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
PAI RENT 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
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’ database to look up information.”
• “Information on where to go once hearing loss is suspected.”
#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
“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

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

- PRIORITY 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

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

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?