



**Challenges in Infant
Diagnostic Hearing
Evaluation:
The Parent Perspective**

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Presentation Objectives:

- JCIH 2007 recommendations
- Early hearing detection and intervention statistics
- Newborn hearing screening to diagnostic evaluation
- Parent survey on infant hearing testing
- Conclusion - where do we go from here?



JCIH 2007 Recommendations

Just In Time

So your baby's care is right on time

Early Hearing Detection and Intervention

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- 1** Before **ONE** Month of Age: Hearing Screening
 - 3** Before **THREE** Months of Age: Hearing Evaluation
 - 6** Before **SIX** Months of Age: Early Intervention



Early Hearing Detection and Intervention Statistics

- Currently, there are 43 states and territories that mandate NHS (National Center for Hearing Assessment & Management (NCHAM), 2009).
- Center for Disease Control and Prevention (CDC) Early Hearing Detection and Intervention (EHDI) Hearing Screening and Follow-up Survey (HSFS) 2007 reported 94% of newborns were screened.
- 45% of newborns, who had failed a final screen, either did not receive a diagnostic evaluation or the results were not reported
- 30% of infants referred for EI either were not enrolled in a program or the enrollment was not documented



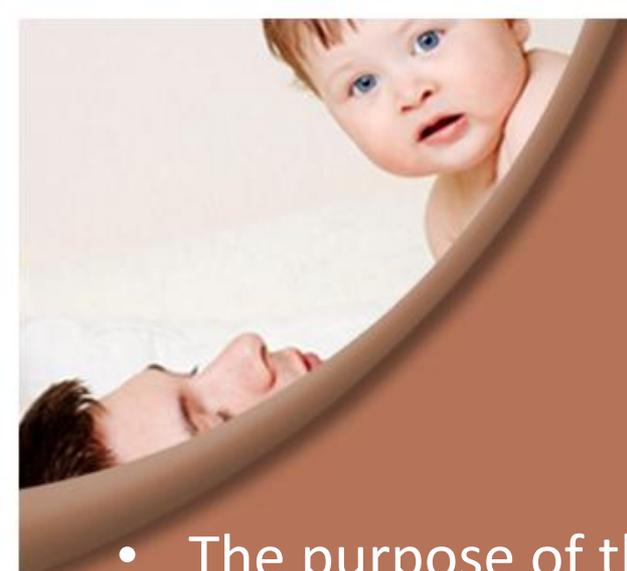
Newborn Hearing Screening To Diagnostic Evaluation

Factors that impact a timely diagnosis

- Hospital protocols for explaining the results and referral for diagnostic testing
- Pediatricians and primary care physicians
 - Typically the first healthcare provider contacted when there is a concern
 - Knowledge and support for NHS, diagnostic testing and early intervention
- Infant diagnostic hearing service facilities
 - Comprehensive test battery
 - Wait time for a diagnostic appointment

Family Survey on Infant Hearing Testing

- The purpose of the study was to investigate the diagnostic process of infant hearing evaluation, from the parent perspective, and to identify the challenges families are facing in accessing appropriate services.





Family Survey on Infant Hearing Testing

- Total surveys received: 416 from 43 states
- Responses represent children born between 1979 to 2009
- The data was organized by age groups to identify trends in experiences across time
 - Group 1: (n=78) children born prior to 1999, represented a period of time when NHS was not part of routine practice
 - Group 2: (n=170) children born between 1999 and 2005, represented a period of time when NHS was rapidly being implemented throughout the US
 - Group 3: (n=168) children born between 2006 and 2009, represented a period of time when NHS had been implemented for a few years and should be representative of current practices



Timeliness of Diagnosis

Average age of diagnosis for Group 3 (2006-2009): 4.59 months compared to 10.27 and 14.21 for the two earlier groups

“I’m really grateful for the Newborn hearing screening, because of that we found out early about our child’s hearing loss...(2008).





Obtaining the Diagnostic Evaluation

- Referral source:
 - Nurse scheduled: 36%
 - Physician advised: 23%
 - Given a list: 13%
 - No information: 9%
 - Other sources: 17%





Parents Want Information!

“There should be some form of guide for the parents of baby who failed the screening outlining steps to fitting of hearing aids and regular testing afterwards. More resources should be provided in explaining the steps of the whole process so that the parents know what to expect instead of not knowing until the next appointment” (2009).



Obtaining the Diagnostic Evaluation

- Type of facility where parents obtained diagnostic services:
 - Hospitals: 68%
 - ENT Office: 13%
 - Audiology Private Practice: 10%
 - University: 7%
 - Other: 2%
- Wait time for an appointment:
 - 1 to 30 days: 51%
 - More than 30 days: 32%
- Number of appointments needed to confirm hearing loss:
 - Two or more: 57%

A circular inset image in the top-left corner shows a baby with blue eyes looking towards the camera, and a woman's face is partially visible below the baby, looking down.

Testing Needed ASAP!

“The diagnostic hearing testing process was not good....The test was done in a noisy environment, and it was very difficult to get an appointment” (2009).

“The availability of appointment and scheduling should have been done sooner” (2007).

“The hospital our child was born at could not give us direct answers on the results of the newborn screening. After the follow-up screening they referred us to their own audiologist, who did not have appointments available for some time. As a result we were forced to go and find help on our own. We tracked down a fantastic program at the Children’s Hospital...” (2008).



Parent Identified Challenges in Obtaining Testing

- Top five most common challenges:
 - Delay in appointment
 - Noisy test results
 - Other health issues
 - Distance
 - Fluid in the ears



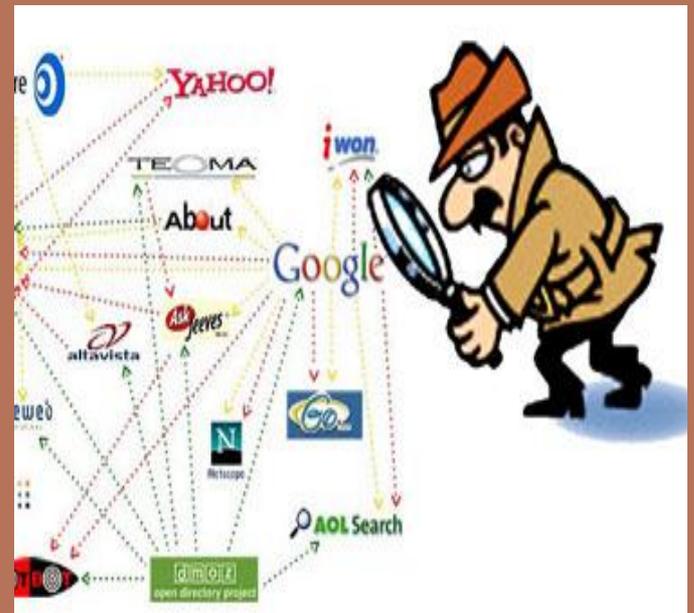
Testing Conditions

- Parents given an option for testing: 40-50%
- Auditory Brainstem Response (ABR) testing preference:
 - Natural Sleep: 80%
 - Sedation: 14%
 - Operating Room: 2%



Information Received at the Time of Diagnosis

- Degree of hearing loss: 94%
- Hearing aids: 55%
- Early intervention: 64%
- Medical referral: 45%
- Parent support: 38%
- Resources on hearing loss: 52%





Parent's Level of Comfort in What to do Next

- “After talking with the audiologist at the time the hearing loss was diagnosed I was comfortable with what I needed to do next for my child”:
 - Strongly agree: 29%
 - Agree: 44%
 - Disagree: 14%
 - Strongly disagree: 13%





Comments from Parents

Theme 1: Professionals (doctors, audiologists, nurses, technicians, etc.) need to be well trained in pediatric audiology, knowledgeable about diagnostic procedures and resources, and sensitive to parents concerns: 25% of parents expressed this concern.

“The first audiologist told us our baby had unilateral hearing loss and that there was nothing else for us to do. The second audiologist looked at the report and thought the results that were given didn’t match the test so our baby was retested and found to have bilateral hearing loss and now wears hearing aids. We lost about 4 months that our baby could have been aided” (2009).

“... It seemed like the doctors (ENT, PED, and AUD) didn’t want to diagnose her loss. Tubes were inserted at 4months and hearing retested by an unqualified audiologist. He was not equipped to test children. I think there should be a special designation for Pediatric Audiologists...” (2006).



Comments from Parents

Theme 2: Positive experience: 21% of parents reported a positive experience throughout the NHS and diagnostic process.

“We were fortunate to have a lot of support from our local hospital/physician & audiologist in getting our appointments scheduled in a timely manner. They were extremely helpful in getting resources to us & providing us with everything they could to get us what we needed...” (2008).

“Testing and diagnosis went as smoothly as possible. Our son had aids at exactly 2 months of age and immediately started speech therapy. Our audiologist specializes in pediatrics and she has been outstanding” (2008).

“After his diagnosis, I was given a notebook that Seattle Children’s Hospital put together. It answered all the “frequently asked questions” it had resources and plenty of hearing loss information. ..” (2008).



Comments from Parents

Theme 3: Lack of information or biased/wrong information given to parents: 21% of parents expressed concern over this issue.

“It was a very isolating experience. We were provided with no resources or support from our audiologist. In fact we found out our child’s hearing loss from the early intervention person before the official results from the doctor came in...” (2009).

“...We were not given adequate information on what to do next. It was very frustrating knowing that something was wrong, but not having any information as to where to go...(2008).

“We need an audiogram to take home so we understand what our child can hear. We had no clue what moderate to severe meant...” (2006).

“Include discussion about learning ASL & Deaf Culture...” (2007).



Comments from Parents

Theme 4: Counseling/communication with parents: 21% parents expressed concerns with communication.

“There needs to be a supportive and knowledgeable person who reports the screening “failure” to parents. Parents need to feel they are not alone” (2008).

“We needed a supportive, understanding, compassionate individual at this time and instead we were simply given the results and told to not miss the follow-up audiology appointment” (2008).

“... we were preparing to take her home from the NICU and I happened to ask the infectious disease doctor handling her care if she passed and was told no, she is deaf...” (2007).



Comments from Parents

Theme 5: Better training and more education for NHS/NICU personnel: 18% of parents suggest more training is needed for NHS personnel.

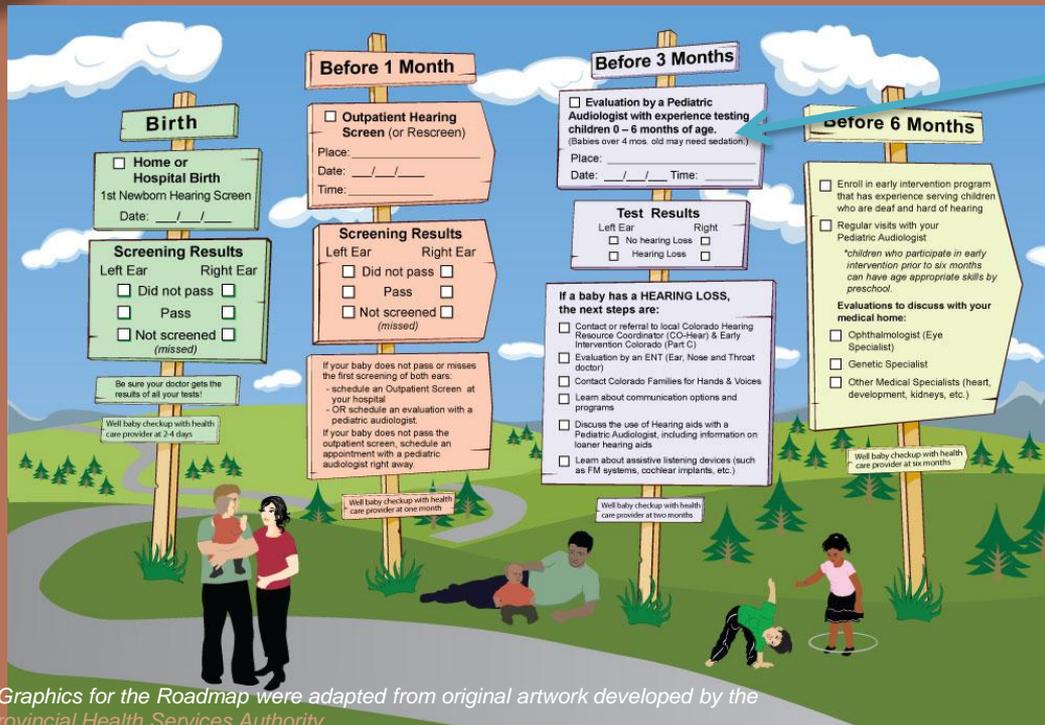
“When my child was screened at the hospital she underwent the process three times. On the third date, the attending nurse gave alarming and vague information that created anxiety for my family. I was told that my child would "hear some" after "the surgery"...(2009).

“I felt that the hospital newborn screening program was quite flawed. On the day of my discharge the tech who did the newborn screen gave me a pamphlet saying that my son failed the newborn screen...I really think an audiologist and not a tech should give the information so people can have their questions answered ...”(2006).

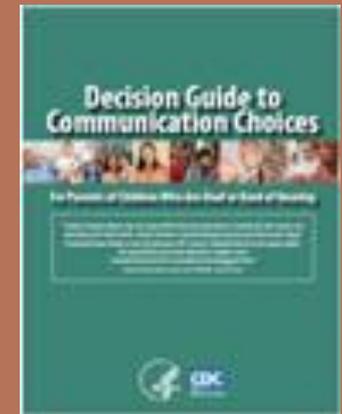
The 'system' responds to families....

The Colorado Road Map

"To Sedate or Not: Parents Right to Informed Consent"



Questions to Ask your Audiologist (CDC)



* Graphics for the Roadmap were adapted from original artwork developed by the Provincial Health Services Authority.

The Challenge: Making sure families get to the resources that exist!!

Where do we go from here?

- Infants are being identified at an earlier age!
- NHS Protocols: referral to a qualified pediatric audiologist
- More comprehensive testing facilities needed
- Parents need accurate and unbiased information



Conclusion

The information learned from the parent perspective reminds us of their important role as a member of the team. In a fast paced practice, the diagnostic process can easily become a practice-centered process rather than a family-centered process. Professionals in NHS programs, diagnostic centers and early intervention programs can use this information to improve and develop services that are family-centered.

