

64TH CONFERENCE ON EXCEPTIONAL CHILDREN

**WORKING TOGETHER
TO ACHIEVE STUDENT SUCCESS**



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

PUBLIC SCHOOLS OF NORTH CAROLINA
State Board of Education | Department of Public Instruction

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**North Carolina's
Early Hearing Detection and
Intervention Program**



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What do you know
about pediatric
hearing loss???

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**How many babies are born
with a permanent hearing
loss?**

–3 out of 1000, 15 out of
1000 or 30 out of 1000?

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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.

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**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

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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

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Standards of Early Hearing Detection and Intervention (EHDl) in the United States



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    graph TD
      A[Screening  
before 1 month] --> B[Diagnosis  
before 3 months]
      B --> C[Intervention  
before 6 months]
  
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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 EHDl 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)

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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)

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Video Example- Early vs. Late Identification

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Birthing Facilities/Hospitals in North Carolina

- 87 Birthing Facilities, all do initial newborn hearing screenings
- 81 do rescreens back at birthing facility

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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.

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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.

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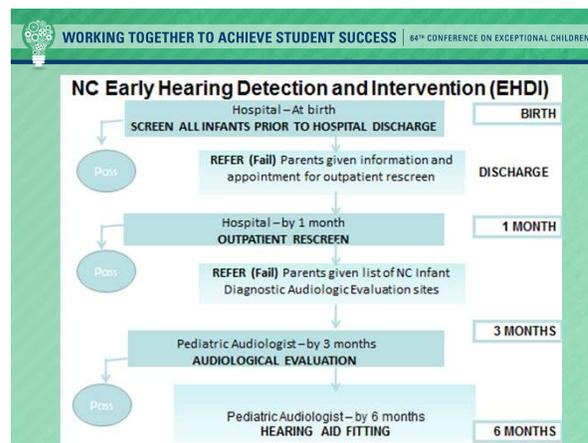
- All facilities that complete screenings and rescreenings are responsible for entering the results, including no-shows
- Hearing Link separates babies based on the status of the screening into the following categories: Do Not Track, Screening, Diagnostic, and Monitor.

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ID#	Facility	Screener	Type	Date Performed	Ear	Result	Designation
09 2012021	LAKE NORMAN RES MEDICAL CENTER	Tracy Houston-Petrey, JARR	12.07.2012	Right	Pass		Officer Initial Screen
09 2012021	LAKE NORMAN RES MEDICAL CENTER	Tracy Houston-Petrey, JARR	12.07.2012	Left	Pass		Officer Initial Screen



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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.

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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.

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- 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.

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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.)

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- Reporting to Hearing Link
- Complexity of the diagnostic process
- Access to pediatric diagnostic audiology sites
- Cost of services and equipment

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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

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- 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

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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”

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NC Location	Name of Facility	Address	Telephone	Medical Affiliation For Referral	Accepts Medicaid?	Interpreter Services Available
Ahokee	Otolaryngology Site* Rainsville Chowan Hospital	500 S. Academy Street Ahokee, NC 27910	Terry Crisp (919) 218-3078	N/A	Free Service	Interpreter services will be arranged upon request
Asheville	Asheville Head, Neck & Ear Surgeons	1065 Hendersonville Rd Asheville, NC 28803	(828) 254-3517	Mission Hospital	Yes for diagnostics and hearing aids	Spanish, Russian
Asheville	Mission Children's Pediatric Audiology	11 Vanderhill Park Drive Asheville, NC 28803	(828) 213-1025	Mission Hospital	Yes for diagnostics and hearing aids	On-site or phone for all languages; audiologist speaks Spanish
Chapel Hill	UNC Hospitals	6203 Neuroscience Hospital 101 Manning Drive Chapel Hill, NC 27514	(919) 843-4479	UNC Hospitals	Yes for diagnostics and hearing aids	On-site for Spanish & sign language; other languages upon request
Charlotte	Carolinas Rehabilitation	1100 Rhyne Boulevard Charlotte, NC 28203	(704) 355-4430	Levine Children's Hospital	Yes for diagnostics and hearing aids	On-site for Spanish; phone for other languages
Charlotte	Charlotte Eye, Ear, Nose & Throat Associates, P.A.	6035 Fairview Road Charlotte, NC 28210	(704) 295-3300	N/A	Yes for diagnostics	Phone for all languages
Charlotte	Charlotte Eye, Ear, Nose & Throat, PA	8035 Providence Road #220 Charlotte, NC 28277	(704) 752-7575	CMC-Lincoln Edgewater Surgery Center	Yes for diagnostics and hearing aids	Spanish
Charlotte	Presbyterian Rehabilitation Center	125 Baldwin Avenue Suite 100 Charlotte, NC 28204	(704) 384-7434	Presbyterian Hospital Main Campus	Yes for diagnostics and hearing aids	On-site for Spanish, Chinese, Vietnamese & Sign Language; phone & video for all languages

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NC Location	Name of Facility	Address	Telephone	Medical Affiliation For Referral	Accepts Medicaid?	Interpreter Services Available
Cornelius	CMC - Northeast Audiology	1000 NC Gateway Court Cornelius, NC 28031	(704) 461-9100	CMC-Northeast	Yes	On-site for Spanish; phone for other languages
Durham	Duke University Medical Center	200 West Duke Clinic 11 Orange Zone Durham, NC 27710	(919) 684-3839	Duke Children's Hospital	Yes for diagnostics and hearing aids	On-site for Spanish, French and Arabic; phone and sign language
Durham	NC Eye, Ear, Nose and Throat	4102 Rockwell Street Durham, NC 27704	(919) 595-2000	NC Specialty Hospital	Yes	Phone and sign language
Edmon	Otolaryngology Site* Chowan Hospital	211 Virginia Road Edmon, NC 27932	Linda Bowen (252) 916-1492	N/A	Free Service	Interpreter services will be arranged upon request
Elizabeth City	Otolaryngology Site* Albemarle Hospital	1144 N Road St Elizabeth City, NC 27909	Linda Bowen (252) 616-1492	N/A	Free Service	Interpreter services will be arranged upon request
Fayetteville	Cape Fear Valley Health System	1638 Ocean Drive Fayetteville, NC 28404	(910) 433-5480	Cape Fear Valley Health System	Yes for diagnostics and hearing aids	Spanish
Farmington	Winnick Army Medical Center (military only)	2411 Reilly Road Farmington, NC 28730	(910) 907-3347	Winnick Army Medical Center	Yes as necessary to be Case	Phone for all languages
Goldsboro	Eastern ENT, Ear, Nose & Allergy Center, P.A.	2307 Medical Office Plaza Goldsboro, NC 27534	(919) 735-9140 ext. 111	N/A	No	English only
Greensboro	The Women's Hospital of Greensboro	801 Green Valley Road Greensboro, NC 27408	(336) 832-8608	Moore-Cove Hospital	Yes for diagnostics	On-site for Spanish; phone for other languages
Greenville	East Carolina University Speech-Language and Hearing Clinic	School of Allied Health Services 2011 Health Sciences Bldg Room 1110 Greenville, NC 27838	(252) 744-4099	N/A	Yes for diagnostics	On-site through Brandy School of Medicine

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NC Location	Name of Facility	Address	Telephone	Medical Affiliation For Referral	Accepts Medicaid?	Interpreter Services Available
Greenville	Vidant Medical Center	2100 Satterthorn Road Greenville, NC 27835	(252) 847-4448	Vidant Medical Center	Yes for diagnostics and hearing aids	Phone for all languages
Kenansville	Telomatology Site* Duplin General Hospital	401 N. Main Street Kenansville, NC 28349	Jason Gueggenmum (919) 218-6672	N/A	Free Service	Interpreter services will be arranged upon request
Laurinburg	Piedmont Surgical	1705B Borwick Drive Laurinburg, SC/Scotland County Office	(910) 277-6509	None	Yes for diagnostics and hearing aids	On-site for Spanish; phone for other languages
Pembroke	Telomatology Site* Julian T. Pierce Health Center - Robeson Health Care Cooperation	307 East Wardell Dr. Pembroke, NC 28372	Jason Gueggenmum (919) 218-6672	N/A	Free Service	Interpreter services will be arranged upon request
Pinehurst	Piedmont Surgical	5 First Village Drive Pinehurst, NC 28374	(910) 295-0243	None	Yes for diagnostics and hearing aids	On-site for Spanish; phone for other languages
Raleigh	Raleigh Capital Ear, Nose & Throat	4800 Lake Boone Trail Suite 201 Raleigh, NC 27612	(919) 571-8135	None	Yes for diagnostics and hearing aids for small children	Spanish
Raleigh	Wake Med	Andrews Center, 2 nd Fl. 8024 New Bern Avenue Raleigh, NC 27610	(919) 350-7856	Wake Med	Yes for diagnostics and hearing aids	On-site for Spanish; phone for other languages
Rockingham	First Health of Richmond County Piedmont Surgical	809 South Long Drive Rockingham, NC 28379	(910) 295-6831	None	Yes for diagnostics and hearing aids	On-site for Spanish; phone for other languages
Sanford	Piedmont Surgical	1818 Rockingham Drive Sanford, NC 27330	(919) 895-6340	None	Yes for diagnostics and hearing aids	On-site for Spanish; phone for other languages

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NC Location	Name of Facility	Address	Telephone	Medical Affiliation For Referral	Accepts Medicaid?	Interpreter Services Available
Troy	FirstHealth Family Care Center Specialty Care Clinic	522 Allen Street Suite 303 Troy, NC 27371	910-571-5710	None	Yes For diagnostics and hearing aids	On-site for Spanish; phone for other languages
Wilmington	Wilmington Ear, Nose & Throat Associates	2111 Delaney Avenue Wilmington, NC 28403	(910) 762-8754	None	Yes for diagnostics	English only
Windsor	Telomatology Site* Berrie Memorial Hospital	1401 S. King Street Windsor, NC 27981	Terry Cudgip (919) 218-3078	N/A	Free Service	Interpreter services will be arranged upon request
Winston-Salem	Forsyth Medical Center Dept. of Audiology	3133 Silas Creek Blvd. Winston-Salem, NC 27103	(336) 718-5780	Forsyth Medical Center	Yes for diagnostics and hearing aids	On-site for Spanish; phone & video for other languages
Winston-Salem	Wake Forest Baptist Health Dept. of Audiology	Medical Center Boulevard Janney Tower 4 th Floor Winston-Salem, NC 27157	(336) 716-3103	Wake Forest Baptist Health (Bremer Children's Hospital)	Yes for diagnostics and hearing aids	On-site for Spanish; phone for other languages

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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.

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Birth-Age 3 Referrals

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

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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.

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Child Health Speech/Language Consultants
North Carolina Division of Public Health

Region	Office Name	Address	Phone	Fax	Cell
1	Sanity Bechtel	1000 S. Salisbury St. Salisbury, NC 28133	(704) 662-1022	(704) 662-1022	(910) 717-3221
2	Marjorie Moore	1000 S. Salisbury St. Salisbury, NC 28133	(803) 474-0800	(803) 474-0800	(803) 224-0600
3	Stephanie Tucker	1000 S. Salisbury St. Salisbury, NC 28133	(336) 748-0200	(336) 748-0200	(336) 81-2-1-18
4	Terry Cudgip	1000 S. Salisbury St. Salisbury, NC 28133	(919) 218-3077	(919) 218-3078	(919) 218-3078
5	Alison Gueggenmum	1000 S. Salisbury St. Salisbury, NC 28133	(919) 218-3077	(919) 218-3078	(919) 218-6672
6	Linda Roberts	1000 S. Salisbury St. Salisbury, NC 28133	(252) 743-0300	(252) 743-0300	(252) 619-1482

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**Child Health Audiology Consultants
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Any Questions???

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Additional Video Clips (if time allows)

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Thank you!

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