

A Second Womb

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Even before Heidelise Als escorted me into the intensive-care unit for newborns at Children's Hospital in Boston, she began to whisper. Als understands, as much as anyone, that premature infants are fragile creatures and that even the smallest noise or disruption can overload their still-developing plum-size brains. Stepping gently, she led me to a tiny boy lying on his back in a plastic bed no bigger than a briefcase. He was surrounded by a tangled nest of wires, tubes and hoses, a respirator and other lifesaving devices.

As we watched, a nurse arrived and fumbled with an IV needle; she grabbed one of the baby's tiny, almost translucent heels and stretched his leg in the air to give herself room to work. The baby tried to retract his leg. He started to cry.

The nurse glanced at Als and then pushed the needle into the heel. Als winced. The nurse couldn't find a vein. She pulled the other leg, tried that heel and failed again. The baby cried harder. Als cupped her hands over her mouth; she knew she shouldn't interfere, but she had trouble restraining herself. A second nurse came and put her hands on the baby's chest to keep him from squirming. Als walked away. She couldn't watch any longer.

Als, a developmental psychologist at Harvard Medical School and Children's Hospital, has spent most of her life trying to see and feel the world through the eyes, ears and fragile skin of premature babies. It is a simple idea, but a radical one. And it holds the promise of a bold and, she would add, necessary reformation of this country's care of the prematurely born.

Preemies -- babies born anywhere from a few weeks to a few months before they are due -- arrive in the world with their brains still under construction. In the last few decades, neonatal intensive-care units, or N.I.C.U.'s, have made it possible for ever more preemies to survive and prosper, often with magnificent results. But even if the infant's body appears to be functioning perfectly when the baby leaves the hospital, difficulties may still lie ahead. Despite their impressive technological sophistication, N.I.C.U.'s cannot ensure that brain maturation follows its proper course.

Recent studies show that preemies are disproportionately prone to learning disabilities and psychiatric illnesses, like anxiety and attention-deficit hyperactivity disorder. The more premature the baby, the more likely the disability.

Als's proclaimed mission is to make the intensive-care unit safe for the development of the brain. In a series of innovative studies, she has shown that a gentler environment in the N.I.C.U. can alleviate many of the complications of premature birth. "You have to watch the baby, to listen to the baby," she says. "The baby is a partner in everything you do." Als argues that N.I.C.U.'s must become quieter, darker and more responsive to a baby's desire for comfort and movement; ultimately, they should be as reminiscent of the womb's nurturing environment as doctors and nurses can make them. She has helped to

institute many of her reforms at the hospitals where she works in Boston, and she has trained a cadre of others to carry her message across the country and to Europe and South America.

Dr. T. Berry Brazelton, the noted authority on child development and a pediatrician at Children's Hospital, has known Als since the 1970's, when she came to Boston to study with him. "She's changed the whole atmosphere of how we approach premature babies from a medical and environmental standpoint," he says. She has shown "how life can be improved for them and what we can do to cut down on the medical cost and the cost for these kids' futures."

Before birth, a fetus is an aquatic creature, bobbing in a warm, dark amniotic pool. After spending nine months bathing in the womb, it is well prepared for its exit into the world. Premies, however, leave their mothers' bodies with vital brain wiring unfinished. In order to make sure that the wiring process is completed, they need to continue their development in as supportive an external environment as possible.

Instead, they trade the soft surroundings of maternal flesh for an alien, high-tech hospital ward where they are subjected to the most unnatural manipulations. They are poked and prodded dozens of times each day. Nurses flip them almost upside down to change their diapers, wildly altering their blood pressure. In the typical N.I.C.U., their senses are overwhelmed by ringing telephones, screeching alarms and cold fluorescent lights that burn 24 hours a day.

Metal carts bang into one another as attendants cross one another's path. Als herself was surprised at how noisy some N.I.C.U.'s can be. Some of her studies require monitoring a sleeping infant's brain-wave activity with an EEG for six minutes. "To get a six-minute quiet sleep EEG, we may have to record for three hours because of the continuous sound interruptions that arouse the baby's brain," she says.

Doctors and nurses in the N.I.C.U. do not aim to treat babies harshly. They are simply making sure the N.I.C.U. does what it must do: deliver oxygen, provide the babies with nutrition and save them from medical emergencies that threaten their lives. Without those essential services, the babies would not survive. But that doesn't protect them from more subtle problems. "A large number of these babies do reasonably well and go home," says Tonse N.K. Raju, a specialist in newborns at the National Institute of Child Health and Human Development, part of the National Institutes of Health. "But can we assure the family that everything is fine? The answer is no."

Als, who is 64, moves delicately and quietly in the cloisters of the N.I.C.U., but she is forceful and direct when out of earshot of the babies. She is passionate about her dual roles as a researcher and an advocate for premature children. Born in Germany, she married an American and soon after moved to Philadelphia, where she studied developmental psychology and physical anthropology at the University of Pennsylvania. She absorbed the work of the primatologists Jane Goodall and Dian Fossey and the paleontologist Richard Leakey. She was particularly interested in how our animal ancestors cared for their children. "We come into the world with a way of processing the

world," she says. "I wanted to find out where that comes from."

While she was in graduate school, she gave birth to a son, Christopher, who was born full term. Within hours of his birth, however, it was apparent to Als that something was wrong: "He cried from Day 1. I found myself adapting in order to get him not to cry. I learned intuitively that I had to be calm to keep him calm." As time went on, further problems developed. He was slow in learning to walk. He was easily overstimulated and would become agitated in response to too much activity, not unlike many premature infants. He began having seizures at age 2, and before long it became clear that he was significantly brain-damaged.

The consequences were devastating. Her marriage collapsed, and she was left to raise Christopher alone. Often, he couldn't tell her what he wanted or needed. When he spoke, she had to interpret what he said. When he didn't, she had to search his eyes and learn to read his movements. She learned to be exceedingly patient and to perceive the subtle signals she was receiving from Christopher. (Her son, now 40, lives in a community for adults with developmental disabilities, where Als and her current husband visit him often.) When Als arrived at Children's Hospital in 1973, she approached premature babies in part using the skills she learned caring for Christopher. She learned to read their subtle cues and signals and began to reimagine the N.I.C.U. from the babies' point of view.

What she saw was dismaying. In the womb, babies are vibrant, active and in constant physical and hormonal contact with their mothers. In the N.I.C.U., they're limp little bundles, lying flopped on their backs, their arms extended and eyes closed. Their noses, hands, chests or feet are often pinned with gauze and adhesive tape. And they are repeatedly stuck with needles, intravenous tubes and catheters. "They are sustaining pain at a level that is completely unexpected," Als says. "It's overwhelming to the brain." In today's N.I.C.U., ventilators pump bursts of pressurized air into their lungs hundreds of times per minute, making them vibrate and shiver as if they were frightened animals. "The technologies are so advanced, yet in comparison to the womb, they are crassly primitive."

Als would like the N.I.C.U. to mimic the womb as much as possible, but that's not easy. Before birth, the baby and the mother are locked in an intricate dance. Each affects the hormonal behavior of the other. They move together, they share the same food and they may even share some of the same feelings. Little is understood about this complicated relationship, but even as more is learned, it is very unlikely that N.I.C.U. doctors will ever perfectly recreate conditions in the uterus. They would need not only a mechanical womb but also a mechanical mother with mechanical hormones and mechanical hopes and fears. Still, anything they can do to make the intensive-care environment more baby-friendly should increase the chances for normal brain development. Of course, not all premature children are in equal need of such measures. Some do well in the hospital and go on to lead normal lives. They develop differently from their full-term peers; it takes them a little longer to catch up. But they don't necessarily suffer any long-term effects.

There is no question, however, that premature babies, as a group, face particular risks. In a study reported in January 2005, Dr. Neil Marlow and colleagues at the Queen's Medical Center in Nottingham, England, examined 241 6-year-olds who were among the earliest surviving premature infants; they were all born more than three months premature. Only about 10 percent had serious physical disabilities. But, Marlow says: "Just over 41 percent were scoring in the learning difficulty range. That was a lot higher than we'd predicted." Studies in the United States have reached similar conclusions. By age 8, one in five premature kids, on average, has repeated at least one grade in school.

An even more recent study of 8-year-olds who were born weighing less than 2.2 pounds, which was published in July in *The Journal of the American Medical Association*, found that the children were far more likely than their full-term counterparts to have low I.Q.'s and poor academic and motor skills. These very premature babies "fared substantially worse than [normal birthweight children] in every type of assessment," the journal said in a commentary.

These statistics would be troubling enough if prospective parents were fully aware of the risks of premature birth. But doctors say that many parents are not adequately prepared -- including parents undergoing in vitro fertilization, who have a higher-than-normal chance of having twins or triplets, which are more likely to be born prematurely. Hellen Russo and her husband, Anthony, of North Branford, Conn., say that they had only a limited understanding of the risks when their I.V.F. twins arrived three months premature 13 years ago. "We had been so focused on infertility that premature babies never crossed our minds," she says. Before their twin boys, Anthony and Michael, were born, Russo and her husband say that they learned little from their doctors about what the long-term consequences of their early births might be. The Russos' doctors did what they were trained to do: they overcame the life-threatening complications in the N.I.C.U. and saved the children.

In the years since, the Russo twins have experienced a variety of complications. At age 3, Michael and Anthony went to a public preschool program for children with learning difficulties. Michael, who had a nearly fatal stroke in the N.I.C.U., is weak on his left side and walks with a slight limp. Anthony has a less severe weakness on his right side. He limps a little, and his handwriting -- he is right-handed -- is a little jagged. Both tried playing hockey, but neither was able to balance well enough on skates. Anthony had reading problems in kindergarten and first grade. "He couldn't read as quickly as the other children, and he couldn't keep up, especially if it involved writing," his mother says. Michael has had more serious problems. While he has become an enthusiastic baseball and basketball player, "he's not focused," she says. "His attention span is poor. He's lazy, and he has no interest in school." Russo says that she didn't anticipate any of this when she brought the boys home from the hospital. "You think once you've got them out of the newborn nursery and you get them home," she continues, "things will be fine."

Researchers don't know precisely how the intensive-care unit interferes with proper brain development. Premature children could be missing vital nutrients or growth factors that

they get in the womb. Or their development could be disrupted by the unnatural environment of the N.I.C.U.

Inside the uterus, Als explains, babies develop their sense of touch in constant contact with warm, gently swirling fluid. In that nearly weightless environment, they can easily curl up and lift their hands to their mouths. That sets up feedback loops in the brain -- "the brain grows from that," Als explains. The child is in constant communication with its mother. "Her rhythms, her eating, her happiness, her upset, all those hormones in her own makeup transmit themselves to the fetus through the umbilical cord," she says. "The fetus is tuned into his environment. It tastes and smells the fluid all the time. For 40 weeks, it's tasting its mother." By the time of birth, the full-term baby has developed sensory filters that allow it to tune out certain sounds and sensations, just as adults tune out other people's conversations in a crowded room. That way, it can focus its attention on the voice and touch of its mother.

When a baby comes into the world prematurely, those filters are not in place. Suddenly it sees light, form and color. It smells soap and disinfectant. It loses its amniotic bath. "It's moved abruptly from being an aquatic animal to a terrestrial animal, and it's stuck on a flat surface," Als says. It can no longer curl forward easily. Many premature babies, active and toned when they are born, lose that tone within days and become unresponsive. Their unnatural environment almost certainly contributes to the brain-related problems that preterm children develop, Als says.

Als has devised a palette of techniques that offer at least a partial solution to these problems. She has turned down the lights while still leaving enough light to work and to see when the babies are in trouble. When the lights are lower, doctors and nurses talk more quietly, for the same reason that a dimly lighted restaurant is usually quieter than a diner. "Everyone simmers down," Als says. "We know that when we talk about 'mood lighting.'"

She has instructed nurses to surround babies with a "nest" of blankets. In the womb, babies' skin registers the constant pressure of amniotic fluid. The nest provides an approximation of that all-surrounding sense of touch. The nest can't be too tight; the baby needs room to move, she says. When babies have to fight to move, they quickly tire, part of the reason they become limp and unresponsive.

Als has encouraged nurses and doctors to change their basic procedures from the moment of the baby's arrival. "When a baby is born, everybody works to get at him" in the N.I.C.U., says Sandra Harmon, the assistant nurse manager in the N.I.C.U. at Brigham and Women's Hospital in Boston. That can include a nurse, triage doctor, intern, one or more residents, a fellow, the attending physician and a respiratory therapist. "They're all trying to do their thing around this little baby, who might weigh only a pound," Harmon says. The N.I.C.U.'s at Brigham and Women's and Children's hospitals now limit the number of people who converge on a new arrival.

Als also encourages N.I.C.U. doctors and nurses to ensure that the babies experience long periods of near-complete darkness. At Children's Hospital, when doctors or nurses aren't working with a baby, the baby's incubator is covered with a blanket to give it a chance to

sleep. Als has explained to her colleagues that the babies are far more aware of their surroundings than the doctors and nurses had thought. When she and I toured the N.I.C.U., she made that point for me by gingerly lifting the corner of one of the blankets. The baby inside the incubator reacted immediately -- his breathing became less stable and he shifted his position, even though he hadn't opened his eyes. "He knows we're peeking," she said.

In 2003, Als and a dozen colleagues reported on the effectiveness of a treatment program that requires doctors and nurses to deliver food and care on a schedule that gives the infants more time to rest, relax and sleep. The care was organized around the needs of the individual infants and families, instead of the work schedules of the doctors and nurses. The findings were remarkable. The babies moved more quickly from intravenous to oral feeding. They spent less time in the N.I.C.U. and had fewer infections, better motor skills and a better ability to focus their attention. They grew faster. And their families displayed less stress and had better relationships with their children. The study provided "clear evidence for the effectiveness of individualized developmental care," the researchers concluded.

In a follow-up study last year, Als and her team studied the brain development of premature kids and found further evidence of enhanced brain function and structure in children in the individualized program. There were more neural connections, and those connections more closely paralleled the wiring that would have developed if the babies had remained in the womb for nine months.

One reason for the success of these programs was the training of nurses and doctors and the offering of support for parents, Als says. She and her colleagues have devised a training program that is now offered by nine centers in the United States, four in Europe and one in Argentina.

Even with these successes, Als says that she has fallen short of her goals. Ultimately, she would like to take a radical step: eliminate the incubator altogether. "My dream is a womb room for each baby and each family." That is, each family would be given a room of its own, with controlled temperature, humidity and oxygen. The mother would receive her postpartum care there; she and the rest of the family would live in the womb room until the baby was ready to go home. Als may not know how to recreate the aquatic environment inside the mother's body, but in a womb room the mother could at least hold the baby against her skin, where it would feel her heartbeat. "For many people, it's a big, big step even to envision this. I don't think it's unrealistic," she says.

Als's efforts to reform the N.I.C.U. come at a critical time, when premature births are taking place more frequently. The decision by many women to wait until later in life to have children, and their growing reliance on fertility treatments, increases the chances that their children will arrive early. Of the 4 million babies born in this country each year, some 500,000 are born after spending 37 weeks or fewer in the womb -- a 29 percent rise since 1981.

Doctors have also vastly improved their technologies for keeping preemies alive. In the 1970's, fewer than 20 percent of newborns weighing less than 2.2 pounds --

approximately three months premature -- survived. In the three decades since then, improvements in the technology have boosted the survival rate to 70 percent, and it is even higher for babies born closer to term. (For unknown reasons, girls do a little better than boys.) In rare cases, doctors are saving even smaller babies, who would have had no chance only a few years ago. In September 2004, for example, a Chicago woman gave birth to a baby girl weighing only 8.6 ounces: she was small enough to curl up inside a toddler's slipper. Dr. Jonathan Muraskas, a neonatal specialist at Loyola University Medical Center near Chicago, was convinced that he could save the girl. She was discharged on Feb. 8, weighing 5 pounds 8 ounces -- more than 10 times what she weighed when she was born five months earlier.

These improvements in care have been a blessing. But an unintended consequence is that growing numbers of children with cognitive and psychiatric problems are being delivered to hospitals, preschools and elementary schools that don't have the resources to care for them. Als's work could change that, reducing the burden on schools and hospitals and easing the financial and emotional toll on families.

Thus far, parents, who might seem to be Als's natural allies, have not been demanding better care for their premature infants. Few realize that N.I.C.U.'s are not what they could be, and even fewer are aware of Als's own work. Muraskas, whose success with tiny babies has excited the public, worries that "miracle newborns," as he calls them, "raise false expectations for families, caregivers and the medical-legal community." He cites one study in which researchers followed a single infant for three months in an intensive-care unit and found that it received help from 483 different people. "With so many people communicating with families, it is not surprising the families are confused," he says.

Not all the news is bleak, even for preemies who are not being treated with the Als techniques. Dr. Laura R. Ment, a professor of pediatrics and neurology at Yale University School of Medicine, has monitored 500 premature children as part of a continuing study of the consequences of prematurity. Almost 60 percent of the children showed improvement in cognitive function. Their I.Q. scores bubble upward, lifting some into the normal range. The improvements have been greatest in two-parent families, in families with more highly educated mothers and in children whose mothers received special services, like assistance with physical therapy and speech therapy for their children. The findings are encouraging. The brains of these children are still growing, and they can recover, at least partly, from the circumstances of their births.

Jerome Kagan, a Harvard University psychologist who has studied children for 40 years, underscores the point about the importance of a good home in improving the outlook for premature infants. Children born only slightly premature show little extra risk of cognitive troubles -- if they are raised by competent, caring parents. The problems tend to be more severe in homes where children aren't properly cared for. "If you're mildly premature and you're raised in a home in poverty where nobody's talking to you and you're not being cared for, the data show you don't do as well in school," he says.

Als has also emphasized the importance of listening to the parents as well as the babies.

Brazelton, the author of many parenting books, including the best-selling "Touchpoints," about the emotional and behavioral development of children, agrees: "If the parents take a baby like this home and treat him or her as if it's a failure, it will be a self-fulfilling prophecy." Brazelton notes that his first grandchild, a boy, was born almost three months premature. He's now 20. "He's 6-feet-3," Brazelton says, "and he's brilliant."

Als is planning further, larger studies on the consequences of improved care for premies. And she is still asking premies what they want. "The baby is our guide," she says. "Can we read your behavior well enough to see how far away you are from being comfortable? And what can we do to help you get there?"

She visits the N.I.C.U. regularly to remind herself of what her work is about. And because she wants to be with the babies, to listen to them. "I always feel extremely humble," she says, "when I go in there, when I think about how little we know -- and how much more that baby wants of us."

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