DEPARTMENT OF HEALTH

Improving Identification of Children at Risk for Deafblindness in the MDH EHDI system through EHR chart abstraction

EARLY HEARING DETECTION AND INTERVENTION (EHDI) | 2022

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Background

The Joint Committee on Infant Hearing (JCIH) and Minnesota guidelines recommend referrals to specialty care, including ophthalmology, after a child is identified as deaf or hard of hearing (DHH). Historically, Minnesota Department of Health (MDH) efforts for increasing adherence to this recommendation have focused mainly on education to primary care providers (PCPs) in the form of phone calls and letters, and to a lesser extent, with information to families printed in a family resource binder. In previous years, MDH EHDI program collected data on referrals to specialty care by calling or faxing the child's PCP. In 2014, 56% of children with hearing loss in Minnesota were referred to ophthalmology by their PCP. Conversely, nearly 97% of children with hearing loss were referred to otolaryngology (ENT). PCP reporting was suspended after several years of data showing similar referral patterns.

In 2019, as part of a quality improvement (QI) project relating to improving referrals to genetics, MDH interviewed PCPs and ENTs who both considered referrals to specialist care as part of their role. By obtaining specialist referral/evaluation information only from PCPs, we were likely underestimating the percentage of children being referred to a medical specialists overall. To improve data quality, we decided to seek referral or evaluation data from otolaryngologists, when possible through chart abstraction.

Starting in 2020, MDH Newborn Screening began working with medical facilities to increase Electronic Health Record (EHR) access for short- and long-term follow-up. MDH EHDI currently has EHR access to nine health systems (covering 54/84 birth facilities and about 71% of births). With this access, MDH EHDI long-term follow up decided to see if medical specialist follow-up referral/evaluation surveillance could be improved.

This poster illustrates a QI process using EHR chart abstraction to improve our data on how often children are referred to and evaluated by ophthalmology.

DeafBlind risks/statistics

Using the Minnesota DeafBlind Project's list of more than 50 conditions/etiologies associated with combined hearing and vision loss. *Deafblindness is one term used to describe this combination that can include mild to profound degrees of hearing loss and the spectrum of low vision to total blindness.* MDH-EHDI started tracking these conditions as risk factors in EHDI-IS in 2021. Information about comorbidities and risk factors known at the time of identification were abstracted from audiology reports and various sources.
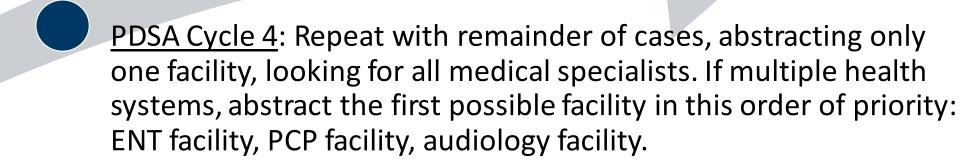
Among 1202 children reported as DHH from 2015-2019 *(includes children identified between birth and age 10)*

- 341 children had at least one risk factor for deafblindness
- 19 children had vision impairment
- Most common risk factors for deafblindness were prematurity, Down syndrome, and congenital cytomegalovirus (cCMV).
- 1/3 of children identified as DHH between 0-2 years of age had at least one reported risk factor for deafblindness

What's the Issue & Why It's Important

- 2014 Minnesota data suggests about 56% of children diagnosed with hearing loss were referred to an ophthalmologist or eye specialist by their PCP. *This is likely an underestimate, since we know that otolaryngologists also make referrals to ophthalmology.*

- Timely access to ophthalmologists should occur by 6 months of age.

- Despite the longstanding recommendation that children who are DHH receive an ophthalmology exam, census data from National Center on Deaf-Blindness suggests that children aged 0-2 with combined hearing and vision loss may be under-identified.

- A referral for an ophthalmology evaluation is a crucial step in systemic efforts to identify children who are DeafBlind as early as possible and connect them to community resources and supports.

- In the Minnesota Commission of Deaf, DeafBlind and Hard of Hearing (MNCDHH) strategic plan to support DeafBlind Children and Youth, respondents and professionals highlighted the need to promote coordinated services and sharing of information among service providers.

Quality Improvement Process

PDSA Cycle 4: Repeat with remainder of cases, abstracting only one facility, looking for all medical specialists. If multiple health systems, abstract the first possible facility in this order of priority: ENT facility, PCP facility, audiology facility.

PDSA Cycle 3: Repeat, prioritizing one specialist (ophthalmology) to see if we could reduce abstraction time to under 10 minutes per case.

PDSA Cycle 2: Repeat with more cases that had PCP and specialists in the same health system and cases that did not have PCP and specialists in same health system. Abstract multiple facilities if needed.

PDSA Cycle 1: From one facility's EHR, look for 1) referrals; and 2) scheduled visits to ENT, ophthalmology and genetics. Track the time it takes to find and enter data in EHDI-IS. If ophthalmology results found and not clearly normal, flag for more investigation.

The team used a Plan-Do-Study-Act (PDSA) QI tool from Institute for Healthcare Improvement (IHI), abstracting records from children born between Oct 2018-Dec 2019 and reported in 2019. We were able to abstract about 70% of children (n=108). The first few abstractions took too much time, so we adapted our tests which reduced the average abstraction time to 10 minutes (range of 4-35 minutes). For the final test, we chose to abstract only one facility per child, prioritizing ENT clinic's facility, as we knew they were likely to make referrals to other specialists. If we did not have access to the ENT facility, we abstracted the PCP facility, and if no access there, the audiologist facility.

Facilities had a range of data systems, so there was no uniform way to search records across facilities. Abstractors used a variety of methods to find information, including keyword searches (i.e., searching "ophthalmology," "vision," or "eye"), filtering by department specialty, names of providers, or document types (progress notes, letters, scans). When providers were in the same facility, we assumed they had access to the other providers' reports. Communication/report routing history between providers that were at different facilities could be found in some data systems but was not easily found in others, possibly due to the level of EHR access.

Resources

(2019). Year 2019 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs. Journal of Early Hearing Detection and Intervention, 4(2), 1-44. DOI: https://doi.org/10.15142/fptk-b748

National Center on Deaf-Blindness: https://www.nationaldb.orghttps://www.nationaldb.org

Institute for Healthcare Improvement, www.ihi.org

MN DeafBlind Project, www.dbproject.mn.gov

What We Learned

- EHR abstraction, in addition to our current processes, increased our knowledge of referrals/evaluations and improved data quality. It is likely that referrals were underestimated in previous years when only PCPs were reporting.

- 78% were known to have been referred to ophthalmology (n=108).

- Of the 62 children with a known referral source, 79% were referred to ophthalmology by their ENT. *(They may have also been referred by their PCP or other sources in addition).*

- The percentage referred was similar between those with and without a known risk factor for deafblindness (79% referred among those without a risk factor; 76% among those with a risk factor).

- 56% of the total 108 are known to have been evaluated by ophthalmology

- Among children with risk factors for deafblindness, 70% were evaluated by ophthalmology.

- Timeliness of evaluation may have been affected by the start of the Covid-19 pandemic. However, of the children with known evaluation dates, 44% were seen by 6 months of age. The median age at evaluation was about 6.5 months and the median time from identification to evaluation was 4.5 months.

- 5 children were flagged for more investigation to determine if they meet case criteria for deafblind.

Next Steps and Questions

- What kind of case consultation does public health need to determine if a child meets the criteria of deafblindness? (i.e., discussions with child's PCP or ophthalmologist, ICD-10 code search)

- Which medical providers are counseling families on the impacts of combined hearing and vision loss and next steps? (i.e., ophthalmologist, ENT, PCP, or in combination?)

- If public health surveillance finds a child who is deafblind, in what ways do parents want support beyond referrals to early intervention? (i.e., printed materials, parent support, and local public health nurse call)

- What data sharing agreements are needed to share EHDI information with the Minnesota DeafBlind project?

- What can we do to make sure children with or without risk factors for deafblindness continue to get the ophthalmology follow-up they need over time?

- How can we continue to improve data quality? (i.e., collaborations with state birth defect surveillance team)