

SOUND MATTERS

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Audiology Newsletter of the Minnesota Early Hearing Detection & Intervention Program

Importance of Genetic Testing for Deaf/Hard of Hearing Children

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Minnesota EHDI Co-Chapter Champion for the American Academy of Pediatrics



A genetics evaluation is recommended by both the American Academy of Pediatrics and the American College of Medical Genetics for all children who are deaf or hard of hearing. Genetic evaluations are typically performed by a clinical geneticist. A clinical

geneticist is a board-certified physician who is frequently double board certified in pediatrics, internal medicine, or obstetrics/gynecology as well as clinical genetics.

The clinical geneticist gathers a full clinical history that includes a birth history, developmental milestones, a three-generation family history and other risk factors. During a genetics evaluation, a complete physical examination is performed looking for evidence of a syndrome or other subtle characteristics associated with hearing loss. The child and their parents may also speak with a genetic counselor. A genetic counselor is a master's level professional with expertise in genetics and counseling and provides information for families to better understand the benefits and limitations of genetic testing.

Genetic testing typically uses Next Generation Sequencing technology to examine the 100 most common genes associated with hearing changes. This avoids the need to go back and re-test should the initial gene tested not provide a definitive answer and is lower cost per gene than older methods.

About half of all hearing loss in newborns has a genetic cause. The testing costs are not insignificant but have the potential to change a child's clinical outcome. Thus, genetic testing is medically necessary and is the standard of care in practice. For example, genetic diagnosis that can positively impact outcomes for children include:

- Usher Syndrome, Type I –can help inform and prepare the family for the possibility of vision loss which may begin around age 5
- Pendred Syndrome – can inform and prepare families of children with unilateral hearing loss about possible progression to bilateral loss

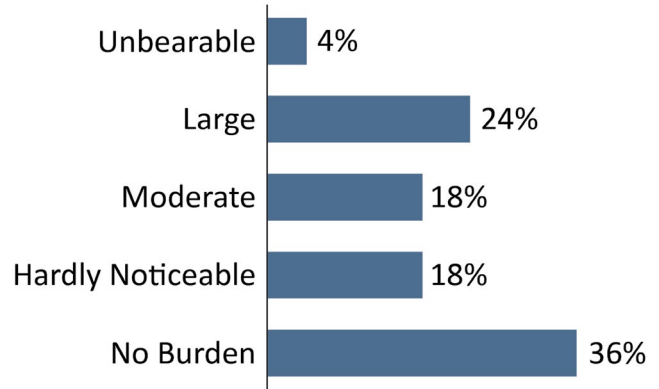
Families can find additional information about genetic testing, including [“A Parent’s Guide to Genetics & Hearing Loss”](#) on the Center for Disease Control and Prevention website.

Did you know? Cost for Hearing Services is a Burden for Many

As part of the [Early Intervention Snapshot survey](#) in collaboration with the National Center for Hearing Assessment and Management (NCHAM), about 42% of Minnesota families surveyed expressed that the cost for hearing services was a moderate to large burden, with 4% describing the cost as unbearable. Close to a third of families spent more than \$100 per month on hearing services and spent more than \$1000 on hearing technology before their child’s third birthday. Even families with insurance coverage may experience large copays or co-insurance. Giving families the online link to the [EHDI parent binder](#) and [ImproveEHDI.org/MN website](#) is an easy way for audiologists to provide families with financial support information early in the process, even before their printed EHDI parent binder comes in the mail from MDH. Contact health.newbornchildfollowup@state.mn.us to order bookmarks that include these links!

“We were lucky to receive his first hearing aid from the Lion’s organization, which is why I chose ‘No Burden.’ Otherwise, the hearing aid was not covered at all by insurance and would have been. I think this is the biggest barrier.”

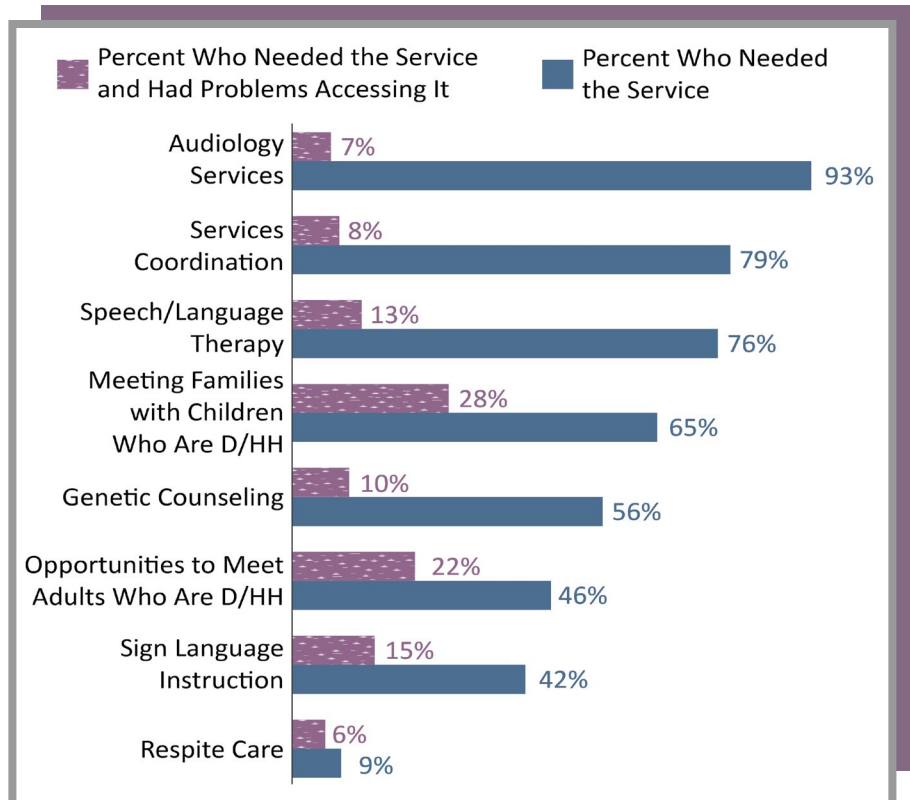
Spending out-of-pocket money on services and hearing technology was a financial burden



Have You Heard?

Challenges to accessing services for Deaf Hard of Hearing (D/HH) Children

The [EI Snapshot Survey](#) showed some Minnesota families report challenges accessing D/HH-specific services and supports. Only a few people had problems accessing the most commonly needed services like audiology and hearing devices. However, close to half of families who needed opportunities to meet with families with children who are D/HH or adults who are D/HH had problems accessing what they needed. Only a few parents reported needing respite care, but most who needed it had problems accessing it. Audiologists can help by connecting families to [Deaf Mentors](#) or [Deaf and Hard of Hearing Role Models](#), parent support organizations like [Minnesota Hands and Voices](#) and [Family Voices](#), and [PACER](#).



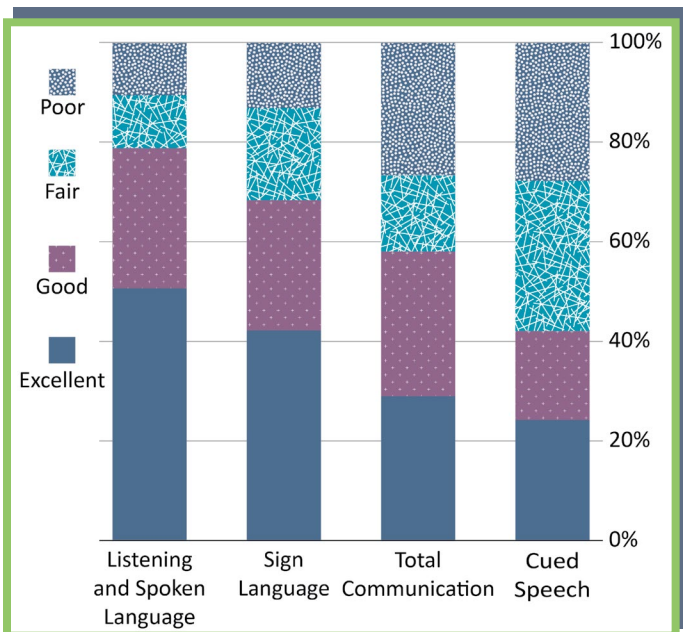
By the Numbers



More Cued Speech Resources are Needed

The [EI Snapshot](#) survey questioned parents regarding their access to information about communication options.

The majority of families reported that they received excellent or good quality information about communication options except for cued speech.



Audiologists can direct families to the online [EHDI parent binder](#) for basic information about communication choices.



Last Words from the Advisory Committee



Meeting highlights...

- Dr. Devin McCaslin, Ph.D. presented on balance disorders as related to congenital hearing loss. Resource website for pediatric balance disorders in general is <https://vestibular.org/pediatric-vestibular-disorders>
- Report on Early Intervention for Deaf/Hard of Hearing Students – program strengths and opportunities <http://www.infantheating.org/ei-snapshot/>
- Co-occurrence of Hearing Loss and Mental Health Conditions <https://ehdimeeting.org/Schedule/griddetails.cfm?aid=7828&day=TUESDAY>

Next meeting:

August 15, 2018
1:00 – 4:00 p.m.
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