Critical Communication Touchpoints in the Journey to Diagnosis:

Multi-Disciplinary Communication Breakdowns that Negatively Impact Families

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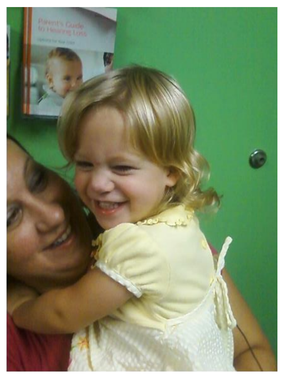
Rationale

From the moment an infant does not pass the universal newborn hearing screen, the family embarks on a journey of which most are extremely unfamiliar. How difficult their journey is depends largely on the specific professionals they come in contact with along the way. Families face uncertainty, questions, anxiety and fear. In order for infants to receive timely and appropriate follow up, diagnosis, and intervention, parents need clear and concise guidance and direction.

This poster highlights the story of Lydia and her family. Lydia's mom shares the challenges, uncertainties, and lack of direction experienced during the first two years of her life. Despite referring on the newborn hearing screen prior to discharge from the hospital, Lydia's diagnosis of bilateral, profound sensorineural hearing loss was not confirmed until the age of 14 months. This story identifies multiple touch points along the way where lack of clear communication, or even miscommunication, resulted in ongoing delays, as well as confusion and anxiety for the parents. Fortunately, given Lydia's parents' persistence and advocacy for their child, they eventually were able to get answers to their questions, obtain necessary services for Lydia, and successfully move forward in their journey – despite the late identification.

Background

- ❑ Fourth of Six Children
- ❑ Full-term – normal delivery – discharged after 48 hours
- ❑ No admission to NICU
- ❑ No Family History of Hearing Loss
- ❑ No Risk Factors
- ❑ No History of Middle Ear Issues or Ear Infections
- ❑ PE tubes placed as a "precaution"



Communication Timeline

Initial Screen

- **Referred in both ears**
- Communication Remembered:
  - **"It's probably fluid."**
  - **"Everything is probably fine."**
  - **"Our equipment isn't the best here."**

1st Follow-Up

- First **Follow-Up** – **No Results Obtained**
- Communication Remembered:
  - **"Your baby is too fussy."**
  - **"Do not bring your other children next time."**
  - **"We need to reschedule."**

2nd Follow-Up

- Second Follow-Up – **No Results Obtained**
- Communication Remembered:
  - **"We have a scheduling conflict."**
  - **"We do not have enough time to complete testing."**
  - **"We need to reschedule."**

Pediatrician Visit

- Usually saw a Nurse Practitioner but parent decided to make an appointment with a Pediatrician
- Pediatrician recommended referral to ENT for diagnostic ABR
- Parent report:
  - **"Until then, I felt like everyone was grasping at straws. This physician said we won't rule anything out, but let's start with hearing."**

3rd Follow-Up

- Third Follow-Up – **No Diagnosis Obtained**
- Communication Remembered:
  - **"Hm. Maybe something is wrong."**
  - **"I think you should see a Pediatric Audiologist."**

Diagnostic ABR

- **Sedated ABR completed when Lydia was 14 months old**
- ENT reported Audiologist would have to review the results
- ENT said to come back in two weeks

Confirmed HL

- Parent reported ENT did not explain the results clearly. **"I felt like he just didn't want to come out and say it."**
- Communication Remembered:
  - There was no response
  - She cannot hear at 105dB
- Parent report: **"All I know was in that office, during that appointment, it was not communicated that <u>hearing loss was *not* the end of the world</u>. I did not feel any support."**

New Audiologist

- We got another referral and went to a different Audiologist
- Parent Report:
  - **"The Audiologist explained Lydia was profoundly deaf in both ears."**
  - **"She explained the difference between hearing aids and cochlear implants."**
  - **"She sped everything up so she could receive cochlear implants and begin receiving language as soon as possible."**

Cochlear Implants

- **Lydia's first implant was activated on her second birthday** – 2 weeks after implantation
- Parent report:
  - Lydia cried the scariest cry I've ever heard
  - **"The Audiologist reassured me that this would be very hard but I trusted her, and I still trust her."**
  - **"She taught me what I needed to do, when I needed to do it, and how I needed to do it."**

Opportunities for Improvement

❑ **Hospital**

- ❑ Family should be counseled regarding the screening results
- ❑ Although a follow-up appointment was provided, instructions should be given regarding appointment details, including who to contact with questions
- ❑ Rather than giving excuses as to why baby did not pass, hospital staff should explain the importance of follow-up

❑ **Medical Home**

- ❑ Whether family chooses to see a Pediatrician or Nurse Practitioner, the Medical Home should verify results of Newborn Hearing Screen and assist family with needed follow-up
- ❑ Medical Home should assess communication milestones at every appointment, and refer for follow-up if milestones are not being met and/or child has risk factors for delayed onset hearing loss

❑ **Audiologist/ENT**

- ❑ Families should be given instructions on what to expect, including length of appointment and preparing baby for optimal testing – can be done by phone call or letter mailed to the family
- ❑ Enough time should be scheduled to complete all needed testing
- ❑ If there is a scheduling conflict, the family should be prioritized and rescheduled as soon as possible
- ❑ Audiologists not equipped to diagnose pediatric hearing loss should refer family to a pediatric audiologist immediately rather than continue to test with inconclusive results, further delaying appropriate follow up
- ❑ Diagnosing Audiologist should be prepared to counsel families effectively and answer the hard questions – this should include implications of the hearing loss, amplification and communication options, and next steps
- ❑ Educate, re-educate, and confirm understanding

Conclusions

This story emphasizes the overall concern that this is not an isolated case and many other families have similar experiences, in which 1-3-6 Goals were not met.

The purpose of this session is to highlight the importance of clear communication from all professionals along the way; from the hospital screening staff, to the medical home, and the audiology and otology providers involved with infants requiring follow up.

Increasing awareness of communication breakdown at each critical touchpoint will hopefully help all professionals involved with early intervention learn from the experience of this family, so that future families may have an easier journey to diagnosis.