Coordinated Referral Process for Intervention for Children of All Ages

Marcia Fort, AuD, Program Development & Evaluation Manager, NC EHDI Program

Mandy Hice, BSW, Intake Coordinator, NC Early Intervention for Children Who are Deaf or Hard of Hearing
About North Carolina

2009 Data

- Population 9,382,609
- Live Births = 128,180
- Children Identified with Hearing Loss = 201

*2009 data NC State Center for Health Statistics – Selected Vital Statistics Volume 1
EHDI in North Carolina

- **1999 Legislative Mandate**
  - Newborn Hearing Screening
    - All birthing facilities must screen for hearing loss
    - Physicians should insure screening for hearing loss by 30 days of age
  - Reporting Requirements
    - Screening results: birth to 6 months of age
    - Diagnostic/Amplification results: birth to 1 year of age

- Multiple intervention/support options
Services for Children Who are Deaf or Hard of Hearing and Their Families

- Part C-Children’s Developmental Services Agencies
- Early Intervention Program for Children Who Are Deaf or Hard of Hearing
- BEGINNINGS For Parents Of Children Who Are Deaf or Hard of Hearing
  - Child Health Audiology Consultants
  - Child Health Speech Consultants
- 115 Local Education Agencies
Who Does What?......When?......How?

Pediatric Audiologist
Before Coordinated Referral

Part C
North Carolina Infant-Toddler Program

- Two page referral form
- Eighteen different offices
- Each office had different intake procedures
- Service Coordinators unfamiliar with other available services/referrals
Before Coordinated Referral

Early Intervention for Children Who are Deaf or Hard of Hearing (EIDHH)

- Phone call for referral
- Three regional offices
- Counties covered by each office changed
Before Coordinated Referral

BEGINNINGS for Parents of Children Who are Deaf or Hard of Hearing

- Two offices (Raleigh and Charlotte)
- Two different referral forms
- Counties covered by each office changed with staff changes
- Required audiological report prior to contacting family
How could we get from.......
How could we get from.......
How could we get from...... to
Collaboration

Involve all stakeholders (including older children)

Eliminate/reduce duplication of effort

Reduce paperwork

Communicate regularly about children, families and services

Capitalize on the expertise of each agency
Question: How can we reduce paperwork and duplication of effort?

- Pediatric audiologists have difficulty keeping up with the particular rules/regulations/changes of each intervention service.
- Each service/agency has its own “referral package” - some lengthy and time-consuming.
  - Parents easily confused by similar, yet different, services available.
- Each agency is best able to describe their own services to families.
- Reducing the number of home visits to initiate services.
Communication is Key!

Quarterly face-to-face meetings

BEGINNINGS’ Bi-Weekly Logs

Hearing Link

ONE Referral Form for All!
Permission for Referral

- One set of paperwork for audiologist
- Obtain parent signature
- Get copy of audiological report
- Simultaneous referral with complete information
- Each agency explains their own service to family in detail
North Carolina has several agencies that assist children with diagnosed hearing loss and their families. Each individual agency can best explain the details of the services they offer and answer questions for you as you make informed choices about accepting or declining services for your child. You have the right to accept or decline any of the services at any time. The signed Permission for Referral must be on file in order for these agencies to contact your family.

The agencies you accept will contact you to tell you more about their services. Please indicate below if you accept or decline the referral to each agency:

<table>
<thead>
<tr>
<th>Child’s Age - Birth to 3 years</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ BEGINNINGS for Parents of Children Who are Deaf/Hard of Hearing</td>
<td>☐ ACCEPT or ☐ DECLINE</td>
<td>☐ ACCEPT or ☐ DECLINE</td>
</tr>
<tr>
<td>☐ Infant Toddler Program-Children’s Developmental Services Agency</td>
<td>☐ ACCEPT or ☐ DECLINE</td>
<td></td>
</tr>
<tr>
<td>☐ Early Intervention for Children Who are Deaf/Hard of Hearing</td>
<td>☐ ACCEPT or ☐ DECLINE</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Child’s Age – 3 years through 21 years</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Beginnings for Parents of Children Who are Deaf/Hard of Hearing</td>
<td>☐ ACCEPT or ☐ DECLINE</td>
<td></td>
</tr>
<tr>
<td>☐ Department of Public Instruction (Public Schools)</td>
<td>☐ ACCEPT or ☐ DECLINE</td>
<td></td>
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</tbody>
</table>
I hereby authorize ______________________ to release audiological evaluation results and contact (Audiologist/Audiology Facility) information to the North Carolina Division of Public Health for the purpose of completing referrals to the agencies accepted above. I further authorize ______________________ to release audiological results upon request to the agencies accepted above for the purpose of assisting the agency to understand my child’s hearing loss.

I understand the terms of this release, the need for the information, and that there are statutes and regulations protecting the confidentiality of the information. I acknowledge that this consent is voluntary and is valid until such request is fulfilled. I further understand that I may revoke my consent by giving written notice to the agency with authority to release the information, except to the extent that action based on this consent has already been taken.

______________________________
Witness

______________________________
Patient, Parent, or Legally Appointed Representative

______________________________
Date Signed

Language Spoken in Home: ______________________

______________________________
Mother’s (Parent’s or Guardian’s) Printed Name

Phone: ______________________

______________________________
Address

Alternate Phone: ______________________

______________________________
City, State, Zip

FAX a copy of the completed form AND audiological report to:
Marcia Fort, AuD
North Carolina Division of Public Health
(919) 870-4881

Revised 10/09
Hearing Link

- Web-based, real-time reporting of results
- Tracking children through screen-rescreen-diagnosis-service system
- Move children and families into services as quickly as possible following diagnosis - simultaneous referrals to all services/agencies (including children over age 3)
- Reduce/eliminate duplication of information
- Include intervention providers
Hearing Link – Data Uses

• Reporting

• Up-to-date demographic information - shared between all service providers

• Pediatric audiologists can monitor status of child in EHDI process; enhance counseling if family could benefit from service, but not enrolled

• Identify service gaps
How the Process Works

- Audiologist completes evaluation and has family sign Permission for Referral at diagnostic appointment
- Audiologist reports diagnostic result in Hearing Link and faxes referral form and audiological report to DPH
- DPH prepares secure PDF files and researches which location (city vs. county schools, correct county of residence) needs to receive information
- DPH emails referral and report to all agencies
Advantages of Coordinated Referral

- Increased communication between agencies serving deaf/hard of hearing children and their families
- Email communication more timely than phone calls
- Less chance of child receiving services from one agency and the other agencies not knowing about the child
- All agencies get referral at the same time
- Services not delayed waiting for copy of audiological evaluation
- Agencies brought together as “Partners”
Working as Partners

- Joint home visits
- Services compliment each other
- Establishing communication between “clinical” audiologist and service providers/educational audiologists
- Improved reporting of diagnostic results to EHDI Program, including late onset/progressive hearing loss
- Public Schools feel like part of the “team”
- Updating demographic information
“Hearing Link has brought North Carolina’s Early Intervention services for children who are deaf or hard of hearing into a more seamless system of referral....Parents have given prior consent for early intervention services when we receive the Hearing Link information. This allows our teachers to contact the families immediately and get started.”

Ruth Anne Everett, Director
Early Intervention Program for Children
Who Are Deaf or Hard of Hearing
“The Hearing Link Referral system is a great way to keep the referring audiologist informed about the babies that need further testing. By knowing the date, time and location of the referral, we now have the information needed to track our babies more efficiently and to decrease the number of babies that are lost to follow-up.”

Shawn Vansteen
Audiologist/Newborn Hearing Screening Coordinator
Wake Med Hospital Raleigh
“This process seems to be working well. The CDSA staff are very grateful for the audiology information, reports, etc. It has been very helpful to be given this referral information through one “single portal”, in order to better ensure those children and families are linked with our program.”

Stephen Vater
Quality Improvement Unit
DHHS/DPH - Early Intervention (Part C) Branch
“It is ALWAYS helpful and necessary to have current audiological information on our students. I love your electronic system of e-mailing the information to us! This allows me to quickly locate the child in our system and get the information to the audiologist serving the student. It also gives us the contact information on the specific provider AND the release so that we can continue to communicate with the private provider on behalf of the student/family.

The only thing I have wanted to do is this….we need access to the Newborn Hearing Screening Data Base so that when we newly identify a child with a loss (and the family reports having had a newborn hearing screening), we could go to the DB and view results to get information as to the progressive nature of the loss or not. If you could help facilitate this for school districts it would be a Wonderful Thing!!”

Danita Sullivan
Lead Audiologist
Wake County Public School System
Challenges

- Making sure parents understand that they will be contacted by more than one person and know what they’re signing
- Services may contact families before the parent(s) have time to bond with their baby
- Referral may be received before baby discharged from NICU
- Deceased babies
- Need for more pediatric audiologists
- Mobile families (move before contact can be made)
- Children are staying in intervention services for longer periods of time due to the lower age of enrollment
  - Need for more teachers
  - Larger caseloads per teacher
Automating the Process – Presents Its Own Challenges

- City/Town crosses county line(s)
- Determination of city vs. county school system
- Changing regions for various service providers
- How to insure that we know a child may not have been discharged from hospital at the time referral is made
- Deceased babies (vital records data not real time)
Improvements on Horizon

- Intervention “module” being added to Hearing Link
  - Allow for direct, web-based data entry for
    - Date of Referral
    - Eligibility
    - Date of Enrollment
    - Date of Withdrawal
    - IFSP date
    - Outcome Data (to be determined)
    - Tracking/Surveillance activities by EHDI Program staff
Permission Form available @

www.ncnewbornhearing.org

Marcia.Fort@dhhs.nc.gov

Mandy.Hice@dhhs.nc.gov