



The Medically Complex Infant: Achieving “6” in the NICU

Kelly A. Baroch, Au.D., FAAA, CCC-A
Pediatric Audiologist III
Infant Hearing and Screening Program Coordinator
Kelly.Baroch@cchmc.org



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.

Screening's Just the Beginning:

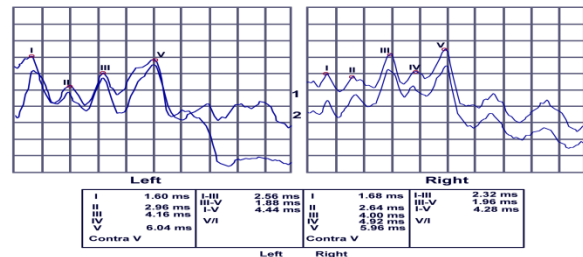
The Joint Committee on Infant Hearing

(JCIH 2002, 2007)

Screening by 1 month of age

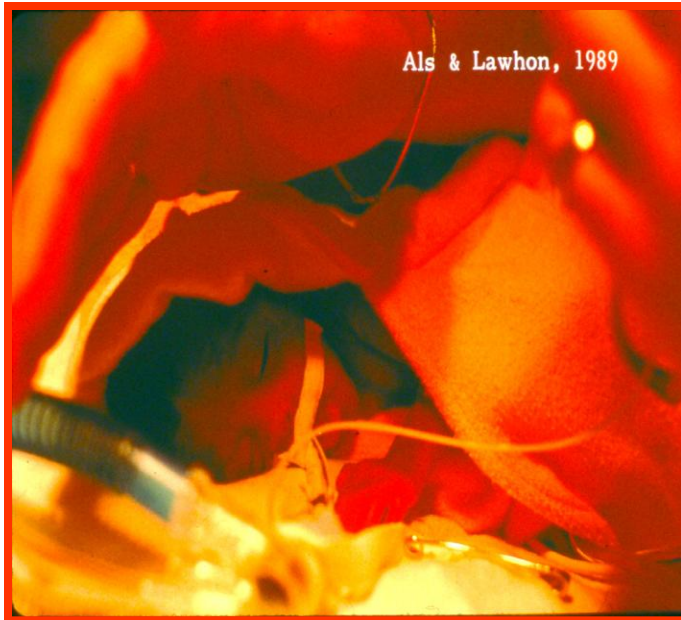
Diagnosis by 3 months of age

Intervention by 6 months of age

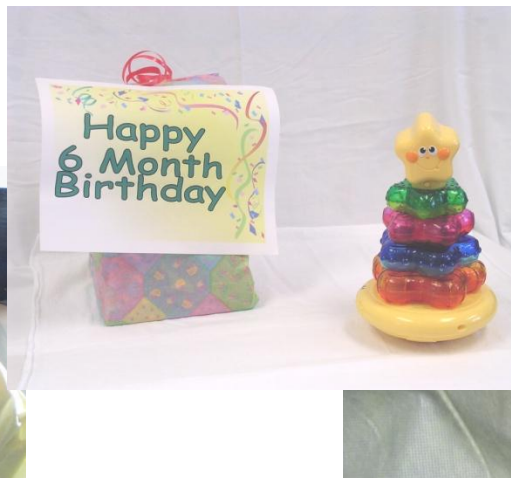


Normal adult ABR waveform response. I-V absolute latencies and interpeak intervals (I-II, II-IV, I-V) are within normal limits bilaterally. Interpeak differences for the I-V interpeak intervals (1.16ms) and wave V absolute latencies (.08 ms) are within normal limits.

The Changing Faces of the NICU

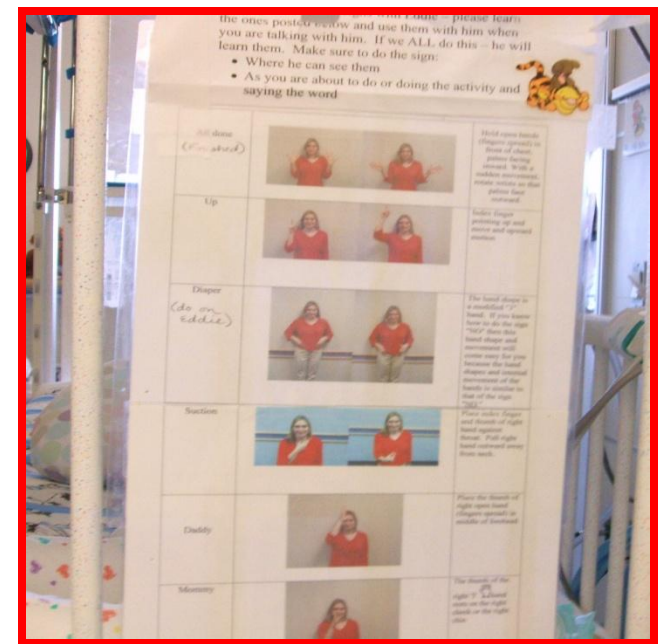


The Challenges of 1-3-6



The Program

- Interdisciplinary Approach
- Screening
- Diagnostics
- Intervention
 - Sensory Care Plan
 - Sign Language Program
 - Amplification
 - Parent Education
 - Staff Education



Barriers to 1-3-6: Screening

- 75.4% of “transferred” infants screened
- 97.5% of non-transferred infants screened

Dauman et al 2009

- NICU status strongest predictor of a missed screen
- 3.2% of NICU infants missed
- 0.15% of well babies missed

Vohr et al 2002

- 99.2% of all Massachusetts births were screened for hearing loss
- Only 96.4% transferred/NICU babies were screened

Farrell et al 2006

Barriers to the 1-3-6 Timeline: Screening

- Screening by 1 month of age
 - Medical instability
 - “Technology focused and crisis driven” D. Vittner
 - Distrust of medical team

- ❖ In-house audiologist
 - ❖ Developmental Team
 - ❖ Medical Rounds
 - ❖ Team member vs. consultant
 - ❖ Diagnostic value



Barriers to 1-3-6: Diagnosis

- NICU infants six times more likely to be lost to follow-up

Vohr et al. 2002



Barriers to Diagnosis

- Medically complex children significantly older at identification
- Median 5.5 vs 3.4 months

Wiley, Choo, Meizen-Derr



Barriers to 1-3-6: Diagnosis

“If the newborn doesn’t pass the initial screening, explore the possibility of using audiologists already in the facility to do a definitive ABR before the baby leaves the hospital.”

Communicating the Need For Follow-up to Improve Outcomes of Newborn Hearing Screening, Workgroup, July 2001

Barriers to 1-3-6: Diagnosis

- Definitive Diagnosis by 3 months of age
 - Multiple surgical procedures and medical setbacks
 - Middle ear effusion
 - Neurological involvement/damage
- ❖ Take advantage of opportunities to improve diagnostic setting
 - ❖ Full diagnostic capabilities (ABR/OAE)
 - ❖ 1000 Hz tympanometry
 - ❖ Collaboration with ENT
 - ❖ Explore new diagnostic possibilities (Wideband reflectance, ASSR)

Barriers to Intervention

- Medically complex children older at EI enrollment (8.6 vs 6.5 months)
- MC children were less likely to be enrolled by 6 months of age (36% vs 49%)
- Both groups received amplification at equal rates (77% MC vs 76%)
- MC children received amplification later (9.5 months vs 7 months)

Wiley, Choo, Meizen-Derr

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?



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



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



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 hearing infant...

- Anticipates daily routines because of the sights and sounds associated with them and can prepare for activities in advance



The Deaf/HOH infant...

- Misses these cues because of limited hearing
- May not understand or be able to anticipate what is happening
- Has many things happen that are unpleasant "surprises"



Newton 2001

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
- Report on 1 preterm infant 24 weeks:
 - 488 painful procedures per hospitalization

Hernandez 2009

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)



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.

**Regional Infant Hearing Program,
Aural Rehabilitation Audiologists,
Cincinnati Association for the Blind**

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.

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 (<i>finished</i>)</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 (<i>do on eddie</i>)</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 shape and initial movement of the hands is similar to that of the sign "up".</p>
<p>Suction</p>		<p>Place index finger and thumb 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 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 impairment, 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

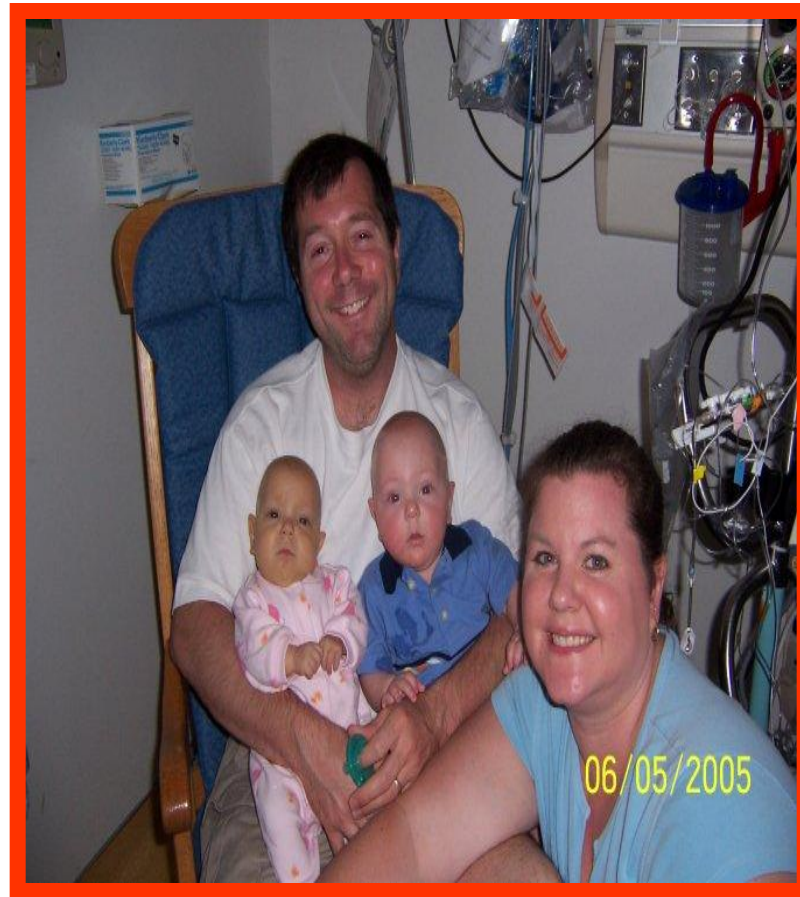
Amplification



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



A(?): Supporting the Family



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

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



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)

“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: Symptoms of PTSD in NICU Parents

- Perinatal PTSD Questionnaire
- Given to mothers within one year of giving birth
- Symptoms of Acute Stress Reactions
 - Derealization
 - Denial
 - Dissociative Reactions
 - Amnesia

Hynan 2009

Counseling in the NICU and Beyond: Breaking the Vicious Cycle

- Parental distress can lead to less than desirable infant development, which can result in greater parental distress

Hynan 2009

Counseling in the NICU and Beyond: Theory of Guarded Alliance

“The erosion of the healthcare relationship has been linked to the technologic explosion, specialization, and the resultant fragmentation, and dehumanization of health care services.”

Thorne and Robinson 1989

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

What Parents Want

- Identification at birth
- Informed by audiologist
- Kindness, empathy
- “Time”
- Unbiased information

Luterman and Kurtzer-White 1999

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

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 early language and 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 30 months.
- 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.”



Priorities for CCHMC Families of Deaf/HOH Infants

- 1) Early identification
- 2) Diagnostic procedures completed on an inpatient basis
- 3) Sensory Care Plan

- 4) Beginning Sign Language Program
- 5) Amplification

Outcomes

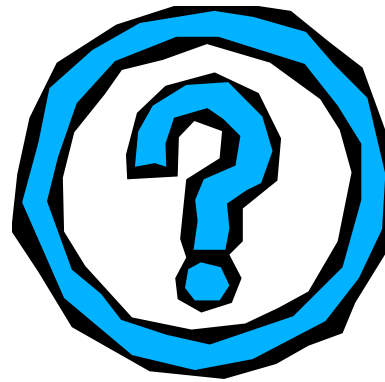
- Lost to Follow-up Rates decreased from 42% to 20%(includes out of state patients)
- Average age of hearing aid fitting decreased from 7 months adjusted age to 4 months adjusted age
- 75% of families utilizing sign language at time of discharge
- 95% of infants identified with hearing loss have a posted Sensory Care Plan

Accelerating Evidence Into Practice

- US Department of Health and Human Services 2008 invitational workshop
- Workshop attendees concluded that work was needed to create widely accepted screening and diagnostic protocols for infants in the NICU
- Perform diagnostic testing in the NICU
- Work with audiology diagnostic centers to facilitate referrals of infants in the NICU with diagnosed hearing loss to EI while they are still inpatients (Russ et al 2010)



**The enormity of the human spirit is independent
of the size of the person.**



Kelly.Baroch@cchmc.org

Cincinnati Children's Hospital Medical Center NICU and The Heart Institute at CCHMC

- RCNIC - 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
- NIDCAP Training and Research Center
- 80% of 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



Prevalence of Hearing Loss in CCHMC NICU/CICU Infants

- 4% of infants have sensory hearing loss
- 5% have conductive hearing loss (>3 months)
- 1% have neural overlay (i.e. ANSD, Chiari II malformation, mm, hydrocephalus)

