

Barriers to Timely Follow-Up From New Jersey's Early Hearing Detection and Intervention Program

Wendy Zeitlin, PhD, MSW¹; Maryrose McInerney, PhD¹; Pamela Aasen²

¹Montclair State University, Montclair, NJ; ²New Jersey Department of Health, Trenton, NJ



SCAN ME

Purpose

Unless addressed early, young children with hearing loss are at-risk for delays in language, social, and educational attainment. In response, Early Hearing Detection and Intervention (EHDI) programs have been instituted in every state to identify the 0.2-0.3% of newborns born each year with hearing loss. EHDI programs are designed to screen all babies for hearing loss by 1 month of age, diagnose those with hearing loss by 3 months of age, and initiate treatment by 6 months of age to mitigate developmental risks (i.e., "The 1-3-6 Plan")(JCIH, 2019).

Currently, 97% of newborns in the U.S. and 98.7% of newborns in New Jersey receive initial hearing screenings, most often in birthing facilities. Being late or lost to follow-up (LTF) is, however, a well-recognized problem for infants who do not pass initial screenings. New Jersey is no exception. For example, in 2020, nationally 29.3% of newborns who did not pass their initial screenings were LTF and only 36.4% were diagnosed (including diagnoses of normal hearing) by 3 months of age. The LTF rate in NJ during this same time was 56.3%, and only 14.4% were diagnosed by 3 months of age (including diagnoses of normal hearing) (CDC, 2023).

Previous research in NJ has identified a constellation of maternal factors that are indicative of being late or LTF. These factors include being Black, having lower levels of education, not possessing health insurance, and young maternal age. Additional risk factors include indicators of maternal postpartum depression and maternal obesity (Zeitlin et al., 2021a; Zeitlin et al., 2021b). While it was possible to build a risk profile identifying who is at risk for not following up in a timely manner, however, the reasons for this are unclear.

The current study sought to address this problem by posing the following question:

What barriers exist to follow-up for those most at-risk?

Methodology

Qualitative design using thematic analysis (Braun & Clarke, 2006)

In-depth interviews with parents who possessed one or more characteristics associated with not following up on time (N=26)

\$25 gift cards were provided as incentives

Recruitment through a variety of sources:

- Social media
- WIC participants in the state
- Head Start families in NJ

To qualify for participation, parents had to:

- Have a child born in NJ in the previous 5 years
- Have been told at the birthing facility that the infant needed additional hearing testing to be completed after discharge
- Follow-up was NOT necessary
- Child did NOT need to have a hearing loss

Methodology (continued)

Characteristics of the sample can be found below:

Characteristic	N	%
Race/Ethnicity		
White, non-Hispanic	5	19.23
Black, non-Hispanic	14	53.85
Hispanic	5	19.23
Other - multi-racial	2	7.69
Education		
HS/GED	4	15.38
Some college	14	53.85
BA/BS	7	26.92
Post-graduate degree	1	3.85
WIC participation		
Yes	20	76.92
No	6	23.07
Child has a dx of hearing loss		
Yes	10	38.46
No	16	61.54

Analytic strategy:

1. Transcripts and video recordings for first 8 interviews were independently open-coded by research team (audiologist, social worker, AuD student)
2. Discussion of initial codes; discrepancies resolved and initial development of thematic map
3. Focused codes developed based on initial open-coding
4. Remainder of transcripts independently coded based on focused codes; new codes identified
5. Research team consolidated findings and finalized thematic map

Results

Two major themes and several sub-themes emerged from the data:

1. **Parents do not consider the possibility of hearing loss during the screening process**
2. **Parents need clearer and more in-depth information**
 - Parents rely heavily on professional advice
 - Parents receive confusing advice
 - Parents seek information on their own, especially when they are worried

Results (continued)

Theme 1: Parents do not consider the possibility of hearing loss during the screening process

During screening, parents are not told that their newborn failed the screen; rather they are told that they "referred" for additional screening. Screeners and medical professionals reassured parents that this is common and they should not be concerned.

"The most thing [the hospital staff] said was that it was normal. It was kind of normal because maybe it was still like afterbirth in his ear or water or something. So that's why I guess they didn't really make it a big thing." (Participant 28)

"[The pediatrician] said that it was pretty normal in babies. That sometimes it would just go away in a couple of months, and I was leaning more towards that because it's like she is a doctor. She does know more than I do." (Participant 67)

Parents associated this idea with not following up unless they saw a problem themselves (and then they were shocked by a hearing loss diagnosis).

Theme 2: Parents need clearer and more in-depth information

Although all parents are provided written and oral information in the birthing center, parents often do not remember receiving it or they don't find it helpful.

"They did give me a paper explaining...to tell where I could go to get his further testing and, like, the phone numbers to call for them, but that was pretty much it. I don't remember them explaining it." (Participant 62)

As a result...

1. **Parents rely heavily on professional advice**

Parents do not typically have experience with hearing loss so they often turn to others, especially healthcare providers

"So, one of the NICU nurses stayed in contact with me and they was letting me know like, make sure you take her. Go to your appointments. If you can't, just call and try to reschedule. So they was really like calling me and stuff. It's like, look, make sure you get her there." (Participant 68)

2. **But, parents receive confusing advice**

"I think it [screening results] could have been explained in more of layman's terms so that way, I could have understood more." (Participant 3)

"So some of this information was in medical terms that you know are not really very understandable for people who are not in the medical line." (Participant 26)

3. **So, parents seek information on their own, especially when they are worried**

Parents frequently turned to social media or the internet when they were confused or worried.

"I mean, I wish they had documentation. You know something I could read. I mean, I did a lot of it. I was researching a lot of it at home through Google. Just to kind of get an understanding of the process...They'll give you paperwork for the types of shots and what they're for, and I wish they had paperwork like that, too, that I could have seen [for my child's hearing testing]."

Discussion

Inadequate messaging and deficient communication from professionals are likely related to being late or LTF:

Conflicting messaging

While families understood that their babies needed additional screening/testing, many were not aware that their babies failed the birth center screen. These same families were also told that it was unlikely that their babies had hearing loss. Some parents specifically noted that this was a reason for not following up:

"They didn't think it was an issue and ...we would could just test him later on if I felt like it was an issue, so they were supportive of my decision not to [follow-up]." (Participant 69)

Use of the terms "fail" and "refer" have been debated as audiologists want to create a sense of urgency, but not produce unnecessary anxiety (Bosteels et al., 2012; Department of Health, 2022; JCIH, 2019)

Quality of communication

- Parents with new infants are often inundated with information and are overwhelmed at the time of birthing center discharge
- Written materials should be reassessed for readability, design, and incorporation of visual depictions, where appropriate

Use of Google and Social Media as an information source

- This is extremely common, and it is used in other situations to get health information, share lived experiences, share resources with others, and obtain emotional support (Gage-Bouchard et al., 2018, Slick et al., 2023; Towne et al., 2021)
- It is imperative that the information people receive, regardless of source, be accurate. This is not possible when parents gather information by "Googling" it.

To better serve families at-risk for being late or LTF, it is imperative that these communication challenges be adequately addressed.

References

- Bosteels, S., Van Hove, G., & Vandenbroeck, M. (2012). The roller-coaster of experiences: Becoming the parent of a deaf child. *Disability & Society*, 27(7), 983-996.
- CDC. (2023). 2020 Summary of reasons for no documented diagnosis among infants not passing screening. Centers for Disease Control and Prevention. <https://www.cdc.gov/od/oc/media/press/2023/s2023-03-23-USDHHS-NoDiag-Reasons-1.pdf>
- Department of Health. (2022). Hearing screening result interpretation and follow-up. <https://www.health.state.nj.us/people/childrenyouth/ctc/hearingscreen/followup.html>
- Gage-Bouchard, E.A., LaValley, S., Warunek, M., Beupin, L.K., & Mollica, M. (2018). Is cancer information exchanged on social media scientifically accurate? *Journal of Cancer Education*, 33, 1328 - 1332.
- Joint Committee on Infant Hearing. (2019). Year 2019 position statement: Principles and guidelines for Early Hearing Detection and Intervention Programs—Executive Summary. American Speech-Language-Hearing Association. https://www.jcih.org/JCIH_2019_Executive_Summary.pdf
- Slick, N., Bodus, P., Badaway, S. M., & Wildman, B. (2023). Accuracy of online medical information: The case of social media in sickle cell disease. *Pediatric Hematology and Oncology*, 40(2), 99-107. <https://doi.org/10.1080/08880018.2022.2075500>
- Towne, J., Suliman, Y., Russell, K. A., Stuparich, M., Nahas, S., & Behbehani, S. (2021). Health information in the era of social media: An analysis of the nature and accuracy of posts made by public Facebook pages for patients with endometriosis. *Journal of Minimally Invasive Gynecology*, 28(9), 1637-1642. <https://doi.org/10.1016/j.jmig.2021.02.005>
- Zeitlin, W., Aveni, K., McInerney, M., Scheperle, R., & DeCristofano, A. (2021). Maternal factors predicting loss to follow-up from newborn hearing screening in New Jersey. *Health & Social Work*, 46(2), 115-124. <https://doi.org/10.1093/hsw/hlab012>
- Zeitlin, W., McInerney, M., Aveni, K., Scheperle, R., & Chontow, K. (2021). Better late than never? Maternal biopsychosocial predictors of late follow-up from new Jersey's early hearing detection and intervention program. *International Journal of Pediatric Otorhinolaryngology*, 145, 110708. <https://doi.org/10.1016/j.ijporl.2021.110708>