

Developmental Care for Premies and their Families: One Neonatologist's Journey toward NIDCAP Practice

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Education Gap

Although most neonatologists are aware of developmental care in general, and the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) approach in particular, their opinions vary because of what some see as a paucity of scientific evidence at the 95% confidence level.

Objectives

After completing this article, readers should be able to:

1. Detail what the NIDCAP approach to developmental care is.
2. Relate what NIDCAP is not.
3. Form an opinion on the advisability of using the NIDCAP approach in the NICU.
4. Avail themselves of NIDCAP training.

Abstract

Over the course of a 40+ year career in pediatrics and neonatology, I moved slowly toward the sort of developmentally sensitive practice with infants and families exemplified by the Newborn Individualized Developmental Care and Assessment Program (NIDCAP). I was somewhat misled by early neurologic teachings, but was put on the right track during pediatric and fellowship training. Finding guidance from mentors in NIDCAP, I learned to "read" my patients' reactions and messages, and to tailor my care to their individual capabilities and expectations. Sharing these insights with other caregivers and parents allowed me to support the infants' neurodevelopment, to avoid negative impacts on their developing nervous systems and to discharge a more intact graduate sooner, and at less expense. NIDCAP makes for better neonatology and it is worthy, both inherently and scientifically, of your consideration.

AUTHOR DISCLOSURE Dr Sheldon is past medical director of the Sooner NIDCAP Training Center in Oklahoma City, and a past member of the board of directors, NIDCAP Federation International. Dr Sheldon has been compensated for his service as a site surveyor for the NIDCAP Nursery Assessment and Certification Program. This commentary does not contain a discussion of an unapproved/investigative use of a commercial product/device.

ABBREVIATIONS

APIB	Assessment of Preterm Infant Behavior
BNBAS	Brazelton Neonatal Behavior Assessment Scale
HFOV	high-frequency oscillatory ventilation
iNO	inhaled nitric oxide
NIDCAP	Newborn Individualized Developmental Care and Assessment Program
RCT	randomized controlled trial

MY EXPERIENCE

Like many of you, I was taught that term infants have little or no cortical brain function, that they feel no pain (or at least, don't remember it) and thus, that pain matters not at all. I was taught that infants function on a brainstem reflex level—the operational equivalent of a frog whose neuraxis has been transected at the level of the superior colliculi—lacking all behavioral involvement of higher brain centers. And as for preemies, they could hardly be any more sophisticated, could they?

This global view colored much of what we did in neonatal care. I didn't do any anesthesia-free laparotomies or thoracotomies (1) personally, but I knew of several. I inserted my share of chest tubes and cut-downs with scanty or no anesthesia. Often there seemed little objection from these children, but I was uncomfortable about the reactions I did see. The tougher, more mature infants let me know that they certainly *did* feel pain while others just slipped into unresponsiveness and let me go on assuming they felt nothing.

As early as 1970, Dr T. Berry Brazelton had started me thinking about the supratentorial functioning of term newborns. Dr Brazelton came regularly to Boston Children's Hospital Medical Center to teach—and often we residents watched closely (with his guidance) as a fresh, 1-day-old infant watched us, turned toward a voice outside the field of view, preferred a female voice to a male one, and ignored (“extinguished”) a noxious stimulus (a tap or bell or even a pin prick) after just a few repetitions. (2)(3) We learned about the preference for the scent of the mother's garments and about the ability to entrain and involve adults in interactions. It was difficult to square these observations with the “brainstem preparation” “reflexes-only” concept of a newborn nervous system.

During my Denver neonatology training, Dr Lula Lubchenko and colleagues demonstrated that changes in formal Brazelton Neonatal Behavior Assessment Scale (BNBAS) scores could be discerned after circumcision (as typically performed without any anesthesia). Some of these changes were still present days or weeks later. Other investigators showed spikes in salivary and blood glucocorticoid levels after circumcision or even after dorsal penile nerve block anesthetic injection alone. (4) These observations likewise did not fit in with the theoretical meaninglessness of pain.

When and how did the infant become so capable? Preemies didn't show these skills, so term infants must have developed them while I wasn't looking! Did these abilities develop in the NICU? Did they develop despite our tender mercies, or were we altering development? Could such capabilities be encouraged or enhanced? Nobody seemed to have the answers.

Then along came Heidelise Als and her coworkers. Working with Dr Brazelton and others, Dr Als began better defining and explaining the capabilities of the premature infant using methods similar to the BNBAS observations, and adding some assessments more appropriate to the tiny premature infant. Building on knowledge of how frequently infants were disturbed in the course of their care, (5) how they experienced “undesirable” hypoxic situations during those episodes, (6) and the insight that visual feedback from oxygen monitors helped staff to decrease such episodes, (7) she proposed more comprehensive, universally available, technology-free ways to avoid these stresses. She originated and polished methods to “read” the preterm infant's communications. She explained what to do when the child can't handle the things we are doing to him or her. She offered insights into the biology and neurology of these capabilities and suggested interpretations and responses. (7)(8) Most importantly, she offered ways to protect the child from potentially negative, even damaging experiences and *showed that such protection altered preemies' developmental outcomes.* (9)

I came to realize that I had failed to “see” all aspects of the infant. I had missed the differences from “normal” by assuming that preemies are just “like that.” I didn't see his developing person and personality. I didn't notice the discomforts and distress that I was causing her, partially because she did not cry out—she just stopped reacting altogether. I didn't know how to help or protect. I didn't realize that the preemie who doesn't show a developmentally appropriate “personality” may well be sedated, sick, or even injured.

When I learned about NIDCAP theory and methods from Heidelise Als, Gretchen Lawhon, Martha Holmes, Linda Lutes, Joy Browne, Laurie Mouradian, and many others, I learned to see these signals, to receive these communications, and to tailor care to the child's personal status and capacities. I thank them all for their help.

I also learned to share these insights with the parents and the staff. I added a behavioral dimension to the biological neonatology I had been taught. I learned how to send home a better survivor to a more capable family, sooner, and not incidentally, at a lower cost.

WHAT NIDCAP IS

NIDCAP is a set of practices by which specially trained infant developmental specialists and NICU staff repeatedly assess an individual newborn preterm infant's developmental status and ability to withstand the stresses of NICU life before, during, and after caregiving procedures. Based on

this assessment, an Individualized Plan of Care is proposed, typically limiting untimely stimuli, protecting sleep, and fostering developmentally appropriate, family-centered interactions with carefully supported parents. (10) NIDCAP is an evidence-based system applicable to all infants, and is especially powerful with very low- and extremely low-birth-weight preterm infants. These out-of-place fetuses are especially vulnerable to inappropriate and ill-timed experiences like those encountered in the NICU. The children who are developmentally ready for more stimuli and interaction are then advanced to those new experiences, while those who are having difficulty coping because of their immaturity or illness are protected.

The formal NIDCAP evaluation involves detailed, systematic observations every 2 minutes, before, during, and after a caregiving intervention, making it possible to discern whether a child is thriving in, or merely coping with the environment's experiences and sensory load, or whether events overwhelm those coping skills and produce an unpleasant, stressful, or even unstable situation. The child's responses in autonomic function, motor activity, sleep state, attention-interaction, and self-regulation are rated every 2 minutes until fluctuations in stability prompted by the caregiving return to baseline, or at least assume a predictable pattern. These observations help the caregiver to discern the child's present developmental "expectations" and needs. The final steps in the sequence include planning and delivering care to match and further support the child's abilities and needs, and avoiding experiences that stress or overload the child's nervous system. This, in turn, will encourage self-quieting, rest, sleep, and application of the child's limited supply of energy to growth and activities within his or her current capacities. Observations are done repeatedly throughout the child's hospital stay, and care plans and experiences are advanced as the child matures. (11)

These detailed and sequential observations allow the careful observer to perceive the complexity and capability of the individual infant's nervous system and to notice when it is functioning well or becoming derailed.

Training in the NIDCAP approach has been formalized and standardized into a tightly organized international hierarchy of approved training centers, master trainers, trainers, and NIDCAP-certified bedside professionals in many disciplines, who apply the approach in a complete and uniformly individualized way. (12) Twenty training centers have been established across the United States, Europe, and South America. Six more are currently under development, in Canada, Israel, Japan, and Southern Europe. Close support at all levels ensures consistency of training and application. In addition, the NIDCAP Federation International,

the foundation responsible for quality and uniformity of NIDCAP practice, has organized the NIDCAP Nursery Assessment and Certification Program to conduct on-site reviews and certify NICUs and special care nurseries as practicing the NIDCAP method in all its aspects. (13)

WHAT NIDCAP IS NOT

NIDCAP has been misconstrued as being a one-size-fits-all prescription for sensory protection using incubator covers, as an array of products (sold for profit by vendors), or as a profit-making enterprise. These are incorrect perceptions. While training is on a fee-for-service basis, fees are in balance with the professional training provided and the benefits to be gained by trainee and patient/family.

NIDCAP is not a single intervention, such as universal sleep preservation or reduced NICU light or sound levels. Although these factors are often included in a selective way, the evidence speaks to the effectiveness of extended exposure to the whole array of NIDCAP recommendations based on the particular child's needs, and change as the child matures, always expressed by and carefully assessed through detailed observation of the child's behavior. These complexities can be lost on those who attempt to "simplify" the method and even on some who have studied the approach.

NIDCAP is not a fad or a set of opinions devoid of evidence. Recent evidence supporting NIDCAP, and evidence failing to support are presented below. Importantly, in our field, no adverse effects of this approach have been reported.

THEORETICAL FRAMEWORK FOR INFANT BRAIN DEVELOPMENT: CURRENT KNOWLEDGE

The brain of the fetus and preterm newborn is a complex, delicate, and rapidly growing structure. Events that would normally take place in the protected environment of the uterus are now often occurring in the NICU instead. Cell proliferation, tapering off at about the age of viability, and numbering many thousand new neurons daily, must not stop ahead of schedule. (14)(15) Migration of these cells to their proper position in the various layers of cerebral cortex and elsewhere must continue. (16) The glial skeleton that the neurons "climb" is being built as it is being populated. (17) Synaptogenesis, driven by the sensory and motor experiences of the brain, proceeds in the tens of thousands of connections per second. (18) These events are likely altered by the child's ectopic location in a brightly lit, noisy, intrusive, even painful NICU.

Programmed cell death and pruning (apoptosis) of unused pathways sculpts the final product well into

childhood, with eventual elimination of a majority of the original neurons. (19) Sequences of events (where A must be completed before B can follow) probably exist, but are very poorly understood.

Until we better understand these myriad processes, we would be wise to keep the NICU fetus in an environment very similar to the intrauterine one.

Genetically determined structure and chemical systems certainly provide the initial form and the potential mechanisms for all these events, but experiences doubtless alter the expression of genetic infrastructure in profound ways. The processes whereby we learn or develop a set of skills begin in utero and can be significantly altered, delayed, or even derailed by peripartum, NICU, and later experiences.

A possible mechanism for some such changes from the underlying genetic legacy can be found in the evolving field of epigenetics. Evidence exists for rapid changes in gene expression based on methylation or histone tagging of the DNA without alteration of the nucleotide sequence. This epigenetic change in the genome can alter phenotype and behavior far more quickly than DNA mutation could, and raises the possibility that these quasi-genetic changes might pass to the next (or the next several) generations. (20)(21)

EVIDENCE SUPPORTING NIDCAP

The evidence behind the NIDCAP methodology begins with several small randomized controlled trials (RCTs) conducted by the originator (Dr Als) and colleagues (8)(22)(23)(24) and a larger RCT from Edmonton, Alberta. (25) Taken together, these trials suggest that infants cared for by nurses and physicians aware of their individual capacities (and other caregivers following the plans set by the NIDCAP team, according to repeated NIDCAP assessments) have shorter hospital stays, better neurodevelopmental outcomes, and perhaps fewer complications of various types, including less acute and chronic lung disease and oxygen dependence. There are also some electrophysiologic and magnetic resonance imaging differences between NIDCAP and control infants (sleep cortical spectral coherence and diffusion tensor analysis). (26) Fewer cases of intraventricular hemorrhage and necrotizing enterocolitis have been reported in some of the studies, but the spectrum of measures and findings showing statistical significance varies from study to study.

EVIDENCE FAILING TO SUPPORT NIDCAP

Some of the nonsupportive studies cited (and included in the meta-analyses) show post hoc selection of outcomes (27) or inconsistent application of the NIDCAP methodology.

(28) The latter study, from Leiden, showed no effect, applied as it was to larger, somewhat older infants who are less likely to suffer demonstrable ill effects from NICU hospitalization in the first place. In addition, the experimental intervention (NIDCAP) was applied for a short period before “back-transport” to the child’s referring hospital for convalescence. The intervention thus stopped. Discharge criteria varied from place to place. Both of these studies are arguably dissimilar enough to fail to qualify for inclusion in any meta-analysis.

THE META-ANALYSES

Although evidence is available on both sides of the NIDCAP balance, the 4 meta-analyses (29)(30)(31)(32) giving equal weight to all the various studies show increasingly significant results in favor of NIDCAP with increasing numbers of studies included over the years. The most recent analysis, (32) while evaluating death and severe disability as target outcomes (although these are expressly not NIDCAP targets), has shown significant reduction in lengths of hospitalization, postconceptional age at hospital discharge as well as in 9 months and 12 months, and mental and psychomotor outcomes as measured with the well-known Bayley Scales of Infant Development.

PARENTS AND PARENTING

The experience of large institutional orphanages from the past, and in Romania more recently, should have given us insight—many orphans, lacking a particular devoted caregiver, entered a depressive cycle, leading to failure to thrive, death, or serious cognitive and social (attachment) disorders. (33) Those who charmed a nurse or other caregiver into a relationship could survive and thrive, even in these desolate places. Long-term NICU patients need this special person as well; and who better than the parents—the lifelong constant people in the child’s life.

Caregivers, as distinct from parents, were not always aspiring to interact with or emotionally “attach” to their young charges. Thus, they may have overlooked the negative effects of their inconsistent, stressful, or painful interactions with the infants. Our current understanding of the importance of soothing and interaction in supporting the child’s health and development (not to mention attachment behaviors) cries out for the early and long-term involvement of the parents to provide this aspect of the child’s care.

Now that life support has become more sophisticated and manageable, and after a child’s vital functions are stabilized, neonatology may have a new opportunity to support the neurodevelopment of our tiny charges, protecting them

from ill effects and providing an environment that preserves their developmental birthright. We ignore the environmental experiences and social events around our patients at *their* peril—data suggest that these events can modify important neural processes, developmental outcomes, and even neuroanatomy. (23)

The influence of parent care and long-term parenting on brain development is subtle and obvious at the same time. Parents are the central caregivers after hospitalization, and they need to be central during the hospital stay as well. Parents may have difficulty “attaching” to new infants with less-than-perfect appearance or health. We know that preterm and unwell infants are overrepresented among those who suffer abuse and neglect. (34)(35)(36) Marriages often suffer or dissolve around a difficult NICU hospitalization or bad outcome.

The parents’ involvement as prime NICU caregivers is intended to preserve family integrity and to recruit and strengthen their essential contributions to the child’s ultimate success. It is essential that NICU staff protect and promote the parents’ role in caring for the child and not preempt that involvement. The NIDCAP approach includes attention to keeping the parents (not just mothers) closely involved, informed, and integral to the care and care plans that are developed. Sharing our knowledge and learning from the parents their understanding of the individual child’s condition and developmental strengths and weaknesses allows the family to participate and collaborate with us in more intelligent care.

Attentive personal care of the child by the parents, including skin-to-skin holding and breastfeeding, provide children with continuity, with living, breathing persons to hold and comfort them, excellent temperature control, reduced apnea, and with a depth of feeling that cannot be fostered through a window or from a distance. Parent “attachment” and long-term commitment to the child’s best interests is thus solidified. The child’s long-term outcome is doubtless altered by this sort of devotion, also called “love.” Measurements show that parents (not just lactating mothers) experience a surge in bloodstream oxytocin during skin-to-skin holding, (37) promoting a sense of calm and well-being that comes no other way. This can be especially profound and welcome during the tense uncertainty of NICU care. Few medical situations prohibit these sessions of skin-to-skin care, which can be extended to long periods (hours to days) with 2 parents or other close family members and surrogate caregivers present. In a few nurseries, especially in Northern Europe, the parents’ bodies have become the default and preferred “bed” for much of an infant’s NICU care, even where incubators and warming beds are

readily available. In the developing world, this practice may be the only one compatible with preterm infant survival.

Thus, attempts are being made to provide the fragile infant an experience like that which he or she would have experienced in utero and to make their postnatal experiences manageable whenever possible.

EVIDENCE IN FAVOR OF NIDCAP’S PARENTING PRACTICES

Involvement of parents in touching and caring for their new child has long been known to play a role in “attachment” and long-term connection between parent and child. (38) Its absence can lead to the shortfalls in these connections sometimes noted between preterm, sick, and malformed infants and their parents. (39) Enhancement of family involvement and direct care is thus a goal of many NICUs. “Family-centered care” (40)(41) takes this to the next level, affirming that the family is the long-term constant and best (perhaps only) hope for the child’s ultimate success, and reinforcing the role of the family in directing the child’s care with full information and support from the health care team. (42) This full concept is supported and buttressed by NIDCAP professionals.

Early, frequent NIDCAP assessments, shared with the family using understandable terms, allow parents to adjust their understanding of their child, to modify their caregiving approach, and to understand the progress and expectations for the child’s development, normal or otherwise. Familiarization with their individual child hastens personification and acceptance of a less-than-perfect situation. Ongoing contact and investment in the child’s daily life builds loyalty and strengthens families, especially for fathers, who might otherwise feel out of control, excluded, or even displaced. The eagerness of fathers, once initiated, to do skin-to-skin holding is impressive and rewarding for all. Affirmation of the family and its continuous involvement provides a powerful antidote to the stress and helplessness NICU parents often feel and helps them become even more involved. Inclusion of fathers likely counters the alienation that can lead to separation or divorce.

SPECULATION

Serious consideration should be given to adopting this approach. Reductions in stress and discomfort are clearly humane. Providing an environment like the “expected” intrauterine environment is more defensible than its alternatives. Support and consideration given to parents in their difficult NICU situation are likewise sensible and likely to influence

events toward better outcomes. Until the individual components of the NIDCAP program are weighed individually, together, and in comparison with other approaches, it seems advisable to apply the full program as it has been evaluated in the studies.

SHOULD WE CHANGE PRACTICES?

The evidence comes down generally on the side of NIDCAP, with statistical significance demonstrated for several benefits. Pooling of all data may fall short of 95% confidence on some measures, for various methodologic, often obvious, reasons. But the balance of the evidence favors NIDCAP care (especially if one discounts the Leiden results based on their mix of older patients and short-term application of the intervention). The proven benefits include shorter times on oxygen and ventilator support, shorter hospital stays (and thus lower costs), and improved neurodevelopmental outcomes.

The absence of notable harms ensures a favorable balance of benefits over harms. Thus, stronger recommendations can be made where reliable evidence exists. This strengthens our recommendation in terms of acceptability and applicability.

COST-BENEFIT ANALYSIS

While the cost of training personnel and implementing the NIDCAP approach is not trivial, subsequent savings for the individual patient, hospital, and society are likely to accrue. The comparison between cost and savings differs for these various beneficiaries. Reduction in hospital stay alone could quickly offset the costs to society, but an individual hospital or neonatology practice may not benefit from reduced stay (and thus reduced billings and collections), and it is they who pay for implementation. The patient may place indefinable, immeasurable value on lifelong neurodevelopmental improvements. Thus, we must not rely solely on economic evaluation, especially at the single-hospital level.

A number of NICU interventions, for example, inhaled nitric oxide (iNO) and mechanical ventilation, have far greater implementation and ongoing costs than NIDCAP training. Many of these high-technology therapies also have limited evidence of effectiveness. NIDCAP compares favorably to these approaches in cost/benefit comparisons. For instance, in recent meta-analyses, several widely adopted treatments, notably iNO for preterm infants (43) and high-frequency oscillatory ventilation (HFOV) for surfactant-deficient lung disease in preterm infants, (44) were found to lack statistically significant pooled evidence for their superiority over existing methods.

There is little defensible reason to continue using iNO or HFOV if studies do not show “significance,” yet many centers continue to use them. There may be a more defensible reason to continue to use (and further study) developmental care in this situation where the evidence falls short of total confidence: it is the humane and appropriate way to care for these tiny children.

In this vein, some centers have adopted a “Humane Neonatology Initiative” involving many approaches drawn from or consistent with NIDCAP ideas. (45)(46)(47) Numerous hospitals in the Americas, Europe, and Israel have adopted the NIDCAP approach for their everyday practice. Six have achieved a demanding certification by their mastery of these methods. More should follow this path.

COMMENT FOR NEONATOLOGISTS AND NEONATAL NURSES

Most neonatal caregivers have been teased about practicing veterinary medicine because our patients cannot communicate their ills to us. This canard was never true, even of veterinarians, and is certainly not true for neonatologists and NICU nurses. Our patients *can* and do “talk” to us, *can* individually communicate what they can tolerate, and *can* indicate when and where they need help. Much of our training is devoted to sensitizing us to these communications. It is time we responded more fully to these messages. NIDCAP enhances this communication.

Neonatal caregivers must leave behind the idea that tiny preemies are brainstem-reflexive or precortical creatures, without responses beyond spinal reflexes, without abilities, memory, or learning. These children are complex and responsive social people, albeit with a nonverbal yet rich vocabulary and with limited endurance in their interactions. They need appropriate experiences to sculpt their abilities and their very neuroanatomy. They cannot be ignored (or worse yet, stressed or sedated into unresponsiveness) without delaying or even distorting their development.

NIDCAP is complex, in correspondence with the complexity of the fetal child in the NICU; it is complex to teach, to adopt, or to practice fully. Indeed, some of the neutral or nonsupportive experimental results may reflect this complexity, resulting in incomplete understanding and limited execution of the approach. However, NIDCAP bears enormous promise for our smallest and sickest patients. Caregivers who learn how to read the child’s communications, and who begin to rely on them and share them with the parents, find it difficult to practice any other way.

NICU caregivers must not underestimate the challenge involved in altering philosophies of care and implementing

such a change in established routines. Both physicians and nurses (and others) will be found who doubt and resist. It can be difficult to accept that our old approaches may have been suboptimal, even harmful, for our most vulnerable patients. Costs in energy and treasure are not trivial, but if improved outcomes and eventual cost savings are dominant goods, it is worth the investment. Well-established systems and experienced people are available to help.

Developmentally appropriate, individualized, and family-centered care is better neonatal care. The NIDCAP approach is the most evidence-based, best organized, and best validated approach to developmental care. It can help your patients and families avoid some of the stresses of NICU life. It can help you, your residents, and your staff to feel better about what you may have to do to infants; it can help you tailor care to the individual child and protect him or her from harmful events.

If you have ever had second thoughts about the things we do to our little people, these microchildren entrusted to us, you owe it to yourself to learn more and to try NIDCAP individualized care.

Dr Maureen Hack has commented regarding NIDCAP:

"I question whether [neurodevelopment] is the appropriate outcome measure for an intervention that aims to reduce stress and promote physiologic stability and well-being of the infant..."

"Through this approach, critically ill preterm infants are treated as we ourselves would hope to be treated in similar situations." (48)

Even the very reliance on evidence-based reasoning and RCTs has come into question for certain topics. In a recent review, Bothwell and associates caution against slavish reliance on RCTs in therapies that are "long term, highly individualized interventions" and those where "each patient had unique ... findings, each [physician] different skills, and each [treatment] involved countless choices." (49) While this concern was expressed regarding psychotherapy and surgery, it may apply equally to the NICU where we encounter all sorts of patients, and where so many different aspects of care and of underlying development may affect the outcomes at a much later time.

Evaluation and analysis must continue, but let us not allow neonatology's laudable devotion to evidence-based practice and avoidance of futile or wasteful treatments to block our awareness that some approaches do not lend themselves to easy experimental demonstration or dissection from confounders. Most of the studies provide statistically significant evidence of benefits to be gained from developmental care, particularly NIDCAP. Let us not discard the premie with the "underpowered" or as-yet-inconclusive bathwater.

American Board of Pediatrics Neonatal-Perinatal Content Specification

- Know the rationale for early intervention programs for infants at risk for cognitive and behavioral problems.

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Parent Resources from the AAP at HealthyChildren.org

- Premie Milestones: <https://www.healthychildren.org/English/ages-stages/baby/preemie/Pages/Premie-Milestones.aspx>
- Is Your Baby's Physical Development on Track?: <https://www.healthychildren.org/English/ages-stages/baby/Pages/Is-Your-Babys-Physical-Development-on-Track.aspx>

For a comprehensive library of AAP parent handouts, please go to the *Pediatric Patient Education* site at <http://patiented.aap.org>.

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