

# How Do I Tell Them Their Child Is Deaf?

EHDI Conference  
March 10, 2025

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# LEARNING OBJECTIVES



**Attendees will recognize the impact of how a diagnosis is share has on the family.**



**Attendees will identify the benefits of family to family connections**



**Attendees will be able to list resources to offer parents at time of diagnoses.**



# TODAY'S AGENDA



**Introduction**

**Meet Our Three Families**

**Additional Family Experiences**

**The Impact and Benefits of  
Family Connections**

**Advice From Families**

**Resources You Can Share**

**Conclusion**

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# MEET OUR FAMILIES



## OUR JENNA

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They told us she had mild to moderate loss in one ear and the other was “essentially normal.” Because she had one good ear they made it seem like it wasn’t a big deal. No one really said how significant of an impact having a hearing loss could have on her.

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## NICOLE & BEAU

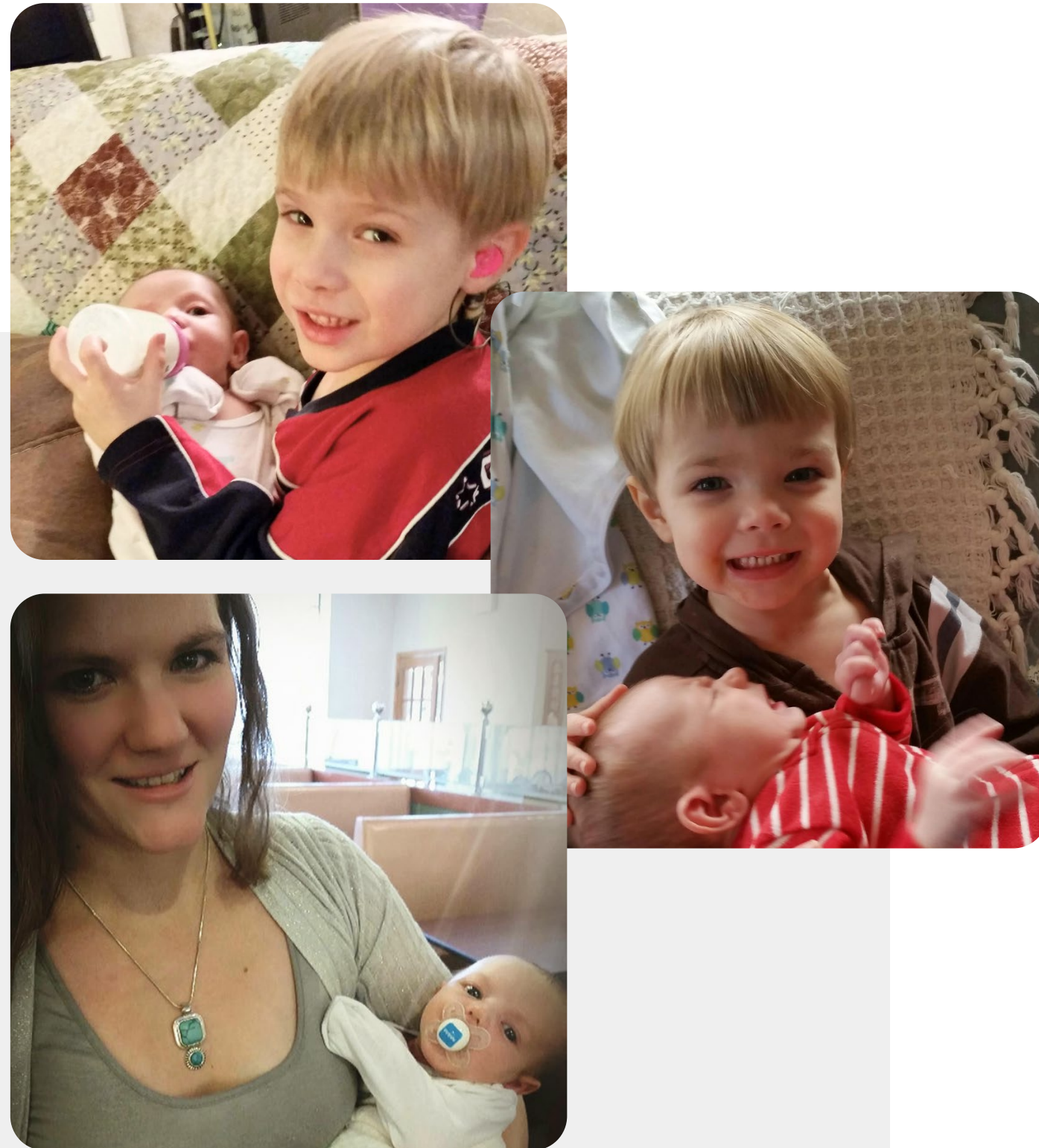
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The woman set her chair down in front of me, holding a box of tissues and told me his diagnosis then left me in the room alone to cry.

I was completely at a loss at to what to do next.

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# MINDY & BOYS

(KENNY, MICHAEL & AARON)

I held each baby for 2 hours while they testing. I couldn't hear much if what was said because we had to be quiet. When they told me their diagnoses, Honestly, I was thrilled! Obviously, I would be happy for my kids if they didn't have a hearing loss, but I feel so very blessed to have 3 children who are like me.

# THE IMPACT AND BENEFIT OF FAMILY CONNECTIONS

IN THE WORDS OF FAMILIES



questions guidance emotional-support  
understanding sign\_language\_support sibling\_help  
you're\_not\_alone advice community insurance feelings  
role\_models  
socializing communication-options working\_together  
next\_steps doctors  
connections older\_children experiences friendships resources  
validation sibling\_support iep\_help what\_to\_expect  
they\_get-it help advocacy sharing support  
empowerment ideas seeing\_success  
suggestions



**You can support one another emotionally, share resources and experiences, and spend time together.**

**I only know one other family personally, but it's nice to know you aren't alone**

**The benefit of connecting with other is you get emotional support.**

**It just helps validate me and my feelings and struggles. It's just so nice to not feel alone!**





**Other parents can tell you things that the doctors don't tell you or forget to say!**

**We can relate on a whole different and deeper level!**

**It's just nice sharing experiences with other families that understand**

**I don't feel alone! We learn from each other, share support and work together to make positive changes.**





**Connecting with families has been such a support in so many ways, from answering questions I had, or suggesting things that helped my son, seeing the success of older children, getting to know the community as a whole and knowing people who have been where I was.**

**Support, both emotional and practical...ideas, insurance questions, communication options, IEP help, friendships, help and support for siblings**

**It was a game changer for me. I had no experience with hearing loss. The other moms would know the questions that I didn't know to ask and what next steps would be. They empowered me to be able to advocate for my daughter.**

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# ADVICE FROM FAMILIES

WHAT THEY WANT  
PROVIDERS TO KNOW



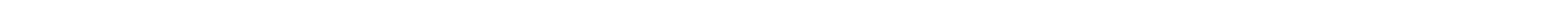


- **Explain everything!**
- **Provide literature to explain next steps**
- **Know who you are talking to - respect our culture**
- **Provide information concerning the diagnosis in writing**

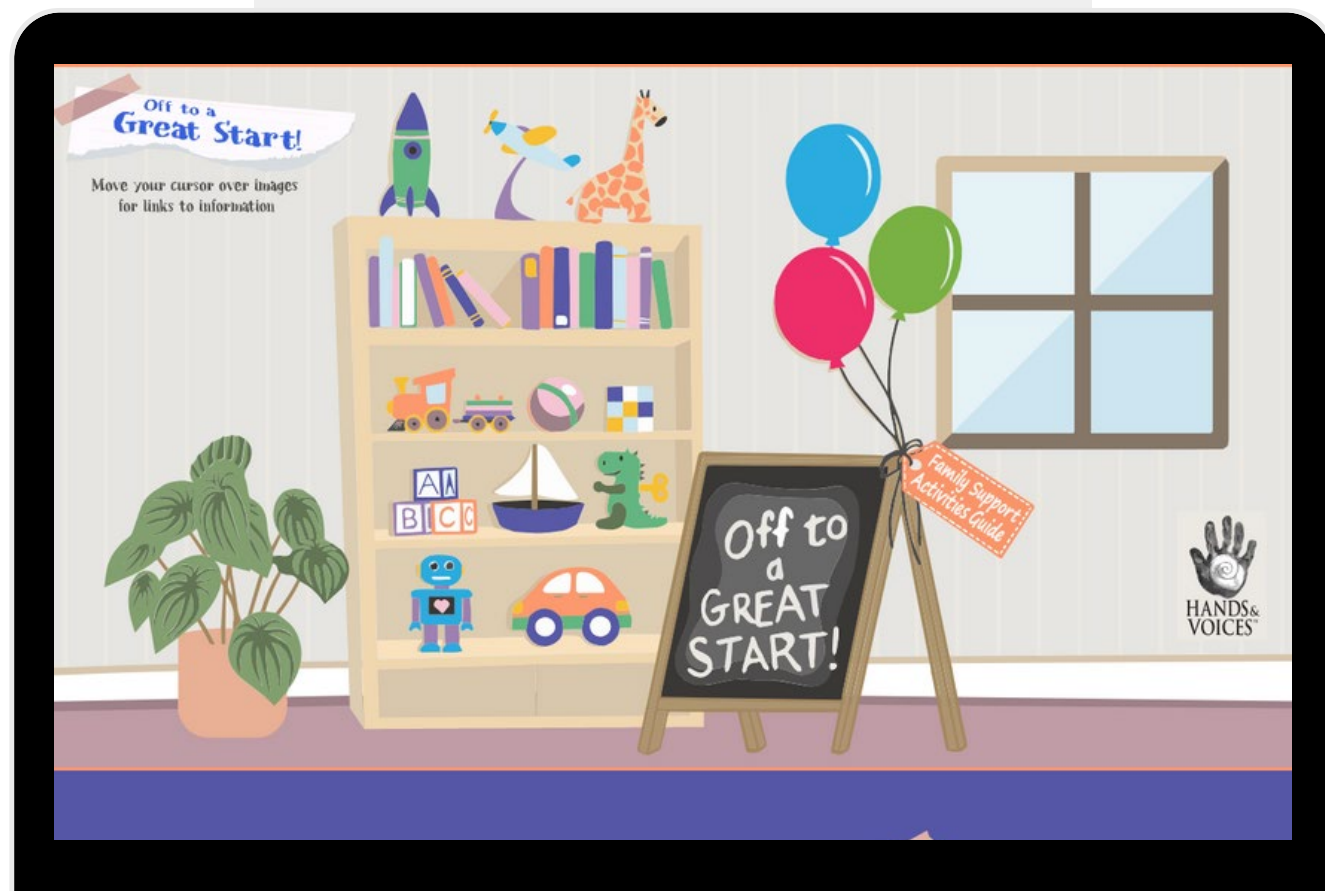




- **Engage families in a straightforward, positive manner**
- **Communicate with understanding and empathy, not pity**
- **It's a huge diagnosis to process and can cause many emotions, but let them know there is a huge amount of help and support available.**
- **It can be intimidating to reach out for support when you're overwhelmed, offer to share their contact information with other parents or support organization so they can make the first move.**



# RESOURCES YOU CAN SHARE



# GREAT START



Explore resources and activities to support the early intervention journey for families of children who are Deaf/Hard of Hearing through this virtual, interactive web site.

<https://handsandvoices.org/great-start/>





# “JUST IN TIME”

This guide is a tool to help families of children who are deaf or hard of hearing connect to family-to-family supports with a focus on state-level resources.

<https://handsandvoices.org/great-start/>

## “Just in Time” Resources to Support Families of Children Who Are Deaf or Hard of Hearing

*Brought to you by the National Center for Hearing Assessment and Management and NCHAM's Family Advisory Committee*

This guide is a tool to help families of children who are deaf or hard of hearing (DHH) connect to family-to-family supports with a focus on state-level resources. NCHAM encourages copying and posting this tool by EHDl and Part C programs, family support organizations, and health care providers. States are welcome to adapt it for their own use, adding resources unique to their state. Additional resources are available at [www.infanthearing.org/familysupport/](http://www.infanthearing.org/familysupport/).

### Essential Information



**ehdiprograms.org**

- ◆ Ensures that every baby receives a hearing screening and needed follow-up testing.
- ◆ Coordinates with early intervention and helps families get access to services.
- ◆ Ensures culturally-competent family support available to every family of an infant who is DHH.
- ◆ State specific contacts available at <http://EHDlprograms.org/>.



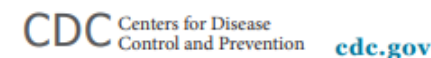
**babyhearing.org**

- ◆ Developed by Boys Town National Research Hospital.
- ◆ Answers questions about infant hearing screening and follow up testing, hearing devices, language & speech, and parenting issues.
- ◆ Available in Spanish and English.



**infanthearing.org**

- ◆ Provides important information for families needing to connect with state newborn hearing screening programs.
- ◆ Features a [Family Support Tab](#) providing links to family organizations that can help families of children who are DHH.
- ◆ Print materials available: Communicate With Your Child booklets and “Learning about Hearing Loss: A Roadmap for Families”.
- ◆ State specific content available.



**A Parent's Guide to Hearing Loss**

- ◆ Features programs and services about understanding hearing loss and how hearing is tested; finding professionals with expertise in serving babies with hearing loss; fitting a baby with a hearing device, and family support groups.
- ◆ Lists national organizations and state contacts.
- ◆ Available in Spanish and English.





# CONCLUSION

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## **Words Matter!**

Help start the family  
on a positive path



## **Foster Connections**

Help establish  
family-to-family  
connections



## **Provide Resources**

Put resources into  
their hands that will  
guide them forward

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THANK  
YOU

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