

The NICU Experience: Its Impact and Implications

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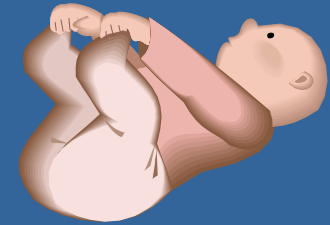


Funded in part by **NTAC** (National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind). This project is supported by the U.S. Dept. of Education, Office of Special Education Programs (OSEP). Opinions expressed herein are those of the author and do not necessarily represent the position of the U.S. Department of Education.

OBJECTIVES

- 1) Increase awareness of NICU experience and its impact on premature and medically fragile infants**
- 2) Increase awareness of NICU experience and its impact on family members of premature and medically fragile infants**
- 3) Introduction to the practice of developmentally supportive care**

IMPACT on BABIES



- Survival rate of infants born younger than 28 weeks gestational age has increased dramatically due to medical and technological advances
- As a result, preterm infants complete their development in a very unnatural environment
- Development is not just delayed--it's altered
- This altered development has implications for learning and for later life

COLLECTOR'S EDITION

LIFE

BORN TOO SOON

The high-tech,
high-risk drama of
keeping the tiniest
babies alive

Jason Michael
Waldmann Jr., who
weighed only 1.2
pounds at birth

MAY 2000/\$3.99



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DISPLAY UNTIL MAY 30

A look at development of sensory systems

Tactile

Vestibular

Gustatory

Olfactory

Auditory

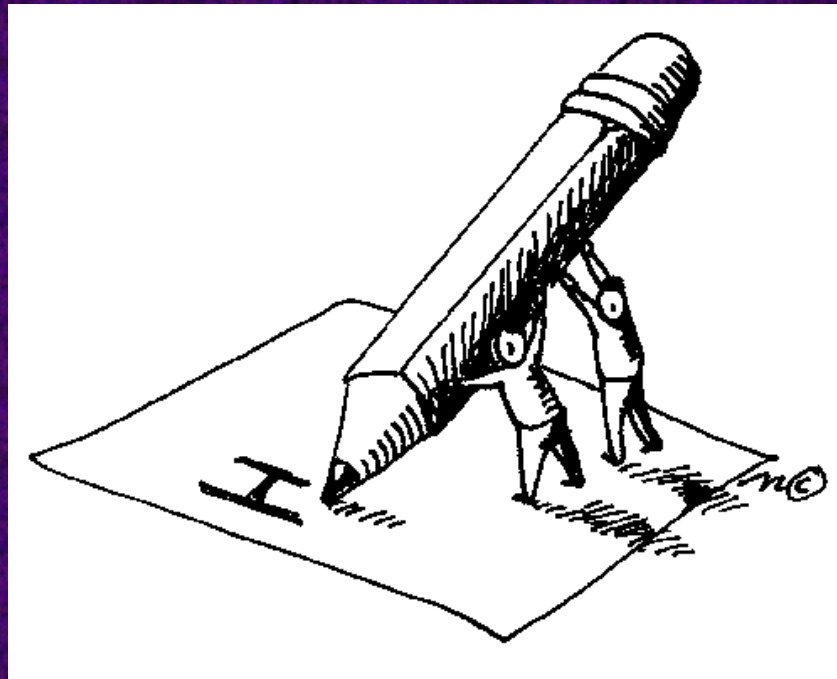
Visual

A look at environments

Intensive Care Nursery vs. **Womb**

HANDOUT:

Prenatal Sensory Development Chart



TACTILE SYSTEM

- **Babies must rest to grow. Over-stimulation of system causes stress; impedes rest, infant expends excess energy**
- **Providing boundaries helps keep baby calm; facilitates flexion development**
- **Baby self-initiates tactile stimulation by thumb-sucking and bringing hands to face; need to allow this to continue**

VESTIBULAR SYSTEM

- **Slow, carefully planned movements and routines help diminish negative effects**
- **Attention to positioning while at rest and containment during handling can make a positive difference**
- **Need to assess appropriateness of rocking**

GUSTATORY SYSTEM

- **Atypical development of this sensory system can contribute to long-term feeding difficulties**
- **Look for ways to minimize negative impacts of items placed in babies' mouths in NICU**
- **Provide time to adjust to different tastes**

OLFACTORY SYSTEM

- **Babies have ability to differentiate maternal smells**
- **Over-stimulation of system can lead to disinterest in feeding**
- **Attention to types of olfactory stimuli in infant's environment can improve developmental outcomes**
- **Gradual preparation for and introduction to oral feeding will improve success**

AUDITORY SYSTEM

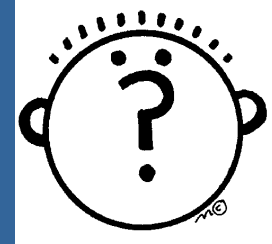
- **Decrease the general noise level in the NICU and around the infant**
- **Limit conversation around the baby and always speak softly to the baby**
- **Observe infant's tolerance for auditory stimuli and use the information to plan appropriate intervention (especially readiness for musical toys)**

VISUAL SYSTEM

- **Provide environment protected from light**
 - › Fetus exposed to less than 1 candle power of light in utero
 - › Delivery lights are about 1500 foot candles of power
 - › Most NICU procedures start at about 300 foot candles
- **Need to assess items in visual field to determine appropriateness and eliminate inappropriate stimuli**
- **Monitor all visual stimuli**



HELP!



What does all this mean
for NICU babies?



Effects of the NICU Environment on Sensory and Neurological Development

The preterm infant is in various stages of development to which we place unrealistic demands. The infant is at the mercy of its care providers . . . How we provide care and what we do or don't do can have a lasting effect on the infant and family.

Linda M. Lutes, M.Ed., Infant Development Specialist

Effects of the NICU Environment on Sensory and Neurological Development

- **Within the protective environment of the uterus, the fetus is a capable being for its gestational age and can develop appropriately without interference**
- **Outside the protective environment of the uterus, infants struggle to meet unrealistic developmental demands**
- **Early introduction of stimuli alters the sequence and development of the sensory system**

Effects of the NICU Environment on Sensory and Neurological Development

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Effects of the NICU Environment on Sensory and Neurological Development

- **Preterm babies miss out on prenatal activities in utero that provide practice for key developmental skills**
- **Early introduction of stimuli and increases in number/type of stimuli alter sensory and neurological development**
 - **Developing brain forms increased numbers of dendrites, bringing increased numbers of impulses to developing brain cells**
 - **Babies become conditioned to these unnatural stimuli**

Effects of the NICU Environment on Sensory and Neurological Development

- **Attempts to accelerate “normal” developmental sequence and time frame can have a variety of consequences.**
- **Altered development often results in :**
 - **Challenges with state regulation (difficulty establishing appropriate sleeping and eating patterns, unable to calm or console self, overreactions to environmental stimuli**
 - **Challenges with attention**
 - **Challenges with sensory integration**
 - **Challenges with sensory defensiveness**

How can we promote better developmental outcomes for babies?



We can provide...



Developmentally
Supportive
Care

But first

let's think

about . . .

the **IMPACT**
on **FAMILIES**



**Can anyone be prepared
for such an event?**



"My husband and I felt a strange combination of happiness and sadness during the first few days of our baby's life. We were happy that our baby was alive and with us, yet sad and fearful for what was ahead."

IMPACT on FAMILIES



- **If unexpected - families face a roller-coaster of emotions, report feeling out of control**
- **If expected - parent(s) probably already tired/stressed/worried; may have feelings of guilt; mother may have health problems**
- **If multiple births - one or more of the babies may die, one or more of the babies may face much more serious challenges than other(s)**

What Families say...

“. . . it was depressing because all that we heard was the bad stuff; we should make a baby book and put in all of our sonogram pictures so that we would have some memories of our baby.”

“Her first surgery lasted four hours. She was only two hours old when they began. I am not sure that I can express the anger I felt when I awoke.”

“. . . we found ourselves asking: Do we insist they continue to do everything possible to keep our baby alive? At what cost to the quality of his precious life?”

Quotes taken from: *You Are Not Alone: 20 stories of hope, heroism, heartache, and healing as told by the parents of children treated in the NICU* (1998). Children's Medical Ventures, Inc., South Weymouth, MA.

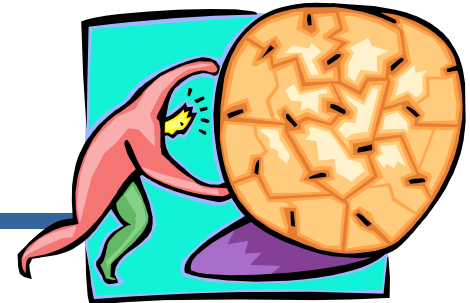
What Families say...

"I have never cried as much as I did during the first week of *my baby's* life. Just being in my hospital room and hearing a woman in the other room talking to her new baby sent me into uncontrollable sobs. One of the hardest days of my life was the day I was released from the hospital without my new baby. . . I resented every pregnant woman I saw."

"I felt very guilty. I kept asking what I had done wrong. Was it because during my shower on the 4th I had bent down and picked up the soap? Had I gotten up too many times during bed rest? Was God punishing me for other sins I had committed during my life? Whatever it was, it was my FAULT!"

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IMPACT on FAMILIES



- **If teen or at-risk mom - the situation may be more than she can handle, abuse/neglect may occur; baby may be placed in foster home**
- **NICU setting makes it difficult to bond with baby, many parents report feelings that baby belongs more to nurses than to them**
- **Prolonged hospital stay for baby often results in missed work and/or having to give up job; this creates financial stress and can have long-term financial implications**

What Families say...

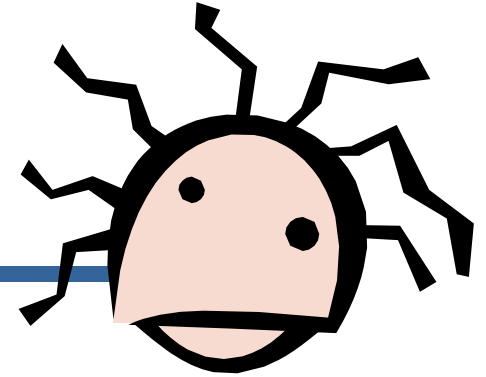
"The birth of a child should be a joyous, blessed event. . . . I remember feeling confused, angry, sad, frustrated and scared."

"When I was discharged from the hospital I felt guilty, like I was betraying my baby by leaving him behind."

"We had no guarantees that our baby would survive. If our child did survive, would we be spending the rest of our lives taking care of a severely disabled child? If the answer was "yes", then we wouldn't have the emotional or financial resources to take care of another child."

Quotes taken from: *You Are Not Alone: 20 stories of hope, heroism, heartache, and healing as told by the parents of children treated in the NICU* (1998) . Children's Medical Ventures, Inc., South Weymouth, MA.

IMPACT on FAMILIES



- **NICU experience places huge strains on a couple's relationship; can also strain relationships with other family members when asked to continue providing support**
- **It's difficult to provide for needs of other children in family, feel torn in many directions**
- **Effects of the experience often exist long after the baby comes home**

What Families say...

"We began to doubt if we would ever have the family we wanted so very much. It took us three years to overcome this fear before trying to have another baby."

"On the good days, I was OK. On the average day, I was bad. On the bad days, I was catatonic. I had shut everyone out of my life except for the babies."

*Star light, Star bright, first star I see tonight.
I wish I may I wish I might, have this wish I wish tonight.
I wish Mommie's baby will stay in her tummy tonight.*

Quotes taken from: *You Are Not Alone: 20 stories of hope, heroism, heartache, and healing as told by the parents of children treated in the NICU* (1998). Children's Medical Ventures, Inc., South Weymouth, MA.



Providing
Developmentally
Supportive
Care

What is

DEVELOPMENTALLY SUPPORTIVE CARE?

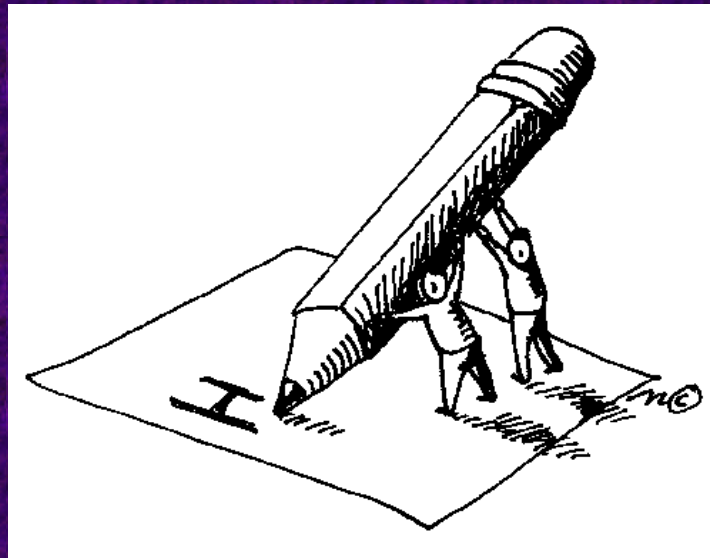
- **Based on principles of NIDCAP**
(Newborn Individualized Developmental Care and Assessment Program)
- **Assessment of overall nursery environment**
- **Assessment of individual infant's environment**
- **Provides individualized care to babies**
- **Provides recommendations to family and medical staff to enhance infant development**

What kinds of RECOMMENDATIONS are made?

- **Overall nursery environment**
 - ✓ Arrangement of equipment and supplies
 - ✓ Ideas for decreasing light, sound, activity levels
- **Individual infant's bedspace**
 - ✓ Type and configuration of bedding/clothing
 - ✓ Appropriateness of pacifier
 - ✓ Ideas to assure bedspace is appropriate based on baby's current gestational age
- **Individualized caregiving strategies**
- **Suggestions for family involvement**

HANDOUTS:

- NIDCAP (Newborn Individualized Care and Assessment Program)
- Developmentally Supportive Care



What practices are involved in providing DEVELOPMENTALLY SUPPORTIVE CARE?

■ Attention to environment

■ Positioning

- ✓ Encourage hands-to-mouth, midline alignment
- ✓ Arms and legs flexed and tucked
- ✓ Nests to provide security, boundaries to facilitate self-regulation and provide proprioceptive input
- ✓ Kangaroo holding

■ Feeding

- ✓ Determine readiness
- ✓ Choose appropriate nipple
- ✓ Model appropriate strategies for staff, families

What practices are involved in providing DEVELOPMENTALLY SUPPORTIVE CARE?

■ **Care giving strategies**

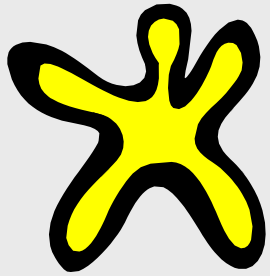
- ✓ Education regarding infant cues
- ✓ Advanced planning to minimize handling, over-stimulation

■ **Education and support for families**

- ✓ Principles of developmentally supportive care
- ✓ Reading infant stress signals
- ✓ Strategies for being involved in their baby's care
- ✓ Resources and referral to early intervention programs/support groups/social service agencies

Why is it good practice to provide DEVELOPMENTALLY SUPPORTIVE CARE?

- **Promotes improved outcomes for babies**
 - Off ventilator sooner, require less oxygen support
 - Increased weight gains
 - Successful nipple feeding sooner
 - Earlier discharge from hospital
 - Decrease in developmental delays
- **Adds developmental perspective to medical approach**
- **Recognizes family members as important members of infant's care team and works to create a partnership**



Can anyone survive such an experience? **MAYBE!**

"The only way we were able to get through the long days was by asking lots of questions and looking up every word the medical staff said."

"Kangarooing was a huge plus for the tactile-starved parent who had been thus far kept out of the way due to a myriad of slithering tubes and cords . . . It seemed that from about the time we started holding the babies they began growing faster and appeared to stabilize."

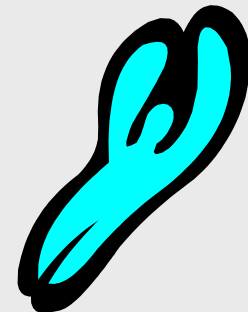
"The doctors and nurses were great about answering our questions over and over again."

"Finally, it seemed like there was light at the end of the tunnel. I began to keep a daily journal. . . I wanted to be as involved as possible. . . my child's advocate."

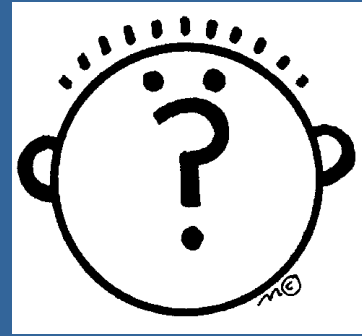
'Even at two weeks we had come to know the personality of our children intimately. I had no idea that an infant that small could have a personality. . . "wide-eyed fighter with a social vent" . . . "sleepy, laid back boy" . . . "easily stressed and needed to have as little stimulation as possible".'

"Our daughter has been hospitalized approximately thirty times since that first year. . . Over the last thirteen years, I have seen many changes in medical technology and many changes in our lives."

Quotes taken from: *You Are Not Alone: 20 stories of hope, heroism, heartache and healing as told by the parents of children treated in the NICU* (1998).
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So



what's an EI person
supposed to do?

IMPLICATIONS for PROVIDING EARLY INTERVENTION SERVICES

- Be aware of sensory impact of NICU experience and implications for intervention strategies.
- Be consistent and proactive in securing and reading medical records/reports of children who spent time in the NICU before coming to EI.
- Give families space and time – they need and deserve it!
- Look for creative ways to make connections within the neonatal medical community.



And last but not least. . .

Take this new
perspective with
you and never let it go!

