Early Hearing Detection and Intervention: Increasing Responsiveness to Hearing Referrals

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National Joint Commission on Infant Hearing (JCIH) Members

- American Academy of Pediatricians, (AAP)
- American Academy of Audiology, (AAA)
- American Academy of Otolaryngology-Head and Neck Surgery (AAO-HNSF)
- American Speech-Language Hearing Association (ASHA)
- Center for Disease Control and Prevention (CDC),
- Council of Education of the Deaf, (CED)
- Directors of Speech and Hearing Programs in State Health and Welfare Agencies (DSHPSHWA)
- Maternal and Child Health Bureau, (HRSA, MCHB)
- National Institute on Deafness and Other Communication Disorders (NIDCD,) National Institutes of Health,
- Boys Town National Research Hospital
EHDI Goals/JCIH Goals

01

**JCIH 1** All infants will receive a hearing screening before 1 month of age

02

**JCIH 3** Infants not passing the screening will receive appropriate audiologic and medical evaluation before 3 months of age

03

**JCIH 6** All infants identified as deaf or hard of hearing will begin receiving early intervention services before 6 months of age
Research Questions

1. When an infant is referred on to an audiologist (i.e., doesn’t pass the final hearing screening) how is that referral managed?
2. If no appointment was made or kept, why not?
3. Was the diagnosis explained to the parent?
4. Were treatment options offered?
5. Was a referral made to a state-sponsored early intervention and/or to a family navigator? Were these services useful?
6. Were non-state sponsored therapy services engaged?
EHDI Survey Project Stages

Planning & Research Design

Interviewer Recruitment, Orientation, Training

Data Collection

Report/Presentations
Sample Population

• Participants were parents of infants who were referred on for follow-up hearing screening, but whose infants did not receive:
  – follow-up screening
  – diagnostic testing
  – early intervention, or
  – were later in receiving follow-up (later) than is recommended in the JCIH (Joint Commission on Infant Hearing)
Demographics and Response Rate

- 45% response rate (96 in the sample and 43 responded)
- 70% of participants had Medicaid or Denali KidCare insurance
- Only three infants received a permanent hearing loss diagnosis
Parent/Interviewer Perspective

• Engagement with Families
• Qualitative Data - Comments
• Resource referrals
• Other
Key Findings
Research Question One

When an infant is referred on to an audiologist how is that referral managed?
Referrals

79% (n=34) referred to audiologist

Of those referred, 73% (n=25) made appointments

Of those who made appointments with the audiologist

29% (n=7) Appointment scheduled by facility of first screening
20% (n=5) Scheduled appointment themselves
37% (n=9) Audiology clinic called participant to schedule
13% (n=3) Had not yet seen the audiologist
Diagnosis Explained

All participants \((n=3)\), whose child had any type of permanent hearing loss, strongly agreed that the audiologist did a good job explaining the diagnosis of hearing loss.
Research Question Two

If no appointment was made or kept, why not?
Reasons appointment were missed (n=15)

- Did not think the infant need to go  n=11
- Did not have time to attend an appointment  n=4
- Could not find a time that worked in their schedule  n=3
- Could not afford the time/money to travel to an appointment outside of community  n=3
- Could not afford the appointment  n=2
- Another reason they could not make or attend  n=1
Reasons participants gave for not scheduling or attending appointments…

• “I had to reschedule the appointment, haven't seen audiologist yet.”

• “Medicaid travel was denied.”

• “Hard to make time to go with other kids. I will go just haven’t had the time.”
Reasons participants did not scheduling or attending appointments…(continued)

- A participant who had not yet gone to the audiology appointment…
- “…not too concerned about it because it was done within 24 hours of birth and nurses said it was common.”
Reasons participants gave for not scheduling or attending appointments......

• “Responded with normal hearing; I didn't think my infant needed it.”

• “Waiting to see what the ENT says.”

• “Was difficult to make it into the clinic.”

• “Rescheduled for January.”
Participant perspective on the referral process

“A little bit more information as far as what the process will be with the referral. They just assume that things will be explained in the next step. If parents are more informed, parent[s] will be more willing.”
Participant Comments

• A participant was not sure if the child “needed to go because he sounded like he had hearing.”

• A participant did not have insurance but received a referral for an appointment but nobody contacted him/her. This participant did receive a letter from EHDI and discussed hearing screening with a doctor.
Things to Consider and Discuss…

• Note that 70% of respondents used Medicaid or Denali KidCare. EHDI plans to target education to this population of parents; posters from ANMC. Parent self-advocates attending ECHO Training.

• 14 of the 17 referred who did not make appointments, discussed the results with their medical providers. EHDI has plan for further educate of medical providers (AAP, ALPHA)
Dissemination

• Healthcare providers
  – Jen Soble, Alaska American Academy of Pediatric, 12/19/2019
• Statewide
  – Alaska Health Summit (Alaska Public Health Association) January 23, 2020
• National
  – EHDI Conference, (March 8, 2020)
  – CDC ECHO
• Parents – education outreach efforts
• EHDI Advisory Committee – Presented to Early Intervention Committee, Governor’s Council to become automatically eligible for EI services (sensory loss)
FY 2020 Survey

• Additional or Refined Questions:
  – Demographics (rural, remote, urban)
  – Affordability (travel vs. appointment costs)

• Sample
  – Including those who received a diagnosis

• Connection between hearing and language acquisition
Contact Information

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