

# 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?

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- 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

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- 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

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- “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.”





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#2 Feel Validated In  
Parent's Concerns  
About Their Child's  
Hearing



- “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


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- “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

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- "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' KNOWLEDGE
  - 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

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- 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?

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- 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

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- 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](http://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?

