

Making Connections: Early Detection Hearing and Intervention through the Medical Home Model Podcast Series

Podcast 1: Shared Decision Making and Parents as Partners for Children who are Deaf or Hard of Hearing

Transcript

SPEAKER AND NOTES	SLIDE GUIDE
<p>MODERATOR: Julia Richerson</p> <p>Good morning and welcome to the American Academy of Pediatrics Early Hearing Detection and Intervention Program—or EHDI—Family Professional Partnership podcast focused on shared decision making and parents as partners for children who are Deaf or Hard of Hearing. My name is Dr Julia Richerson and I will be the moderator for this podcast.</p> <p>This podcast series is sponsored by a cooperative agreement between the American Academy of Pediatrics and the Health Resources and Services Administration Maternal and Child Health Bureau.</p> <p>It is the first episode in the Making Connections: Early Hearing Detection and Intervention through the Medical Home Model podcast series. All episodes in the series will focus on how to improve communication between pediatricians and other pediatric health care providers with parents or caregivers of children who are Deaf or hard of hearing. Practical strategies, tools and information will be shared throughout the series.</p> <p>This first episode will focus specifically on the exchange of information between families and clinicians or other healthcare providers as it relates to the care and management of a child who is deaf or hard of hearing. We will discuss how to do the following:</p> <ul style="list-style-type: none">• Share news of a hearing-related diagnosis;• Explain the next steps in seeking appropriate care for a child who is deaf or hard of hearing once a diagnosis is made, and• Create a partnership between the health care team and families where an open discussion related to hearing and communication options for a child who is deaf or hard of hearing can happen.	Slide 1
<p>MODERATOR: Julia Richerson</p> <p>After listening to this podcast, participants will be able to do the following:</p> <ul style="list-style-type: none">• Explain the principles of shared decision making as they relate to early hearing detection and intervention.• Discuss strategies to promote optimal conversations between clinicians and families based on the principles of shared decision making.• Construct a strong family-professional partnership for all aspects of care related to children who are deaf or hard of hearing.	Slide 2
<p>MODERATOR: Julia Richerson</p>	

<p>I would like to take a moment to introduce our guests, Dr Maureen Cunningham and Stephanie Olson.</p> <p>Dr Cunningham is an Assistant Professor of Pediatrics at the University of Colorado Denver School of Medicine and a member of the section of Hospital Medicine at Children’s Hospital Colorado. She has been the EHDl Chapter Champion for the Colorado Chapter of the American Academy of Pediatrics since 2015 and is a member of the Colorado Infant Hearing Advisory Committee.</p> <p>Stephanie Olson is the Family Consultant for the Bill Daniels Center for Children's Hearing at Children's Hospital Colorado and serves as a liaison between families and the health care system. She also is the Co-Director Deaf and Hard of Hearing Infusion at Colorado Hands & Voices</p> <p>Thank you both for being here today to share your insights and experiences. Stephanie, I will now turn the conversation over to you.</p>	<p>Slide 3</p> <p>Slide 4</p>
<p>SPEAKER 1: Stephanie Olson</p> <p>Thank you and I would also like to add that my hearing was confirmed as severe-to-profound at the age of three even though my mother had been asking for support and guidance from my family physician. I was fitted with hearing aids and then began the process of learning language since I missed the first three years of that. It is my experience that has led me to my work in support of strong family partnerships.</p> <p>I’d like to touch specifically on shared decision making as it relates to clinical encounters between families or caregivers of children who are Deaf or hard of hearing, clinicians and other providers.</p> <p>To set the stage, I want to be sure that we have a common understanding of “shared decision making”. Oftentimes individuals “think” they know what shared decision making means and how to integrate it into clinical practice. But we have found that sometimes there is confusion or misunderstanding. So.....</p> <p>Shared decision-making promotes strong relationships and collaboration between families and clinicians with the ultimate goal of improved health and satisfaction of patients and families.</p> <p>Often in the discussion of options for services related to hearing and communication methods for children who are Deaf or Hard of Hearing, there are gaps between the child’s or family’s values, priorities, and understanding of perceived “best choices” versus what the clinician believes is the “best care option” for the child.</p> <p>Shared decision-making provides an opportunity for all those involved in the care for the child to have shared responsibility in decisions regarding the child’s care. The primary focus is to provide support for the child, their family, the primary care clinician, and other healthcare providers in the child’s medical home and beyond.</p> <p>As general knowledge and the practical use of shared decision-making skills are collectively embraced by everyone involved in the child’s care, the relationship between the family and others involved will become stronger, ultimately enhancing family-centered care and partnership.</p>	<p>Slide 5</p>

<p>The desired outcome of shared decision-making is that the autonomy and well-being of the child is at the forefront, the family or caregiver is an equal player in the decision-making team, and the clinician’s role is supported.</p> <p>The different options related to care and support of children who are deaf or hard of hearing can sometimes be overwhelming for families. The nature and complexity of decisions are varied and can be confusing.</p> <p>Decisions must be made at each phase in the process—starting with hearing screening, diagnosis, ongoing evaluation, a care plan developed mutually between the family and provider, early intervention, care management, education and associated support services.</p> <p>The most optimal manner in which clinicians and other providers can support children who are Deaf or hard of hearing and their families is to engage in partnerships that are patient- and family-centered.</p> <p>The American Academy of Pediatrics says, “patient- and family- centered care is an innovative approach to planning, delivery, and evaluation of health care that is grounded in a mutually beneficial partnership among patients, families, and providers that recognizes the importance of the family in the patient’s life.”</p> <p>Family-centered and compassionate care recognizes and acknowledges that families/caregivers are the primary supports for children and ensures that all medical and other care decisions are made in true partnership with the family/caregiver.</p> <p>Dr Cunningham– How do you see this play out in practice?</p>	
<p>SPEAKER 2: Maureen Cunningham</p> <p>Families or caregivers of children who are Deaf or hard of hearing face decisions about health care, language and communication options, and the benefits of early intervention services and support. They also face decisions about education beyond the early childhood period.</p> <p>As part of the pediatric medical home, it has been shown that optimal outcomes for children and youth require interaction and collaboration among multiple care systems and individuals, including the following:</p> <ul style="list-style-type: none"> • medical, social, and behavioral health professionals; • the educational system; • insurance companies or other payers; • medical equipment providers; • advocacy groups; • needed supportive therapies/services; and • families and family support organizations. <p>Coordinating care allows for integration of services that is centered on the comprehensive needs of the patient and family, leading to decreased health care costs, reduction in fragmented care, and improvement in the patient and family experience of care.</p> <p>An example of this in the clinical setting may play out in the following way: A one-month old baby and her mother have an appointment with their pediatrician to discuss the re-screening results related to the babies’ hearing and options available for the child and family. The results from the audiologist show that the</p>	<p>Slide 5</p>

baby has moderate hearing loss. The pediatrician informs the mother of this news and confirms with the mother that the family has been referred to the audiologist for a follow up appointment. encourages the mother to make an appointment to meet with the audiologist to review the results in greater detail.

Understandably, the mother feels very overwhelmed and somewhat confused on the details related to next steps. Fortunately, the mother feels very comfortable with the child's pediatrician and expresses her concerns and anxieties over choosing the route for the baby's care plan. The pediatrician takes the opportunity to remind the mother that the family has been referred to the audiologist so that she can learn more on the screening test results and to begin thinking about possible options for next steps.

The mother moves forward with scheduling an appointment with an audiologist, so they can discuss in detail options available for the child and make a decision together on which option will be the most appropriate. In the meantime, the pediatrician provides the mother with contact information for the local organization that supports children who are deaf or hard of hearing and their families, so that she can reach out and gain support from a family organization with expertise in this area.

Many times, there is not one clear and obvious choice for care for a child who is deaf or hard of hearing. Especially in these situations, it is critical the healthcare providers and families work together through shared decision making to choose the best options and services available for their child. Some decisions that are relevant to the family include types of technology or visual communications to be used or if the family would like to use them at all. There are also numerous communication options that can be considered.

One wonderful resource includes Hands & Voices— “a non-profit, parent-driven organization dedicated to supporting families of children who are deaf or hard of hearing. Hands & Voices is non-biased about communication methodologies and believe that families can make the best choices for their child if they have access to good information and support.”

Another decision relates to whether the family should see a geneticist to determine if there is an underlying condition that may have led to the infant's hearing loss.

These are just a couple of examples that may involve shared-decision making in a pediatric medical home.

Successful shared decision making occurs when both the family or caregiver and the care team have an active partnership –

- all members of the team providing care and services for the child feel heard and understood;
- there is mutual respect between all participants;
- all participants share information related to the health and overall wellbeing of the child; and
- all participants agree on a decision for the child's plan of care.

A critical part of families and providers **creating strong partnerships is communication!** There can be challenges for both clinicians and families in effectively and meaningfully communicating—but if practiced consistently and if the communication is genuine and bi-directional, reaching mutually agreed upon consensus for the care plan treatment for the child can be incredibly rewarding and satisfying.

Communication challenges can occur through the shared-decision making process. However, there are **effective communication strategies** both families and providers can engage in to reach the best treatment plan for a child who is deaf or hard of hearing.

For example, there may be challenges surrounding mutual understanding of families' strengths / values and expectations – these are key to conversations as part of shared-decision making. Providers can elicit these conversations at the start of a shared-decision making process and encourage families to be open to discussing their fears and reservations.

Additionally, there maybe challenges in mutual understanding of the “question/situation” that needs a decision. Providers may not recognize the family is struggling with a decision, such as a communication decision. It is important for providers to be on the lookout for situations / decisions families maybe be struggling with. It is also important for providers to be aware some decisions are strictly made by the family; and the family may not want involvement from their provider.

Let me summarize the key strategies for successful shared decision making:

- ensure all participants feel heard and understood;
- focus on building mutual respectful between all participants;
- commit to sharing information related to the health of the child with everyone involved in the child’s care;

recognize the importance of all participants agreeing on healthcare decisions for the child.

MODERATOR: Julia Richerson

Thank you, Stephanie and also Dr Cunningham for sharing your insights and experiences related to **shared decision making** and parents as partners in the context of children who are deaf or hard of hearing.

I would like to point to everyone’s attention the resources we have listed on this slide. Please feel free to contact the American Academy of Pediatrics for more information. I would also encourage you to find about more about the:

- National Center for Hearing Assessment and Management at www.infanthearing.org....and....
- Hands and Voices at www.handsandvoices.org

Both of these organizations serve as excellent resources on early hearing detection and intervention.

Please take a moment to fill out the brief survey included on this Web page.

Thank you and we hope you’ll listen to our second podcast, **Utilization of the Teach-Back Methodology in Early Hearing Detection and Intervention**. The second podcast can be found on the American Academy of Pediatrics’ Early Hearing Detection and Intervention Web site at www.aap.org/ehdi. No advance registration is required.

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