

Supporting Families Through Diagnosis

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Introductions

- Tabitha Belhorn
- Sandra Domoracki
- Allyson VanHorn

Objectives

- You will learn how the Ohio EHDI program collaborated with family support organizations to develop training for diagnosing audiologists in the state.
- You will hear from at least three families about their experience and feelings when their child was diagnosed with a hearing loss.
- You will learn at least three strategies to adjust their counseling services to assist families at the moment.

Collaborative Opportunity

Recommendations from the Ohio Universal Newborn Hearing Screening Subcommittee

- Ensure diagnosis before 3 months of age
- Support families and professionals through the diagnosis process

Training for Diagnosing Audiologists

- In person or web-based training option
- Opportunity for free professional credit hours
- Reflect the attitudes and views of families of babies who are deaf/hard of hearing to increase awareness for diagnosing audiologists
- Resources and information for audiologists on how to deliver the diagnosis information to parents



Development of the Training

- Informal questionnaire
- Open to all families
- Incentivised
- 36 families responded
- Presenter Selection

PDSA: Plan, Do, Study, Act Cycle

- Round One

- Literature Reviews
- Developed Draft by Parent and Audiologist
- Questionnaire for Families
- Reviewed by FCLC and ODH for feedback

- Round Two

- Incorporated changes from feedback
- Reviewed by four audiologists, three diagnosing and one educational audiologist
 - Presentation script was written and reviewed
- Final presenters were determined

Families Perspective on Diagnosis

Stahl Family

“I felt responsible, overwhelmed, sad, angry, and felt like I had failed my daughter.”

“I’m not sure she could have done anything differently because of being upset about her diagnosis, that pretty much consumed me.”

“I don’t remember anything helpful really. Mostly because I was so devastated of her diagnosis I think I was just consumed with sadness.”



Families Perspective on Diagnosis

Family Two:

“I was relieved we had an answer, but nervous about the next steps.”

“Not acted like it was a life or death situation. Give us information in a way that isn’t all gloom and doom—my brain pretty much shut down at that point because it was overwhelming to hear all of the ways life is going to be hard. Be positive—it’s my child we’re talking about and he’s pretty fantastic. Bring an actual deaf adult in to help share what life is really like!”

“Gave us the speech banana chart so I understood what all of the technical jargon meant.”



Families Perspective on Diagnosis

Family Three:

“It was life changing. My husband and I felt a sense of loss, confusion on what to do, and an overwhelming feeling of knowing our child would have greater hardships ahead to challenge her.”

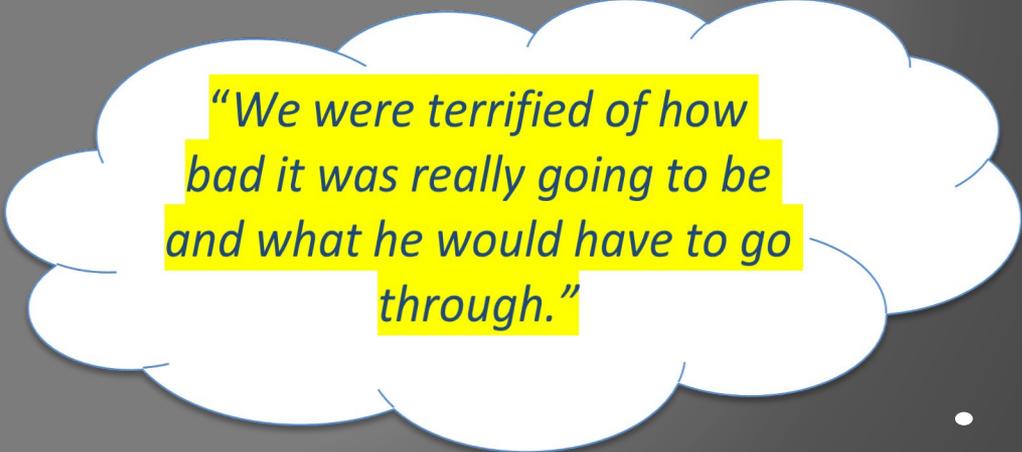
“Write stuff down. I was alone with my daughter for her testing because my husband stayed home with our older child since the ABR is a long test. The audiologist was great though and gave me the news then let me summon my husband to the dr office where she went over everything/the results again and where we go from diagnosis with hearing aids. She even found us a grant for hearing aids since our health insurance was terrible benefits for people with hearing loss and only would cover \$500 for 2 hearing aids annually- the insurance companies need to change their policies on hearing loss coverage. It took us changing insurance 3x's before we found a company with adequate coverage!!!!”

“Referral to Regional Infantt Hearing Program.”



Counseling Strategies

- Informational vs. Adjustment Counseling
- Unbiased Support
- Focus on the individuality and needs of the family in front of you.



"We were terrified of how bad it was really going to be and what he would have to go through."

Informational vs. Adjustment Counseling

Informational

- Providing Information to families about a variety of topics, such as understanding and reading an audiogram, types of hearing loss, resources, technologies, educational options, communication options, etc.

Adjustment (to hearing loss)

- Providing support to families as they learn about, understand, grieve, accept the realities of raising a child with hearing loss.

Counseling Families

- Processing and retaining info can be even more difficult because of the many emotions families may be experiencing after the diagnosis

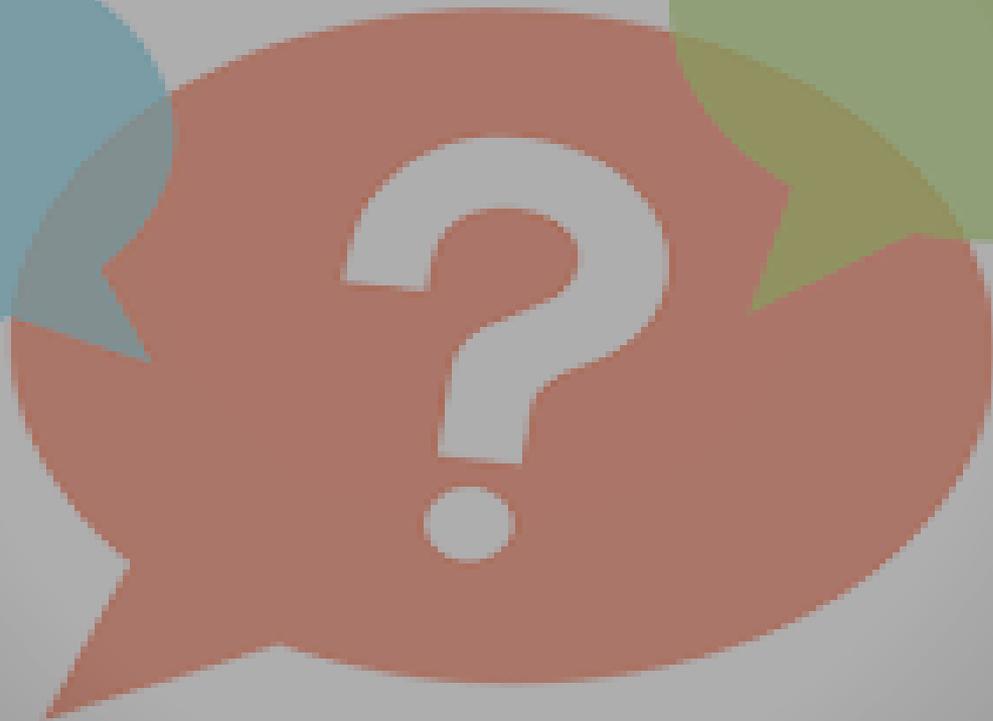
Unbiased Support

- JCIH
- Know Your Personal Bias
- Your Words Matter
- Personal and Professional Growth

Individual Family Needs

- Family Perspectives and Culture
- Value and Respect Families
- Family Stressors
- Empower Each Family
- Information and Resources as Next Steps
- Follow Up with Families

Questions



For More Information

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