PARENT PERSPECTIVES ON PHYSICIAN'S ROLE IN PARENT SUPPORT

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HOW ARE PHYSICIANS INVOLVED?

- Physicians play a central role in a child's care
- Parents look to their physicians to answer questions and give guidance



SO, WHAT IS THE PROBLEM?

- Physicians can't be "experts" on hearing loss
- Most physicians will only serve a small number of infants with hearing loss in their careers
- Physicians are not always up-to-date on the topic of hearing loss
- They may not know what resources and information are available

PARENT PERSPECTIVES? WHY?

Goals

- Identify what parents want/need physicians to do when their child is identified with a HL
- Understand what information parents were given to support them through the identification and diagnostic process



PARENT INTERVIEWS

- Investing in Family Support Conference in Phoenix, AZ, October 6-7, 2009
 - 18 parents participated
 - Questionnaire
 - 6 questions
 - Asked in an open interview format



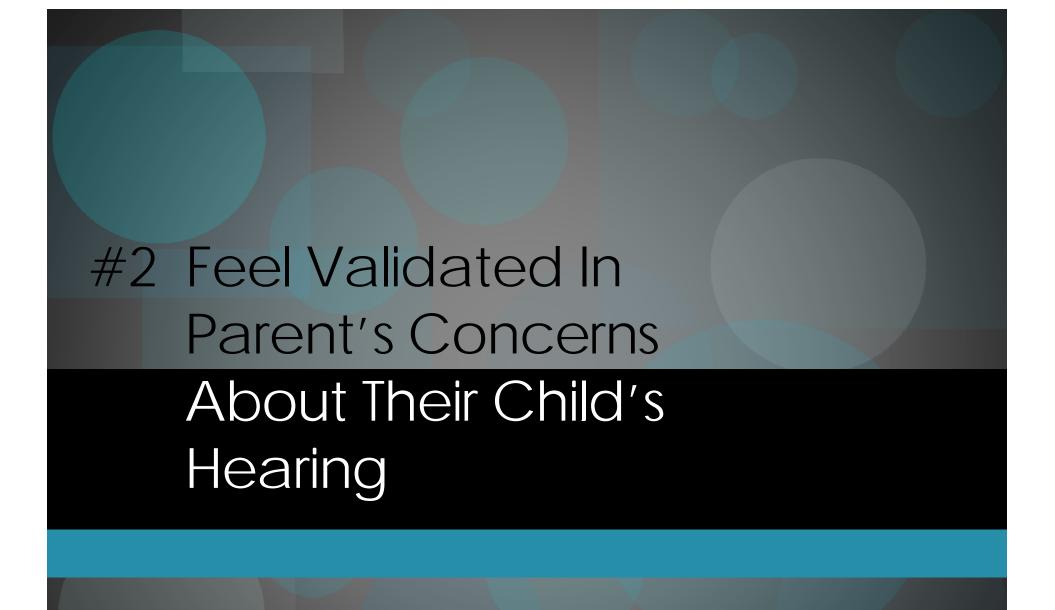
WHAT WE DISCOVERED

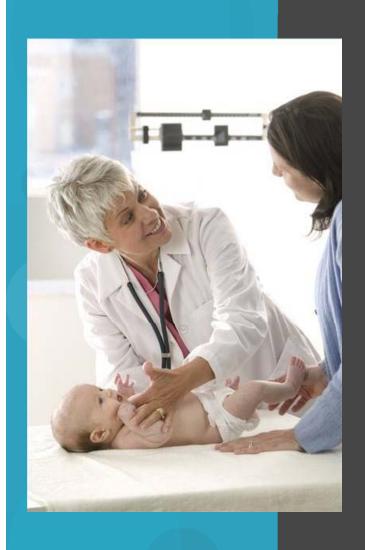
- Parents were more than willing to share their personal experiences
- Common themes
 - Parents wanted the following five main things from their child's physician or early hearing interventionist:
 - 1- Information about hearing loss
 - 2- To feel validated in their concerns about child's hearing
 - 3- Information about early intervention
 - 4- Information about how to connect with parents and adults with hearing loss, as well as the deaf community
 - 5- Humility, honesty, and understanding

#1 INFORMATION ABOUT HEARING LOSS

- "Non-biased information."
- "Concise information"
- "Pamphlets."
- "Access to a 'clearing house' data base to look up information."
- "Information on where to go once hearing loss is suspected."







- "Listen to parents when they are concerned their child has a hearing loss."
- "Be patient with the parents/family."
- "Remember that parents are the ultimate decision makers."
- "Don't present information as if you know exactly how we are feeling. You don't have a deaf child. You don't know."

#3 INFORMATION ABOUT EARLY INTERVENTION

- "Explain ALL OPTIONS available for children with hearing loss."
- "Provide the communication developmental milestones."
- "Discuss early intervention."
- "Information provided in a professional, organized, and non-biased manner."



#4 INFORMATION ON HOW TO CONNECT WITH OTHER PARENTS, ADULTS WITH HEARING LOSS, AND THE DEAF COMMUNITY



- "Having another family to talk to is invaluable!!!"
- "Parent-to-parent connections; hear other people's journey."
- "Talk to others who have been there."
- "Offer access to Deaf and Hard of Hearing adults."
- "Provide connections with support groups."

#5 HUMILITY, HONESTY, AND CONCERN FROM PHYSICIAN

- "If you don't know the information, find it out."
- "Follow-up to insure failed screening is tested.
- Give parents the time they need to understand what to expect."
- "Don't condescend."
- "Don't be proud."
- "Don't rush us!"



LET'S ASK THE PHYSICIANS

- Physicians Survey (2006)
 - 1968 surveys
 - 3 Focus groups
 - 26 pediatricians from 9 states



Moeller, M.P., White, K.R., & Shisler, L. (2006). Primary care physicians' knowledge, attitudes, and practices related to newborn hearing screening. *American Academy of Pediatrics*, 118(4), 1357-1370

LET'S ASK THE PHYSICIANS

- GAPS IN THE PHYSICIANS' KNOWELDGE
 - Steps that follow identification of HL
 - Communication approaches
 - Hearing aids & Cochlear implants
 - Causes of hearing loss
 - Management of profound deafness
 - Management of unilateral or mild hearing loss



LET'S ASK THE PHYSICIANS

- PRIORITIES FOR EDUCATION RELATED TO UNHS
 - Protocol steps for follow-up
 - Information on early intervention
 - Contacts for more information
 - Patient education resources
 - Impact of varying degrees of hearing loss on infant language development

WHAT DO PHYSICIANS WANT?

- Don't provide too much information
 - All information be evidence-based
- Want to be directed to where they can get more information
- Want information when needed
 - They want access to information when a child is diagnosed with hearing loss in their practice



Munoz, K., Shisler, L., Moeller, M.P., & White, K.R. (2009). Improving the quality of early hearing detection and intervention services through physician outreach. *Seminars in Hearing*, *30*(3), 184-192

WHAT DO PHYSICIANS WANT?

- Want to know what to give to parents
 - What information do parents need to know?
- Printed materials and graphic materials
 - Laminated cards with clear protocol steps
 - Brochures to use in patient education
 - Frequently updated websites

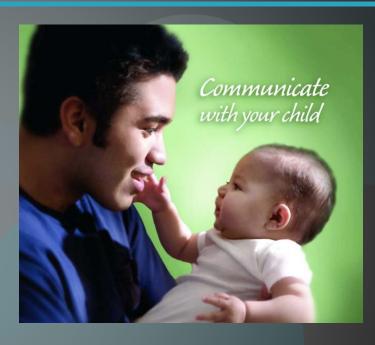
OTHER SUGGESTIONS

- Contact information for State EHDI Program coordinators
- Guidelines for UNHS
 - Flow chart
- PediaLink online continuing medical educational model, specific to HL
- Access to the Sound Beginnings video
 - Can be viewed or downloaded from www.infanthearing.org

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WHAT WE DID

- Identified all primary care physicians, pediatricians, and midwives within a 50 mile radius of our clinic
- Sent them a series of mailings
 - Information about NHS
 - Websites about early identification and hearing loss management
 - Locations for referrals and contact information for qualified pediatric audiologists
 - Pamphlets and access to resources to give to parents



WHAT
HAS
WORKED
FOR
YOU?

