Keys for Discussing Genetic Testing With Families

A Guide for Professionals

"What works for your child is what makes the choice right." ™

HANDS & VOICES™

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Foreword

When a child is identified as deaf or hard-of-hearing (DHH), parents and providers alike must navigate a myriad of intersecting and unfamiliar worlds to find a pathway that enables the child and family to thrive. Genetics is one of them. In recent years, genetic testing has become the most accessible and powerful way to learn the biological underpinnings of hearing and deafness in DHH children and impact their care. These changes have outpaced the ability of most providers to develop comfort with how to talk about genetics with families and help them make informed decisions. Parent/professional partnership to understand how genetics intersects with the unique clinical, cultural, and personal identity of each DHH child is essential for ethical and effective deployment of this powerful diagnostic tool. This guide, developed by parents and care providers of DHH children, provides a valuable framework for how providers can achieve this goal in a way that is sensitive to the diverse perspectives and needs of families and their DHH children.

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For years we have been anticipating the 'genetic revolution' in care for children with hearing loss and that time has arrived. Along with imaging (CT and/or MRI), genetic testing is now widely seen as the standard of care in clinical evaluation and work up for children with hearing loss. This has been spurred by the development of new genetic tests that provide a diagnosis more often, faster, and cheaper than ever before.

Hearing loss is a symptom of an underlying alteration in the hearing pathway. Genetic testing allows us to provide patients and families with a diagnosis for their hearing loss. From a prognostic standpoint, identifying the underlying genetic etiology can clarify whether a child's hearing loss is likely to be stable, progressive, or fluctuating. This knowledge allows clinicians to counsel families more accurately, set expectations for long-term management, and make timely decisions regarding interventions such as hearing aids or cochlear implantation.

Genetic testing also plays a critical role in identifying syndromic forms of hearing loss, which may not be clinically apparent at the time of presentation but encompass approximately 20% of genetic diagnoses in children with hearing loss. More than 400 syndromes include hearing loss as a symptom, and early detection of associated conditions, like Usher Syndrome, the most common cause of hereditary Deaf-Blindness, enables anticipatory guidance and surveillance for families. This highlights the importance of a diagnosis not only for audiologic and otologic care but also for comprehensive, multidisciplinary care of the child.

Perhaps most importantly, a confirmed genetic diagnosis empowers patients and their families by providing an explanation for the hearing loss, ending a period of uncertainty and stress as they search for a cause for hearing loss. A diagnosis can reduce feelings of uncertainty or guilt and connect families with support groups and communities. Finally, in the era of precision medicine, identifying the genetic basis of hearing loss is essential for determining eligibility for clinical trials for emerging gene therapy approaches. As targeted therapies move from research to clinical practice, timely genetic testing ensures that children with hearing loss are not only receiving optimal care today but are also prepared for the treatment opportunities of tomorrow.

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Executive Summary

Keys for Discussing Genetic Testing with Families of Deaf and Hard of Hearing Children

This guide is designed for professionals who support families considering or receiving genetic testing. Conversations about genetic results are not only about science — they are about trust, identity, and family well-being. Providers who communicate with clarity, humility, and cultural awareness can reduce stress, strengthen decision-making, and promote equitable access to genomic medicine.

Key Recommendations for Practice for Otolaryngologists, Audiologists, Geneticists and Genetic Counselors:

- **Center the Family Experience**
  - Recognize that families bring their own expertise and emotional history.
  - Allow time and space for processing difficult information.
- **Communicate with Care**
  - Use plain, family-friendly language; avoid jargon and technical shorthand.
  - Apply *"Say This, Not That"* strategies to build trust and clarity.
- **Explain Results Clearly**
  - Discuss results in context, including what is known and unknown.
  - Address Variants of Uncertain Significance (VUS) honestly while reassuring families that understanding may evolve with time.
- **Respect Ethical Considerations**
  - Protect family privacy and autonomy.
  - Acknowledge concerns about stigma, labeling, and possible implications for siblings or future children.
- **Address Systemic Barriers**
  - Recognize inequities in referral patterns, insurance coverage, and geographic access.
  - Advocate for cultural and linguistically responsive supports.
- **Support DHH Plus Families**
  - Acknowledge the heightened risk of medical trauma for medically complex children.
  - Provide trauma-informed communication and anticipate added caregiver stress.
- **Plan for Continuity**
  - Offer follow-up appointments and repeated opportunities for questions.
  - Connect families with peer support, family organizations, and genetic counseling resources.

Takeaway

Genetic testing can bring answers, uncertainty, or more questions — but every conversation is a chance to empower families. Professionals who listen, respect, and adapt can ensure that testing is not just a medical process, but a partnership that strengthens family confidence and resilience.

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Keys for Discussing Genetic Testing with Families: A Guide for Professionals

Introduction: Why this Guide?

What if there was a guide that recognized the unique expertise of professionals and emphasized partnership with families of young children who are deaf or hard of hearing?

This guide, written for Otolaryngologists, pediatricians, audiologists, geneticists, and genetic counselors, is based on the personal experiences of parents and those who have been trained as leaders representing the parent perspective in the systems that serve us. We recognize that our dedicated, family-centered professionals in every field support parents of deaf and hard of hearing (DHH) children with their insight, experience, and research, and our children truly benefit from that.

Parents of DHH children and DHH professionals identified a need to inform professionals on best practices for introducing genetic testing to families based on family perspectives.

Although this guide was created with funding from a genetics research partner, the information compiled here was not directed or influenced by that funding.

The Complexity of Hearing Differences

Healthcare providers discussing genetic testing with families are often unfamiliar with the wide range of community perspectives and lived experiences related to deafness. About 1 in 500 babies born is born with a hearing difference (from unilateral to bilateral, mild to profound), and another 1 in 500 acquire hearing loss during childhood, which is considered a “low incidence” condition. .

Some providers may not encounter many families raising children who are DHH or be exposed to the diversity of their experiences, and the many choices they must make regarding care planning (Morton & Nance, 2006; NCHAM, 2020). Up to 60% of DHH children have additional needs, and these complexities impact decisions about early education, amplification, language opportunities, visual language and supports, navigating health services and coverage gaps, and school challenges (Gallaudet Research Institute, 2011; Stevenson et al., 2015). Families have diverse cultural and linguistic backgrounds, and this can create barriers to accessing care (Yoshinaga-Itano, 2003). Importantly, 95% of families have no prior experience with hearing differences or Deaf Culture, making their learning curve especially steep (Mitchell & Karchmer, 2004).

The early identification of hearing loss in children is essential for promoting optimal engagement by parents, as a child’s first teacher. Babies identified with hearing differences after

three months of age or entering early intervention after six months often fall short of established public health benchmarks for timely detection and intervention/support. Studies suggest a substantial proportion of children with hearing loss are either identified later than recommended benchmarks (e.g., 30% of infants) or develop hearing loss after infancy (estimates suggest up to 35-50%), depending on definitions used for late-onset, late-identified, or delayed diagnosis (Nance, 2003; Dedhia et al., 2013). As a result, many children face an increased risk of diminished language acquisition outcomes. Families who have children identified after three years of age frequently miss vital early intervention resources that facilitate understanding of hearing differences, early language acquisition, and have implications for educational outcomes and access.

Adults who are DHH, particularly within Deaf Culture, may view hearing differences as a sensory difference rather than a disability, something that may be novel to medical professionals. This guide emphasizes the importance of approaching genetic testing discussions with families in a positive way and encourages reflection on potential biases in professional perspectives. This guide can help offer more culturally respectful care in a complex landscape where hearing differences may be seen as either a new, positive identity or a disability—even within the same family.

Early Moments Matter: Offering Testing at a Vulnerable Time

A recent study in the USA suggests genetic testing is only offered to about 50% of families, and typically this occurs shortly after a confirmed diagnosis of hearing loss when parents are still navigating a new and unfamiliar landscape. (Barnett, et al, 2025.)

Fear of the unknown, overwhelm, grief, relief, and hope all come into play at times, coloring a family's ability to process information and make informed choices. As a provider, it is important to understand this pivotal moment for families and provide unbiased information without undue influence. Later in this document, families will share which statements they found helpful and unhelpful during their adjustment and decision-making process. (see Say This, Not That on page 11)

Partnering With Families: Should Genetic Testing Be a Choice?

Making decisions for a child who is DHH requires an incredible amount of research, networking, and time. With all the decisions families face in their young child's life, it's no wonder parents can feel overwhelmed. Deciding whether to undergo genetic testing is part of that early decision-making process. Offering a genetics referral is recommended by the Joint Committee on Infant Hearing (2019), however, a referral and/or genetic testing may or may not be offered, depending on local systems of care and provider familiarity.

Multiple guidelines recommend that families be offered genetic testing to learn more about why their child has a hearing difference and to inform them about any possible related health concerns. Genetic *testing* is always an option for families; it is not required. However,

genetic *counseling* is always recommended so that families can participate in a fully informed discussion about testing before making a decision.

Here's the key: it should be the family's informed choice. They should never feel pressured to undergo genetic testing. If they do choose to pursue it, they deserve clear, compassionate support to understand the implications of results. No matter what the results show, those results can't define their baby's future. Their child is full of potential, and their hearing status is just one part of who they are. Hands & Voices has a motto, *"What works for your child is what makes the choice right."tm* Parents need to trust their instincts, ask questions, lean on support groups and experienced parents, and know that as they move through the considerations of whether to test or not, they can make the decision that is right for them. (adapted from pg. 4 of A Parent's Guide to Exploring Genetic Testing)

Timing, Pacing, and Emotional Readiness

Careful timing, pacing, and monitoring parents' understanding is *critical* when introducing genetic testing. These elements can profoundly influence how parents process information, make informed decisions, and ultimately engage with services. Here's why each is important:

1. Timing Matters: Meeting families where they are

Why it matters:

- A diagnosis of hearing loss often brings emotional overload. Introducing genetic testing *too soon* can overwhelm families.
- Some parents may be in a state of shock, grief, or denial and are not yet ready to consider complex decisions.
- Others may want as much information as possible and as soon as possible.

Best practice:

- Personalize the timing based on the family's readiness and emotional state.
- Offer initial *awareness-level information* early (e.g., "Genetic testing is one way to learn more. We can talk more about it later.") and revisit it later during follow-up appointments.

2. Pacing builds trust and aids comprehension

Why it matters:

- Genetic testing can involve an unfamiliar science and results, with possible emotionally loaded implications.
- Pushing for consent may lead to confusion, fear, or mistrust.
- Parents need time to consider how genetic testing aligns with their values, goals, and cultural beliefs.

Best practice:

- Adapt to the needs of the family. If needed, you can break information into digestible pieces over multiple conversations. Some families may want all the information immediately.
- Be comfortable with waiting or delaying the decision if the family isn't ready, while ensuring they know the option remains open.

3. Checking for understanding promotes informed decision-making

Why it matters:

- Misunderstandings can lead to mistrust, unnecessary worry, or false expectations about what testing can reveal.
- Informed consent requires more than a signature; it requires clarity and comprehension.

Best practice:

- Use teach-back methods: "How would you describe what this testing might show to a family member? Ask open-ended questions: "What questions do you still have about this?" (Ha Dinh et al., 2016)
- Be sensitive to language and literacy needs; use interpreters and visual supports when necessary.

Considering and addressing these elements can be highly beneficial because it respects the family's emotional process while building trust in providers and systems. It also encourages equitable access and true informed consent, while improving a family's satisfaction with care and increasing follow-through with next steps.

Emotional Journeys: Supporting Reactions and Questions

As you seek to support families considering genetic testing, it's important to understand that informed decision-making is not only about reviewing objective information but also about navigating the emotional context each family experiences in a unique way. Guilt, fear, and curiosity are all 'normal' reactions when deciding whether to pursue genetic testing for one's child. Emotions may be delayed, layered, or contradictory. Different members within a family unit may experience feelings that are unique to them that other family members may not experience.

Being aware of the emotional layering within conversations with parents is a skill that can benefit your medical practice. There is no single "right" answer when it comes to genetic testing. Families are diverse, and so are their values, beliefs, and needs. For some, testing provides clarity, peace of mind, or direction for the future. For others, it introduces uncertainty, emotional strain, or difficult questions they're not ready to answer. While genetic testing can assist in a medical management plan and even save a child's life (for example, identifying Jervell-Lainge Nielson syndrome where profound hearing loss may coincide with a preventable risk of cardiac arrest), choices to test or not must still be given, along

with clinical judgment about personalized medicine and other options for testing. Choosing whether to pursue genetic testing is a personal decision for families.

The informed decision-making process is at its best when families get input from a variety of sources, including medical professionals, Deaf Culture/Community, parents and parent groups, and those with specific genetic expertise (i.e., genetic counselors). Parent groups are uniquely suited to come alongside families to explore and support the emotional context of these complex decisions, often providing opportunities for one-on-one support with experienced parents.

The following is a list of ways that parent support can help. (For more on how experienced parents and parent groups can help, see A Parent's Guide to Decision Making, page 9)

How Family-to-Family Support Can Help

- **Emotional Support and Understanding:**
  - Share experiences running the gamut of curiosity, guilt, helping others, and preparation.
  - Help normalize the experience and reduce feelings of isolation.
  - Provide validation through hearing stories, which may affirm a parent's experience, offering comfort in a tough decision-making process.
  - Parents can share reasons why they did or didn't pursue testing for other families to consider in light of their own journey.
- **Firsthand Insights and Practical Advice**
  - Real-world perspectives (what the process was like, how long it took, how their child reacted, what they learned).
  - Questions to ask, including questions a new parent might not think to ask.
- **Informed Decision-Making**
  - Discuss the pros and cons, benefits, potential limitations, or emotional impacts of testing.
  - Hear a variety of outcome stories: positive, neutral, or unexpected, to help parents make a more informed and personalized decision.
- **Navigating the System**
  - Resources and referrals: parents/parent groups can often share recommendations or financial aid options.
  - Advocacy: Parents can learn how to better advocate for their child's needs from other parents.
- **Ongoing Community**
  - Continued support after the decision is made or testing is completed, as parents remain connected to other families for sharing and growth.
  - Celebrating milestones where progress and small victories can be celebrated by those who truly understand the journey.

Refer families to family-led organizations (like Hands & Voices chapters or other support groups) or offer to facilitate connections to families with shared experiences after gaining consent.

> *"We wanted to understand why, but it wasn't easy to decide. Learning from others helped."*
>
> ***– Parent of a DHH child***

Explaining Results to Families

Explaining genetic test results is one of the most sensitive and impactful moments in a family's journey.

While a particular result may bring relief and peace of mind to one family, it might be upsetting to another. Providers can never presume how results will be received as these family experiences note.

"I was upset for a long time after I found out the cause of my child's deafness was genetic. Because the DNA had come from me and my partner, I carried that burden and worried about our future children. In time, with support, I came to realize that it wasn't our fault, but it was hard in the beginning." -Parent blaming themselves for a genetic cause.

> *"I worried that I'd done something wrong when I was pregnant with my child to cause their deafness. When I found out the cause was genetic, I was relieved to know that it was down to chance and not something that I had done!"*
>
> ***– Parent relieved to learn a genetic cause was identified.***

Say This, Not That When Discussing Genetic Testing

Because the words you use can both empower or overwhelm families, this section offers practical examples of supportive versus unhelpful phrasing when discussing genetic testing with families of children who are DHH. Common phrases that may unintentionally create pressure, imply judgment, or cause fear are contrasted with thoughtful language that respects family autonomy, values, and emotional experiences. Each suggested phrase pairs with a rationale explaining why the alternative approach matters, promoting informed decision-making and sensitivity in conversations around genetic testing that can open the door to wider learning. Small shifts in language can change a conversation from directive to collaborative.

Say This, Not That

Instead of:	Say this instead:	Why it Matters
"You *should* get genetic testing."	"Some families find genetic testing helpful to understand the cause of their child's hearing difference and find other related conditions that could be treated or managed more quickly. Would you like to learn more about what it can offer?"	Avoids pressure and supports informed decision-making.
"We need to know what's *wrong* with your child."	"Sometimes, genetic testing can help us understand more about your child and may point to important treatments sooner than we would learn about otherwise.	Avoids framing deafness as a defect or problem and leads to opportunities for families to learn more about possible benefits of genetic testing.
"If you want to be a responsible parent, you'll do this."	"Every family approaches this decision differently — I'm here to support whatever you decide."	Reinforces that the decision is personal and values-neutral.
"You might regret not finding out now."	"Some families prefer to know more information early on, while others choose to wait or not test at all. While that is your choice, there are some reasons I could share that might help you decide."	Respects the family's autonomy and timeline.
"This is the *only* way to really understand your child's hearing loss."	"There are many ways to understand and support your child's needs — genetic testing is one option that may give more insight."	Avoids overpromising or minimizing other available approaches.
"This could prevent future children from being deaf."	"Genetic testing can provide information that may be useful for future family planning, if that's something you're considering."	Avoids implying that being deaf is something to be 'prevented'.
"It's just a simple test; there's no reason not to do it."	"Even though it's a simple process, it can bring up complex questions. I'm here to walk through genetic testing with you."	Validates emotional and ethical weight of the decision.
"A positive result means your child will *definitely* have other health problems."	"Some results may suggest risks for other conditions, but not all do. If that's something you'd like to explore, we can talk about what to expect."	Prevents fear-based interpretation of results.
"We need to rule out any syndromes right away."	"Some types of hearing loss are part of a broader medical picture. Testing can sometimes help identify other health information, if you're interested."	Frames testing as optional and useful, not urgent or alarming.
"You will definitely get answers to your questions regarding your child's hearing loss."	"While genetic testing can often give you insights into the cause of your child's hearing loss or other medical conditions, many times testing is inconclusive."	Avoids overpromising and leads to opportunities to discuss all possible outcomes and manages expectations.

1. Before Sharing Results

- Ask first: “What have you heard so far about the test?” or “What do you hope these results might tell you?”
  Check readiness: Gauge emotional state, who is present, and whether an interpreter or support person is needed.
- Clarify expectations: Families may hope for certainty or actionable answers; it helps to know this before sharing results.

With this knowledge of a family’s understanding, hopes, and concerns, you’ll be ready to deliver and discuss the results in a family-centered manner and in a culturally safe way.

2. Sharing Results

- Use clear, jargon-free language. Genetic change is more positive than mutation. Analogies with recipes or instruction manuals can explain DNA and uncertainty.
- Positive (pathogenic/likely pathogenic): “We found a change in DNA that explains your child’s hearing difference.
- Negative: “We found no clear genetic reason for your child’s hearing difference.”
- Inconclusive: including Variants of Unknown Significance (VUS): “We found a change in DNA, but right now, science cannot tell us if it causes hearing differences.”

3. Pause and Listen

- Silence is okay. It gives families time to process.
- Listen to questions behind the questions, paraphrasing to check understanding.
- Some families describe relief in finally having an explanation or empowerment in using results to advocate for needed supports.

4. After Results

- Acknowledge emotions: Families may feel guilty (e.g., “Did I pass this on?” or relieved, (e.g., “Now we know why and can make a better plan”). Normalize both.
- Extend the circle: Discuss whether siblings and extended family may benefit from testing.
- Discuss next steps: Medical management, shared resources, referrals e.g., to genetic counselors, parent groups, mental health providers.
- Plan for follow-up: Some families should be encouraged to follow up with geneticists every three years in limited circumstances (Alford, et al, 2014). Certainly, families should be contacted if changes occur in testing or they have questions as testing evolves, especially for VUS results. Offer more than one opportunity to revisit results and questions. Families process differently over time.

More About Discussing Variants of Unknown Significance (VUS)

Parents often describe VUS results as “answers that aren’t answers.” Normalizing this frustration and planning follow-up conversations can help families manage uncertainty.

If an inconclusive result is received, a genetic alteration is detected that has an unclear association with deafness (called *variants of unknown significance* (VUS). Help families digest that, in cases of both negative results and VUS, current knowledge is incomplete. While no genetic cause has been confirmed, there are genetic causes of deafness that we cannot yet test for, so a chance remains that the cause is genetic. The consequences of VUS are not always well understood; families need to be given objective information from a genetics counselor to understand whether the VUS is realistically a possible risk or if it is more likely benign and not related to childhood hearing loss. More information will likely become available in the future as more data is collected, and research continues to learn more.

Families want to know these important points:

- **What do the technical findings mean?** Use clear, jargon-free language to ensure understanding and reduce confusion. Break the explanation down into small chapters of the whole story. After each piece of information has been shared with a family, go beyond asking, ‘Does this make sense?’ to gauge their understanding e.g., I hope I’ve been able to clearly explain this to you. Can you tell me what you understand to make sure I’ve given you the correct information before we move on?’
- **How do families decide about sharing results with other family members?** Help a family understand the results in the context of genetic risks across generations while encouraging open dialogue. This includes supportive conversations about family planning, what results could mean for siblings or other family members, how to decide if this will be shared, and how. Parents may ask if siblings should be tested. Also, give considerations when thinking about sharing results more broadly with others.
- **What further support does my child or my family need?** The findings may bring about the need for support in new or existing areas. For example, if an underlying cause of the child’s hearing difference has been confirmed, the family may want to know how to connect with others who share the same cause, and/or with those who provide support and/or early treatment options to those with a particular condition. If an underlying cause has not been confirmed, a family may want to know if there are any other medical procedures that they can explore to help them fill in some gaps in their knowledge, such as CT or MRI scans, ophthalmology exams, and/or how they can stay informed about future opportunities for further genetic testing and/or diagnostics as technologies improve. In either circumstance, family members may benefit from access to counseling or other mental health services to help them through the journey of understanding their child’s diagnosis.
- **How can follow-up questions or concerns be answered?** Are you able to provide them with up-to-date resources on topics that arose in your discussions? Can you direct them to trustworthy information, research opportunities, and clinical trials that

could inform or improve care? For example, findageneticcounselor.nsgc.org can guide families to a local genetics' counselor in the USA and Canada.

- What are a family's rights and responsibilities regarding their data and privacy? Review genetic testing data protection so the family is aware of what they consented to regarding the use and storage of their data, and their rights and responsibilities (see more about privacy on page 19)

Working with Families of DHH Plus Children

When professionals work with families who know or suspect additional health concerns beyond hearing loss, it's essential to recognize that genetic testing may provide valuable insights. For some families, testing can provide a clearer understanding of possible future diagnoses, the likelihood of progressive hearing loss, allowing for more specific and earlier interventions, decisions about amplification, cochlear implant candidacy, visual language, and potentially improved outcomes. It can also prevent ototoxicity. Certain mitochondrial DNA variants in newborns are a common risk factor for deafness and can be detected through genetic testing. These mitochondrial DNA variants lead to high sensitivity to aminoglycosides, such as Gentamicin, a commonly used antibiotic in neonatal intensive care. One dose of gentamicin can cause significant deafness in babies with this variant. Diagnosis could prevent aminoglycoside-induced deafness in vulnerable maternal relatives as well.

Certainly, for some families--especially those navigating complex care needs, multiple diagnoses, NICU stays, frequent medical appointments, financial burdens, other children, and daily stress—genetic testing may feel like one more overwhelming task. In some cases, families may choose to delay or forgo genetic testing altogether, needing to focus on immediate priorities.

Medical Trauma

Many families of medically complex children report experiencing medical trauma and even posttraumatic stress disorder related to their child's medical care. Frequent hospitalizations, invasive procedures, and ongoing uncertainty can take a toll on both the child and their caregivers. (Franck et al., 2022; Nelson & Gold, 2020). For some, the decision not to pursue genetic testing is an intentional step to minimize further trauma.

Key Considerations When Supporting DHH Plus Families:

- **Impact on Decision-Making:** Families may weigh whether genetic results could meaningfully influence decisions, such as communication choices. For instance, a diagnosis like Usher syndrome, (a rare inherited condition affecting hearing and causing early or late onset vision loss through gene changes in the inner ear and retina) could shift how a family approaches communication methods, knowing their child may lose functional vision. Early diagnosis can also accelerate discussions around cochlear implants or the use of visual language and other interventions.

- **Life Changes Based on Results:** Some families may consider significant changes—such as relocating—to access services and supports better aligned with anticipated outcomes identified through genetic testing.
- **Extended Family Implications:** Genetic testing can also provide information for siblings and other relatives. Some conditions do not present at birth, and testing may reveal risks for additional family members—an especially relevant concern for DHH Plus families already managing multiple medical needs.
- **Future Planning:** Genetic testing can sometimes provide information for family planning and the likelihood of additional children with special needs as families assess their readiness to (potentially) raise another child with multiple needs or understand what to anticipate for future grandchildren.
- Belief Systems: Cultural and religious values may influence how families view genetic testing. Some may oppose testing for hearing loss but feel differently when it comes to testing for broader health conditions. Professionals should approach these conversations with cultural humility and curiosity. (See more about this on page 18)
- **Emotional Burden of Results:** A DHH Plus diagnosis can already carry emotional weight. Learning about additional risks or severe prognoses through genetic testing may heighten anxiety and emotional distress. Some families choose not to pursue testing to stay present with their child and avoid anticipatory grief.
- **Dealing with Medical Trauma**: Families may need additional support if impacted by medical trauma. Narrative medicine (the listening and understanding of patients' stories) may be one way to honor a family's concerns; supportive counseling is another. If pursued, genetic testing may help end years of uncertainty for families whose children have multiple, seemingly unrelated medical concerns, and who may have felt dismissed by professionals, despite their concerns. Families experiencing trauma may take extra time to build trust with partnering providers and need concrete facts about how testing may change their child's trajectory, even in the face of uncertainties.

As professionals, it is crucial to provide balanced, compassionate, and individualized support when discussing genetic testing. Acknowledge the family's lived experiences as a DHH Plus family, validate the range of emotions that can surface as a result of multiple diagnoses, and ensure the family feels empowered—rather than pressured—in making this complex decision. All choices are valid, and DHH Plus families deserve space and support to decide what's right for them.

Recognizing Deaf Culture, Identity, and Belonging

When supporting families of DHH children in decisions about genetic testing, professionals need to recognize the broader cultural, ethical, and faith-based landscape that surrounds this deeply personal choice. Deafness is not only a medical condition, but for some, can also represent a vibrant cultural identity and a sense of belonging within the Deaf community. For others, hearing differences highlight barriers to full inclusion in the community. To provide truly informed support, professionals must approach each family's decision-making

process with cultural humility, respect for diverse belief systems—including faith-based values that are foundational to ethical and respectful care. This includes considering the lived experiences, values, and insights of DHH individuals.

"Nothing about us, without us" is a commonly understood concept within disability rights and advocacy communities. With regards to genetic testing for DHH children, professionals must center the lived experiences of DHH community members when supporting families with DHH children. DHH community members can offer valuable insight to hearing parents of DHH children and share about the Deaf community and culture. The awareness that parents gain from DHH community members is a crucial aspect of ensuring informed decisions on genetic testing for their DHH children.

> *"We have found that we can hold two things at the same time, our identity about seeing deafness as part of who we are and also pursuing medical information at the same time."*
>
> ***– a Deaf individual***

Unlike many other health-related conditions, being Deaf is not just a description of health status but can also include identity and belonging. Deaf culture is distinct with its own beliefs, customs, attitudes, language, and behavioral norms. Within Deaf culture, there is a widely held belief that being Deaf is not something in need of a fix or cure, but rather, a beautiful and rich part of human diversity that should be cherished.

While the Deaf community largely supports the availability of genetic testing when families/individuals are provided with comprehensive information with which they can make informed decisions (Guillemin & Gillam 2006), it is important to be aware of the historical context when having these conversations. Deaf people were targeted by eugenics movements in developed countries, including the U.S., Germany, and Scandinavia, where sterilization and restrictions were imposed. (Lane, 1992; Baynton, 1996; Broberg & Roll-Hansen, 2005; Friedlander, 1995). Research in trauma studies further suggests that such systemic oppression by hearing people can have intergenerational and even epigenetic consequences (Yehuda & Bierer, 2009).

When working with families on decision-making about genetic testing for their DHH child, consider the following practices to support informed consent:

- Reflect on your own biases as well as the depth of your understanding of Deaf culture and history. Work to unpack biases and learn more about the Deaf experience before discussing genetic testing decision-making with families. (See Reflection Tool: Supporting Families Without Bias in the appendix.)
- Ensure that the family has access to members of the DHH community and/or resources to connect with the DHH community in their area.
- Share personal stories, quotes, case studies, etc. from DHH individuals on their experiences with genetic testing, both positive and negative.

- Recognize that some individuals do not see that being DHH is a “problem” to be fixed but a natural part of human experience and diversity.
- Encourage families to think beyond the medical lens and consider whether they see deafness as a negative outcome or as a different way of being.
- Bring ethical depth to the decision, highlighting the impact on the dignity and visibility of Deaf and hard of hearing people.

> *“I’m Deaf and I’m proud of who I am. I don’t see the need to know more than that.”*
>
> ***– a Deaf individual***

Cultural Considerations in Genetic Testing: Inclusive Engagement Strategy

Genetic testing carries profound implications for individuals and families, especially when viewed through the lens of cultural diversity. Cultural beliefs, language barriers, historical mistrust of medical systems, and varying levels of health literacy can all influence how communities perceive and access genetic services. In addition, “families from historically marginalized groups often experience systemic barriers when accessing genetic services. Without deliberate equity strategies, advances in genomic medicine risk deepening existing health disparities (Roberts, et al., 2021).” Recognizing these differences is essential to ensure that testing is not only scientifically sound but also socially and ethically responsive.

How to address these nuances

It is important to find ways to elicit meaningful *community-driven engagement* that centers diverse voices and builds trust through culturally relevant outreach. Building a community of understanding between professionals and the DHH community is essential to find ways to address family concerns, disseminate comprehensive information, and create transparency regarding genetic testing. Community engagement works best by being inclusive of multicultural teams, including professionals and families that represent diverse communities in addition to DHH individuals. This ensures that engagement efforts reflect lived experiences and cultural values.

Create opportunities for regular *Stakeholder Meetings & Feedback Loops*: Regular forums with families, educators, and health professionals allow for continuous input, fostering transparency and adaptability.

Why This Matters

Cultural sensitivity when it comes to genetic testing isn’t just about science, it’s about equity. By embedding diverse perspectives into every layer of engagement, this initiative strengthens systems, builds trust, and ensures that every family—especially those from historically underserved communities—has a voice in shaping their future.

Addressing Faith-based Concerns and Value Systems

Existing communities of faith can have a powerful influence on a family with a child who has been diagnosed with a hearing loss, regardless of the degree. Belief can inform and influence a family's experiences of support beginning with diagnosis, through decisions about technology, genetic testing, communication choices, educational options, and parenting.

The impact of a family's faith, religion, and spiritual reflections in response to these things is often a primary driving force for families and may or may not be communicated to support providers. The necessary skills and self–reflection needed to provide support in this context can be complicated and sometimes ignored or seen as *"not part of my job."* However, it is important to contemplate one's own beliefs about faith and how they may influence a conversation potentially supporting or disregarding a family's faith system as they seek to make decisions about their child.

A family's perspective on how they perceive the identification and etiology of deafness from a spiritual context often varies widely. A family may see the diagnosis as a gift from God - a blessing that shapes their child and family in unique ways; that God has also sent professionals (who are a part of the 'helping professions') into their lives to help support the journey. Conversely, the experience may be seen as a 'curse' from God - a shameful reflection of the family based on spiritual beliefs and cultural background. These beliefs may be deeply held but not always openly shared, creating a need for professionals and support providers to approach families with sensitivity, humility, and self-awareness. As Anne Fadiman wrote in *The Spirit Catches You and You Fall Down*, "I thought of how often people misunderstand each other even when they have the best intentions, and how much of one's life is shaped by such misunderstandings." (Fadiman, 1997)

> *"When we learned our child was deaf, our faith gave us peace, and genetic testing gave us answers. We never saw them as opposites — we believe God works through science to help us understand and care for our children in the best way possible."*
>
> ***- Parent of a Deaf child***

Supporting families of DHH children in decisions about genetic testing requires a thoughtful balance of cultural awareness, ethical sensitivity, and respect for faith-based values. Recognizing that DHH individuals are just as varied in their viewpoints as hearing people. Viewing hearing differences ranging from disabilities or medical conditions to rich cultural identities is essential to honoring the diverse perspectives families may hold at the start of their journey. Professionals must approach these conversations with humility, openness, and a commitment to providing comprehensive, unbiased information while connecting families of all cultures to the DHH community and honoring their spiritual beliefs. By doing so, families can make informed, meaningful choices that reflect their values, identities, and hopes for their children's futures.

Privacy, Ethical and Access Considerations in Genetic Testing

Parents also have questions about privacy and ethical considerations in genetic testing. Let's look at privacy considerations first.

Privacy

Parents may worry that their child will be labeled, that results will follow them into school or insurance systems, or that extended family will misuse information. Genetic data is personal information that can reveal medical predispositions and family risks. Other technologies, like MRI or lab testing, can also determine conditions that run in families or have serious implications. Families want to understand the potential risks to their privacy. They want to know how and where their child's data will be collected, used, and protected. Families also want to know their rights and responsibilities. Families may have questions and concerns before genetic testing, and important topics they may want to discuss when seeking assurance can include:

What are they agreeing to?

Families want to have a thorough understanding of what information will be collected and how it will be used. Some families may want to know if they have the right to access their genetic data and request its deletion.

What genetics laboratory will carry out the testing (i.e., public versus private body) **and where will it be done** (i.e., under which jurisdictions)**?**

In a healthcare setting, genetic testing is done by a clinical laboratory that meets national and federal regulations, depending on the country. This means they meet guidelines for privacy and data protection. Sometimes the genetics lab is part of a hospital; sometimes it is a private healthcare genetic testing company.

What legal protection covers them?

The genetic testing process may involve multiple jurisdictions. Regulations like the Genetic Information Nondiscrimination Act (GINA) in the U.S, and similar legislation in other countries, aim to safeguard genetic information from discrimination and misuse. (GINA is a U.S. law that protects people from being discriminated against by health insurers or employers based on their genetic information.)

Companies offering genetic testing usually have privacy policies that outline how they collect, use, and protect data. In the U.S. these companies comply with HIPAA and other federal regulations (such as CAP and CLIA certification). There are similar regulations across the world.

What will be done with their data afterwards?

How will it be stored and kept secure from unauthorized access? Could the data be used for other research or purposes and/or be shared with other third parties without further consent from the family? If the data was shared with others or there was a data breach, could the data identify their child?

Families are aware of significant data breaches in direct-to-consumer DNA testing, as well as in the broader digital world of personal emails and financial information. Families want to know how their genetic data will be safeguarded. It is important for families to know that clinical genetic testing is different from direct-to-consumer tests like *23andMe.* It is ordered and interpreted by healthcare providers, uses medical-grade laboratories that meet strict quality standards, and is designed to detect variants in genes known to cause hearing loss.

Taking the time to work through these discussion points with a family will help them feel confident in their understanding of the process and their decision about genetic testing. Directing them to further resources can help them get more information when needed; local geneticists, genetic counselors, or genetic testing laboratories should be able to answer specific questions on these privacy topics.

> *"When new genetic testing became available, we asked about it for our pre-teen as earlier, simpler testing hadn't given us a clear answer. The genetic counselor talked us through the possible outcomes and our concerns about privacy and data protection. We realized the results wouldn't alter anything in our child's circumstances, and we had some concerns about potential data sharing and leaks, so we decided not to go ahead with testing after all."*
>
> ***- Parent of an older DHH child.***

Ethical Considerations

Before you begin a conversation with family members about genetic testing, do you have in mind what they should do for their child? Reflection helps uncover biases, even those gained through your specific training. These conversations may be quite emotional for families, carry lifelong impact, and be deeply personal. It is critical that as a professional, you enter the conversation with a non-biased, family-centered framework. This means appreciating the family's autonomy and right to informed decision-making, and providing comprehensive information, without attempting to steer the family's decision.

Below are some considerations in offering and discussing genetic testing with families with DHH children:

- Offer clear, jargon-free explanations of what genetic testing is and what it can and cannot reveal, potential outcomes, and potential limitations of testing.
- Ensure that families understand that genetic testing is optional.
- Respect that testing is a personal decision.
- Ensure that information about genetic testing is delivered in the family's native language, and with culturally relevant information; provide interpreters and translation of resources to ensure access if needed.

- Consider the timing for offering genetic testing and/or discussing genetic testing.
- Discuss how the results of genetic testing may have a psychosocial impact on the child's identity development.
- Ensure that the family has access to Deaf community members and/or perspectives of the Deaf community on genetic testing so that they can learn more about Deaf cultural perspectives on deafness and genetic testing. Collaborate with Deaf professionals when possible.
- Connect parents with other parents of DHH children who can provide family-to-family support.
- Thoroughly explain privacy, confidentiality, and legal protections related to genetic testing. Discuss how data/results are stored and/or shared.
- Have a clear and easy process for parents to refuse genetic testing and to document refusal and clearly communicate with parents how/when/if they might reconsider or if they want to know about opportunities in the future.

Access Considerations

Comprehensive genetic testing is now widely recommended as standard of care for children with hearing loss (Shearer et al., 2019). Yet in practice, access remains uneven. "Systemic barriers may include lack of insurance coverage, long distances to specialists, limited culturally and linguistically accessible information, and provider bias...Without deliberate attention to equity, genomic medicine risks reinforcing health disparities." (Roberts, et al., 2021). Studies specific to childhood hearing loss confirm that families from underserved backgrounds are less likely to benefit fully from genetic testing, despite its potential to inform care and management (Sloan-Heggen et al., 2016). What barriers do your families face in receiving genetics services?

Access

Barriers:

- Limited availability of pediatric genetic services, especially in rural or underserved areas.
- High out-of-pocket costs or lack of insurance coverage for some families.
- Long wait times and difficult travel for appointments in some regions.
- Lack of trained professionals who understand both genetics and pediatric hearing loss.
- Medical home models of care for children who are DHH are disparately low. This includes family-centered care, ease of referrals, and effective care coordination, all contributing to lack of support for meeting Early Hearing Detection and Intervention (EHDI) milestones. (Khalsa & Chan, 2024)

Potential Solutions:

- Tele-genetics services: Expand remote consultations and testing to reach rural and underserved families.

- Insurance advocacy: Push for coverage mandates and inclusion flow charts for EHDI programs and the 1-3-6 timeline.
- Just-in-time training for pediatric audiologists, early intervention providers, and other stakeholders to explain and refer families for testing.

Trust

Barriers:

- Historical and ongoing medical mistrust, particularly among communities of color and indigenous populations.
- Miscommunication or lack of culturally sensitive information.
- Fear of stigmatization or misuse of genetic information.

Potential Solutions:

- Community-informed outreach: Partner with community leaders and organizations to co-create messaging.
- Cultural humility training for genetic counselors and other providers.
- Transparent communication: Clearly explain what testing can (and cannot) reveal, including benefits and limitations.

Equity

Barriers:

- Disproportionate referral and testing rates among families based on race, income, primary language, or immigration status.
- Limited availability of materials and services in languages other than English.
- Bias in provider assumptions about which families “would benefit” from testing.
- Lack of follow-up care after a genetic result is received.

Potential Solutions:

- Universal offering of genetic testing to all families of children with confirmed hearing loss, with opt-in education.
- Language access: Provide interpreters and translated materials for all major languages in the region.
- Cross-sector coordination: Ensure that genetics, audiology, early intervention, and primary care are aligned and that families are receiving follow-up.

Conclusion

This guide has uniquely walked you, as a professional, through a conversation with us at Hands & Voices, and we are extremely grateful. Supporting families in decisions about genetic testing for children who are DHH requires humility, cultural awareness, and a

commitment to family-centered care. These conversations are layered with medical facts, emotional responses, cultural perspectives, and personal beliefs. Professionals who approach families with sensitivity—by respecting their values, acknowledging their lived experiences, and offering clear and unbiased information—help ensure that families can make decisions with confidence and dignity. Recognizing the expertise that families themselves bring, and centering the voices of DHH individuals, strengthens the decision-making process and fosters trust.

Ultimately, there is no single "right" choice when it comes to genetic testing. Each family must weigh their unique circumstances, hopes, and concerns to determine what is best for their child. The role of professionals is not to direct a family's decision but to walk alongside them, providing support, connection, and resources. By centering respect, equity, and compassion, we can create a landscape where families feel informed, supported, and empowered to take the path that is right for them.

Resources for Further Learning

When supporting families through conversations about genetic testing related to childhood hearing loss, access to accurate, up-to-date, and family-friendly resources is essential to providing compassionate and effective care.

The curated resources below are designed to help clinicians, early interventionists, audiologists, and family support professionals deepen their understanding and offer families accessible, parent-centered information.

For Professional Learning

These resources will help you stay up-to-date when speaking with families:

National Society of Genetic Counselors. (NSGC)(n.d.). *Genetics & hearing loss*. Retrieved August 29, 2025, from https://www.nsgc.org

Callahan, K. P., et al. (2024). Frequency and reasons that parents decline genetic testing for critically ill neonates. *Genetics in Medicine Open, 2*, Article 101896. https://doi.org/10.1016/j.gimo.2024.101896 A research article exploring parental decision-making and ethical considerations.

Young, T. L., Frush Holt, C., McLaughlin, K., Patel, H., & Chung, W. K. (2024). Parent experiences with genetic testing for pediatric hearing loss. *JAMA Otolaryngology–Head & Neck Surgery, 150*(10), 905–912. https://doi.org/10.1001/jamaoto.2024.

Barnett, C. L., Malhotra, P., VanHorn, A., Zaharieva, B., Myers, J., Riggs, W. J., & Jordan, E. (2025). Utilization of genetics services in the diagnosis of hearing loss in newborns in the state of Ohio. *Journal of Community Genetics, 16*, 603–613. https://doi.org/10.1007/s12687-025-00816-0

Middleton, A., Mendes, Á., Benjamin, C. M., & Howard, H. C. (2017). Direct-to-consumer genetic testing: Where and how does genetic counseling fit? Journal of Genetic Counseling, 26(6), 1160–1169. https://doi.org/10.1007/s10897-017-0149-9

GenomeConnect Webinar – "Genetics 101" and "How to Read Genetic Sequencing Test Report." A two-part series from the Clinical Genome Resource to better understand genetic testing and interpretation.

Part 1: Genetics 101
Part 2: Reading Lab Reports

For Sharing with Families

These parent-friendly resources are ideal for helping families understand genetic testing in the context of hearing loss:

Baby's First Test – Genetic Testing 101
A gentle accessible introduction to genetic testing for families.
https://www.babysfirsttest.org

CDC – A Parent's Guide to Genetics and Hearing Loss
Interactive guide with visuals and videos to support family learning.
https://www.cdc.gov/hearing-loss-children-guide/parents-guide-genetics/index.html

Hands & Voices – Genetic Education Page
A hub of resources with tip sheets, real stories, infographics, and guidance created with families and for families.
https://handsandvoices.org/resources/genetic-testing

Hands & Voices Genetics Infographic – *Family and Child Genetic Testing Considerations.*
A printable infographic for parents and caregivers.
https://handsandvoices.org/resources/genetic-testing/genetics-infographic.pdf

Video: Why Are Genetics Important for Children with Hearing Loss?
Short, captioned video from Michigan Medicine with translated subtitles.
Watch on YouTube (2 min)

National Deaf Childrens Society (UK) – Genetic and Genomic Testing
Clear, family-focused guidance on the role of genetics in deafness.
https://www.ndcs.org.uk/advice-and-support/all-advice-and-support-topics/causes-types-and-signs-deafness/causes-deafness-and-hearing-loss/genetics-and-deafness/genetic-and-genomic-testing

Find a genetic counselor: Guide for families to locate genetics counselors in the USA and Canada: https://findageneticcounselor.nsgc.org in person or through telehealth.

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Barnett, C. L., et al. (2025). Utilization of genetics services in the diagnosis of hearing loss in newborns in the state of Ohio. *Journal of Community Genetics*, 16(5), 603–613. https://doi.org/10.1007/s12687-025-00816-0

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Broberg, G., & Roll-Hansen, N. (2005). *Eugenics and the welfare state: Sterilization policy in Denmark, Sweden, Norway, and Finland*. Michigan State University Press.

Dedhia, K., et al. (2013). Children with sensorineural hearing loss after passing the newborn hearing screen. *JAMA Otolaryngology–Head & Neck Surgery*, 139(2), 119–123.

Fadiman, A. (1997). *The spirit catches you and you fall down: A Hmong child, her American doctors, and the collision of two cultures*. Farrar, Straus and Giroux.Franck, L. S., et al. (2022). The lived experience of parents of children with medical complexity. Children, 9(2), 162. https://doi.org/10.3390/children9020162

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Shearer, A. E., et al. (2019). A proposal for comprehensive newborn hearing screening to improve identification of deaf and hard-of-hearing children. *Genetics in Medicine, 21*(11), 2614–2630. https://doi.org/10.1038/s41436-019-0563-5

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Stevenson, J., et al. (2015). Emotional and behavioural difficulties in children and adolescents with hearing impairment: A systematic review and meta-analysis. *European Child & Adolescent Psychiatry, 24*(5), 477–496. https://doi.org/10.1007/s00787-015-0697-1

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Appendix

Reflection Tool: Supporting Families Without Bias

Purpose: A quick self-check for professionals to help ensure conversations about genetic testing are balanced, respectful, and family centered.

What's My Intention?

Is my goal to support and inform - or am I guiding the family toward my own Personal Belief System (PBS)?

- Have I considered that "the right decision" may differ for each family based on culture, faith, or personal priorities?
- Am I unintentionally presenting this as the "most common path" instead of one of several valid options?

1. **Honoring Family Values**

- Am I centered on the family's unique needs, values, and goals?
- Have I considered the family's primary language and whether they have full access to the information in that language?
- Am I prepared to discuss both medical benefits *and* potential cultural or ethical concerns?
- Am I offering options in a balanced way – or am I emphasizing one approach over others?

2. Language & Presentation

- Is my language neutral and informational, not persuasive?
- Could any words I've chosen, or my tone of voice, convey unintended judgment or bias?
- Am I using open, respectful phrasing like: "some families find this helpful" instead of "you should…"

3. Encouraging Empowered Choice

- Have I created space for the family to share their own goals and values before offering recommendations?
- Have I invited them to ask questions without feeling rushed or judged?
- Do families leave the conversation feeling informed, not directed?