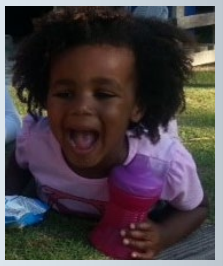
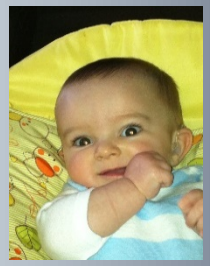





NC Department of Health and Human Services

Risk Factors and Hearing Loss: Development of a Parent Education Tool

Charlotte Destino, Au.D.
NC-EHDI Regional Consultant

EHDI Annual Meeting, March 2-4, 2021

Learning Objectives

1. Participants will be able to discuss changes to the risk factor table in the 2019 Joint Committee on Infant Hearing (JCIH) position statement.

2. Participants will be able to describe the development of a parent education tool using quality improvement methodology.

3. Participants will be able to discuss ways to educate providers and families about risk factors for late-onset or progressive hearing loss and need for audiologic follow-up.

Facts About Hearing Loss

- National statistics indicate approximately 2-3 per 1000 children are born with hearing loss annually.

Source: https://www.nidcd.nih.gov/health/statistics/quick-statistics-hearing#

- Infants who received care in the neonatal intensive care unit (NICU) represent 10% to 15% of the newborn population and have been shown to have a higher prevalence of elevated hearing thresholds compared to infants from well-baby nurseries.

Source: https://digitalcommons.usu.edu/jehdi/vol4/iss2/1/

North Carolina Statistics

- 2019 Statistics
  - 120,638 births
  - Over 99.2% were screened
  - 1115 babies did not pass their newborn hearing screening (NHS)
  - Of the 1,115 babies that failed the NHS:
    - 234 (21.0%) were confirmed with permanent hearing loss (1.94 per 1000 births)
    - 288 (25.8%) were lost to follow up/documentation

- NICU
  - 9,848 of total births had “NICU” as a risk factor (8.2%)
  - Of the 234 confirmed with hearing loss, 73 (31.2%) had “NICU” as a risk factor, although length of stay was not specified.

Joint Committee on Infant Hearing (JCIH) – 2019 Position Statement

The new JCIH position statement includes a periodicity table for babies who pass their newborn hearing screening but are at risk for developing late onset or progressive type hearing loss.

Changes from 2007 JCIH position statement:

1. Diagnostic audiologic follow-up for infants with risk factors was changed from “prior to 30 months” to 1 month, 3 months or 9 months depending on the risk factor.

2. Zika virus was added as a risk factor.

3. Monitoring Frequency was added to the risk factor periodicity table.

Risk Factors for Early Childhood Hearing Loss: Guidelines for Infants who Pass the Newborn Hearing Screen

	Risk Factor Classification	Recommended Diagnostic Follow-up	Monitoring Frequency
	Perinatal		
1	Family history of early, progressive, or delayed onset permanent childhood hearing loss	By 9 months	Based on etiology of family hearing loss and caregiver concern
2	NICU stay of more than 5 days	By 9 months	As per concerns of on-going surveillance of hearing skills and speech milestones
3	Hyperbilirubinemia with exchange transfusion regardless of length of stay	By 9 months	
4	Aminoglycoside administration for more than 5 days**	By 9 months	
5	Asphyxia or Hypoxic Ischemic Encephalopathy	By 9 months	
6	Extracorporeal membrane oxygenation (ECMO)*	No later than 3 months after occurrence	Every 12 months to school age or at shorter intervals based on concerns of parent or provider
7	In utero infections, such as herpes, rubella, syphilis, and toxoplasmosis	By 9 months	As per concerns of on-going surveillance
	In utero infection with cytomegalovirus (CMV)*	No later than 3 months after occurrence	Every 12 months to age 3 or at shorter intervals based on parent/provider concern
	Mother + Zika and infant with *no* laboratory evidence & no clinical findings	Standard	As per AAP (2017) Periodicity schedule
	Mother + Zika and infant with laboratory evidence of Zika + clinical findings Mother + Zika and infant with laboratory evidence of Zika – clinical findings	AABR by 1 month AABR by 1 month	ABR by 4-6 months or VRA by 9 months ABR by 4-6 months Monitor as per AAP (2017) Periodicity schedule (Adebanjo et al., 2017)
8	Certain birth conditions or findings: • Craniofacial malformations including microtia/atresia, ear dysplasia, oral facial clefting, white forelock, and microphthalmia • Congenital microcephaly, congenital or acquired hydrocephalus • Temporal bone abnormalities	By 9 months	As per concerns of on-going surveillance of hearing skills and speech milestones
9	Over 400 syndromes have been identified with atypical hearing thresholds***. For more information, visit the Hereditary Hearing Loss website (Van Camp & Smith, 2016)	By 9 months	According to natural history of syndrome or concerns
	Perinatal or Postnatal		
10	Culture-positive infections associated with sensorineural hearing loss***, including confirmed bacterial and viral (especially herpes viruses and varicella) meningitis or encephalitis	No later than 3 months after occurrence	Every 12 months to school age or at shorter intervals based on concerns of parent or provider
11	Events associated with hearing loss: • Significant head trauma especially basal skull/temporal bone fractures • Chemotherapy	No later than 3 months after occurrence	According to finding and or continued concerns
12	Caregiver concern**** regarding hearing, speech, language, developmental delay and or developmental regression	Immediate referral	According to findings and or continued concern

Notes. AAP (American Academy of Pediatrics); ABR (auditory brainstem response); AABR (automated auditory brainstem response; VRA (visual reinforcement audiometry).

*Infants at increased risk of delayed onset or progressive hearing loss

**Infants with toxic levels or with a known genetic susceptibility remain at risk

***Syndromes (Van Camp & Smith, 2016)

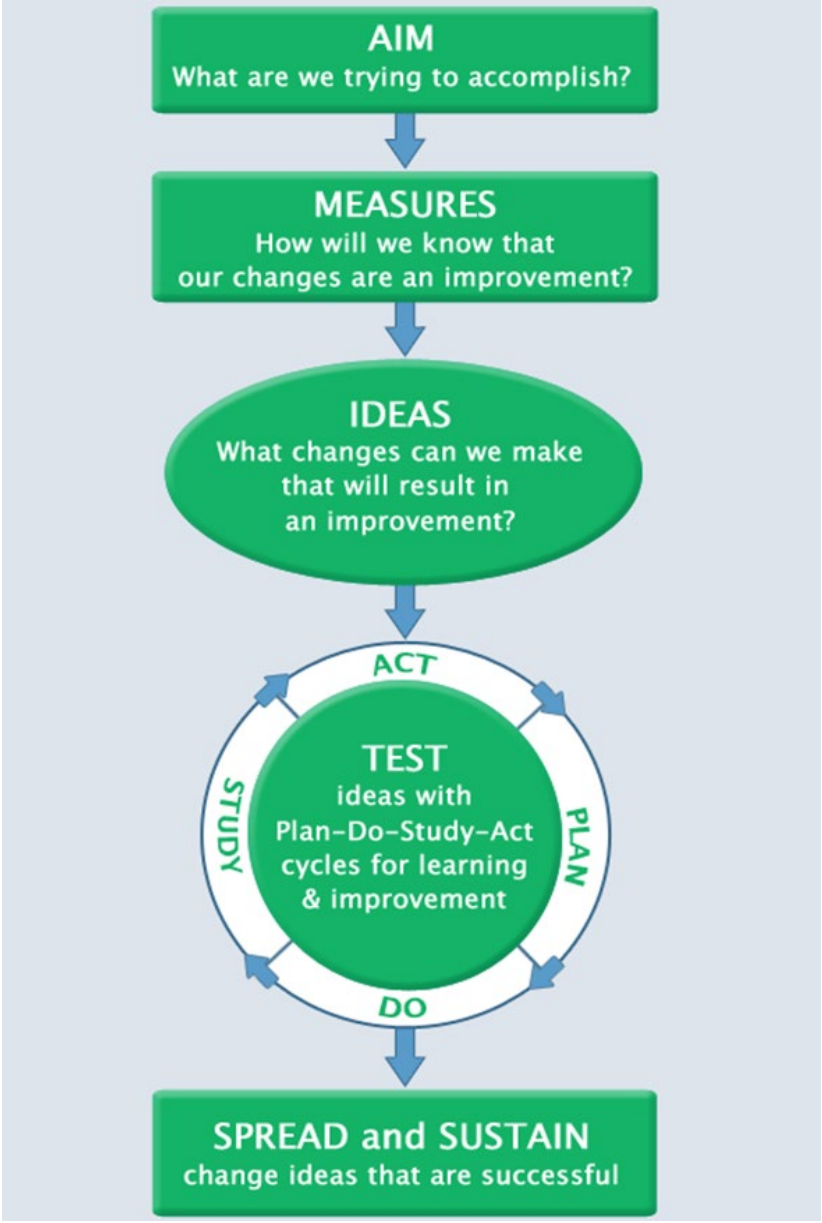
****Parental/caregiver concern should always prompt further evaluation

Source: Year 2019 Joint Committee on Infant Hearing (JCIH) Position Statement, Table 1

Risk Factor Parent Education Card Pilot Study

Model for Improvement

Continuous Quality Improvement (CQI) Methodology



Source: Population Health Improvement Partners
www.improvepartners.org

Aim Statement: What We Are Trying to Accomplish.

For NICU grads who pass their initial newborn hearing screening:

Educating parents about their baby's risk factors associated with late onset or progressive hearing loss will increase the likelihood of audiologic follow-up according to the new JCIH Risk Factor Periodicity Table.

Baseline: What We Know

- Approximately 1-3 per 1000 children who pass their newborn hearing screening will develop permanent hearing loss prior to school age.
  - For babies born in NC from 2015-2019, there were 151 reported to have late onset hearing loss. *NC mandate does not require audiologists to report on children >1 year of age.

- The incidence of late onset permanent hearing loss is greater in NICU grads with certain risk factors.
  - Of those 151 babies diagnosed with late onset hearing loss, born in NC from 2015-2019, 52 had NICU as a risk factor. (34%)

- Most PCPs in NC do not have the ability to perform on-site physiologic hearing screenings on children under the age of four.
  - As a rough estimate, there are approximately 30+ PCP offices that are able to perform hearing screening on babies <4 years old

Measures: How will we know the changes are an improvement?

- # of infants with known risk factors given the new parent education card.
- # of parents who shared the parent education card with their Primary Care Provider.
- # of infants that had audiologic follow-up according to best practices guidelines set forth in the 2019 JCIH position statement.

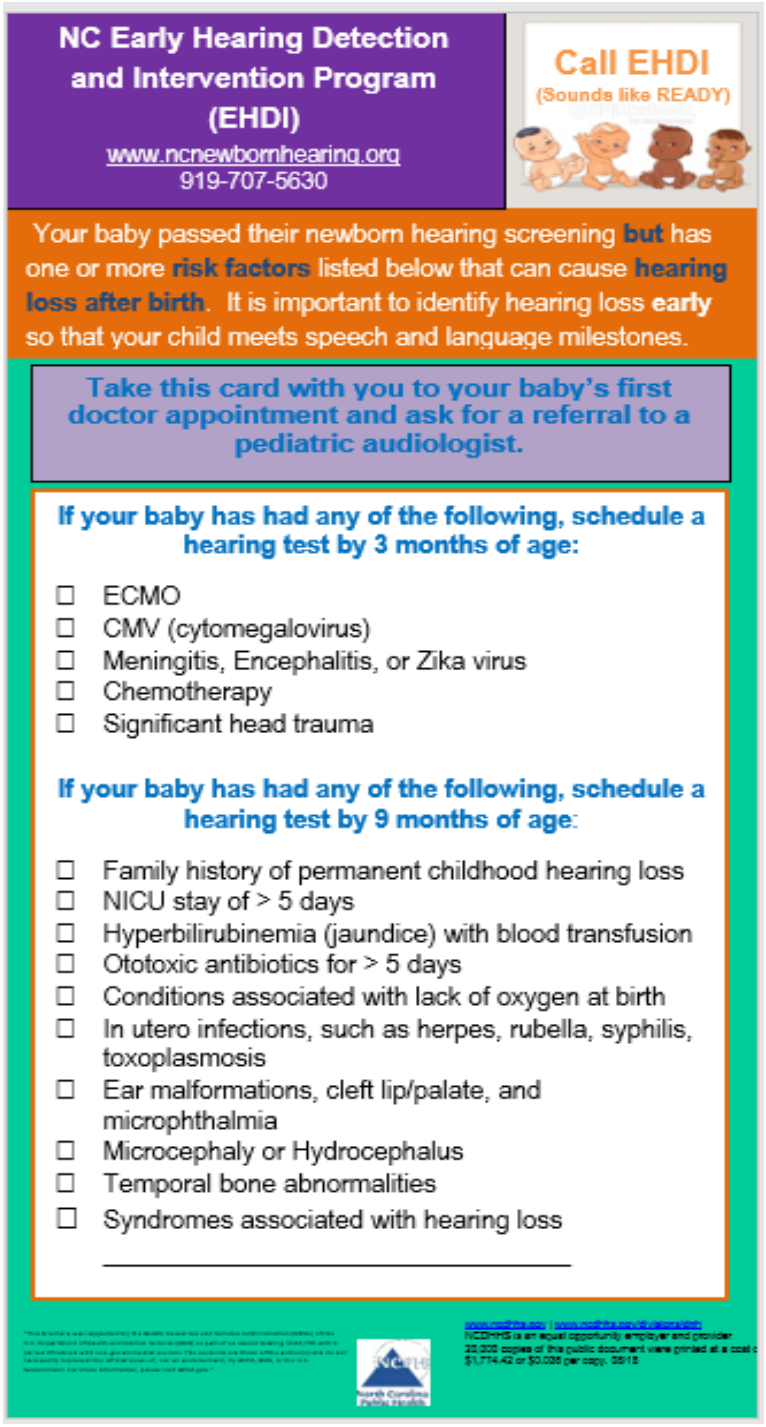
Change Idea: Educating Parents

Create a new risk factor parent education card that will be shared with families of NICU babies who passed their newborn hearing screening but had one or more risk factors for late onset or progressive hearing loss.

PDSA Cycle - Plan

- Develop the “Risk Factor Parent Education Card” with parent input.
- Identify two NICUs to participate in the Pilot Study for a 1-week period.
- Develop a pre- and post-knowledge test that will be administered to NICU nursing staff.
- Develop a NICU nursing staff training on the use of the parent education card.
- Develop a satisfaction survey for the NICU nursing staff.
- Develop a survey that will be administered to parents who were given the card.
- Review hearing link data to see if infants with risk factors at birth received a diagnostic evaluation per the JCIH periodicity table.

Risk Factor Parent Education Card



NC Early Hearing Detection and Intervention Program (EHDI)

www.ncnewbornhearing.org
919-707-5630

Call EHDI
(Sounds like READY)

Your baby passed their newborn hearing screening **but** has one or more **risk factors** listed below that can cause **hearing loss after birth**. It is important to identify hearing loss **early** so that your child meets speech and language milestones.

Take this card with you to your baby's first doctor appointment and ask for a referral to a pediatric audiologist.

If your baby has had any of the following, schedule a hearing test by 3 months of age:

- ☐ ECMO
- ☐ CMV (cytomegalovirus)
- ☐ Meningitis, Encephalitis, or Zika virus
- ☐ Chemotherapy
- ☐ Significant head trauma

If your baby has had any of the following, schedule a hearing test by 9 months of age:

- ☐ Family history of permanent childhood hearing loss
- ☐ NICU stay of > 5 days
- ☐ Hyperbilirubinemia (jaundice) with blood transfusion
- ☐ Ototoxic antibiotics for > 5 days
- ☐ Conditions associated with lack of oxygen at birth
- ☐ In utero infections, such as herpes, rubella, syphilis, toxoplasmosis
- ☐ Ear malformations, cleft lip/palate, and microphthalmia
- ☐ Microcephaly or Hydrocephalus
- ☐ Temporal bone abnormalities
- ☐ Syndromes associated with hearing loss

_____

If your baby has had any of the following, schedule a hearing test by 3 months of age:

- ☐ ECMO
- ☐ CMV (cytomegalovirus)
- ☐ Meningitis, Encephalitis, or Zika virus
- ☐ Chemotherapy
- ☐ Significant head trauma

If your baby has had any of the following, schedule a hearing test by 9 months of age:

- ☐ Family history of permanent childhood hearing loss
- ☐ NICU stay of > 5 days
- ☐ Hyperbilirubinemia (jaundice) with blood transfusion
- ☐ Ototoxic antibiotics for more than 5 days
- ☐ Conditions associated with lack of oxygen at birth
- ☐ In utero infections, such as herpes, rubella, syphilis, toxoplasmosis
- ☐ Ear malformations, cleft lip/palate, and microphthalmia
- ☐ Microcephaly or Hydrocephalus
- ☐ Temporal bone abnormalities
- ☐ Syndromes associated with hearing loss_____

Instructions for Nursing Staff

- Present the card along with the NBHS brochure to the family before discharge. Explain to the family that their infant PASSED the NBHS but had one or more risk factor(s) for late onset or progressive hearing loss. Check off the risk factor(s) that applies to the child.

- Review the risk factor(s) checked, emphasizing when to follow up based on those risk factor(s).

- Remind the family to take the card with them to the baby's first doctor appointment.

Nursing Staff Knowledge Survey
Pre- and Post Test

1. **An infant can pass the newborn hearing screening and be at increased risk for late onset or progressive hearing loss.**

   - **True** ✓
   - **False**
   - **Don't know**

2. **The following risk factors present during the birth admission can cause late onset or progressive hearing loss (circle all that apply).**

   - **ECMO use during birth admission**
   - **Cytomegalovirus**
   - **Meningitis**
   - **Family history of permanent childhood hearing loss**
   - **NICU stay of more than 5 days**
   - **Hyperbilirubinemia with blood transfusion**
   - **None of the above**
   - **All of the above** ✓

3. **Some antibiotics have ototoxic properties if given for more than 5 days.**

   - **True** ✓
   - **False**
   - **Don't know**

4. **If an infant passes the newborn hearing screening but has one or more risk factors that increases the possibility of late onset or progressive hearing loss, it is important for the baby to see a pediatric audiologist for follow-up.**

   - **True** ✓
   - **False**
   - **Don't know**

Family Risk Factor Survey Post NICU Discharge

1. **Did the hospital staff give you a card about risk factors for hearing loss?**
   - **YES**
   - **NO – end interview**
   - **Don't recall – end interview**

2. **Did the hospital staff person review the card with you and talk to you about the risk factor(s) your baby has for hearing loss?**
   - **YES**
   - **NO**
   - **Don't recall**

3. **Did you share the risk factor card with your baby's doctor?**
   - **YES**
   - **NO**
   - **Don't recall**

4. **Did your baby's doctor talk with you about seeing a pediatric audiologist to check your baby's hearing?**
   - **YES**
   - **NO**
   - **Don't recall**

5. **Did you find the card helpful in learning about your baby's risk factors for hearing loss and what to do next?**
   - **YES**
   - **NO**
   - **Don't recall**

6. **Do you have any questions about the card?**
   - **YES**
   - **NO**

NICU Nursing Staff Satisfaction Survey

1. Did you give the risk factor card to parents of infants that passed their newborn hearing screening but had at least one of the known risk factors for late onset/progressive hearing loss? all of the time, some of the time, did not use it
2. If you did not use it, what prevented you from using it?
3. Were you able to explain the card to parents? Yes, No
4. If no, what prevented you from explaining the card to parents?
5. What part of the card was most helpful?
6. What part of the card was least helpful?
7. Is there other information you would recommend on the card?
8. Would you recommend the card to other Neonatal Intensive Care Units?
9. Other comments _____

Do

- Request that NICU nursing staff complete a pre-knowledge test.
- Train NICU nursing staff in the use of the education card.
- Implement 1-week pilot study.
- Request that NICU nursing staff complete a post-knowledge test.
- Request that nursing staff complete a satisfaction survey after the pilot study.
- Contact parents 1-2 weeks post discharge and asked them six survey questions.
- Collect all measured data.

Study: Hospital Data

1. Distributed card at one Level III NICU the week of 8/3/20 – 8/7/20.
2. Three (3) families were given Risk Factor Parent Education Card. These infants passed the NBHS and had at least one risk factor for late onset or progressive hearing loss.
3. Four (4) NICU nurses completed the pre-knowledge test and 12 completed the post-knowledge test.
4. None of the nurses completed the satisfaction survey.
5. Two (2) of the three (3) families were able to be contacted to complete the family survey.

Study: Nursing Staff Knowledge Survey Pre- and Post-Test Results

1. **An infant can pass the newborn hearing screening and be at increased risk for late onset or progressive hearing loss.**

   Pre-test- 4/4 = 100%
   Post-test- 10/12 = 83%

2. **The following risk factors present during the birth admission can cause late onset or progressive hearing loss (circle all that apply).**

   Pre-test- 3/4 = 75%
   Post-test- 11/12 = 91%

3. **Some antibiotics have ototoxic properties if given for more than 5 days.**

   Pre-test- 4/4 = 100%
   Post-test- 12/12 = 100%

4. **If an infant passes the newborn hearing screening but has one or more risk factors that increase the possibility of late onset or progressive hearing loss, it is important for the baby to see a pediatric audiologist for follow-up.**

   Pre-test- 4/4 = 100%
   Post-test- 12/12 = 100%

Study: Family Risk Factor Survey Post NICU Discharge – Results n=2

1. Did the hospital staff give you a card about risk factors for hearing loss?

2 YES

2. Did the hospital staff person review the card with you and talk to you about the risk factor(s) your baby has for hearing loss?

1 YES

1 NO

3. Did you share the risk factor card with your baby's doctor?

1 YES

1 NO

4. Did your baby's doctor talk with you about seeing a pediatric audiologist to check your baby's hearing?

2 NO

5. Did you find the card helpful in learning about your baby's risk factors for hearing loss and what to do next?

1 YES

1 NO

6. Do you have any questions about the card?

2 NO

Study: Satisfaction Survey Results

- There were no satisfaction surveys returned from NICU staff after two requests.
- The nurse manager indicated that even though NICU staff did not complete the satisfaction survey, their NICU is interested in continuing to use the risk factor card going forward.

Study: Diagnostic Testing Results

Baby 1

- gestational age 35 weeks
- 6 days in NICU
- Respiratory Distress
- Recommended follow up in 9 months

Baby 2

- gestational age 33 weeks
- 9 days in NICU
- Recommended follow up in 9 months

Baby 3

- gestational age 33 weeks
- 37 days in NICU
- Respiratory distress
- Recommended follow up in 9 months

Act

- Pilot Parent Education Card at 2 or more facilities.
- Obtain feedback on the card from NICU staff and revise if necessary.
- Modify the satisfaction survey (create an online survey) and eliminate the pre- and post-knowledge surveys.
- Offer Risk Factor Parent Education Card to all NICU's once the testing is complete.
- Continue educating PCPs about follow-up testing for NICU babies that pass NBHS.

PCP Education

- Most babies are identified through the NBHS process, but there is little evidence that PCPs are aware of the need for periodic screening/testing based on risk factors present at birth.
- A statewide mailing to all the pediatricians and family practice physicians in NC regarding the need for periodic screening for babies with known risk factors following the NBHS period was completed in the fall of 2020. The new periodicity table was mailed with the letter. Future training on this topic needs to be developed.

Lessons Learned

- It was difficult for nursing staff to take time to fill out and explain the card to families.
- In some facilities, audiologists complete the screenings and do not always have access to a complete list of risk factors for the babies.
- Some birthing facilities are unable to use outside materials as part of their discharge/education packets.
- For the small sample group we had, the PCPs did not go over the need for further testing, even when the risk factor card was brought to their attention.
- Our data is only as clean as the people who enter. Risk Factors are not always indicated in the state database. More education of birthing facility staff is warranted.
- Trying to conduct a pilot study during COVID-19 was incredibly challenging as hospitals needed to postpone participation due to NICU priorities during the pandemic.

Thank you!

Questions?

Charlotte Destino, Au.D.

North Carolina EHDI Program

Charlotte.destino@dhhs.nc.gov