Who Should EHDI Programs Target for Increasing Referrals for Genetic Evaluations?

EARLY HEARING DETECTION AND INTERVENTION | 2019

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Background

The Joint Committee on Infant Hearing (JCIH, 2007) recommends "all families of children with confirmed hearing loss should be offered, and may benefit from, a genetics evaluation and counseling." Historically, Minnesota Department of Health (MDH) efforts for increasing adherence to this recommendation have focused mainly on education to primary care providers (PCPs), and to a lesser extent, with information to families printed in a family resource binder.

Just-in-time information/education to PCPs to increase offered referrals to genetics included:

Phone Call/Voice Message
Phone call to PCP care team was made to verify correct PCP and contact information, and leave voice message regarding recommended specialty referrals.

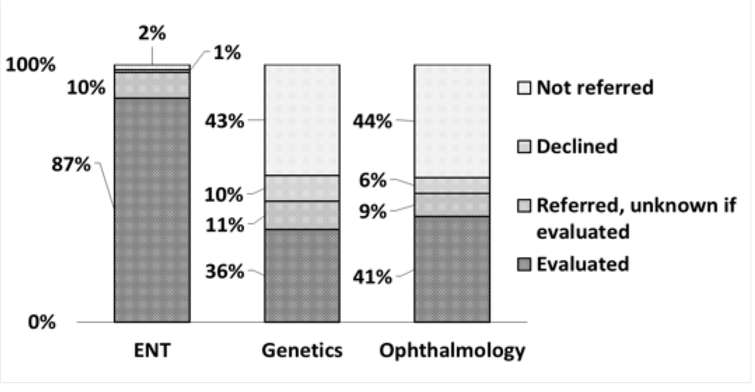
Written Letter Addressed to PCP
Letter includes the child's name and specifies that JCIH recommends the PCP facilitate referrals to medical specialists. Letter contains checklist and information sheet for PCPs regarding referrals, family resources, and interventions.

Reporting Form*
PCPs were asked to complete a reporting form regarding specialist evaluation status for children with hearing loss. Reporting form included rationale for why genetics and ophthalmology are also important for clinical management. PCP reporting was suspended after several years of data showing similar referral patterns (Figure 1).

Follow-up Fact Sheet*
This document replaced the reporting form and included rationale for why genetics and ophthalmology are important for clinical management.

*Documents have since been discontinued.

Figure 1. Specialist Evaluation Status for Children reported to MDH with Permanent Hearing Loss in 2014.



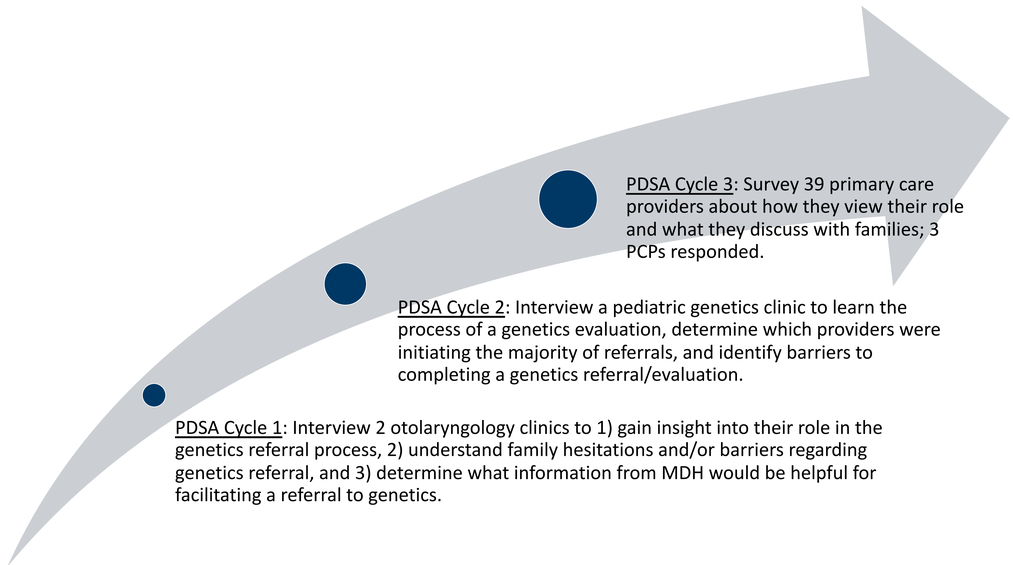
What's the Issue & Why It's Important

- 2014 Minnesota data suggests about 40% of children diagnosed with hearing loss are not referred to a genetics specialist.
- Alternatively, 90% of that same cohort of children are referred and subsequently evaluated by an otolaryngologist.
- Children who are deaf/hard-of-hearing (D/HH) may not be getting timely access to all medical specialists.
- JCIH 2007 guidelines and MDH guidelines specify that primary care providers are responsible for initiating referrals for medical specialty evaluations (otolaryngology, genetics, and ophthalmology) necessary to determine the etiology of the hearing loss.
- Timely access to otolaryngologists, ophthalmologists, and geneticists should occur by 4, 6, and 12 months of age, respectively.
- A referral for a genetics evaluation could provide necessary information for medical intervention, prognosis for progression, associated disorders (e.g. renal, vision, cardiac, etc.), and the likelihood of recurrence in future children.

Quality Improvement Process

We employed quality improvement tools 1) A3 from LEAN (Shook, 2008) and 2) cause and effect (fishbone) diagram to investigate root causes of low referrals to genetics. One path focused on family factors (e.g. Do families understand recommendations? Do families have financial or other barriers?), and one path focused on PCPs (e.g. Do PCPs make the referrals but families don't follow-up, or are they not making the referrals? Do PCPs think making these referrals should be their role, or do they think it is otolaryngologist's role to refer to genetics as a part of determining etiology?).

Initially, we wanted to interview families about their views on genetic evaluations. As a preliminary step, we decided to first talk with clinics (PCP, otolaryngology, and genetics) about their conversations with families regarding genetics and their role in referral to genetics, to help us determine what questions to ask families. Information learned from each plan, do, study, act (PDSA) cycle challenged our previous assumptions and lead to additional questions.



What We Learned

- 2 otolaryngologists interviewed indicated that a substantial portion of the children they saw in clinic had not previously been referred to a geneticist by their PCP. These physicians also reported that if they saw a child with hearing loss that had not already been referred to a geneticist, then they would take on the responsibility of discussing the option of a genetics referral with the family.
- 1 pediatric genetics clinic interviewed confirmed that a large number of referrals came directly from otolaryngologists.
- All provider/clinic types (PCP, otolaryngology, and genetics) indicated that many families still had hesitations about genetics referral or evaluation. Referrals to genetics may be lower than referrals to otolaryngology due to possible hesitations from families around cost or privacy.
- A limited number of PCPs responded to the survey, however they all indicated that offering referral for a genetic evaluation is part of their role.

Next Steps

Consider re-examining data for genetics referral/evaluation status for children reported to MDH with permanent hearing loss.

- By obtaining genetics referral/evaluation information only from PCPs, we may be underestimating the percentage of children being referred to a geneticist overall. To improve data quality, we will consider asking for genetics referral or evaluation data from otolaryngologists as well as PCPs. Additionally, we will consider getting evaluation status though chart abstraction directly from otolaryngology and genetics clinics.

Enhance our work with otolaryngologists regarding offering genetics referrals to families.

- Conduct additional interviews with more otolaryngologists to understand their views and implementation of offering genetics referrals to families of children with hearing loss (i.e. Are there different considerations due to suspected etiology or challenges due to geography (urban/rural), insurance, or other factors?)

Identify and address barriers for families to completing a genetics evaluation.

- Begin by interviewing families with children who are D/HH for their opinions and experience with genetics evaluations and potential barriers to completing a genetics evaluation.

References

Joint Committee on Infant Hearing (JCIH:2007). Year 2007 position statement: Principles and guidelines for early hearing detection and intervention programs.(Policy Statement)(Professional standards). (2007). *Pediatrics, 120*(4), 898-921.

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