



Longitudinal Follow-Up of Children with Unilateral Hearing Loss in Minnesota

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Minnesota Early Hearing Detection & Intervention (EHDI) program

In 2007, Minnesota added hearing to the newborn screening panel, specified members of a newborn hearing screening advisory committee and identified parents and deaf and hard of hearing adults as strategic partners in the EHDI system. In Minnesota:



Minnesota Department of Health (MDH) provides both short-term and longitudinal follow-up to track EHDI outcomes.



MDH EHDI has secure data sharing with Minnesota Department of Education to track enrollment in Part C Early Intervention.

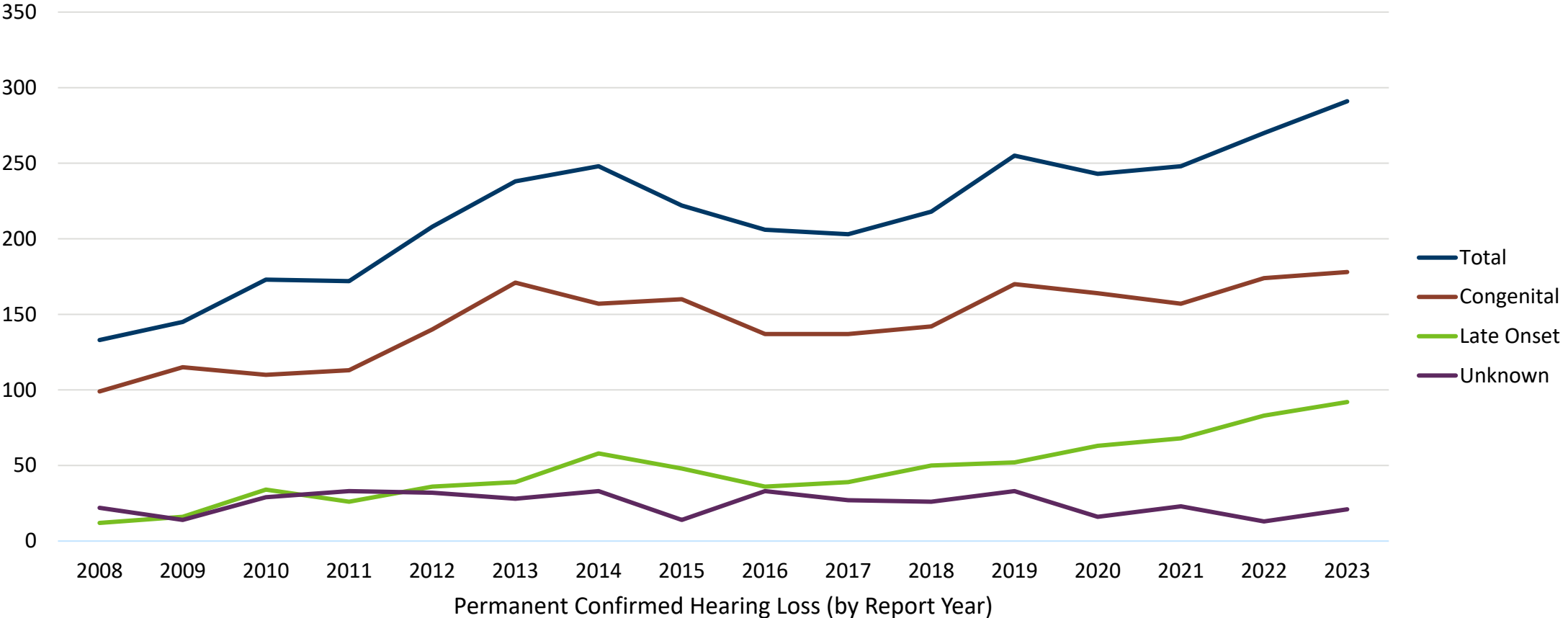


Audiologists report children with newly identified and late onset permanent hearing loss from birth through age 10 to MDH.

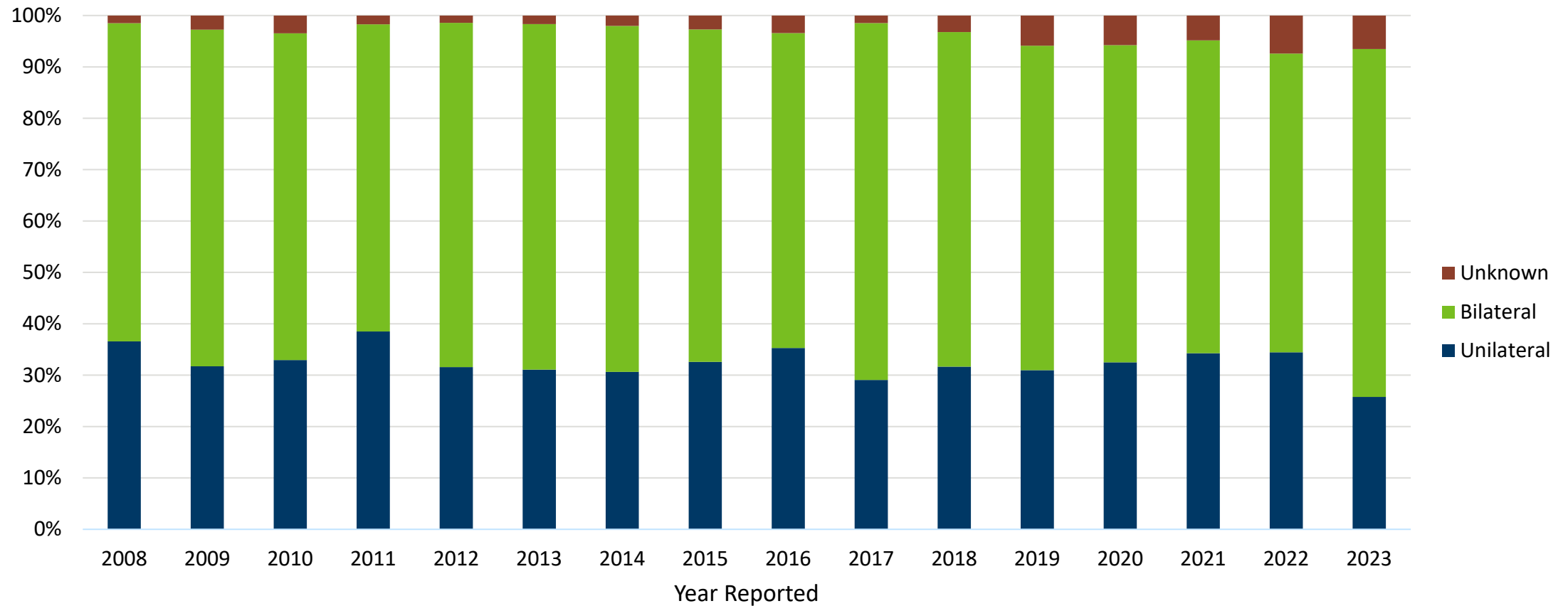


MDH EHDI participates in the Early Childhood Longitudinal Data System (ECLDS) which includes kindergarten and 3rd grade outcomes.

Improvements in reporting of late onset cases are resulting in a greater total number of children reported to MN EHDI.



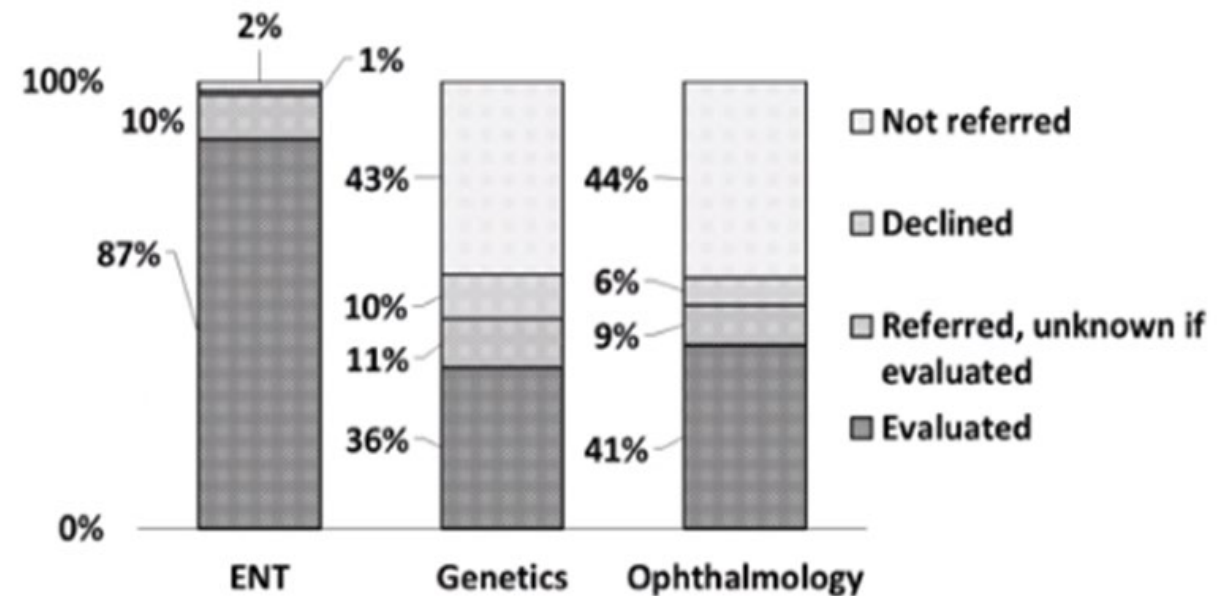
On average, 1/3 of all children reported to EHDI (congenital + late onset) are initially identified with unilateral hearing loss.



Background: Longitudinal follow-up activities over the past 10 years and challenges to data completeness

- MDH EHDl provided just-in-time information to primary care providers (PCPs) to boost referrals of children to JCIH recommended medical specialty evaluations (ENT, ophthalmology, genetics).
- MDH EHDl asked PCPs to provide follow-up data on whether children completed evaluations (faxback forms, phone calls)
- MDH EHDl asked audiologists to provide follow-up data on hearing aid fittings and etiology of hearing loss (faxback forms, phone calls). This time consuming process took around 20 hrs/wk and was often incomplete.

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



Hearing status and 3rd grade academic achievement

Minnesota Early Childhood Longitudinal Data System (ECLDS) –
online interactive database

MDH EHCI Data

Unilateral vs Bilateral

Degree of Hearing
Loss

Department of Education Data

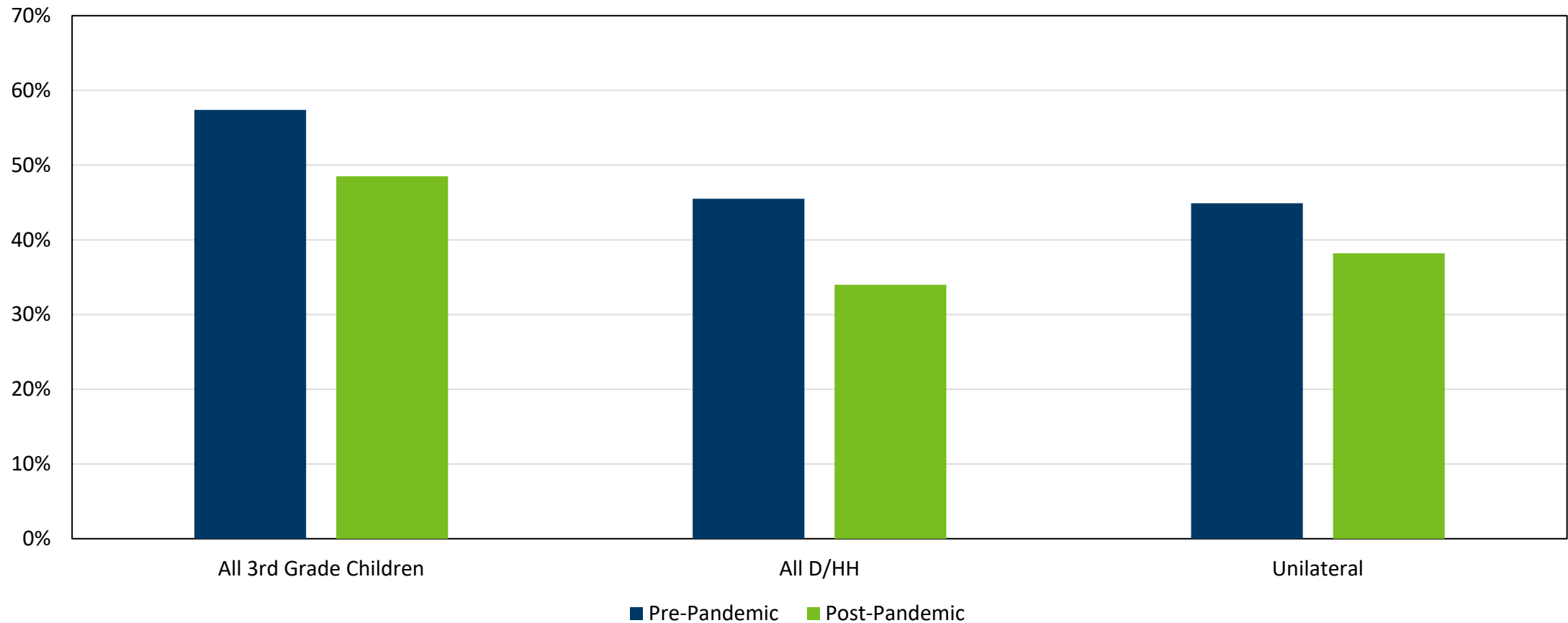
Birth to Pre-K, Kindergarten, 3rd Grade

Language Acquisition

Grade Level
Achievement

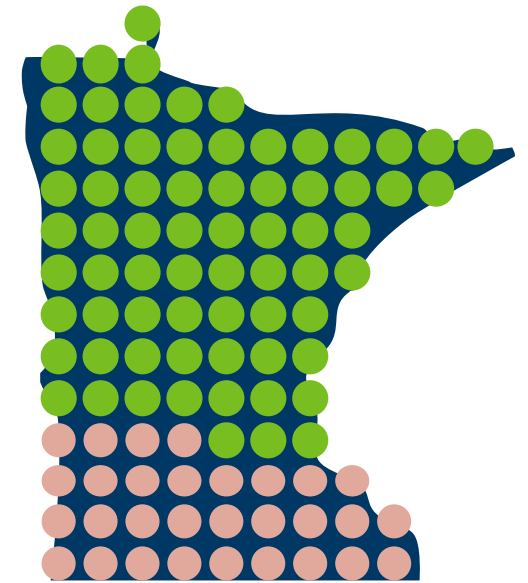
Degree and Laterality of Hearing Loss data in ECLDS for some children is from the time of their initial identification. This project aims to update that data through abstraction.

MN ECLDS: Hearing status and 3rd grade reading proficiency (historical data)

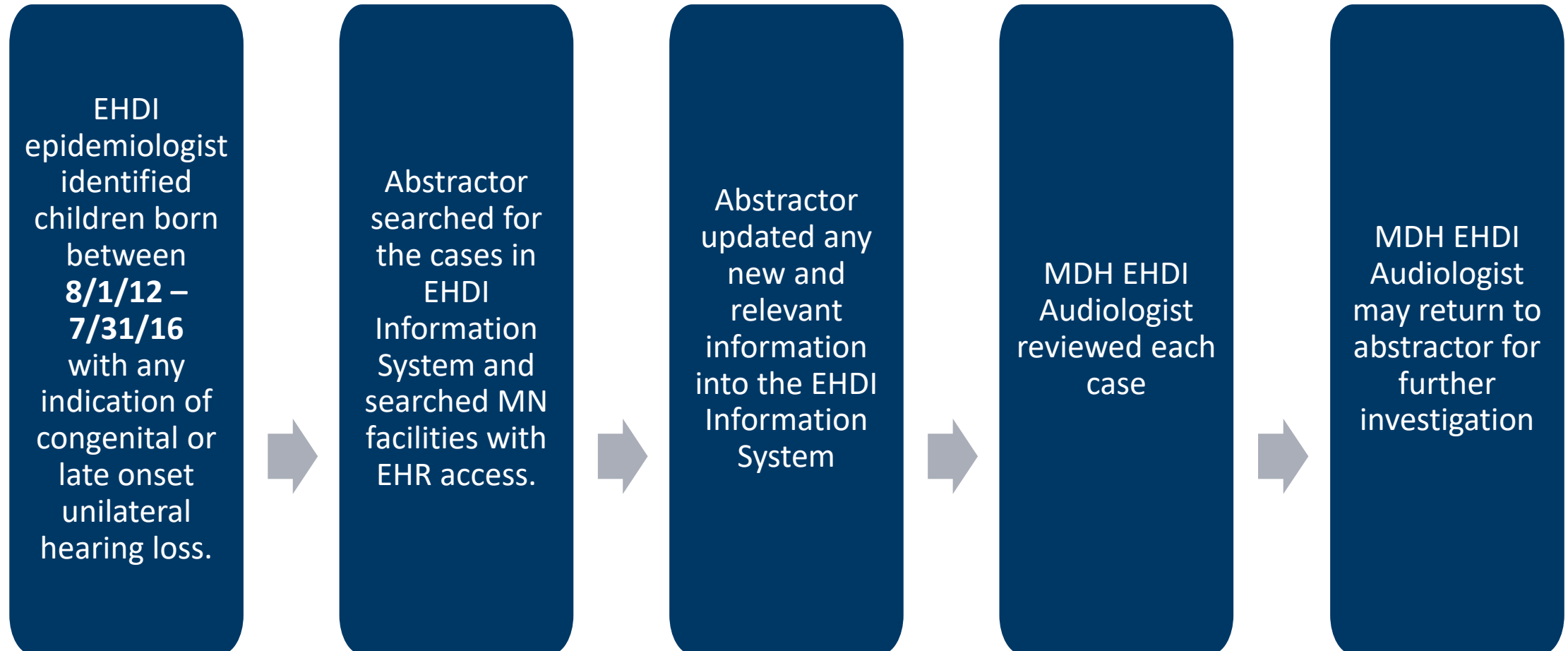


Abstraction process: project cohort

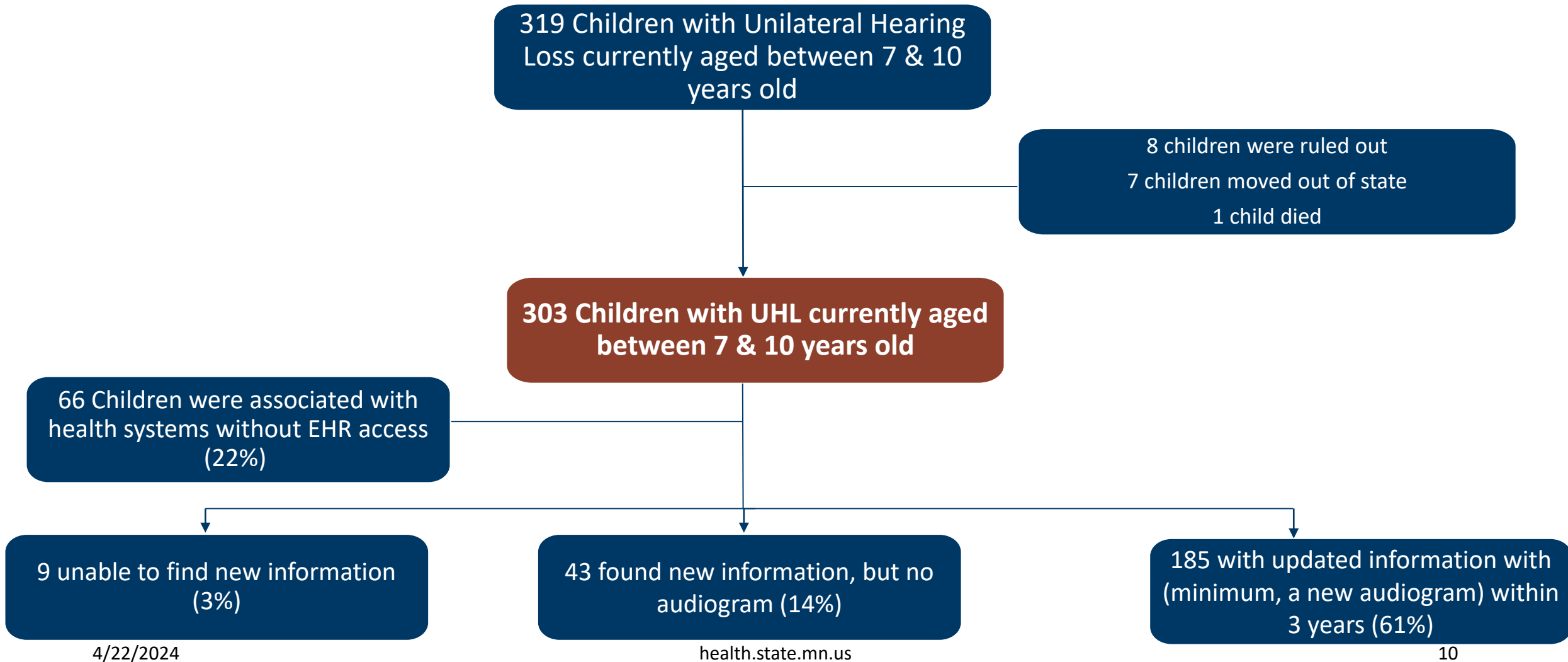
- MDH EHDI program has electronic health record access covering more than 70% of MN births.
- Program evaluation focused on nearly 300 children initially reported to have unilateral permanent confirmed hearing loss.
- Age groups were abstracted between ages 7 and 10 to look at specialty care evaluations and hearing technology fittings over time, and to better assess longitudinal outcomes, especially when matched through ECLDS with 3rd grade reading and math outcomes.
- Electronic health records were abstracted to determine rate of technology use (hearing aids and cochlear implants), connection to specialty care, and etiology of hearing loss, if previously unknown.



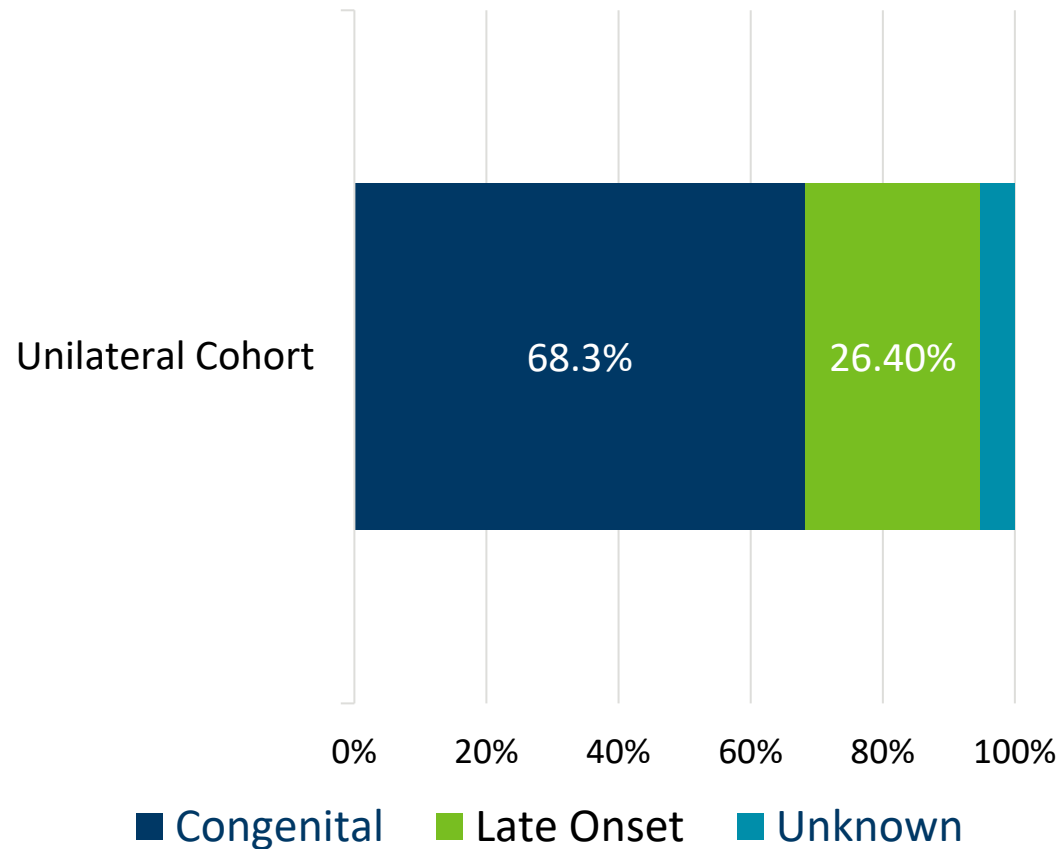
Abstraction process: overview



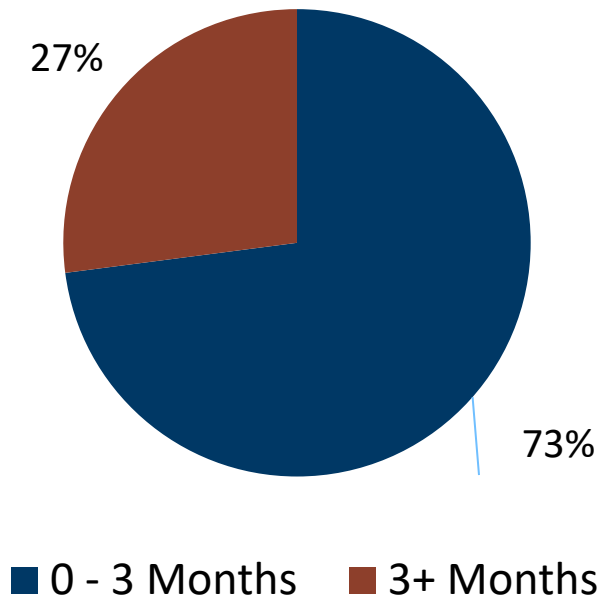
Abstraction process



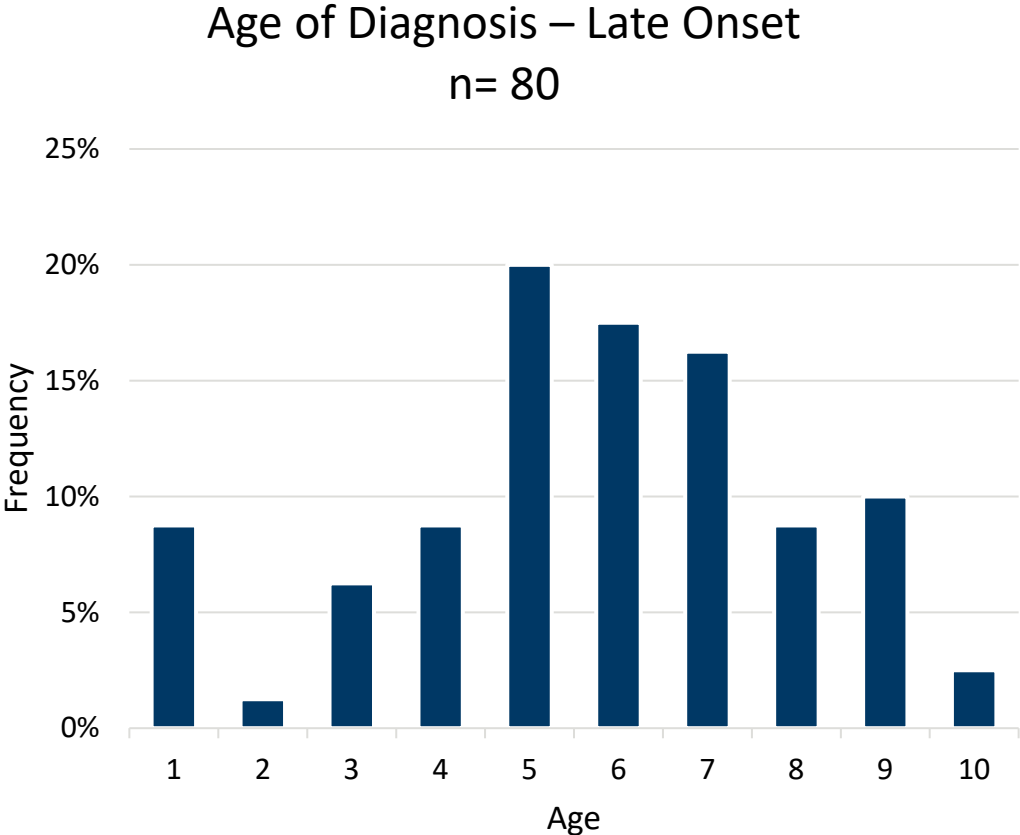
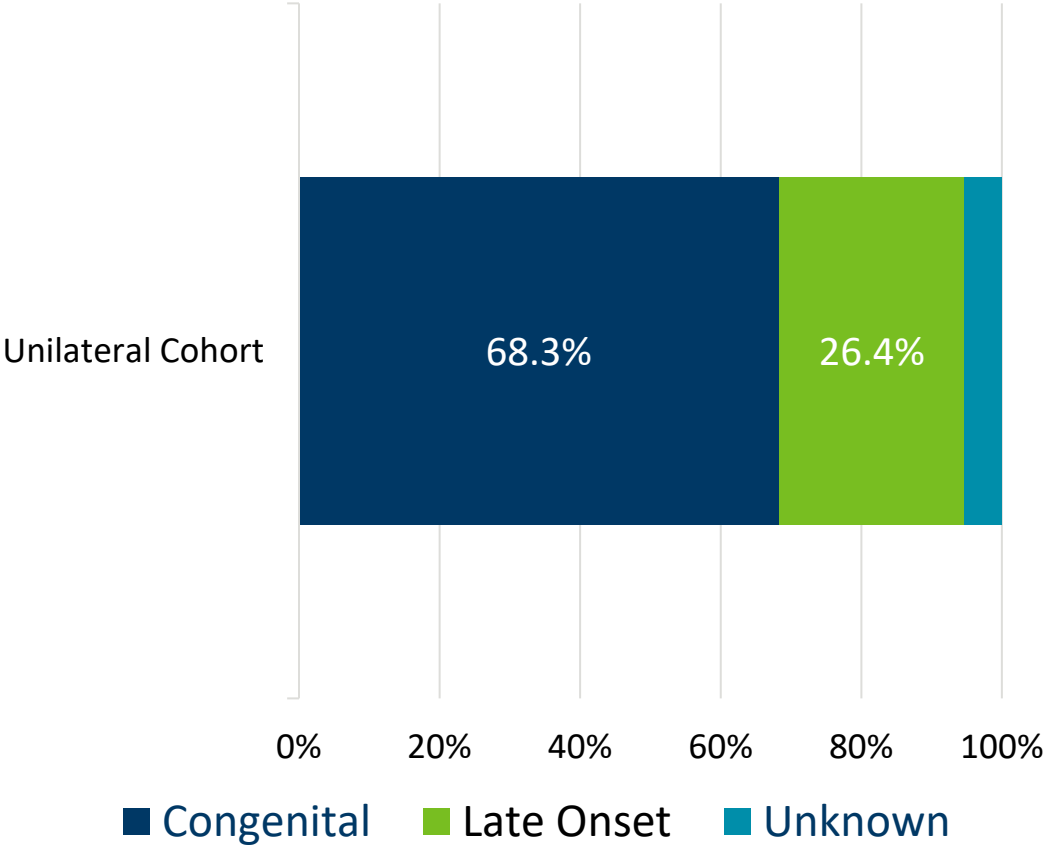
About 3/4 of children with congenital unilateral hearing loss were diagnosed by 3 months of age.



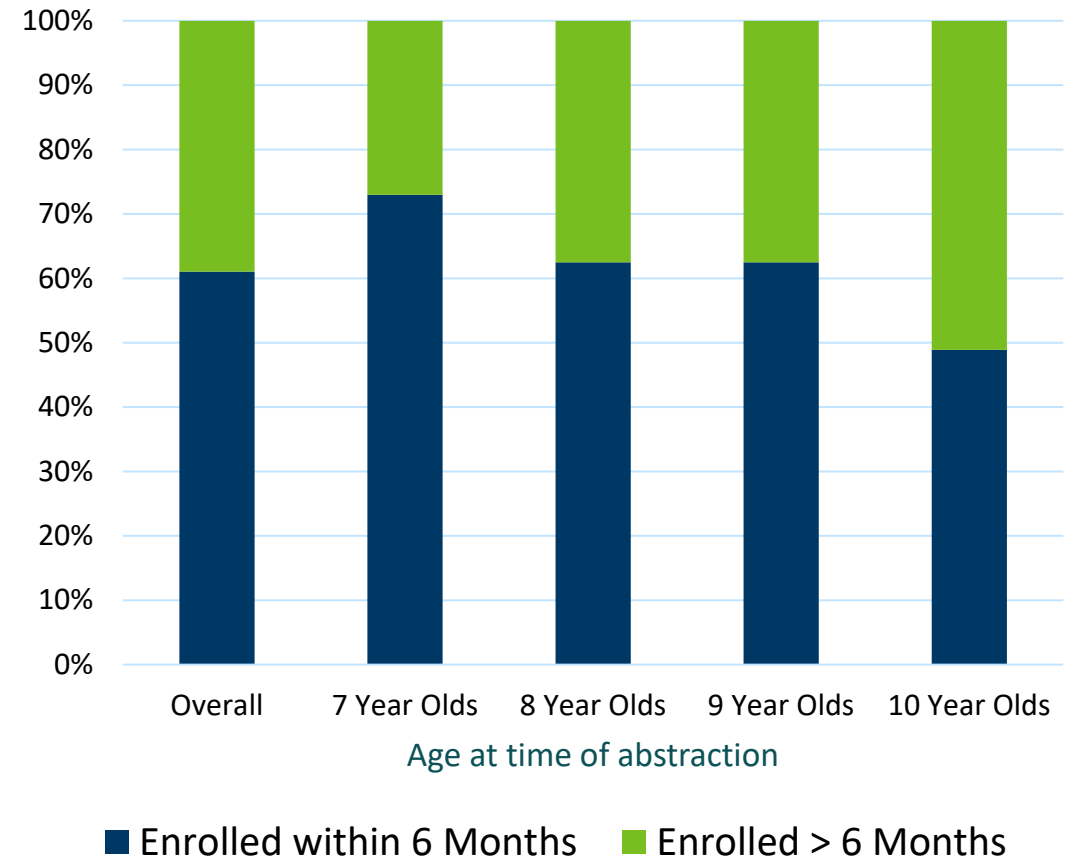
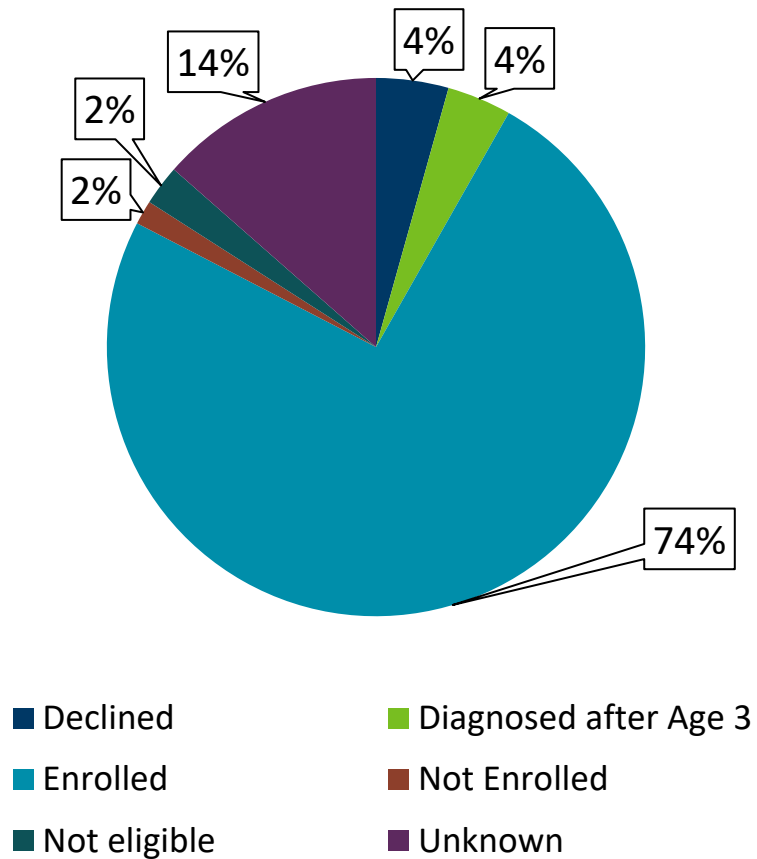
Age at Diagnosis - Congenital
n=207



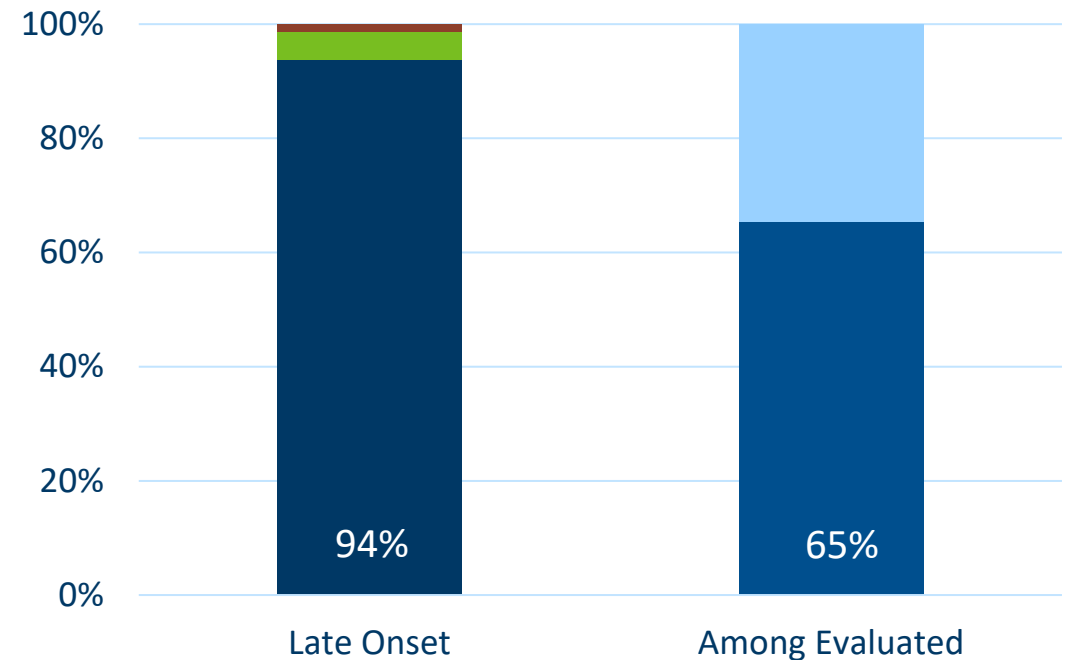
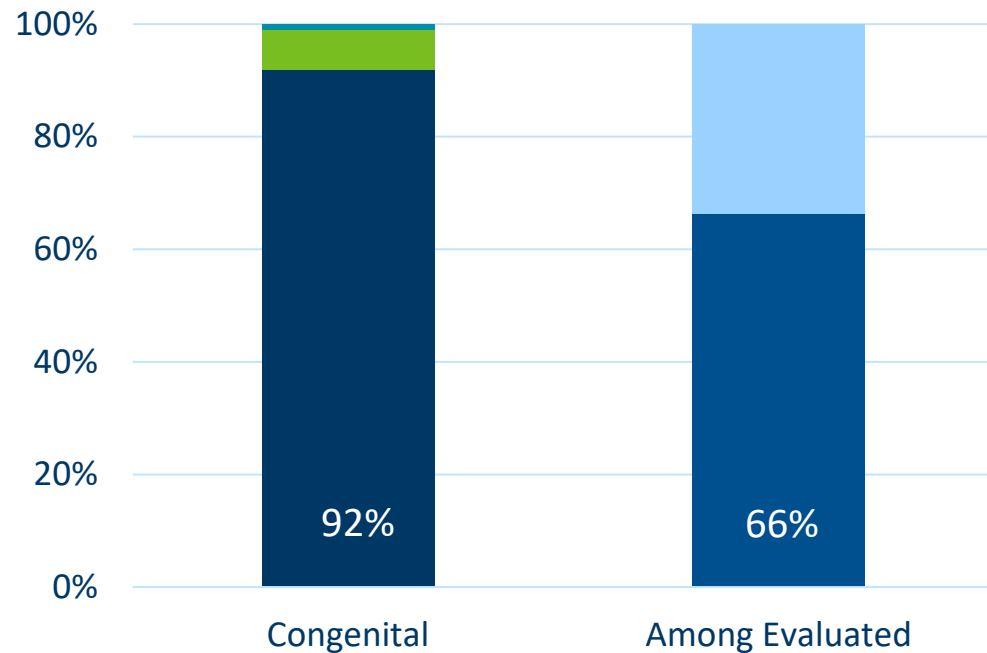
About 3/4 of children with late onset unilateral hearing loss were reported after age 5.



About 3/4 of children with congenital unilateral hearing loss enrolled in Part C (60% by 6 months of age).



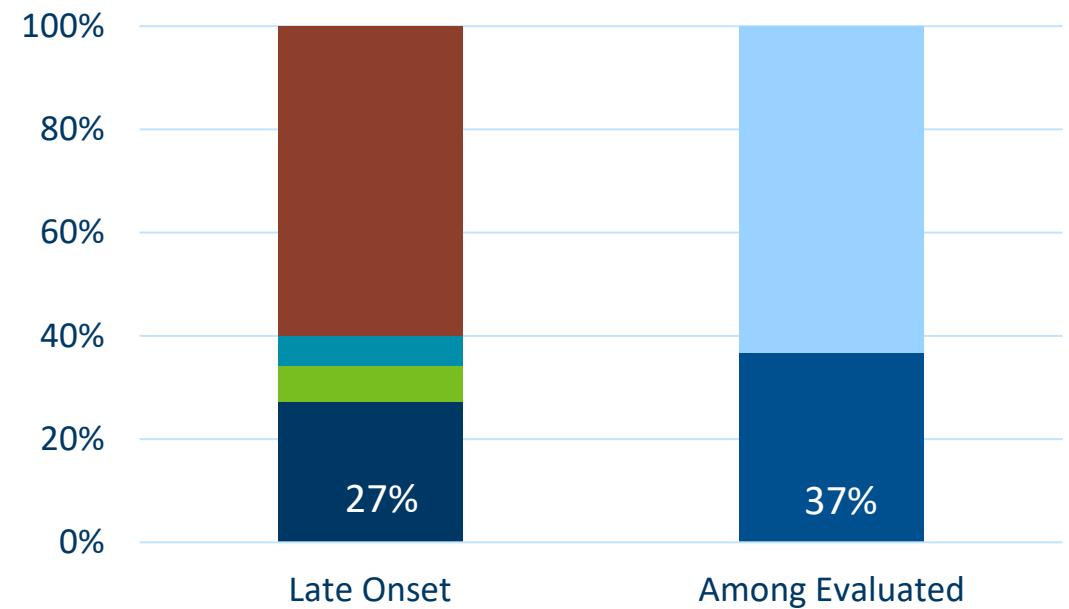
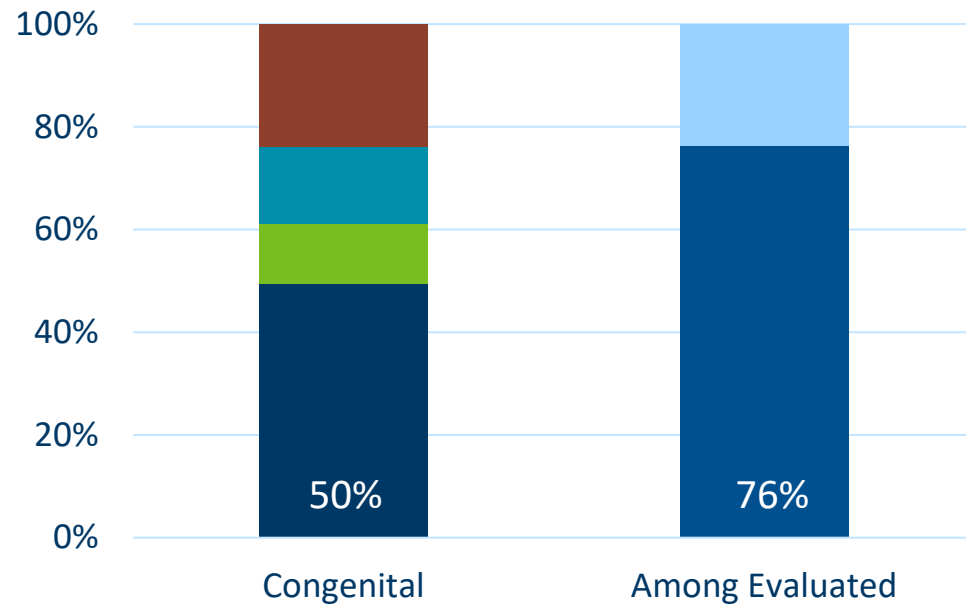
More than 90% of total unilateral cohort were evaluated by ENT. More than 60% are evaluated within 4 months of birth or diagnosis.



■ > 4 months of birth
■ Within 4 months of Birth
■ Not Referred
■ Declined
■ Referred, Unsure if Evaluated
■ Evaluated by ENT

■ > 4 months of diagnosis
■ Within 4 months of Diagnosis
■ Not Referred
■ Declined
■ Referred, Unsure if Evaluated
■ Evaluated by ENT

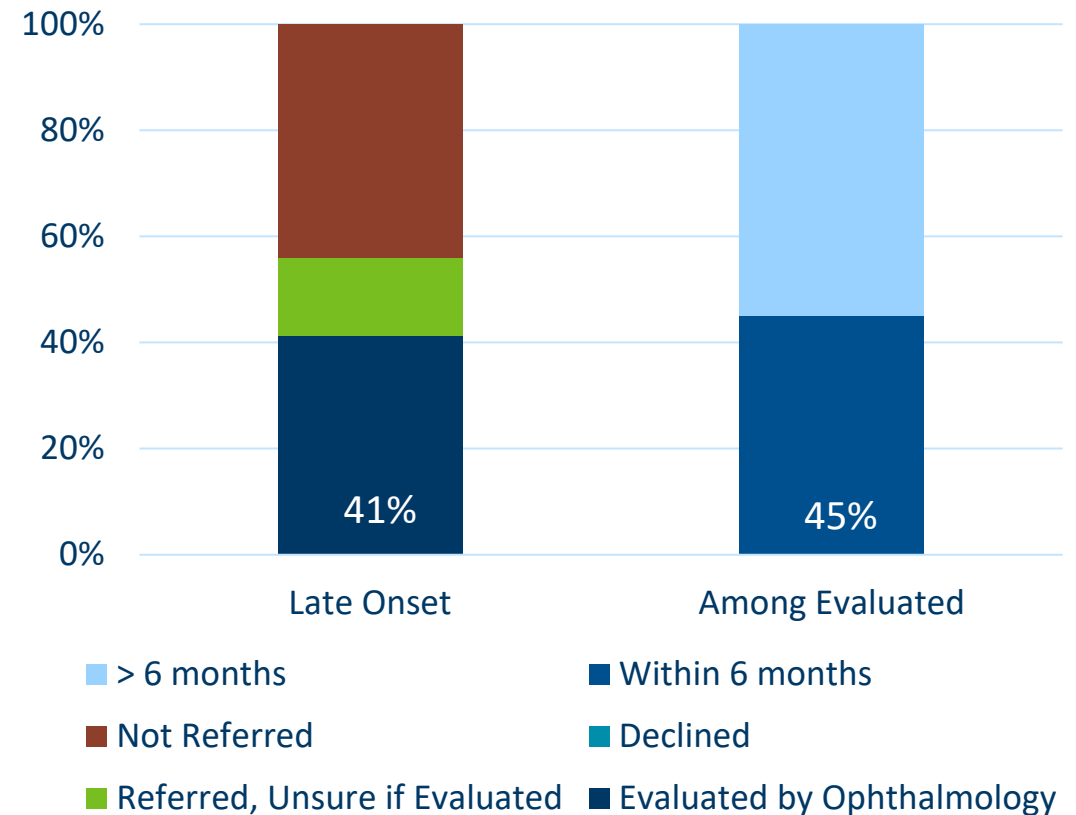
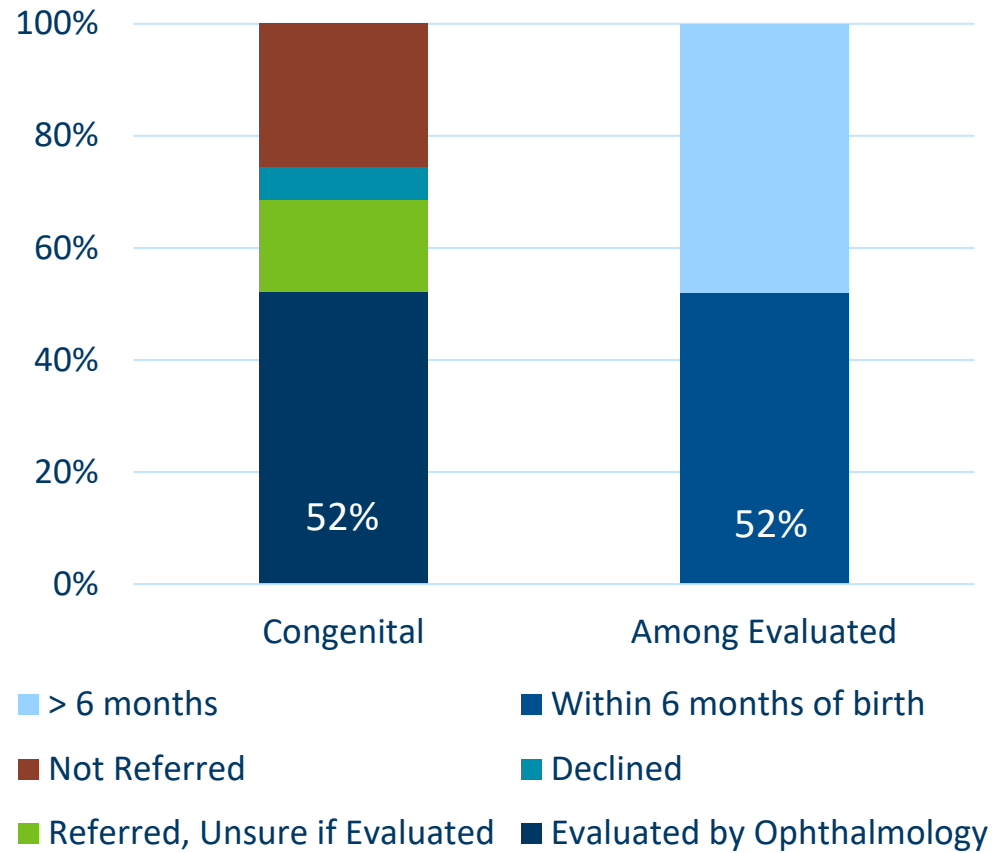
Children with congenital unilateral hearing loss were more likely to be evaluated by genetics (50%) than children with late onset hearing loss (27%).



■ > 1 year of birth ■ Within 1 year of birth
■ Not Referred/Unknown ■ Declined
■ Referred, Unsure if Evaluated ■ Evaluated by Genetics

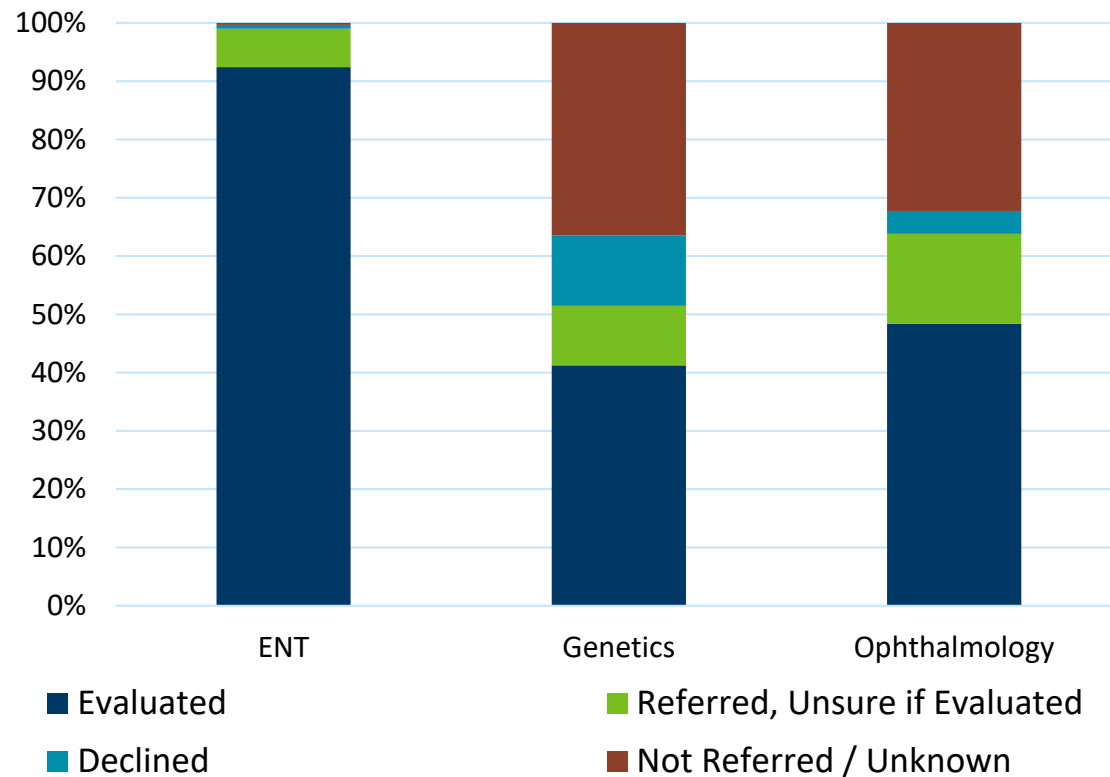
■ > 1 year ■ Within 1 year
■ Not Referred/Unknown ■ Declined
■ Referred, Unsure if Evaluated ■ Evaluated by Genetics

About half of children with congenital unilateral hearing loss were evaluated by ophthalmology (>50%), and less for late onset (40%).



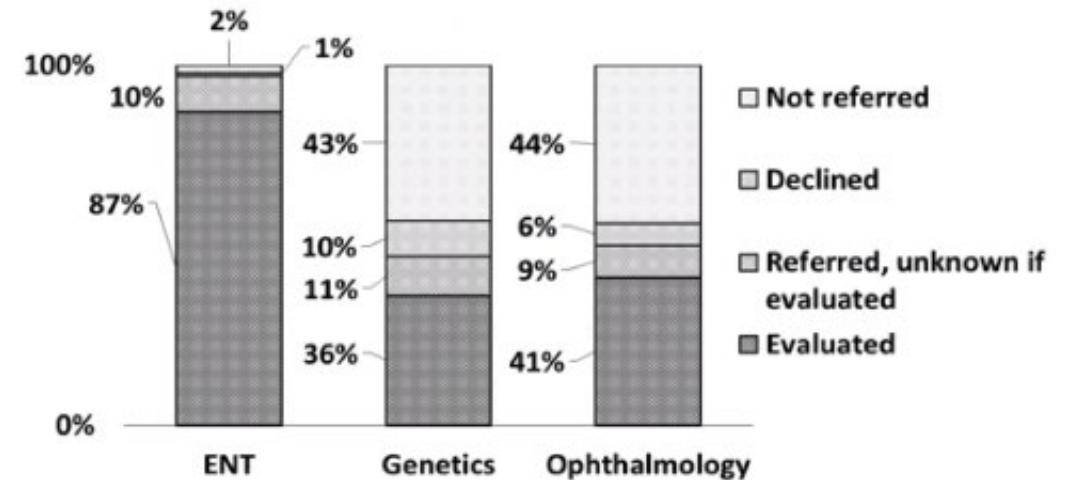
Overall, children in the unilateral cohort were evaluated by specialists at rates similar to 2014, suggesting evaluation rates are consistent over time.

Unilateral Project Cohort

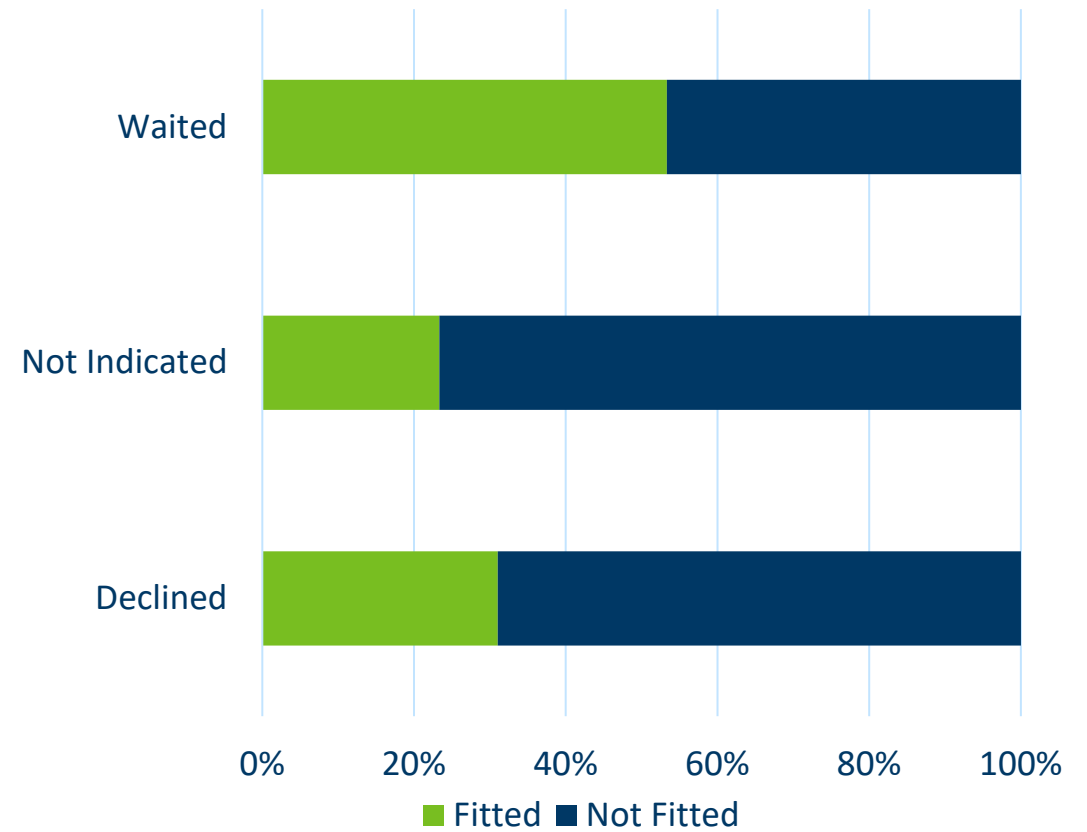
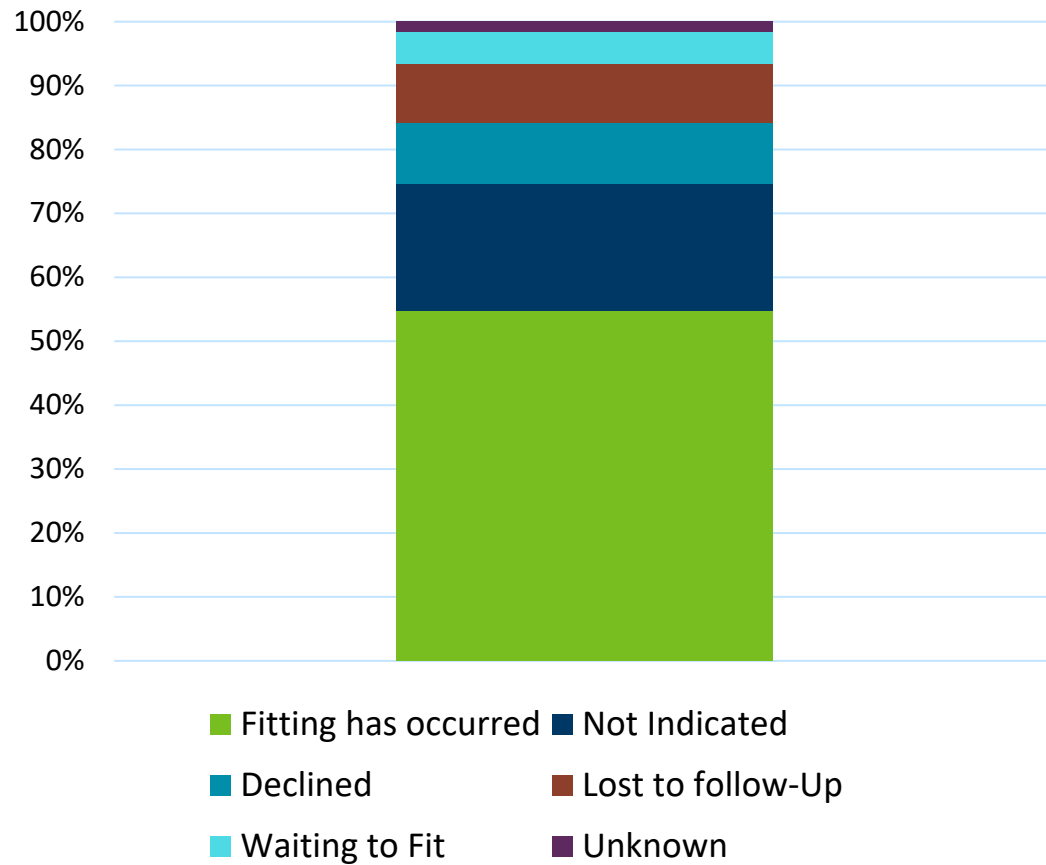


Specialist Evaluations reported to MDH in 2014 (includes bilateral)

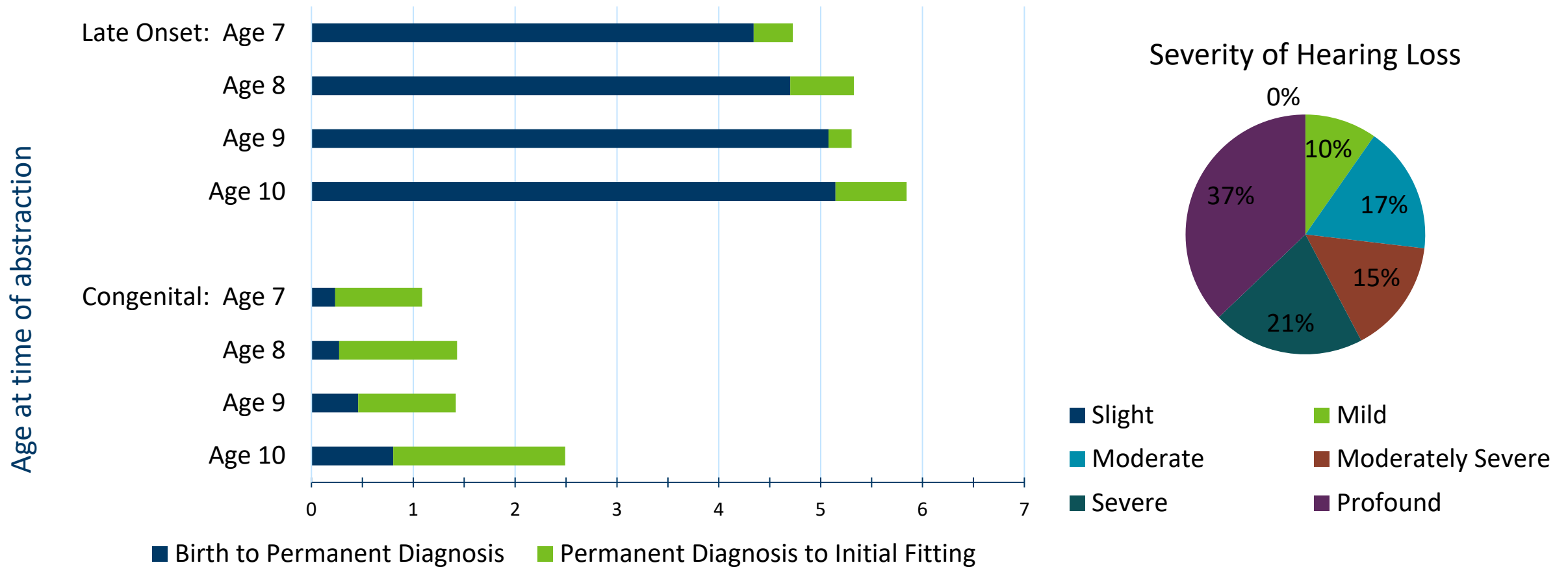
Figure 1. Specialist Evaluation Status for Children reported to MDH with Permanent Hearing Loss in 2014.



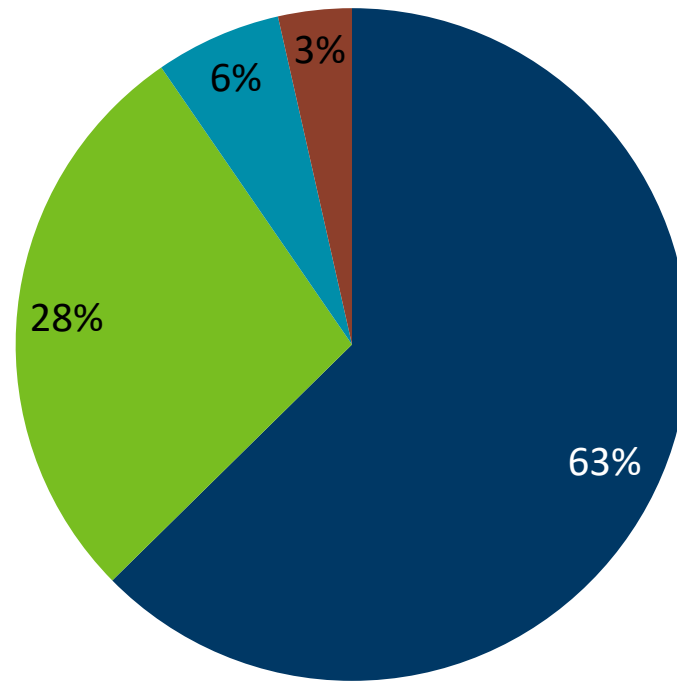
55% of the unilateral cohort were fit with hearing technology. Almost one-third of those who waited, declined or for whom technology was initially not indicated were eventually fit.



Those with late onset unilateral hearing loss were more likely to be fit with technology in a more timely manner than those with congenital unilateral hearing loss.

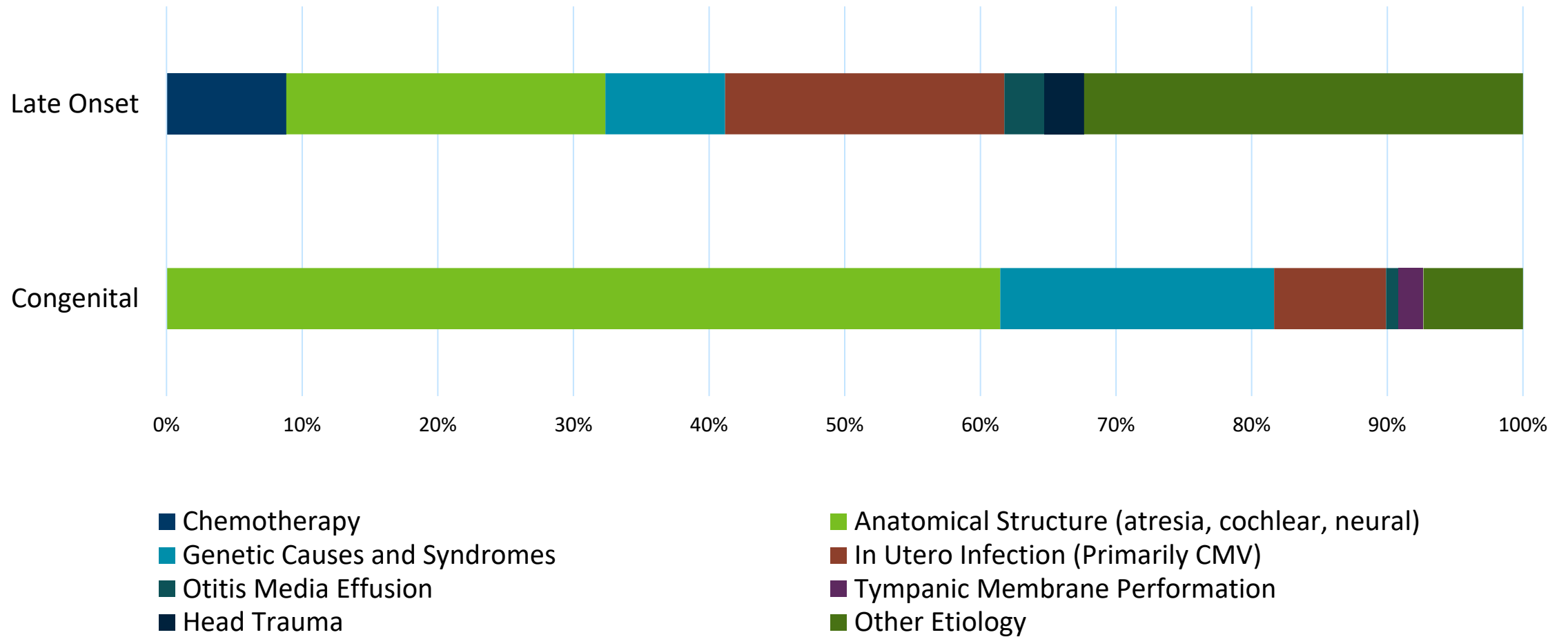


Hearing aids and bone conductive hearing aids were the most common hearing technologies.



■ Hearing Aid ■ Bone Conductive Hearing Aid ■ Cochlear Implant ■ FM

Etiology was known for nearly half of children. The most common etiologies were structural (i.e. atresia, cochlear or neural hypoplasia, enlarged vestibular aqueduct).



Progression of unilateral to bilateral hearing loss

Characterize and describe the abstraction process used to identify children initially diagnosed with a unilateral hearing loss who have progressed to bilateral hearing loss.

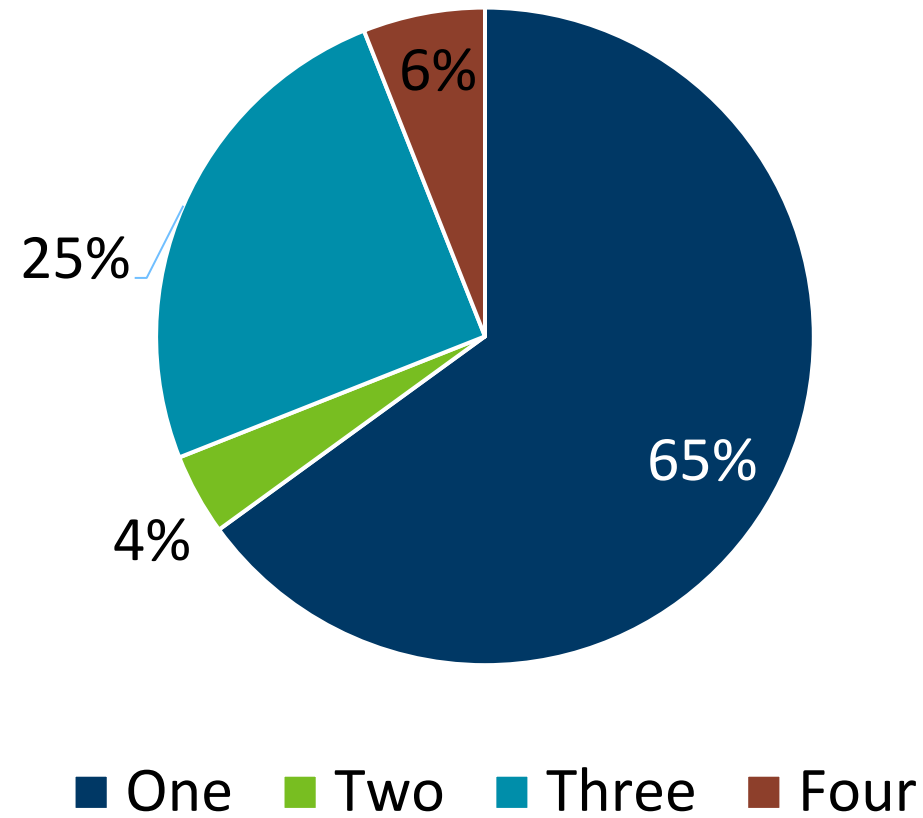
29 children were newly identified through abstraction as having progressed from unilateral to bilateral hearing loss, about 10% of the project cohort

Abstraction took 80% less time and was more secure than faxing/calling clinics to get the data; AND abstraction also had challenges.

Describe challenges to data completeness in surveillance of characteristics of children with unilateral hearing loss.

- 66 children were identified as receiving care from facilities where MDH does not have EHR access. (22% of children)
- Children who moved to areas without EHR access
- Tracking child through multiple facilities (half at one facility, half at another) – Takes time
- Time needed to abstract complete information took double / triple amount of time compared to standard cases
 - Standard case abstraction took less than 10 minutes

Abstractors needed to review one facility for more than half of cases



Ways to make Abstraction Successful

Identify practices and methods that result in successful abstraction of longitudinal follow-up data.

- Experienced abstractors
- Clear and concise Job Aid with clear expectations of needed information
- Clear determination of sufficient evidence to document the information
- Flexibility in the process
- Time for the project
- Data system in place to accept data in fields that can be analyzed

- Increase efficiency by optimizing the number of needed medical records searches based on when we expect to find the data.
 - See if rates of specialty care generalize to a bilateral cohort
- Re-analyze unilateral ECLDS reading and math outcomes after updated data is loaded (later in 2024).
- Update parent print materials about unilateral hearing loss, with family-friendly statewide data and targeted recommendations aiming to increase uptake of JCIH guidance.

Thank You!

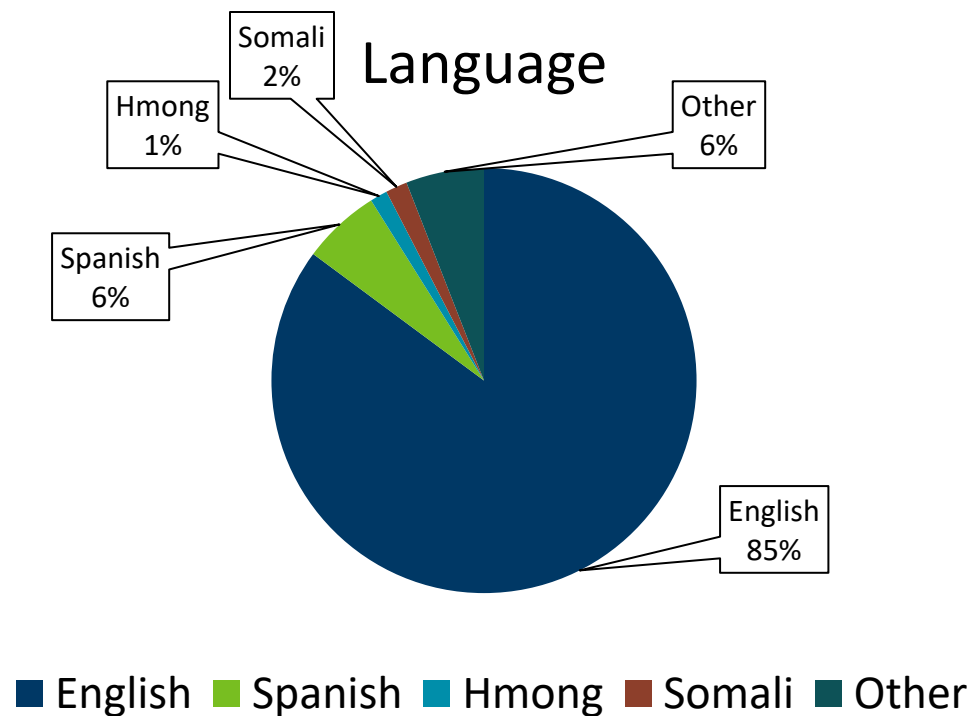
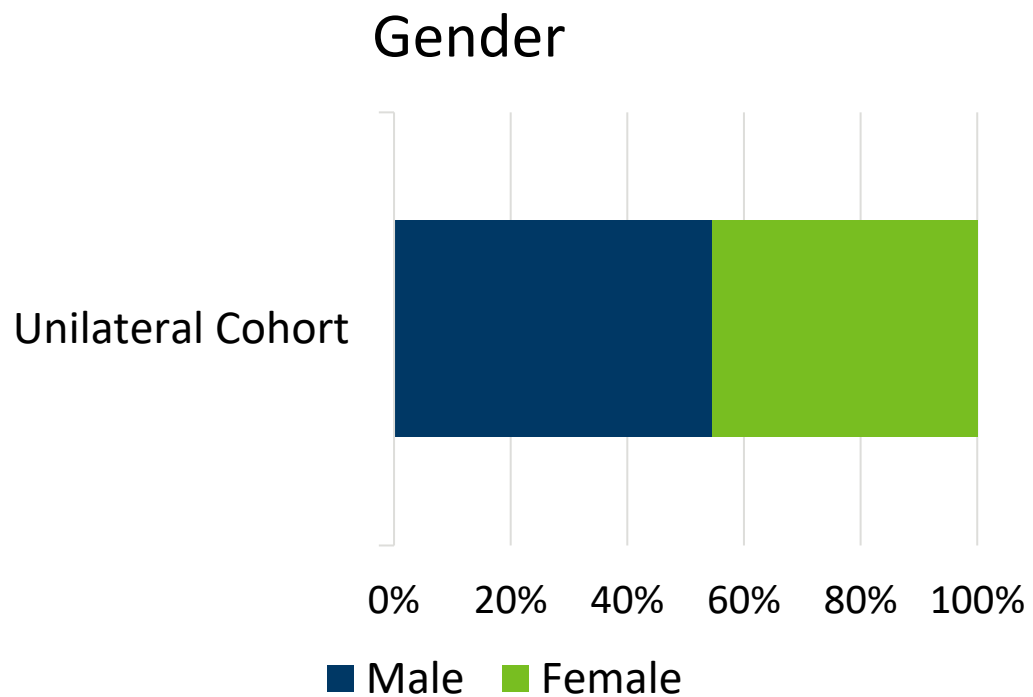
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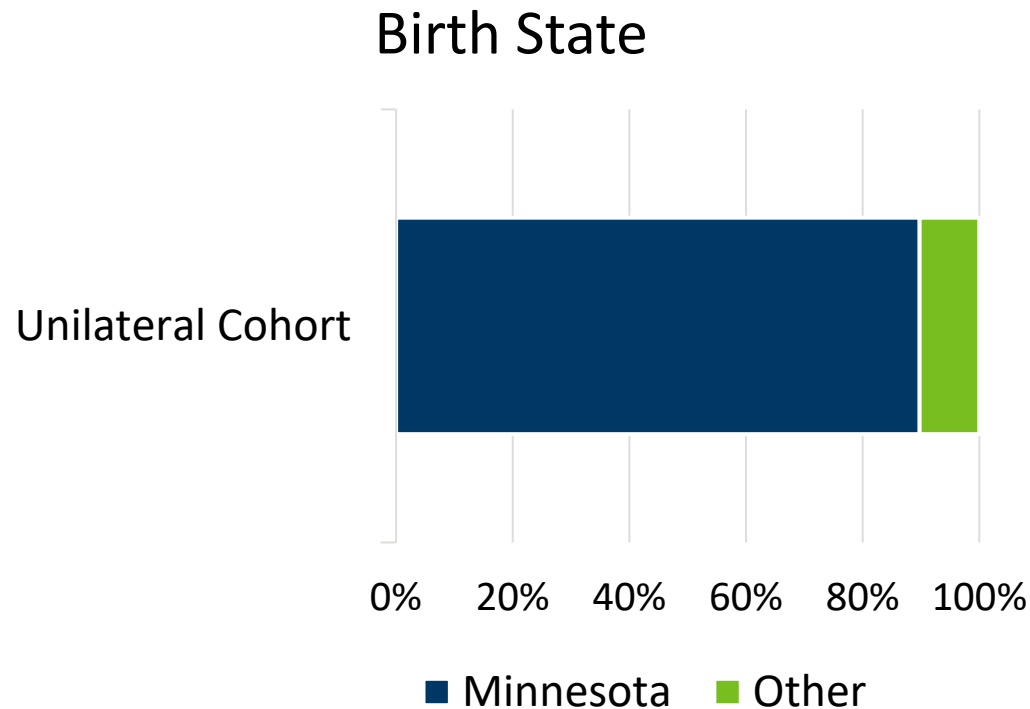
Venessa.Heiland@state.mn.us

Special thanks to our student worker, Youa Vang,
who assisted with abstraction!

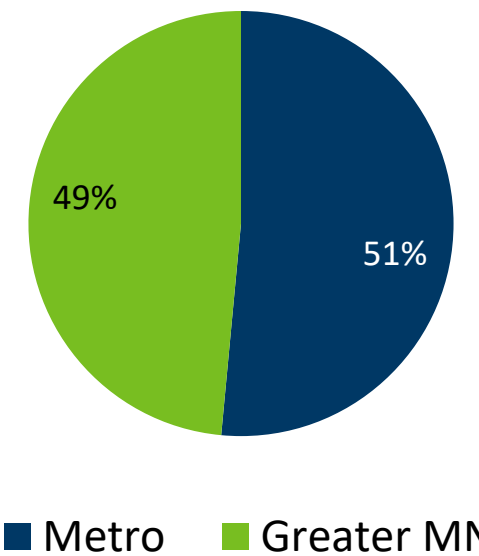
In the unilateral project cohort, male and female gender was reported at a similar rate. More than 85% use English.



Most children in the cohort were born in Minnesota. About half live in the Twin Cities metro and the other half in Greater MN.



Metro or Greater MN



Congenital

- identified with permanent type of hearing loss
- officially reported REFER result for at least one ear on final newborn hearing screening/rescreen
- INCLUDES: children with a medical diagnosis of atresia, and any child with a risk factor for hearing loss whose initial hearing evaluation is diagnostic.
- EXCLUDES: children who had an officially reported diagnosis of normal hearing in both ears after a REFER screening result.

Late onset

- identified with permanent type of hearing loss
- officially reported PASS result for both ears on final newborn hearing screen or an officially reported diagnosis of normal hearing in both ears after a REFER screening result.
- INCLUDES: any child whose permanent hearing loss is known to be acquired after birth.

Unknown

- identified with permanent type of hearing loss
- no officially reported newborn hearing screening results
- onset cannot be determined based on a known cause of the hearing loss

MN ECLDS: Hearing loss and 3rd grade math proficiency (historical data)

