Reducing Lost to Follow Up: North Carolina’s Early Hearing Detection and Intervention Program

What do you know about pediatric hearing loss???

Answer:
- Approximately **3 in 1000** babies are born with permanent hearing loss, making hearing loss one of the most common birth defects in the United States.

How many babies are born with a permanent hearing loss?
- 3 out of 1000, 15 out of 1000 or 30 out of 1000?

What percent of children with a permanent hearing loss are born to 2 hearing parents?
- 28%, 55%, or 92%?
Answer:

- **92%** of children with permanent hearing loss are born to two hearing parents.

What percent of babies born with a hearing loss exhibit other risk factors?

- 25%, 50%, or 75%?

Answer:

- Of the 12,000 babies in the US born annually with some form of hearing loss, **only 50% exhibit other risk factors**—meaning that if only high-risk infants were screened, half of the infants with some form of hearing loss would not be tested and identified.

The NC EHDI Program

The overall goal of the NC Early Hearing Detection and Intervention Program (EHDI) is to provide **hearing screening** to all children born in a North Carolina birthing facility before discharge so that children with hearing loss are identified and receive **early intervention**.

(NC EDHI Program, 2009)

NC EHDI Program

- 3 Central Tracking Staff based in Raleigh who track the baby through rescreen
- 6 Speech-Language Consultants- regional staff who track the baby through diagnosis of a hearing loss
- 6 Audiology Consultants- regional staff who track the child from diagnosis of a hearing loss to the age of 21
- 1 Program Manager-based in Raleigh who oversees the hearing screening program

Statistics on Hearing Loss

- Hearing loss affects 12,000 children born in the United States each year, making it one of the most common birth defects
- Nationally 39.4% of children referring on newborn hearing screen were lost to f/u prior to definitive diagnosis in 2010.
  - In NC, 35.1% were lost to follow up after referring on the newborn hearing screen.
- Taken from CDC data
NC Statistics for 2012
- Approximately 121,101 live births
- 99.6% had initial screening
- 2.8% referred on initial screening
- 195 were confirmed with hearing loss
- 126 were enrolled with Early Intervention by six months of age

Why Screen?
- Until the 1990s, children born with a permanent hearing loss typically would not have been identified and diagnosed until 2.5 to 3 years of age.
- Since the initiation of newborn hearing and EHDI programs, the average age of hearing loss identification has decreased to 2-3 months of age. (White, 2008; Hoffman & Beauchine, 2007; Harrison et al., 2003)

Why is Early Identification of Hearing Loss so Important?
- Late identification of hearing loss or lack of early intervention services can negatively impact speech and language development, academic achievement and social-emotional development (Yoshinaga-Itano et al, 1998)
- The most critical time for stimulating the hearing centers in the brain is during the first few months of life (Sharma et al, 2007).
- The critical language learning window is from birth to approximately 3 years of age when brain neuroplasticity is the greatest (Sharma et al, 2002)

Birthing Facilities/Hospitals in North Carolina
- 87 Birthing Facilities, all do initial newborn hearing screenings
- 81 do rescreens back at birthing facility
The Rescreen Process Varies

- Ideally, rescreen is performed at the birthing facility on an outpatient basis.
  - In general, birthing facilities that do the outpatient rescreening have a lower lost to follow up rate
- The birthing facility makes a referral or appointment at an outside agency (such as an ENT office or hospital rehabilitation facility)
- The PCP reviews the newborn hearing screening results and makes a referral for rescreen if needed
- EHDI staff serves as a “safety net” to complete rescreens as a last resort.

Hearing Link

- Data collection system for infant screenings, rescreenings, diagnostics, hearing aid fittings, developmental assessments and early intervention.
- Password protected, HIPAA compliant
- All babies that receive a birth certificate are entered into the database.

• All facilities that complete screenings and rescreenings are responsible for entering the results, including no-shows
• Hearing Link separates babies based on the status of the screening into the following categories: Do Not Track, Screening, Diagnostic, and Monitor.
Tracking Status

- Do Not Track - Baby passed the screening in both ears.
- Screening - Baby did not pass the screening in one or both ears and has not completed a rescreen or babies who have not had an initial screening.
- Diagnostic - Baby did not pass the rescreen and has not completed a diagnostic audiological evaluation.
- Monitor - Baby has been diagnosed with hearing loss.

Tracking

- Each birthing hospital sends the newborn hearing screening results to Raleigh either electronically (via Hearing Link database system) or on the Metabolic Screening form.
- Central tracking staff in Raleigh follow babies through completion of the rescreen by contacting hospitals, primary care providers, and families.

Speech Language Consultants follow babies through the completion of a diagnostic audiological evaluation by contacting parents, primary care providers, audiologists, ENT offices, local health departments, and early intervention programs.
  - The diagnostic evaluation should be completed by a pediatric audiologist.

Audiology Consultants follow babies that have been diagnosed with a hearing loss through intervention including treatment options (amplification, cochlear implants, etc) and educational referrals.

Barriers to Completing the Tracking Process

- Families move with address and phone number changes.
- Families change medical home.
- Non-compliance.
- Importance of follow up is minimized (by hospital staff, PCP, other family members, etc.)
- Medical complications (including NICU stay, ear infections, other medical issues, etc.)
• Children are considered “lost to follow up/documentation” when:
  – Families do not complete the appropriate follow-up
  – EHDI staff is unable to reach the family
  – EHDI is unable to document that the follow-up occurred
  – If families decline the screening/rescreening or diagnostic evaluation, they are asked to sign a waiver

Lost to Follow Up Statistics for North Carolina
• In 2004, 73% of babies who needed diagnostic evaluation were lost to follow up
• In 2009, 56.2% of babies who needed diagnostic evaluation were lost to follow up
• In 2010, 35.1% of babies who needed diagnostic evaluation were lost to follow up

What is a Pediatric Audiologist?
• Experienced with the assessment of infants & children with hearing loss and the knowledge and equipment necessary for use with current pediatric assessment methods.
  • Go to www.ncnewbornhearing.org
  • Click on “Physicians”
  • Click on “Diagnostic Testing Sites”
Referral Process after Diagnosis

- When the audiologist diagnoses a permanent hearing loss, they will have the family sign the permission for referral form.
- This form should be used for newly diagnosed children of any age.

Birth-Age 3 Referrals

- For children ages birth-3, the following referrals are offered:
  - Infant Toddler Program (CDSA)
  - Beginnings

Referrals Ages 3+

- For ages 3 and up, the parent has the option to accept or decline a referral to their local LEA and/or Beginnings.
Any Questions???

Additional Video Clips (if time allows)

Thank you!
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