



# Optimizing Hearing Services for NICU Babies Through Interdisciplinary Collaboration

Kelly A. Baroch, Au.D., FAAA, CCC-A  
Pediatric Audiologist  
Infant Hearing and Screening Program Coordinator  
[Kelly.Baroch@cchmc.org](mailto:Kelly.Baroch@cchmc.org)



# Cincinnati Children's Hospital NICU and The Heart Institute

- ▣ NICU- 59 bed level IIIC care center with approximately 800 admissions annually
- ▣ Home to the Fetal Care Center, the only fetal center in the Midwest
- ▣ The Heart Institute - is a 25 bed unit with 25% of open heart surgeries performed on newborns within first month of life
- ▣ Over half of NICU admissions receive surgical interventions with abdominal wall defect, airway reconstruction, and open heart surgeries being the most frequent procedures
- ▣ Average weight at admission >2500 grams
- ▣ Average length of stay >30 days





# Screening's Just the Beginning:

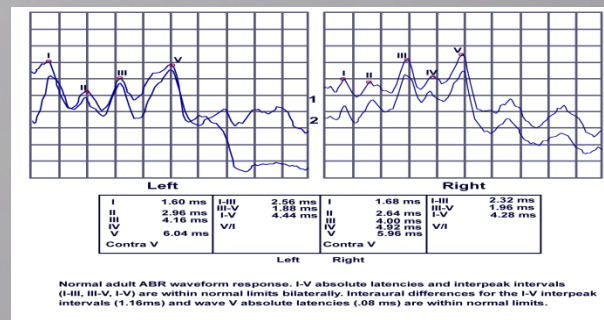
## The Joint Committee on Infant Hearing

(JCIH 2002, 2007)

Screening by 1 month of age

Diagnosis by 3 months of age

Intervention by 6 months of age



# Survival Rate

- ▣ 75% of 500-749g infants survive
- ▣ 25% of <500g infants survive

Hernandez 2009

- ▣ As technology improves and we keep more infants alive, the length of stay in the NICU also increases.





# The Challenges of 1-3-6: Inpatient





# The Plan:

- ▣ Design an interdisciplinary program which maximizes collaboration and allows for an approximation of 1-3-6 to be achieved.
- ▣ For deaf and hard of hearing NICU infants, adapt interventions traditionally provided on an outpatient basis to fit the needs of the infant and family on an inpatient basis.



# The Program

- ▣ On site coordination
- ▣ Interdisciplinary approach
- ▣ Full diagnostics
- ▣ Intervention ????
  - Parent Education
  - NICU Team Education
  - Amplification
  - Speech Therapy
  - AR Therapy
  - EI



# Barriers to 1-3-6: Intervention

- ▣ Traditional intervention by 6 months of age
  - Unstable babies
  - Excessive background noise
  - Caregivers not present for quality interaction
  - Overwhelmed families who may need to prioritize
  - Multiple therapies for babies who may have very little energy reserves due to chronic illness





# Q: What is the Definition of Early Intervention for the Long-Term Hospitalized Infant?



# Sensory Impairment in the NICU



# What We Know: Hearing and Vision

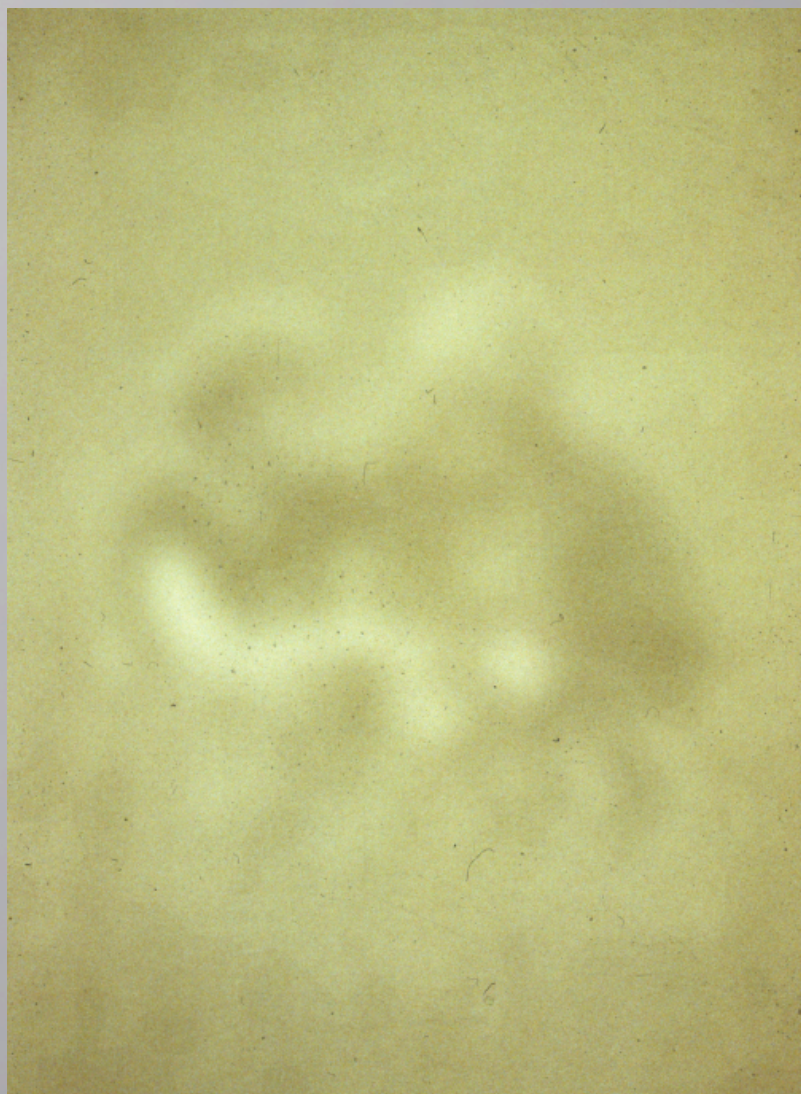
- ▣ “Distance Senses”
- ▣ Connect a baby with the world that extends beyond his personal body space
- ▣ Help the baby organize information from the environment

Aitken, 2000

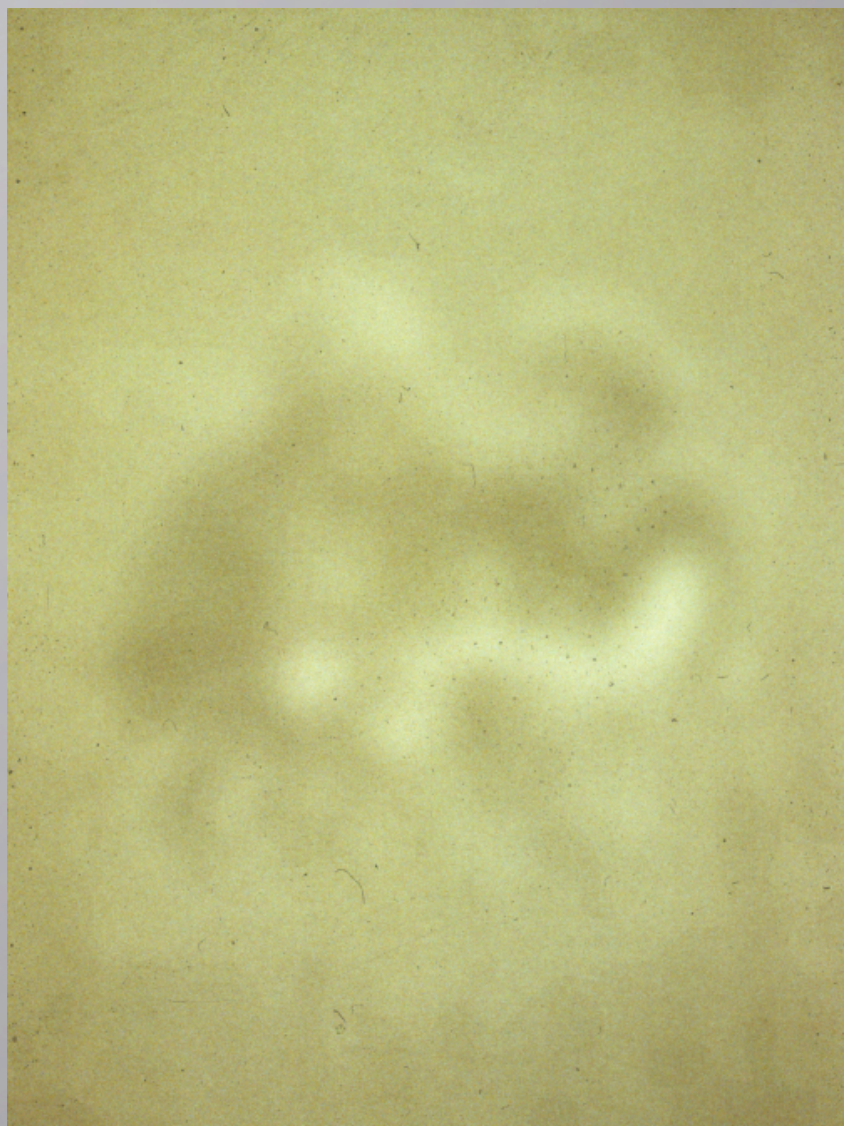
























# For the deaf and hard of hearing infant...

- ▣ The opportunity for “incidental learning” is reduced
- ▣ The information obtained from contact with people and the environment is often fragmented or distorted



# The Deaf/HOH infant...

- ▣ Misses cues associated with daily activities due to limited hearing so can not prepare for activities in advance
- ▣ May not understand or be able to anticipate what is happening
- ▣ Has many things happen that are unpleasant "surprises"
- ▣ NICU becomes unpredictable, frightening, scary



# NICUs and Neonatal Pain: Frequency of Painful Procedures

- ▣ Average for all NICU admissions:
  - 60 to 100 painful procedures per hospitalization
- ▣ Premature infants 27-31 weeks:
  - 134 painful procedures per hospitalization
- ▣ Premature infants <27 weeks:
  - 300 painful procedures per hospitalization
- ▣ Premature infants 24 weeks:
  - 488 painful procedures per hospitalization



# What We Know: Clinical Experience

- ▣ NICU infants with sensory impairments
  - Disorganized
  - Rapid state changes
  - Difficult to calm
  - Easily startled
  - Do not tolerate care
  - Tactile defensive



# Changing the Outcomes

## Frequent State Changes

**Developmental Delay**



**Behavioral Deficits**

**More medical problems later on**

# Every baby is different

- ▣ Amount of information babies are able to gather depends on the amount of hearing and how they learn to use that hearing
- ▣ Each baby learns to make use of available sensory information in their own way





# Every baby is different

- ▣ Using vision, hearing, and touch all at one time may be too confusing
- ▣ In different situations, may choose to rely primarily on one sense
- ▣ Some use hearing inconsistently
- ▣ May seem to hear things some days and not on other days (Can be confusing for parents and caregivers)



# A(?): Supporting the Deaf/HOH Infant in the Hospital Environment





# The Program

- ▣ On site coordination
- ▣ Interdisciplinary approach
- ▣ Full diagnostics
- ▣ Intervention
  - Parent Education
  - NICU Team Education
  - Sensory Care Plan



# Sensory Care Plans

## Grayson's Sensory Care Recommendations

12/11/08

- Please approach my bed slowly and gently. If I am awake, please let me see you before you approach. If I am sleeping, please touch me gently on my legs and then work your way up to my head and face where I am most sensitive.
- Please help me by giving me lots of positive touch and hold me as much as possible. This gives me good sensory input.
- When you hold me or talk to me, please sit or stand near an overhead can light so that your face is illuminated. This helps me focus on your face more clearly.
- Holding me when you talk and sing to me lets me feel the vibration from your voice while I listen.
- Please always call me by my name. This will help me learn my name since I don't hear you clearly.

# Sample Sensory Care Plan

- ▣ Please approach my bed slowly and gently. If I am awake, please let me see you before you approach. If I am sleeping, please place your hands on the mattress of my crib; then touch me gently on my legs and work your way up to my head and face where I am most sensitive.
- ▣ Please help me by giving me lots of positive touch and hold me as much as possible. This gives me good sensory input.
- ▣ When you hold me or talk to me, please sit or stand near an overhead can light so that your face is illuminated. This helps me focus on your face more clearly.
- ▣ Holding me when you talk and sing to me lets me feel the vibration from your voice while I listen.



# Sample Sensory Care Plan

- ▣ Please always call me by my name. This may help me learn my name since I don't hear you clearly.
- ▣ Please give me time to use my vision to know what is coming next. Give me a visual cue for activities whenever you can. For example, before my diaper change, hold my diaper where I can see it and then let me feel it in my hand.
- ▣ Please try to keep my daily routine as consistent as possible. This will help me learn to anticipate what is happening next.

# Sample Sensory Care Plan

- ▣ What I see in my world is familiar and comforting to me. Changing my room or the orientation of my bed can be frightening. If you want me to see my world from a different perspective, please do it gradually and when my Mommy is with me so that I feel safe and have time to adjust.
- ▣ Many different caregivers can be overwhelming for me. Consider a primary nursing team for me so I have caregivers who are familiar and know me.

# The Program

- ▣ On site coordination
- ▣ Interdisciplinary approach
- ▣ Full diagnostics

- ▣ Intervention
  - Parent Education
  - NICU Team Education
  - Sensory Care Plan
  - Speech Therapy
  - Sign Language Program












# Sign Language Program

the ones posted below and use them with him when you are talking with him. If we ALL do this - he will learn them. Make sure to do the sign:

- Where he can see them
- As you are about to do or doing the activity and saying the word



<p>All done (finished)</p>		<p>Hold open hands (fingers spread) in front of chest, palms facing inward. With a sudden movement, rotate wrists so that palms face outward.</p>
<p>Up</p>		<p>Index finger pointing up and move and spread motion</p>
<p>Diaper (do on Eddie)</p>		<p>The hand shape is a modified "J" hand. If you know how to do the sign "up" then this hand shape and movement will come easy for you because the hand shapes and internal movement of the hands is similar to that of the sign "up".</p>
<p>Suction</p>		<p>Place index fingers and thumbs of right hand against thumb. Pull right hand outward away from neck.</p>
<p>Daddy</p>		<p>Place the thumb of right open hand (fingers spread) in middle of forehead</p>
<p>Mommy</p>		<p>The thumb of the right "J" hand rests on the right cheek or the right chin</p>

# Sign Language Program

- ▣ For some medically complex infants, as well as those with hearing loss, signing is a way to provide both receptive and expressive language
- ▣ For all babies, the language that they can best access, should be presented to them from birth onward to maximize their ability to understand and eventually use a symbolic language

# Sign Language Program

- ▣ A core vocabulary was developed to be used with all baby's that are appropriate for the Total Communication approach
- ▣ The family chooses additional signs that they feel are important for their baby





# Sign Language Program

- ▣ Pick a few signs to start with and add a few each week
- ▣ Gives all the chance to learn the signs, learn how to use them with the baby and incorporate them into their functional interactions
- ▣ Consistent use is critical
- ▣ Caregiver's responsibility to be the "models"
- ▣ Works best when all are relaxed

# The Program

- ▣ On site coordination
- ▣ Interdisciplinary approach
- ▣ Full diagnostics

- ▣ Intervention
  - Parent Education
  - NICU Team Education
  - Sensory Care Plan
  - Speech Therapy
  - Sign Language Program
  - Amplification



# Hearing Aid Fitting

- ▣ When to fit is a collaborative decision between family, audiologist, and medical team
- ▣ NICU Audiologist collaborates with outpatient audiologist who will be following infant
- ▣ Conservative settings
- ▣ Infant wears aids only when family or therapist is present to monitor infant cues





Q: What is the Definition of Early Intervention for the Long-Term Hospitalized Infant?



# The Experience of the NICU



**“The neonatal intensive care unit is probably one of the most highly charged emotional and ethical areas within the health care arena.”**

**Janet Green  
Professor of Nursing**



# The Experience of the NICU



"On most days it takes great courage and inner strength to walk into the unit to visit; it takes even more to leave at the end of the day."



# NICU Families

- ▣ PTSD (Hyman 2009)
- ▣ Acute stress disorder (Shaw 2006)
- ▣ Family adjustment (Doucet 2004)
- ▣ Divorce rate (McAulay 2006)
- ▣ Financial strain (McAulay 2006)



# NICU Parents of Deaf/HOH Infants

- ▣ More than 90% of deaf infants are born to hearing families
- ▣ Newborn hearing screening has shifted the diagnosis from a parent-driven model to an institution-driven model (Kurtzer-White 2003)
- ▣ Parents may be overwhelmed to learn of hearing impairment even in the face of more critical medical conditions

# The Power of the Parent-Child Relationship

The best predictor of a child's developmental outcomes is the strength of the relationship with the primary caregivers





# Parent-Infant Bonding: Beyond The Numbers

- ▣ Other variables impacting language development in children with hearing loss (Meadows-Orleans 1994, 1995, Yoshinago-Itano 2003)
  - resolution of grief
  - maternal-child interaction and bonding
  - parental stress
  - parent emotional availability
  - the child's development of self
- ▣ Maternal sensitivity, warmth and emotional connectivity to the child predicted significant and positive expressive language gains (Moeller 2001)

# A(?): Supporting the Family



# Beyond The Numbers:

“The current emphasis on evidence based practice I find worrisome because emotional growth does not readily lend itself to measurement, yet it is in the emotional realm where a great deal of the action takes place”

Dr. David Luterman, Audiology Today, March 2010



# Counseling in the NICU and Beyond: Theory of Guarded Alliance

- ▣ Three stages of trust with health care providers
  - Blind Trust
  - Disenchantment
  - Guarded Alliance

# Counseling in the NICU and Beyond:

- ▣ It may take 4 meetings for an effective working relationship to occur between high risk parents and a health care provider

Boberg 2007



# Supporting Families Through Counseling

- ▣ Family Centered Care Principles
- ▣ Motivational Interviewing
- ▣ Self Management Techniques
- ▣ “Difficult Conversations in the NICU”



# Priorities for CCHMC Families of Deaf/ HOH Infants

- 1) Diagnostic procedures completed on an inpatient basis
- 2) Early identification
- 3) Consistent audiologist in the NICU
- 4) Sensory Care Plan
- 5) Beginning Sign Language Program
- 6) Amplification

# Counseling in the NICU and Beyond:

- Time of incredible stress, grief, and emotions
- Parents need opportunities to participate in care
- Parents need to tell their story
- Parents may need permission to prioritize and resign





Kelly.Baroch@cchmc.org



# Ben



# Ben: An Audiologist's Perspective

- ▣ Born at 32 weeks gestation
- ▣ CHARGE Association
- ▣ Bilateral coloboma
- ▣ Choanal atresia
- ▣ Cardiac anomalies
- ▣ Laryngomalacia
- ▣ Pinna Malformation

## Ben: A family's Perspective

“I was so afraid of having a deaf child because out of everything Ben had, that was the one defect I truly understood. I knew the challenges it would pose in his life. In addition to everything else he was facing, that just seemed to be one more obstacle that wasn't fair – an obstacle I was terrified of. I instantly wanted to have his hearing tested.”



# Ben: An Audiologist's Perspective

- ▣ 36 weeks GA
  - No response ABR at limits of equipment
    - ▣ Clicks
    - ▣ 500 Hz
    - ▣ 4KHz
    - ▣ bone conduction
  - Normal 1000 Hz tymps
  - Absent DPOAEs

# Ben: An Audiologist's Perspective

- ▣ 38 weeks GA
  - Second ABR confirmed results
- ▣ Referred to ENT
  - CT scan of temporal bones revealed bilateral cochlear dysplasia
  - Developed MEE during the hospitalization. PE tubes placed.
  - Repeat ABR post PE tubes to monitor thresholds

## Ben: A Parent's Perspective

“We were easily able to add PE tubes, CTs and any other ear related procedures to Ben's inpatient surgeries. This was a huge relief since putting Ben under anesthesia is a huge risk.”



# Ben: An Audiologist's Perspective

- ▣ Sensory Care Plan Developed
- ▣ Referred to Speech Pathology for Sign Language Program
- ▣ Referred to Developmental Rounds



## Ben: A Parent's Perspective

“We worked together to create a Sensory Care Plan to post by his bed to let everyone know how to approach and work with Ben. I also think this helped create awareness. In the chaos of the NICU, Ben’s caregivers were focused on his life and death needs... it was easy to forget about hearing loss and how that affected him.”

# Ben: A Parent's Perspective

“Prior to Ben’s diagnosis, everything upset him – I think hearing loss played a HUGE role in that.. He never knew what to expect, who was coming when and was constantly being startled.”



## Ben: An Audiologist's Perspective

- ▣ Discussed fitting of amplification with medical team and family
- ▣ Consultation with outpatient audiologist to select loaner hearing aids
- ▣ Binaural aids fit at 3 mo. CA, 1 mo. AA
- ▣ Trach and Gtube surgery. Parents chose to remove amplification until discharge (“permission to resign”)
- ▣ Re-fit with binaural amplification at 4.5 mo. CA, 2.5 mo. AA as outpatient

# Ben: An Audiologist's Perspective

- ▣ Aural rehabilitation therapy
- ▣ Regional Infant Hearing Program
- ▣ Help Me Grow
- ▣ Continued Speech Therapy

## Ben: A Parent's Perspective

“When we left the hospital, we had every aspect of Ben’s hearing loss covered. Thank goodness it was done ahead of time because when I got home, I had no idea how crazy life was going to be! I wouldn’t have had the time or energy to set up any of it.”



# Ben: A Parent's Perspective

- 176 appointments at Children's in 2 ½ yrs.
- 11 surgeries in 20 months



# Ben: An Audiologist's Perspective

- ▣ Cochlear implant surgery at 12 months CA



# Ben: A Family's Perspective

“Ben wears his implant all day and finds great joy in sound – something I NEVER thought possible the day I found out about his hearing loss.”

