

## Powering Potential Podcast

### Episode 3: It Takes a Village

Dr. Teresa Caraway:

When I first met Maggie, I was the last person her parents really wanted to have to talk to that day. It was the holiday season, and our office was closing, and the team was heading off to be with their families, and just then, Maggie's parents called. They suspected Maggie was having trouble hearing. They asked us to stay so they could receive an evaluation.

When Maggie came in, we conducted testing in the sound booth and quickly realized that Maggie was profoundly deaf. It was a hard conversation with the family, but it was also the first step in a beautiful journey to Listening and Spoken Language. A dedicated team of interventionists, audiologists, surgeons, and others guided Maggie's family along the way. Today, because of that diagnosis and a dedicated team of interventionists, Maggie is a thriving fourth grader who enjoys playing sports, singing karaoke with her friends, and playing the flute in her elementary school band.

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. Teresa 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.

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Finding out that your child has hearing loss may come as a surprise. At times, you may feel isolated and uncertain of what to do. I want to assure you that you are not alone. Not only are there vibrant communities of families who have taken their children on the path to listening and speaking, but on the road there, you'll find professionals such as audiologists, teachers, pediatricians, therapists, nurses and doctors, and more who are well-prepared to help you and your child on your journey.

In this episode, we'll talk to parents about how they built the right support team for their children as they learned to listen and speak. For many parents who are just finding out what is possible for their child with hearing loss, connecting with other families on the journey can be a huge turning point.

Mercedes wasn't sure what the future would hold for her son Kevin after his diagnosis, so she visited a school for children who are deaf. At that school, they had a classroom for children with cochlear implants, and for Mercedes, hearing a child who was deaf listening and speaking— well, that was the moment that changed everything.

So you're finding out about cochlear implants and that there's technology available so that Kevin can learn to listen and talk, and so, for the first time, you see a child that's deaf listening and talking. What was that child doing and saying, and what was the interaction that you observed?

Mercedes:

O.K., **actually... she [was talking] to me about the implants, so she [said]**, "And we have here a group of kids that... got implanted. They're in another program because **[they're]**

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learning to speak." So she took me actually to the group, and I saw... But **[they're]** all little, so a lot of them, they're still working on the speech. But she introduced me to this family—mother, father was a Spanish speaker but **also [an]** English speaker— and I met them. So I met them, and he was so nice and the lady also, she was really nice. But one night, we were waiting in the living room...

Dr. Caraway: The waiting room?

Mercedes: Waiting area.

Dr. Caraway: Waiting area?

Mercedes: ... Waiting area and **[the little boy]** was running all over, and his dad called him in Spanish. He told him, "Ven acá les." He'd say that, "Ven acá." And he went right away, **but when the daddy [said], "Ven acá," he [started] talking** to him in Spanish, and also the kid responded to him. I think he was telling him about something, **he [wanted] a car** or something. So I hear him talking, so for me, I had to turn my head, and I start talking to him, so he [says], "Oh, hi, how are you?" So he was kind of shy, but the dad came and approached, **and he [said], "Talk to her. Talk to her." And he [said], "Hola." He [said], "Hola." I [said], "Oh my God, this is amazing."** I was so excited to see.

When I saw first to the class, I didn't really see them interact so much, yeah, but not really interacting. But this time, I was interacting with him. So for me, that's why it's so important when I see a family that they wanna go in through this new path, I tell them, "Meet my kids. Talk to them. Spend time with them. Don't ask me. Just go and observe. If you wanna ask

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questions, go, go ahead, go ahead." **Because [that's]** what is for me, made me to decide to do this for my son. For me, it wasn't easy, but to see this kid, it really made me see this differently. There is hope. O.K., my son could do the same thing like this kid.

Dr. Caraway:

Right.

Mercedes:

Maybe a lot of other parents, we are afraid to ask because we think maybe it's dumb, any questions, but I think it's not dumb... dumb to ask questions. We gotta ask anything it is. Even if you think it's a dumb question, you have to ask, because in part, we understand that. Because sometimes I see, I see parents that they don't want to ask because, I don't know, they don't feel comfortable. And even when I see moms going through that time, like myself already went through that emotional... talking about emotional things, some feelings, it's O.K. It's O.K. to cry, it's O.K. to feel what you feel. You're upset, it's O.K.

Dr. Caraway:

I will never know what it's like to be a mom, to have to receive that news about their baby. I can have great empathy. I can share the journey as a professional, but I don't really know what that's like, and that's why parents and professionals need to be good partners.

Yes, parents and professionals need to be good partners, but finding the people who will be on your team, when you don't even know the name of the game, can be tricky.

Fiona's parents, Matthew and Sarah, both have professional backgrounds that gave them insight into the kinds of medical and educational resources they would need to tap into. Still, it was a learning curve.

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What were the types of professionals that were on your team that joined you along your journey?

Sarah:

In the beginning, there were audiologists to help us make the diagnosis. Then there were speech and language pathologists, specifically ones who were certified in auditory verbal therapy or Listening and Spoken Language. And there were, at the center, there's also like an educational coordinator who's given us a lot of good advice, especially as we've come down to the IEP things. You know, the surgeon, obviously, who still we see him once a year. Actually our pediatricians, when she was a little baby, were ... I think it wasn't something that they'd really been through before, but they were really supportive, too. They were helping us also with other, whatever, my breastfeeding problems and just trying to get through that first year of life.

Matthew:

It's a very people-oriented profession, and you just meet so many great people along the way, and they've all been just really excellent.

Dr. Caraway:

So that's the pediatric audiologist who made the confirming diagnosis of Fiona's hearing loss. Then, there's the surgeon who placed Fiona's cochlear implants. When Fiona got home from the hospital, her early interventionist set up weekly sessions with a speech-language pathologist who was certified in Listening and Spoken Language or LSL. The LSL professional works as much with Matthew and Sarah as they do with Fiona because parents are their child's first and best teacher.

In LSL intervention, parents learn to incorporate LSL strategies throughout their daily life, so that they can teach their child

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spoken language through listening. Now, Matthew and Sarah were able to connect with highly qualified speech-language pathologists and teachers and get going on the LSL journey right away.

But for other families, the path isn't as straight-forward. Ketty felt like her daughter Nura was not making progress towards developmental milestones in the way that she should be. Remember, it had taken some time to get confirmation of Nura's diagnosis.

So when that evaluation to leave early intervention to enter preschool, what were her skills like at that point?

Ketty:

Very limited. The recommendations were very strong. She really needs a place that specializes in hearing loss and that could address those skills like ... Really, her communication was so limited. This is a child who was almost 3 and could use two-word phrases, and they were not easily understood. Then when she engaged in more, sort of like a jargon kind of language, it was very broken, it was not easily understood, and she would become frustrated. But the worst part was, I was permanently frustrated. I became the mother who was usually angry, because I'm like, "But repeat it, repeat it." I was so harsh in that sense at that beginning because I was like, "What am I not doing? What is it that is going on? What is it that I don't know that Nura cannot move forward the way that would have been expected?"

Dr. Caraway:

Those feelings of frustration and sadness are very common. For parents who are doing all they can for their child but the pieces haven't fallen into place yet, it's perfectly normal to feel

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discouraged. Ketty is a wonderful, caring mother, and she pushed on in her search for help. When Nura was about to transition into preschool, Ketty discovered Listening and Spoken Language.

Ketty:

They do something called oral-auditory approach. They teach your child to listen properly, and the speech, the way they work with it, is from approach of hearing loss. And I'm like, I didn't know that existed. I have done a lot of research here, I guess I did the wrong type of research here. And she gave me the name, the number, and that's when I first visited in 2009. I was able, in addition to the visit, to look through the two-sided mirrors on how the approach to therapy was, and then the guilt surely gripped me because as I said, that's not what the speech therapist has been doing with my daughter. What did I do? I didn't find the right therapy. She's never gonna learn to talk typically. Her speech was very limited even at that time.

Dr. Caraway:

So you have some delays you're gravely concerned about, and she starts preschool, and you find a place that you say, as she transitions, that you're matched up with individuals who have a significant history and experience of working with children who are deaf, to teach Listening and Spoken Language. You start watching through a two-way mirror, and what do you see that's happening differently?

Ketty:

The complete approach from the clinician, number one, noticing that during, yes, regular speech intervention, they are consistently working with localizing ... I didn't know that's the word at that time. I noticed that they were always sitting differently, in regards to the

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position of a child, different angles. They would cover their mouths, either with their hands or a little screen, so the children wouldn't see their mouths and immediately rely on lip-reading. I was like, "What? What is she doing?" It's explaining to me, "Oh, it's so that the child doesn't rely on the movement of the lips to understand what is being said. This child is at another stage. At first, yes, you want to show movement through the mouth to help them imitate how you move your lips, et cetera, but this is about them listening."

So during the entire session, there's always a focus on listening, not just imitating, so you'll get better at pronunciation. But relying on what you listen to become better and understand better, that was the first thing that really was very striking to me, like, "Oh, this is—

Dr. Caraway:

This is different.

Ketty:

... so different."

Dr. Caraway:

Finding experienced speech-language pathologists and teachers of the deaf who are certified in Listening and Spoken Language made a huge difference for Nura. As children get older, you'll find that different kinds of professionals will come into your life and become a part of your journey. Matthew and Sarah are building new kinds of partnerships now that Fiona is transitioning into a mainstream school.

Matthew:

Her teachers in the preschool setting right now, in nursery school, excuse me, and then the new staff that's gonna be accepting her into the public school, they were all so excellent. It's a very people-oriented profession, and you meet

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so many great people along the way. They've all been just really excellent.

Dr. Caraway:

Along the way, did you ever meet a professional who wasn't so helpful? Don't name them, but what did they do or say that wasn't so helpful?

Matthew:

I can't think of any. That's not to say that maybe that person doesn't exist somewhere in the world, but every interaction I've had with any of the professionals have just been positive and just really professional. It seems like everybody in the field that I've met is dedicated, is highly qualified, and just really cares about people.

Dr. Caraway:

Yeah, I think as a professional sitting here in the conversation, I'm a person, I have to remember, I chose this, and families didn't chose this. I recognize that I'm a person that in your wildest dreams, you never thought you would have to meet or have in your lives. But I think what the message I hear you saying is that the people you're gonna meet along the way are genuinely going to care about your child and about you as a family, and even though you don't know them yet, they will.

Sarah:

Yes, definitely.

Matthew:

Absolutely.

Dr. Caraway:

It always takes a village to raise a child. In the case of a child with hearing loss who is on the path to listening and speaking, that village just happens to be a little bigger. Know that wherever you happen to be on the journey, doctors, speech-language pathologists, teachers, and other families are out there ready to embrace your child and help them

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reach their full potential. What's most important is to keep searching until you find the right village to support your child. They're out there ready to help.

Up next on *Powering Potential*, we'll hear about these families' exciting progress. Join us for episode four, "First Words and Other Celebrations."

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