



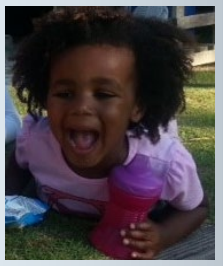
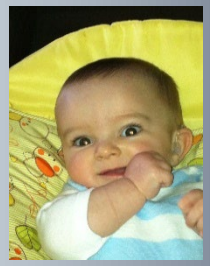


NC Department of Health and Human Services

Risk Factors and Hearing Loss:

Parent and Medical Home Education- North Carolina Update

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EHDI Annual Meeting, March 9-11, 2025

Learning Objectives

1. Participants will be able to describe the development and implementation response of a parent education tool using quality improvement methodology.

2. Participants will be able to describe the development of a provider 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 audiological 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/

Photo Credit: NC-EHDI Program

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

The 2019 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

Baseline: What We Know

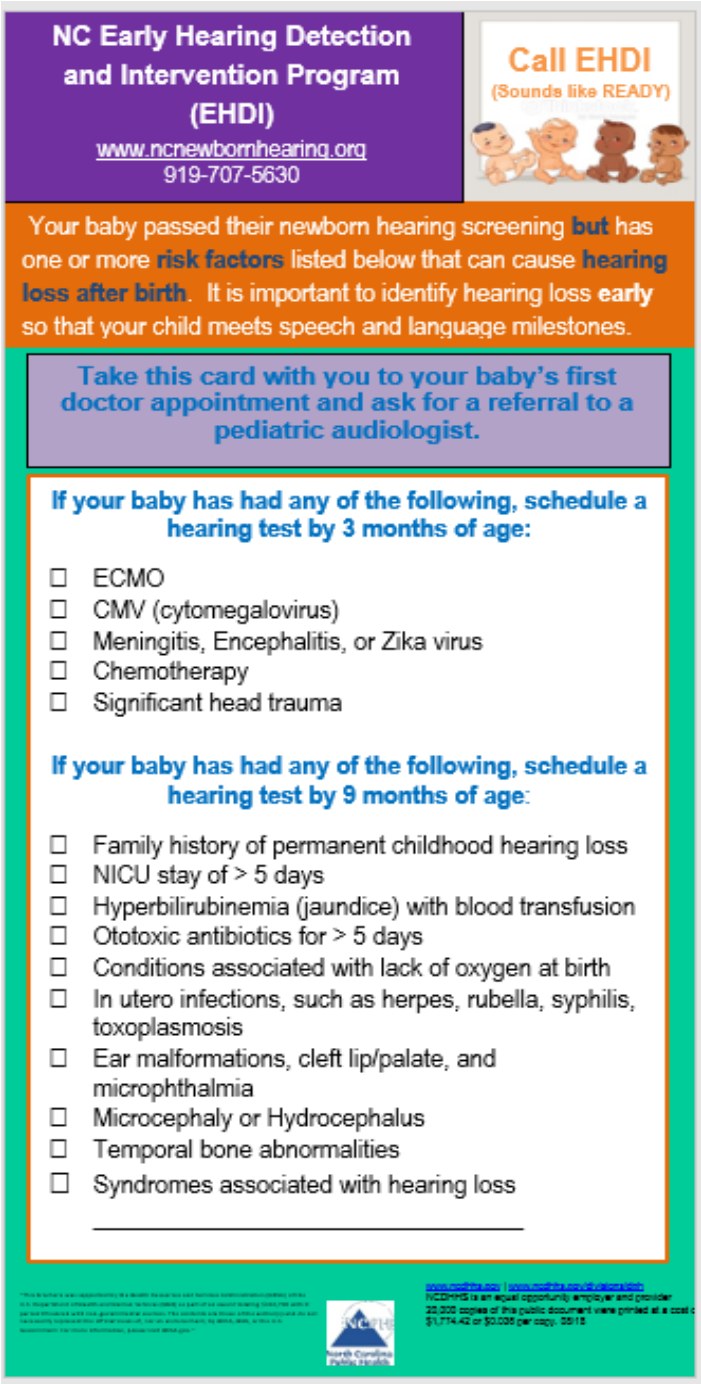
- Approximately 1-3 per 1000 children who pass their newborn hearing screening will develop permanent hearing loss prior to school age.

- The incidence of late onset permanent hearing loss is greater in NICU grads with certain risk factors.

- Most medical homes in NC do not have the ability to perform on-site physiologic hearing screenings on children under the age of four.

Photo Credit: Getty Images

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

_____

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- ☐ 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 more than 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_____

Following the Pilot Study

- Based on survey feedback from the pilot study, the original risk factor card was updated, and was printed as a two-sided English/Spanish card.
- The card was disseminated to multiple NICUs statewide.
- Modified and created an online satisfaction survey for NICU staff for ongoing monitoring related to the parent education Risk Factor Card.
- Created a “Risk Factor Instructional Video” designed for providers which was reviewed and evaluated.

Parent Education Card - Distribution 2025

- 12 NICUs were approached, 7 NICU's agreed, 5 declined.
- Risk Factor Cards were distributed for 1 month prior to completion of the Satisfaction Survey.

Photo Credit: Getty Images

Reasons for NICU's Declining Distribution

- Declines came from large facilities with Level IV NICUs, some with multiple sites.
- Have their own audiology departments.
- Were told that they already have a system in place for NICU graduate follow up, or referral to developmental clinics.
- Material distribution approval is required by higher level management.
- Concerns regarding excessive referrals to providers and ENT practices and overburdening staff.

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?
2. If you did not use it, what prevented you from using it?
3. Were you able to explain the card to parents?
4. If no, what prevented you from explaining the card to parents?
5. Did you feel the parent understood the purpose of the card?
6. Did parents have any questions about the card after you explained it?
7. What part of the card was most helpful?
8. What part of the card was least helpful?
9. Is there other information you would recommend on the card?
10. Would you recommend the card to other Neonatal Intensive Care Units?
11. Other comments

Satisfaction Survey 2025- Lessons Learned

- Of the NICUs that used the risk factor card:
  - All found it to be helpful and will continue to use it.
  - Most NICU staff felt comfortable in explaining the card.
  - Some were unsure of the parents' level of understanding as parents did not ask many questions.
  - Some staff felt they needed clearer or more comprehensive instructions on how to distribute the card.
  - One comment suggested having space on the card for location of follow up testing.

- What staff found to be most helpful:
  - Card was two sided in English and Spanish.
  - Listed risk factors and timeline for follow up.

Risk Factor Instructional Video

- A 15-minute “Risk Factor Instructional Video” was designed for providers which includes a short introduction by Dr. Robert Nutt, an NC developmental pediatrician with hearing loss.
- The video was sent to 12 providers to review and evaluate.
- Eight (8) providers completed the evaluation.

Risk Factor Instructional Video Introduction

https://youtu.be/FtcMKVmXgIk?si=DFDv_VW4QBzQ_HhI

Photo credit: Getty Images

Provider Training Content

- Common signs, barriers and consequences of late onset or progressive hearing loss.
- JCIH 2019 risk factor guidelines for infants who pass newborn hearing screening.
- Definition and importance of pediatric audiology.
- Role of the medical home in risk factor monitoring, referral and follow up.
- Role of EHDI and its relationship to the medical home.

Provider Training Evaluation

- **Of the providers who evaluated the training:**
  - All providers understood the content and felt confident in identifying the risk factors and making appropriate referrals.
  - All providers understood the significance of verifying initial hearing screening results and the importance of remaining vigilant for late onset or progressive hearing loss.

- **What providers found to be most helpful:**
  - The introductory video was felt to be powerful.
  - The training itself was very useful in improving their ability to support the at-risk children.

- **Provider Suggestions:**
  - The training was well received by providers and they felt it should be disseminated statewide. Several were interested in sharing immediately with colleagues both within and outside of their practices.
  - Some providers requested clarification which was addressed.

Moving Forward

- Continue dissemination of Risk Factor Card statewide.
- Determine whether NICUs that declined using the Risk Factor Parent Education Card currently have a system in place for audiological follow up.
- Modify the risk factor section in Hearing Link (HL) to match the 2019 JCIH guidelines.
- Generate child-specific letters from HL for kids with known risk factors and centralizing the mailing of these letters.
- Create and disseminate risk factor instructional video statewide.
- Update Hospital Compliance Guide – add risk factor section.
- Develop short risk factor training for birthing facilities.

Thank you!

Questions?

Photo Credit: Getty Images

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North Carolina EHDI Program