 2000. *National Vital Statistics Reports, 50*(5).
Martin, J. A., & Park, M. M. (1999). *Trends in twin and triplet births*, Retrieved on December 1, 2003 from www.cdc.gov/nchs/data/nvsr/nvsr46/nvsr47_24.pdf
Mastropieri, D. and Turkewitz, G. (1999). Perinatal experience and neonatal responsiveness to vocal expression of emotion. *Developmental Psychobiology, 35*(3), 204-214.
Ment, L. R., Vohr, B., Allan, W., Katz, K. H., Schneider, K. C., Westerveld, M., et al. (2003). Change in cognitive function over time in very low birthweight infants. *Journal of the American Medical Association, 289*, 705–711.
Michelsson, K., & Noronen, M. (1983). Neurological, psychological and articulatory impairment in five-year-old children with a birthweight of 2000 g or less. *European Journal of Pediatrics, 141*(2), 96–100.
Monk, C. S., Webb, S. J., & Nelson, C. A. (2001). Prenatal neurobiological development: Molecular mechanisms and anatomical change. *Developmental Neuropsychology, 19*(2), 211–236.
Morris, B. H., Philbin, M. K., & Bose, C. (2000). Physiological effects of sound on the newborn. *Journal of Perinatology, 20*(8 Pt 2), S55–60.
Mouradian, L. E., & Als, H. (1994). The influence of neonatal intensive care unit caregiving practices on motor functioning of preterm infants. *American Journal of Occupational Therapy, 48*(6), 527–533.
Neu, M., Browne, J. V., & Vojir, C. (2000). The impact of two transfer techniques used during skin-to-skin care on the physiologic and behavioral responses of preterm infants. *Nursing Research, 49*(4), 215–223.
Nidus Information Services (2001). What are the complications of assisted reproductive technologies? Retrieved December 21, 2003 from www. ucdmc.ucdavis.edu/ucdhs/health/A-Z/67Infertilitymen/doc67complications.html
Philbin, M. K. (1996). Some implications of early auditory development for the environment of hospitalized preterm infants. *Neonatal Network — Journal of Neonatal Nursing, 15*(8), 71–73.
Philbin, M. K. (2000). The influence of auditory experience on the behavior of preterm newborns. *Journal of Perinatology, 20*(8 Pt 2), S77–87.
Philbin, M. K., & Gray, L. (2002). Changing levels of quiet in an intensive care nursery. *Journal of Perinatology, 22*(6), 455–460.
Philbin, M. K., & Klaas, P. (2000). Hearing and behavioral responses to sound in full-term newborns. *Journal of Perinatology, 20*(8 Pt 2), S68–76.
Philbin, M. K., Lickliter, R., & Graven, S. N. (2000). Sensory experience and the developing organism: A history of ideas and view to the future. *Journal of Perinatology, 20*(8 Pt 2), S2–5.
Porter, F. L., Grunau, R. E., & Anand, K. J. (1999). Long-term effects of pain in infants. *Journal of Developmental & Behavioral Pediatrics, 20*(4), 253–261.
Ramanathan, K., Paul, V. K., Deorari, A. K., Taneja, U., & George, G. (2001). Kangaroo mother care in very low birth weight infants. *Indian Journal of Pediatrics, 68*(11), 1019–1023.
Rickards, A. L., Kelly, E. A., Doyle, L. W., Lex, W., & Callanan, C. (2001). Cognition, academic progress, behavior and self-concept at 14 years of very low birth weight children. *Journal of Developmental & Behavioral Pediatrics, 22*, 11–18.
Robison, L. D. (2003). An organizational guide for an effective developmental program in the NICU. *Journal of Obstetric, Gynecologic, & Neonatal Nursing, 32*(3), 379–386.
Schaal, B., & Marlier, L. (1998). Maternal and paternal perception of individual odor signatures in human amniotic fluid—potential role in early bonding? *Biology of the Neonate, 74*(4), 266–273.
Standley, J. M. (2002). A meta-analysis of the efficacy of music therapy for premature infants. *Journal of Pediatric Nursing, 17*(2), 107–113.
Stevens, B., Johnston, C., Franck, L., Petryshen, P., Jack, A., & Foster, G. (1999). The efficacy of developmentally sensitive interventions and sucrose for relieving procedural pain in very low birth weight neonates. *Nursing Research, 48*(1), 35–43.
Stevens, B., Yamada, J., & Ohlsson, A. (2001). Sucrose for analgesia in newborn infants undergoing painful procedures. [update of Cochrane Database Syst Rev. 2000;(2):CD001069; PMID: 10796405]. *Cochrane Database of Systematic Reviews*.(4), CD001069.
Sullivan, P. M., & Knutson, J. F. (2000). Maltreatment and disabilities: A population-based epidemiological study. *Child Abuse & Neglect, 24*(10), 1257–1273.
Sweeney, J., & Gutierrez, T. (2002). Musculoskeletal implications for preterm infant positioning in the neonatal intensive care unit. *Journal of Perinatal and Neonatal Nursing, 6*(1), 58–70.
Taylor, H. G., Klein, N., Minich, N. M., & Hack, M. (2001). Long-term family outcomes for children with very low birth weights. *Archives of Pediatrics & Adolescent Medicine, 155*(2), 155–161.
Talmi, A., & Harmon, R. J. (2003). Relationships between preterm infants and their parentsdisruption and development. *Zero to Three, 24*(2) 13–20 .
Tornhage, C. J., Serenius, F., Uvnas-Moberg, K., & Lindberg, T. (1998). Plasma somatostatin and cholecystokinin levels in preterm infants during kangaroo care with and without nasogastric tube-feeding. *Journal of Pediatric Endocrinology & Metabolism, 11*(5), 645–651.
Turkewitz, D. J., & Mellon, R. C. (1989). Dynamic organization of intersensory function. *Canadian Journal of Psychology, 3*(2), 286–301.
Uvnas-Moberg, K. (1998). Antistress pattern induced by oxytocin. News Physiological *Science, 13*, 22–25.
Uvnas-Moberg, K., Johansson, B., Lupoli, B., & Svennersten-Sjaunja, K. (2001). Oxytocin facilitates behavioural, metabolic and physiological adaptations during lactation. *Applied Animal Behaviour Science, 72*(3), 225–234.
Van Riper, M. (2001). Family-provider relationships and well-being in families with preterm infants in the NICU. *Heart & Lung: Journal of Acute & Critical Care, 30*(1), 74–84.
Volpe, J. J. (1991). Brain development—normal and abnormal. *Journal of Perinatal Medicine, 19*(Suppl 1), 29–34.
Volpe, J. J. (2001). *Neurology of the newborn* (4th ed.). Philadelphia: W. B. Saunders.
Webb, S. J., Monk, C. S., & Nelson, C. A. (2001). Mechanisms of postnatal neurobiological development: Implications for human development. *Developmental Neuropsychology, 19*(2), 147–171.
Weisel, T. N. (1982). The post natal development of the visual cortex and the influence of environment (Nobel Lecture). *Bioscience Reports, 2*, 351–377.
Westrup, B. (2003). *Developmentally supportive neonatal care. A study of the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) in a Swedish environment*. Unpublished doctoral dissertation, Karolinska Institute, Stockholm.
Westrup, B., Kleberg, A., von Eichwald, K., Stjernqvist, K., & Lagercrantz, H. (2000). A randomized, controlled trial to evaluate the effects of the newborn individualized developmental care and assessment program in a Swedish setting. *Pediatrics, 105*(1 Pt 1), 66–72.
Wheeler, J. L., Johnson, M., Collie, L., Sutherland, D., & Chapman, C. (1999). Promoting breastfeeding in the neonatal intensive care unit. *Breastfeeding Review, 7*(2), 15–18.
White, R. (2003). *Recommended standards for newborn ICU design*. Report of the Fifth Consensus Converence on Newborn ICU Design. °1S4-S21.