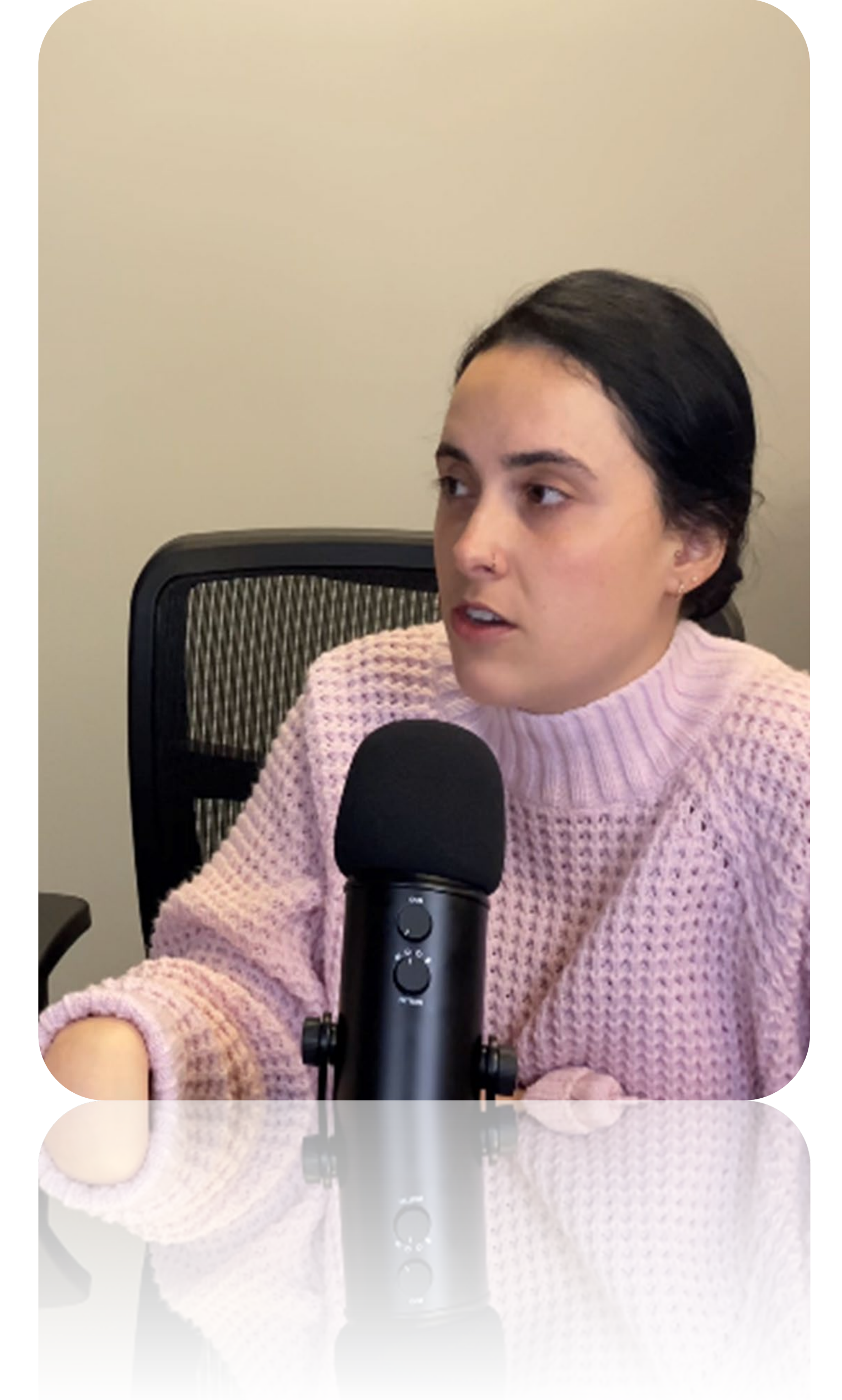




## Interviews with parents of children with hearing loss to explore the impact of hearing loss on families and gain advice for parents and professionals



### Introduction

Parents of children newly diagnosed as deaf or hard of hearing (DHH) experience a myriad of emotions and, for most, begin a journey into unfamiliar medical, audiological, and intervention services. They learn new terms and vocabulary and begin making important decisions within a relatively short period of time.

Some parents experience a breadth of support from professionals, family members, and friends within their community. However, many families have described feelings of fear, isolation, loneliness, and confusion, particularly if no one close to them has had similar experiences. Learning from other families of children who are DHH and knowing of their challenges and successes can be of great support and comfort. This parent-interview project was conducted to listen to parents who are experiencing this journey and gain their thoughts and suggestions for other parents and for the professionals who serve them.

### Emerging Themes from Parent Interviews

**Be Compassionate.** We are experiencing fear and uncertainty – and remember this is involving the most important person in the world to us.

**We Need Information.** The internet is not helpful. Direct us in a timely manner to relevant and reliable resources.

**See Our Child's Potential.** Our child will grow up to do everything other children do. Help reassure us during the early stages after diagnosis.

**Give it to Us Straight.** Spending time in uncertainty is isolating and scary. Help us know our options without bias.

**Help us Know How to Advocate.** We want to be the best advocate for our child, but we may not always know how to do that.

**Be our partner.** We need to be empowered as equal partners. We rely on professionals for information, but we know our child and family best!

#### Interview Quotes: Advice for Other Parents

**Q:** "What would you tell a parent that is just beginning to go through this?"

**A:** "It's almost impossible to tell somebody not to obsess and worry about it, I'm a worrier, I'm an obsessor, I get it. But, the time you spend obsessing and worrying should be spent on doing. Your road has to begin somewhere. Taking that energy and learning and moving."

**Q:** "Looking back, what would you tell a parent who is about to embark on a journey of their own with a child with hearing loss?"

**A:** "I think my best piece of advice would be make sure you are always advocating for your child. If you feel in your gut something that is happening is not the right thing, you need to speak up because you will find someone who will listen to you. Making sure they have the best possible services, and the best possible help, because there are people out there that will give it to you."

**A:** "I remember holding my son, and music is a big part of my life, and I remember rocking him in the chair and singing to him and just crying because I thought he couldn't hear what I was singing. And I look at him now, and he plays the piano, he can pick out the melody of a song and sing it. It's far better than I thought it would be. He is so much more capable than I thought he could ever be."



#### Interview Quotes: Advice for Professionals

**Q:** "If you could tell all the professionals working with newly identified children with hearing loss, something that you wish they knew, what would that be?"

**A:** "It's like anything, when it's your job, and you've told so many people the same thing so many times, it becomes so matter of fact that it can almost feel cold to someone who's just had a baby. I knew in my heart, but my head hadn't heard it yet. So, I think it's just more . . . be gentle."

**Q:** "Looking back now, is there anything you wish professionals at the very beginning would have done for you?"

**A:** "I definitely think more resources could have been provided to us. Everything that we found for help and support and information was research that we did on our own. We would go in and they would do the testing they needed to do, and gave us that information, but extra support, that's definitely what we needed."

**Q:** "What advice to you have for new professionals entering the field?"

**A:** "Keep at it because we need you. I love my children and it was hard for me to realize I did not have the knowledge to get him where he needed to be. Keep pressing forward to be that tool in a family's life to bridge that gap from where they are to where to need to be. And you will impact these children's lives in ways you cannot even imagine."



### Conclusions and Next Steps

Parents, caregivers, and families embark on their own unique journey, and many want to share their stories and hear from other parents who are going through similar experiences. They want to find answers, access resources, and obtain the support that best meets the needs of their child and their family. Knowing they are not alone and they have professional partners who share the journey with them can make all the difference.

### Resources

- Hear to Learn: [hearttolearn.org](http://hearttolearn.org)
- Hands and Voices: [handsandvoices.org](http://handsandvoices.org)
- Hearing First: [hearingfirst.org](http://hearingfirst.org)
- Infant Hearing: [infantheating.org](http://infantheating.org)