

Powering Potential Podcast

Episode 2: Opportunities and Outcomes

Matthew:

If Fiona is profoundly deaf, but we can do something to give her access to sound, and give her a voice, and give her the ability to interact with us, it was almost an immediate decision for us because we knew that we had to try. We had to try to give her access to sound so that we [could] give her the possibility of having her own voice.

Dr. Teresa Caraway:

Welcome to *Powering Potential*, a podcast from Hearing First, where we explore the unique joys and challenges of raising children who have hearing loss. I'm Dr. Theresa Caraway, your host, a mother, and a speech-language pathologist specializing in Listening and Spoken Language. I'm here to share the incredible stories of families who are teaching their children who are deaf or hard of hearing to listen and speak.

In the first episode, we met four families who have children with hearing loss. We learned about how these families persisted in getting a diagnosis for their children and the whole range of emotions that came with it. In this episode, we'll learn about how they moved from diagnosis and took the first steps towards early intervention.

Today, even children who are profoundly deaf can learn to listen and speak thanks to advances in newborn hearing screening, hearing technology, and specialized early

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intervention. This outcome is called Listening and Spoken Language or LSL.

When we left Matthew and Sarah in the first episode, they had just received confirmation through an ABR (Automated Brainstem Response) that their daughter Fiona was profoundly deaf. The ABR test tells how the inner ear, called the cochlea, and the brain pathways for hearing are working.

How were you given the diagnosis?

Sarah: You know, whatever. We got through as much of the test as we could, and we were sitting in the room with all the equipment and the audiologist, and she just told us ... I don't know if you remember it better than I do.

Matthew: Well, she went through the results, and basically, it's like a graph. And she showed us what sounds Fiona has access to, and it was very little. And basically, that was when she basically said that given the amount of hearing she does have, she really will not have access to speech sounds as is. So it was a profound enough hearing loss where, without intervention, she would not develop spoken language.

Dr. Caraway: Yeah. So what was going through your mind? Your Rolodex of mind?

Matthew: Well, I remember—

Sarah: I was crying.

Matthew: You were crying. I was really upset. I know we called our family, and we let them know. Obviously, they knew the story coming in, so they were anxiously waiting for the results. We

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told all of our family, and it was obviously a tough moment, and I think it was really hard, but at the same time, like, we had been waiting for that answer one way or the other. So it was actually kind of... for me, [it] was almost a relief, because I had sort of felt that this was the result anyway, and now that we knew, it felt like we could go forward and actually try to find solutions and start getting to work.

Sarah:

One thing I remember the audiologist did: She must know the person at the school where Fiona eventually ended up going for services, so she emailed the director there, and that person emailed us. We were still in the office when I got this email, and there was, like, a really nice, short documentary, almost like a commercial, and there were a bunch of kids on there who had cochlear implants, and you could tell [they] were doing really well and were talking and everything. So in that moment, that was really helpful to me.

Dr. Caraway:

Cochlear implants are a type of hearing device that bypasses the parts of the ear that aren't working so that the brain has access to all the sounds of speech, but it takes a step to get there. Most babies begin wearing hearing aids immediately after diagnosis. In fact, babies as young as 1 week old can be fit with hearing aids. Then, depending on the type and severity of hearing loss, cochlear implants may be recommended. This way, young brains have access to sound and start building strong neuropathways for listening and speaking.

Matthew and Sarah had Fiona fitted for hearing aids when she was 2 months old.

So, you received the diagnosis, and then tell me about that process and her first set of hearing aids.

Matthew: They have this, I guess it's like silicone or something, and they inject it into the ears—

Sarah: To make the molds.

Matthew: They make the molds for the hearing aids. And it was very interesting, because we knew going in that these were going to have very little impact to give her sound because of the severity of her hearing loss, but we knew we had to go through this step. And the way it was explained to us is that once we establish that hearing aids don't work, it allows us to move to the next step, which would be cochlear implants.

Sarah: And I think the hearing aids were important. Although she couldn't access speech sounds, I think through them— because of the degree of her hearing loss— it was important to keep the auditory nerve stimulated, and also so that you could prove to the insurance company that [the hearing aids] weren't working so that they would then pay for the cochlear implants.

Matthew: Yeah. And it's interesting because when we were sitting, getting them fitted, I was like, "Why are we doing this?" But by the end, I realized that her having... even if it was a little bit of access to a tiny bit of sound, it helped her understand that sound existed, and it helped her brain at least develop an attention for sound. And that's what was explained to us by the caretakers that we worked with in the beginning.

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Dr. Caraway:

And that's a really good point that you raised, is that you ... And I appreciate you expressing that you thought, "Why in the world are we even doing this?" But as you learn and move along, you realize that babies do have residual hearing, and keeping those auditory pathways stimulated are critical to prepare that little brain for the cochlear implants.

So, what was that like? Here, you have a little 2-month-old, now with hearing aids. And hearing aids have feedback, and hearing aids need ear molds. Tell us about that process.

Sarah:

Well, she had the hearing aids, and she was also going for speech therapy and kind of group therapy at the school where she was getting her early intervention services. So my husband and I both worked full-time, so my mother, actually, was the one who was driving her around to all these things and did the bulk of these appointments for the hearing aid molds because they grow so quickly, and the feedback gets worse if the mold doesn't fit tightly in the ear. So I think probably at least monthly, she was having to get new molds for the hearing aids. So it was a challenge. I remember once I lost one of the hearing aids. Oh my gosh, do you remember that?

Matthew:

I do remember that. I forgot about it until just now, but I remember now.

Sarah:

Oh gosh.

Dr. Caraway:

Did you find it?

Sarah:

We found it. It was under the radiator, but it was a very stressful few hours. And luckily our speech therapist was like, "O.K., you need one of these retention clip things." So after that, we

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didn't lose them anymore, but it was terrifying for a little while.

Matthew: And the hearing aids, they were either making feedback, or falling off, or Fiona was pulling them off, or it was always something. It was a lot of maintenance.

Sarah: It is.

Matthew: But it was worth it. It took a lot of extra effort, and like we talked about, it was worth it to give her that access to sound.

Sarah: Yeah. One thing we had, actually, that was really helpful was these— they're called pilot caps. And so she had, like, a variety of different colors of pilot cap that she would wear around. It's kind of a close-fitting cap that you tie under the chin, and that helped her keep them on.

Dr. Caraway: Keeping hearing aids on a little one is a familiar struggle for many in this stage. Daily and Phin found themselves in a similar situation as Matthew and Sarah.

Tell me about that routine and what that was like, keeping hearing aids on a baby.

Daily: I mean, we were a very consistent. So, I mean, as soon as I got him, I believe I put them in while he was nursing. It would just be right on the boob, and then he would be settled enough to kind of get the mold in, and until he was pulling them out or they were coming out, he would sleep with them, even. Like, I just wanted every possible moment for him to be wearing his hearing aids from the moment he woke up, but when he was napping, he would nap with them in. And then it got kind of

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hazardous, like I don't want him eating it or something like that. And if he pulled them off, we stopped until we put them back in.

And when he got older there was... Even to this day, it's no processor, no play. That's the motto of our household. He never got to go to... We never had the option that he could play without it. He was never... We have friends. They'll go to a class, and if their kid doesn't want to wear their listening device, they don't do it. We never allowed a second of that.

Dr. Caraway:

So what was that drive? Why? Why did you know it was important to wear the hearing technology all waking hours and to maximize that wear time?

Daily:

I mean, that's what they told us, and someone had given me the example of, there was an experiment done with kittens where if a kitten is blindfolded— with normal eyes, is blindfolded at birth, and you take the blindfold off— I don't know if it's three weeks later or whatever— the kittens still can't see, because it never created the neuropathways, and you have that critical period. And I reflected on that a lot, which is like, we have a finite amount of time to get the auditory nerve stimulated and to get language in there, and so we were vigilant about it.

Dr. Caraway:

You knew that it was about the brain.

Giving babies with hearing loss exposure to stimulating sounds and a rich spoken language environment is so important. Making sure they have their hearing aids on at all times while they're awake will help their brain build strong neuropathways for listening and speaking.

Getting fitted with the appropriate hearing technology to provide access to sound is one of the first steps on the journey. The next step is helping children give meaning to the new sounds they hear.

So one of the first steps in the auditory skill development is that alerting to sound, recognizing the presence and absence of sound. Do you remember the first time where you felt like she was comprehending what you were saying to her?

Sarah:

Well, part of her early intervention services was she was going to a significant amount of speech therapy, I would say. And part of the auditory verbal therapy that she did was working a lot with the Ling sounds. So there were a kind of a variety of toys that were associated with different sounds. And really, it's amazing. I mean, I was a new parent, so you kind of don't really grasp, I think, what babies are actually capable of, hearing or not hearing babies. So like, eventually ... And I think before she was a year old, she really would be, you know, if I said, "E-e-e" she would pick out the monkey, things like that. I was like, "Oh my gosh, that's amazing."

Dr. Caraway:

That's a huge comprehension thing, isn't it? That if you could make a sound, and she picks up the animal that makes that same sound that you probably thought, "Ah-ha, she's getting this. She's comprehending this."

Sarah:

Definitely.

Dr. Caraway:

Making connections.

Matthew:

Yeah. The Ling sounds, that was the first milestone, I feel like, of her actually

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comprehending. And it was... We played with those toys a lot, and we just loved seeing her work through the sounds and recognize the sounds. And that was through her services, and they really helped us kind of recognize that that was the first step, like, this is one of the most important things in the very beginning that you can work on.

And I think their advice to us is what really got things going, because they worked with her, but then at home, using the advice from the service providers, we really started to feel like we were going in the right direction.

Dr. Caraway:

So you began to feel empowered to do some of the same things at home and carry them over.

So, O.K. Talk to us about the learning to listen sounds and “monkey says ‘e-e’” and all that? Can you explain what that is?

Sarah:

Yeah, yeah, it's been now ... She's a little bit past it—

Dr. Caraway:

If you can remember.

Sarah:

So there's six Ling sounds, I think, and one of the ways that they teach them to kids... And it's important because, I think, if they can access these six Ling sounds, then they have access to all the frequencies that are needed to learn speech, basically.

So there's, at least for our center, I think sometimes it can be a little different on the toys, but the monkey is “e-e-e.” The airplane says, “Ah”. The ice cream cone we had was “mm”.

Matthew: There was oo-oo.

Sarah: Oo. What was oo?

Dr. Caraway: Was it a ghost?

Matthew: Yes.

Sarah: Yeah.

Matthew: I think it was a ghost.

Sarah: There was a ghost, and then “sh” was the baby.

Matthew: And then “ss” was the snake.

Dr. Caraway: So “ah,” “ee,” “mm,” “ss,” “sh.”

Matthew: Yes. Those six sounds, those were, like, all we did for a long time, aside from your typical talking, but like, that was the game that we always played with her in the beginning.

Dr. Caraway: And like you said, Sarah, that the reason why that's critical is that because if a child's responding to those Ling Six sounds, we know then they are accessing all the sounds of speech to their ears. So. Wow, I'm impressed... I made you recall that back from... You called that out really nicely. You must have had some practice with it.

Sarah: I know, we have a little bag of all the toys that kind of went a lot of places with us.

Dr. Caraway: Now practicing the Ling Six sounds every day is a quick and easy way parents can make sure their child has access to speech through their hearing technology. The Ling sounds

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cover all the frequencies found in speech: mm, ah, oo, ee, sh, and ss.

Initially, the child learns to alert to the sounds, and as their auditory skills develop, they began to imitate the sounds, demonstrating the ability to discriminate between the sounds of speech. Activities like this become a normal part of life for families who choose Listening and Spoken Language, and early interventionists helps parents integrate LSL learning into their daily routines in a way that feels natural for each family.

Through use of LSL strategies throughout daily living and play, parents teach children to know when sound is present or absent, to tell the differences between sounds, and to label what they're hearing. All are important building blocks to developing conversational skills.

That doesn't mean it's always easy, though. Mercedes was at a loss when she found out that her son Kevin was deaf.

Mercedes:

Because I remember one of the things that I did in the beginning, I didn't want to talk. I don't know why I [didn't], but they said, "No, you have to talk to him."

Dr. Caraway:

Tell me more about that, why you didn't want to talk.

Mercedes:

Because I knew he couldn't hear me.

Dr. Caraway:

And so because you thought he couldn't hear you, you thought there was no reason to talk.

Mercedes:

Exactly, and especially when Kevin was so little. I put him on my chest, and I [wanted] to sing a song like my mom sang to me, or they

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teach me that song, and I remember, like, he couldn't hear me, and I didn't [sing to Kevin] at that time. But then I said, "Why not?" So I started... I had to pass that... whatever stopped me [from doing] it. And then I started do it, so that it really helped me and [made] me feel better.

Dr. Caraway:

I love it that you have family traditions that get to be passed on, and every family has some of their favorite things that they like to do with baby.

Mercedes:

Actually, a lot of them I invented myself.

Dr. Caraway:

That's the best kind! What was the song that your mother sang to you?

Mercedes:

It's that traditional song [passed down] through generations and (singing in Spanish).

Dr. Caraway:

It's beautiful.

Mercedes:

And then, you know, so I meant in my own songs, so [inaudible]. Spanish is my best way to express.

Dr. Caraway:

Absolutely. Because that's your first language, and it's the language of your heart. And I think that's fabulous. So then, you realized you can start singing to Kevin. You need to talk to him and talk to your babies. Do you remember that time when Kevin or Keily first had their implants, and the first time you took them home, and the first night you sang that song? Tell me about the first time you sang that song to them when they had even more access to sound?

Mercedes:

Oh, that was amazing. [I'm] telling you that even if they don't really respond because

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what's most of the time when they're going to go to sleep—

Dr. Caraway: You hope, right?

Mercedes: That was really something. [There was] a time when Keily used to be upset. So for me, it was important to put her in my lap, on my chest, close to my heart because that I know ... I felt that way, I could help her to calm down. Yes.

Dr. Caraway: Tell me about that.

Mercedes: I think that's one of the things... That's why she likes to sing.

Dr. Caraway: Oh, probably so, because you sang.

Mercedes: That's one part of the really something that in our family we enjoy the music. So yeah, I used to sing to her, and she kept crying but then, "Oh, O.K." And then she kind of ... That actually was a challenge because then when I stopped, she started crying again.

Dr. Caraway: How wonderful that just like a hearing baby is quieted to the mother singing, then you have that same experience with Keily that she quieted when you were singing, when she was wearing her hearing technology. That's wonderful.

Mercedes: And actually, we have a really nice connection for that, like, for myself and my daughter.

Dr. Caraway: And I think one of the things that happens is that sometimes, families might be hesitant to sing a lot because they think, "I'm not a good singer. I don't know all the songs." But I love it that you just made up your own songs, too.

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Mercedes:

It's just... For me, also, [singing] helps. It's a therapy thing. It's a therapy for me, also, and I know I don't sing that well, but—

Dr. Caraway:

No. You sing. But that isn't what matters. It doesn't matter how good you sing, it's that you sing and have fun with your kids. That's what's important.

As parents, we all want to connect with our children through the songs and words that mean so much to us. Today, that dream can become a reality for all families, even if it takes a little time to get there.

I want to thank these families for sharing about the first steps on the journey to listening and speaking, getting access to as much sound as possible, and starting early intervention to learn how to create LSL learning opportunities in their everyday lives. After that, the sky's the limit for children who are deaf or hard of hearing.

The diagnosis of hearing loss may feel like a private loss and pain, but you are not alone. In episode three of *Powering Potential*, we'll hear about the parents and professionals who are ready to partner with you and your family.

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