

Will Eiserman:

Welcome to EarWorm. Dialogues on Hearing Health you can't stop thinking about. EarWorm is brought to you by the National Center for Hearing Assessment and Management at Utah State University known as NCHAM. I'm Will Eiserman and I'm the Associate Director of NCHAM and I'm your host today. When a child is diagnosed as deaf or hard of hearing, families suddenly face an unexpected and often challenging situation. They have to start navigating a flood of information and start making crucial decisions about how they're going to be communicating with their child. Although these families often have access to highly qualified experts for guiding them through this process, the support of primary care providers, child care providers, extended family and friends is also vital. These supporters can be especially helpful to families if they have at least some understanding of the decisions the family is facing and the importance of the family being supported in making choices that seem to be best for their specific child and family at that time.

In this episode of EarWorm, we'll explore the critical decisions these families face in the early stages and discuss how others can provide meaningful support. Today's guest is Amy Spencer from Maine, a speech language pathologist and coordinator of Early Intervention and Family Services at the Maine Educational Center for the Deaf and Hard of Hearing. Amy's involved in the Maine Newborn Hearing Screening Advisory Board and the Maine Interagency Coordinating Council. Amy actively participates in Earliest Interactions Maine, a program supporting families from the hearing screening process all the way through to the delivery of early intervention services funded by the Health Resource and Services Administration. Her expertise and language and communication development was honed through Gallaudet University's Infant-Toddler Family Leadership and Collaboration Certificate Program. Amy, welcome.

Amy Spencer:

Well, hello.

Will Eiserman:

In your role, Amy, you engage with families of children with diverse hearing levels ranging from mild to profound, reflecting different causes or reasons for the hearing loss and with varying degrees of stability over time. Despite their diversity, all these families face the common challenge of having to wrap their heads around the fact that their child is deaf or hard of hearing and almost immediately needing to make some decisions about how they're going to communicate with their child.

Amy Spencer:

The first big question is, oh, how am I going to do this? How am I going to communicate with my baby if they can't hear me? If spoken language is the language of the home, which for over 90% of babies, that is the case, and so very often technology is an option that comes up that's offered by the audiologist pretty immediately, post identification of deafness and families sort of have to consider technology options. And for families that have a child that has a mild to severe hearing level or hearing difference, the audiologist will likely recommend a behind the ear hearing aid if it's a sensorineural hearing loss or a bone anchored hearing aid, if it's a conductive permanent hearing difference and they might fit a child that has a profound hearing difference just to potentially stimulate the auditory nerve for potential later cochlear implantation, which brings us to the other type of technology that is often considered for kids that are born with severe to profound hearing levels or maybe have auditory neuropathy spectrum disorder.

Will Eiserman:

And you're referring to cochlear implants here.

Amy Spencer:

And that candidacy is typically determined by a cochlear implant team, and that can occur between 6 and 12 months of age. And there is a strong correlation between when the cochlear implantation occurs and if it occurs prior to 12 months, there's a strong correlation between that and later language outcomes.

Will Eiserman:

Ah, so the earlier a cochlear implant is done, potentially the more promising the results, but that does add additional pressure to families early on.

Amy Spencer:

Yes, we know it's important to move through the process with some haste moving through, but also acknowledging that sometimes that might feel really overwhelming to families.

Will Eiserman:

And cochlear implants are only possible under certain conditions, right? So there's a process in determining whether a given child is even a candidate.

Amy Spencer:

There is a process, so they do have to go through like MRI scans and things because they need to make sure that there's proper anatomy, right? So if there's not a cochlear there, then there is no ability to do a cochlear implant. And then also educating around what's follow up for that. So how often are you going to have to drive to that hospital that's three hours away from you for activation, for mapping, for all of those things and making sure that families are prepared with that information is really important.

Will Eiserman:

So who should be talking to the family at least initially about exploring potential candidacy for a cochlear implant and what's involved in that?

Amy Spencer:

They could either be seeing an early interventionist that specializes in working with deaf and hard of hearing children, but also just connecting with that cochlear implant team that's closest to you, so that whether that's... For us, it's Boston Children's Hospital, we're usually connecting with them and they're always willing to answer questions.

Will Eiserman:

I could see that just learning about hearing aids and perhaps the prospect of a cochlear implant can give families plenty to think about, but that's only part of what they need to be considering.

Amy Spencer:

Certainly. So the technology is one piece, and usually the technology is being explored so that a child might have more access to spoken language. There are limitations to the technology in different circumstances, right? So hearing aids are great, but when you get into noisy situations like there still are going to be... They're not going to be hearing like a typically hearing child in different environments. And the same with cochlear implants, it's going to be the same thing. It's not fixing the hearing and making it exactly ideal for all situations. It's really going to be improving amplification and access to spoken language, but it's not a perfect fix. So having that in mind and knowing that there will still be strategies and accommodations that your child will need, it's not, "Oh, put the hearing aids on and you're good." And every circumstance in this busy birthday party, what's going on, we have to sort of take those things into consideration.

Will Eiserman:

So even though I'm sure many families are hoping for that perfect fix, you then have to support them in learning about other ways to support communication.

Amy Spencer:

Absolutely. Really, we know language is key to developing relationships and knowledge and about the world later literacy development, and we know that that can be accessed both through audition. So maybe utilizing that technology and utilizing audition to access language. We can access language through vision and regardless, as long as the child acquires language, they're going to develop all of those skills that we want them to develop, those relationships, the knowledge. So the most important thing is that we have early access and exposure to full languages.

Will Eiserman:

Okay, Amy, so what are the language options families need to learn about at this stage when they're getting to know their child and their child's abilities and inclinations about accessing language?

Amy Spencer:

A couple of the language options themselves are American Sign Language, which is a language that uses the hands, body movements, facial expressions to communicate the same kinds of words and thoughts that spoken languages do. It's the language used by the deaf community and it's definitely been found that children that have a strong first language base in American Sign Language are able to learn a spoken language as a second language. So if a family doesn't know American Sign Language, there's a lot of different ways to learn and hopefully your early intervention providers can hook you up with that in your state.

Will Eiserman:

An American Sign language, also known as ASL, is a complete language with its own grammar syntax and sentence structure. What may be distinct from other common spoken languages is there is no written analog to ASL, but otherwise it's just like any other language in its uniqueness and complexity.

Amy Spencer:

Yes, it's important to know that there isn't a written form of American Sign Language and that the child will likely utilize another spoken language as access for literacy. Another one of the language opportunities is listening and spoken language, so whether that's English in your family, Spanish in your

family, and really those listening and spoken language approaches focus on maximizing the use of hearing and hearing technology so that you can learn the natural language of your home if that's spoken and the child's really encouraged to use listening to understand spoken language in their environments and communicate with spoken language.

Will Eiserman:

Boy, I can see how for some families and children, they might have a hard time choosing between ASL and listening and spoken language, given that they both offer uniquely valuable elements.

Amy Spencer:

Another language-based approach really is combining those two languages, right? So not utilizing them at the same time because we know that their American Sign Language and spoken English or another spoken language won't have the same grammatical form, so we can't really use them at the same time. But some families do choose a bilingual bimodal approach, and that approach really supports the acquisition of both American Sign Language and spoken language. And so bilingual sort of refers to being fluent in both languages, and it includes really early access to visual language while also utilizing technology and spoken language and really just families kind of start... Maybe they don't know American Sign Language, they start to learn an American Sign Language.

There is some early research, even when families aren't fluent in American Sign Language, but they're providing that support for their child as much as possible, visual signs around routine. So they have some prediction abilities before maybe they get their cochlear implant at nine months of age, that actually is still demonstrating a positive impact on their early language development. And so those are sort of the language options, but then there also are tools that can support visual access for spoken language.

Will Eiserman:

So like an actual system you'd use with spoken language where you intentionally add physical or visible cues to help with comprehension.

Amy Spencer:

Right. Right. One of those is... And I'm grouping them together, manually coded language systems. So those might be systems that basically will utilize signs to represent spoken English, so those might include signed essential English or signed exact English, you might hear conceptually accurate signed English. And then some families just sort of use a sign supported speech. I want to give my child the context that we're going outside, and so they might use one sign while they're talking about going outside to give them context for their spoken language.

Will Eiserman:

You mentioned that ASL, American Sign Language cannot be used at the same time as using spoken language, I get that. But sometimes, we actually see people doing just that both signing and speaking English, for example, what's going on there?

Amy Spencer:

Signed exact English can be used at the same time as speaking because it does have the same grammar as spoken English and signed exact English would denote the words and word parts that are happening

in spoken English so that a child would have access to all of that information, both grammar and vocabulary.

Will Eiserman:

So they're using the signs of ASL but not the rest of the language structure, syntax, etc. And that's how they can do it simultaneously.

Amy Spencer:

Right.

Will Eiserman:

Now there's one other method, isn't there? What about cued speech as a method for supporting spoken language?

Amy Spencer:

Cued speech is another way that we can put a visual system to spoken language, and that actually is a visual system of hand shapes and movements that a speaker might use to clarify the speech sounds and words that look alike on the lips. And because we know that we can lip-read, people can lip-read, but they're not getting all of the information, they're getting actually very little of the information with just lip-reading. So words do look the same on the mouth, so the cuing system can make them look a little different. So if you say to yourself, me and B, and look at yourself in the mirror, if you didn't have auditory access, those would look exactly the same. So this system actually clarifies those two sounds by making a different hand shape for me and B, the M and B have a different hand shape next to the mouth.

Will Eiserman:

So I think we're gaining a much deeper appreciation for all the options and considerations families are faced with. I can see how important it is that a healthcare provider or another person in the life of the family can benefit from knowing all of these considerations that the family is making.

Amy Spencer:

There are a lot of things to consider when you're thinking about the communication and language opportunities that are sounding right to you. So thinking about right now where your family is, what can you take on, right? So can you take on learning a whole new language? Is that not really feasible for your family right now?

Will Eiserman:

So a family may learn about a communication option or a type of intervention that they're really interested in, but there may not be anyone nearby who can really support them in using that option. So what then? Choosing the best option has to also factor in the feasibility concerns of that option, I would imagine.

Amy Spencer:

Is that service going to be available live to you? Are you going to be able to get ASL family training from a person that comes to your home or are you going to have to access that through telehealth or through

online learning? Some other things might be that you're considering a cued language system, but there's no cued language transliterators in your state, so that might be something to consider that if you do learn cued language and you use it with your child, is that going to be something that's going to be able to carry over into their educational setting? So I think families need to think about the right now, but also think about five years from now, what am I envisioning? And then that does help guide us in, all right, well if we're here right now and you're envisioning that, what are we going to have to do to get there?

Will Eiserman:

As a relative outsider who wants to support the family in this process, it's important not only to be aware of why a family may be drawn to a particular set of options, but also why there could potentially be concerns or barriers that also need to be addressed and that could slow down the decision-making process a bit.

Amy Spencer:

Right, right. We know that caregivers report is the most difficult decision that they make is how they will communicate with their baby, and I really like our team to start the conversation and focusing on what we can do right now because I feel like parents feel very out of control and overwhelmed in the beginning and really focusing on that connection that's not really based in language, but it's really based in touch and movement and that face-to-face interactions that responding to your child's bids. So whether that's a cry and respond or a movement or an eye gaze, really kind of valuing and validating the connections that you see with a family and their baby, it really can make all the difference in the world.

Will Eiserman:

Oh, I can see that, communication starts with those very connections and language builds upon that affirming that parents are already connecting with their child and how can be a very powerful message, I would think. When you point out to them the connection you are seeing them having and developing and assuring them that they will find their way to the best means for communication. So in order for families to learn about these options and consider them fairly, what needs to happen?

Amy Spencer:

I think access to unbiased and comprehensive information about communication modalities is really critical that we're providing that information without providing our opinion about those different language and communication opportunities, so that families really do feel like they're sort of navigating their own journey and their own decision-making.

Will Eiserman:

We know though that there are some people with really strong opinions for good reasons, not only about what is right for them and their child, but opinions about what is right for every other deaf or hard of hearing child too. Families are probably going to hear those opinions at some point, and those opinions may contradict their own choices.

Amy Spencer:

I really just think that it is really important to let families know that that exists. They're going to come across strong opinions and I really want to help them use those opportunities as times to learn and

gather information and not necessarily as a way to define what they're going to do or not do with their child. I think that families knowing and being informed about all of the communication and language opportunities really provides families with confidence that they have options to go back to, to look at, to reflect on so they don't feel like they're sort of stuck if something's not working.

Will Eiserman:

That seems really key. As important as these decisions are, they really are just a starting place. Families can and very likely will change some of their decisions over time. Is that what you're saying?

Amy Spencer:

Absolutely. This is going to be an evolving exploration for the family. This isn't going to be a one-time decision that they're going to be reflecting back on their language and communication decisions based on a lot of different things, monitoring their language development, monitoring how their family is doing, utilizing certain approach within their daily routine. And it's okay to change. There's nothing wrong with it, as long as there's the supports in place to support that change and support the family in making those changes, then great.

Will Eiserman:

So Amy, this is a ton of information that families are sorting through. I know I keep saying that. Who exactly is the most likely person they should be getting this information from?

Amy Spencer:

I would say most likely the big picture. I would hope the audiologist would have a little bit of information about access and access to language and the importance of that and that they would be able to lay out some of that. But I would say it would be your early intervention provider or in early intervention that you would get the biggest overview of everything. There typically are resources in every state that can be accessed and hopefully through your early intervention system. Let's hope that those systems are connected and if they're not looking on the early hearing detection and intervention website and looking at your state and seeing on your EHDI site what comes up for you and how you can help make those connections for families.

Will Eiserman:

By EHDI, you mean the acronym E-H-D-I, which stands for Early Hearing Detection and Intervention, and you can find your state's EHDI program by Googling, your state's name and the acronym E-H-D-I. For providers who might have an occasional child they see who is deaf or hard of hearing, or maybe if you're a family member, what are some of the questions you'd want to ask to make sure the family has in fact received this information and in a good, fair and balanced way?

Amy Spencer:

Say asking them some open-ended questions like, "I know you went to the audiologist, tell me what you know about Joey's hearing difference," kind of getting that information. "Tell me, did you guys talk a little bit about communication? Tell me what you know about that and what are you thinking about when you're thinking about how you're going to communicate best with your daughter?" And then listen. Listen to families, give them space to tell you what they do know, what they are thinking about, and I think you're going to be able to kind of tease out if they only talk about one communication and

language approach, "Oh, do you know that there are visual language approaches?" So having a little awareness. You don't have to be the one... Obviously you're not going to go through all of the language and communication approaches, but just knowing that, okay, they haven't said anything about any sort of visual component, so do they even know that those are available to them or not?

Will Eiserman:

And if you have a sense that maybe they haven't learned about all of the main options?

Amy Spencer:

There are a lot of great online resources that can be accessed to go through some of that. And a lot of those state EHDI sites have some resource or another, Maine's Earliest Interactions site has our whole exploring language and communication opportunities, interactive tool that you can kind of go across the overview, get a little information, watch a video from a professional, watch a video from a parent, utilizing that approach. So it gives a place where people can go to sort of explore that on their own.

Will Eiserman:

Okay. And that website is [earliestinteractions.com](http://earliestinteractions.com) Amy, you've helped paint quite a vivid picture of the considerations families face when their child is diagnosed as deaf or hard of hearing. Clearly it has got to feel weighty at times. For those of us who are fortunate enough to be in their lives, acknowledging their challenges can be supportive. I can see that. Fortunately, as you've discussed, children with hearing differences can thrive with various approaches or combinations of approaches. There's no one size fits all solution, and families should have the flexibility and encouragement to adapt and evolve their strategies over time. Any parting thoughts?

Amy Spencer:

We know that the answers to your questions about your child's hearing levels and how they're going to communicate and learn language is going to shift and mold over time through experiences. And some of the most critical experiences that families have shared are connecting with other families that have deaf and hard of hearing children and meeting a variety of deaf and hard of hearing adults. Oftentimes, we get resistance in the beginning from families. They feel a little nervous, awkward, they're not sure if they're ready to meet a deaf and hard of hearing adults very early on. But in looking back, many families say to me that they wish they met deaf and hard of hearing adults sooner in the process. So encouraging families to have these experiences with deaf and hard of hearing adults, with other families early on in their process, so they can kind of use that information as part of their exploring and decision-making. And that's going to continue throughout their journey.

So having those experiences, kind of comparing it to their life, their values, it's really going to shape and mold their thought process, looking at their child's assessment data and seeing how things are going. And using that reflective process of looking at is language developing? Why or why not? And in having these experiences with other deaf and hard of hearing adults, you really see that the journey does look different for everybody. And success can be in ASL, success can be in spoken language, success can be using acute speech transliterator. As long as that child has access to a full language, then we are doing it right and the child is going to be able to learn, build knowledge, have relationships, do all of the things that we really want our children to be able to do in this world.

Will Eiserman:

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That was Amy Spencer. I'm Will Eiserman from the National Center for Hearing Assessment and Management at Utah State University. Check out [earwormpodcast.org](http://earwormpodcast.org) for other episodes of EarWorm. Dialogues on Hearing Health you can't stop thinking about.

Speaker 3:

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