

Powering Potential Podcast

Episode 5: Words of Wisdom

Ketty:

The first time that I had to deal with another aspect of hearing loss, and it was other children looking at her ears and seeing the hearing aids and questioning... I remember that we were at an activity in the park in the school, and one of the children comes running, and he says very loud, "What is that in her ear? It looks like a machine."

And Nura didn't cry, didn't lower her head, but she was startled. She just had this blank face, didn't know what to say, because Nura at that point didn't have an issue with having hearing aids. So I say, "Oh, it's called a hearing aid. It's the coolest thing ever because she cannot hear so well in that ear, and she can hear you perfect with it. Do you want to look at it? It's really fun."

And the kid says, "Sure." I said, "Come, Nura, come." And we show him, "Look. It goes through here and here, it's so amazing. And look at the color, it's so nice." They were colorful. And she puts it back. And the kid says, "That is actually very cool. Bye." And he left.

That's how I always approach it with her, because I said, "Well, this is sort of, like, the first time she's going to be dealing with this. I have to teach my daughter by example that there's nothing to be ashamed of. You shouldn't let anyone put you down for it." So it's just like it's an everyday thing, because it is for her.

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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. 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.

In this episode, we're going to hear from parents who have become advocates for their children on the journey toward listening and speaking.

The transition from preschool to a mainstream school can be nerve-wracking for both parents and children. It's full of unknowns. And as much as we prepare, there will be unexpected bumps in the road. But hearing from parents who've been there and learning their tips, tricks, and words of wisdom can make this journey a lot easier, especially when interacting with people who may not be familiar with children who have hearing loss. It's a big concern, and parents have lots of questions about what happens when their child realizes they're not the same as other kids.

Roark is only 4 years old, but his parents Phin and Daily are already asking themselves these kinds of questions all the time.

Daily:

And I wonder about, he started to ask a few questions about... And it's always kind of out of the blue, of like, "Why do I have processors? Will I have processors when I'm older, or will you need processors? When will the baby get his processors?" We usually kind of give a generic answer like, "Everyone's different,

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some people need glasses to see, you need processors to hear." He's been [letting] it go at that. But I have anxiety about him starting to get asked more questions, especially now that his peers are talking, that they're going to ask him questions, he's going to have to explain things more. And at this point, he just says, "These are my processors," and the conversation moves on, but it's going to get more complex. And he's not at a bullying age yet, but that happens. And if it wasn't the processors, I'm sure they'd pick something else. Those kinds of things give me anxiety, and we'll see. I think that finding friends, finding love, those are the next frontiers.

Dr. Caraway:

Yeah. And I think some of those... I think as moms, we get concerned about those no matter what, right? Those are just some typical kid things. But I'm sure it's... Weighs heavier on your mind a little bit.

Daily:

Just to tell a little anecdote, when I just... We've... We have a nanny who is amazing, and when our son was 3 months old, I was saying, "Oh, he has hearing aids, and I'm just worried about him having friends." And this other nanny looked to me and she's like, "Don't put that on him." And I was so shocked that anyone would just... Would say that to, like, a new mother. But I was like, "You're totally right. Don't put that on him." She was like, "He, look ... He seems fine. Don't put your own anxieties onto your child that way." But I think about the mentality of a lot of like my own anxieties. He doesn't have anxiety, so my husband has to help me a lot.

Phin:

Every kid goes through something. If it's not this, it's going to be something. So you never

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want it to be what it is, but then you don't think about what else it could be as much.

Dr. Caraway:

Yeah. Yeah. And what types of conversations are you having with him?

Phin:

He gets very excited about things, and he asks a lot of questions, and it's a lot of question-answering, it's all ... Especially when we read books. He's gotten into this superhero phase, which I don't remember being involved in. Everyone likes Superman and Batman, but he knows all of them, so it's reading superhero stories and making up superhero stories. And it's an interesting thing to me because you learn about the origins of these superheroes, and it all comes from an area of weakness that turns out— they become superheroes. I'm sure that somewhere deep inside of him, that's not lost on him. And he's Roark the Superhero, and he wears processors.

Dr. Caraway:

One of the goals of Listening and Spoken Language is for children to become fully independent and integrated into the hearing world. For many of them, transitioning to a mainstream school alongside their hearing friends is an important step toward reaching that goal. But to make that transition successful, parents have to advocate on behalf of their child.

Now that their daughter Fiona is transitioning out of preschool and into a mainstream school, Matthew and Sarah began to have a lot of these questions.

Sarah:

Now that she's almost 3, we've been transitioning from early intervention where we live to the school district services, which was an anxiety-provoking experience.

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Matthew: Right. Just when you got comfortable in the current preschool setting, now it's all going to change. Although, we were fortunate that it worked out really well, but it was another little mini journey along the way.

Dr. Caraway: It's a big step. It's a big step leaving early intervention to go into school-based services. And it's another big scary time for, I think ... That I've heard parents express. And so what were you worried about, and what was fearful about the process, and how did you work through that?

Matthew: I think the biggest thing we were worried about is that we wanted to make sure that the recommended services from all of her prior professionals would be offered by the new setting. So we basically got a bunch of information from all of her speech therapists and audiologists and everybody that we've been working with, and they laid it out for us and said, "This is the ideal program." And I think our main concern was, we want every single thing on that list, because they are the experts, and especially with Fiona. And so, I think that was my biggest concern, was getting the program to be exactly what was recommended.

Sarah: Yeah. It's hard to go from early intervention where at least... We've been very fortunate, I would say, in the sense that where we live, she... They go to a nursery program that was led... Her teacher was a teacher of the deaf, and she had speech therapy for an hour twice a week with someone who was LSL certified, which not all speech therapists are. So you go from a place where you're confident that these people know how to work with cochlear implants, they know more about it than I do, I

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have total faith that what they're doing and what they're recommending is the thing that I need to be doing, to a school district where that may or may not be the case. It depends on the school district and what services they have, and if they had kids with cochlear implants before, like maybe not. So that was the thing that I was worried about. And just like Matt said, wanting to make sure that the experts have recommended to us that she have these services, so I want these services, because you want to make sure you're doing the best for your child.

Dr. Caraway:

Under federal law, all public schools must ensure that children who are deaf or hard of hearing have access to effective communication and classroom instruction on par with their hearing peers. These services are granted according to the Individuals with Disabilities Education Act, or IDEA, Part B or Part C. The individualized family service plan, or IFSP, is for the youngest children, ages 0 to 3, to support your family in reaching your desired developmental goals for your child. As your child turns 3, there's a big transition moving from the IFSP to an IEP, the Individualized Education Plan. The IEP is focused on preparing a child to enter school, often with the goal of integrating into a regular classroom alongside classmates with typical hearing.

That was a good tip, in terms of sitting down with your early intervention providers and saying, "What is it that you feel your recommendation is, that you feel like she's going to need?" and the supports and the services, so that you had that plan and you prepared your information going in, so you even knew what to request and what to

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navigate. Did you take someone with you at that IEP meeting?

Sarah: We didn't because he's in education.

Matthew: Yeah, I work in education, and so I didn't bring anybody with me. But I have a lot of friends who work in special education, and so I was actually consulting with one of the directors of special education in the area who is a friend of mine. I had a very good background knowledge myself just because of my work and through my contacts. But I think for a set of parents who may not have that link to education, I think it's a great idea to bring somebody with you or really just to do a bunch of research with an expert, because there's a lot to it.

And the other thing to think about, too, and this is just an easy tip— if you're a set of parents going into an IEP meeting, don't sign it at the meeting. Bring it home and have a couple people look at it, and take your time, because it's a big moment, and it's a big document. Just, if you're not sure, and you can't bring somebody with you, take the document, and take that to somebody who is an expert and can review it and help you navigate through it.

Sarah: I can say as a person who's not in education, I found it very confusing and stressful, and I would be talking to Matt every day, being like, "Well, what does this mean? What should we do?" The other concern that we had with Fiona, and which I think is becoming more common as children are implanted earlier and have more access to the appropriate services from the 0 to 3 stage, is that what the school district will do is evaluate them and do a bunch of tests, and she was average on all the tests. So

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there can be some contention about whether she should even get an IEP. Because normally, they're looking for some kind of deficit on the testing. So that was another big concern that we had.

Matthew:

Right. The tests that the school district gives don't necessarily target the specific learning areas that are suffering due to the hearing loss. So it does take a dialogue between the parents and the team. And I think... Like I said, getting that advice from somebody who's in that, is really a great way to go.

Dr. Caraway:

And I think you raise a really good point and that is that we have this new population, this new child that looks very different than any other child ever before who's been deaf in terms of their Listening and Spoken Language skills and how they perform on testing, but yet, they still function as a hard of hearing student when they go into the classroom because they have to have that clear, consistent signal. So there are some supports and resources that have to be put in place, and that's stressful for parents to have to carry that banner at a time when perhaps our educational systems or our professionals don't know what they need to know at this point for kids like Fiona. She's lucky she has you for parents. That's for sure.

Dr. Caraway:

Matthew and Sarah mentioned their IEP, which will serve as the roadmap for how the school plans to help Fiona learn and progress academically. Every parent is a member of the IEP team and has a right to give input on that IEP. You as a parent play an active role there advocating for your child.

Both of Mercedes's children are in mainstream schools. Keily goes to private school in the family's parish.

So tell me about Keily today. Talk about the main ... Because it's a mainstream school, is Keily the only child there with hearing loss?

Mercedes: Yes. Yes.

Dr. Caraway: O.K. And so she's playing and interacting with hearing ... Her hearing friends?

Mercedes: Yes. Yes.

Dr. Caraway: And is that a school where you would have wanted her to go to if... Even if she didn't have hearing loss?

Mercedes: I think so. Yeah. I think so. Yes. It's close, it's convenient. She has frame for our neighborhood. That's what I like. And I could go ... And if they call me, I'm so close.

Dr. Caraway: That is awesome. You've mentioned that Keily goes to a school where she's the only student with hearing loss in this whole school.

Mercedes: I was afraid, actually. Yes. And actually my school... My son's school is a very, very big school, crowded school, so that's why I did not put her in that school. And it also was very far from us. That's why I decided to put her in my parish school. And I think it's a good decision. Of course, I have to go to [the] Department of Education to tell them and my daughter, "This is the IEP, and she needs these services." One thing that had happened was that she was doing so well [inaudible], so well that they didn't want to approve the services because she says she's doing really good. She's even doing

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not average; she's doing better than that. It was hard to go for the meeting, I tell them, "I know she's doing so well, I'm very proud of that, but the way she's doing ... This is because [of] the school she was on. So I really think my daughter needs the support."

Dr. Caraway: And what kind of support were you asking for? What kinds of things did you think she needed?

Mercedes: Speech therapy and hearing services.

Dr. Caraway: O.K.

Mercedes: Hearing service, which includes the hearing teacher or the FM system unit, and accommodation sometimes, make sure that she's listening, repetitions. And I always tried to be aware of that in the IEP. Make sure that is... that in the IEP, because we know by law it's mandatory, so they have to do that. You see, it's also something that I learned through this. Be sure [to check] the IEP, make sure that they have all that.

Dr. Caraway: All right. Keily's at a private school.

Mercedes: Yes.

Dr. Caraway: Does the speech therapy come to her school?

Mercedes: Yes.

Dr. Caraway: O.K. And then tell me about the hearing services. How does that work and support her? What happens at the private school?

Mercedes: Really, there's also a team, which is the Department of Education Team for Hearing Services. So I already know people who already works there. I call and I say, "Where do

I have to go to have these services for my daughter?" Because also in private school, it's different. Locally, that year, they accept that school, having the providers be in school. Before my daughter, they didn't have that. That was our first thing. We had to [be] looking for that, looking at agencies. I did not have the answer right away. Again, I'm not the one saying, "O.K., we don't have that for your daughter." No, I had to go in and say, "O.K., I couldn't do ... I couldn't find the providers myself. I need your help." I went and she got the services there.

Dr. Caraway: More perseverance on your part.

Mercedes: Yes.

Dr. Caraway: And so, she's in the private school, but the public school provides the speech therapy services that come into that school. Do they provide a teacher of the deaf that acts as a consultant to the... That classroom teacher?

Mercedes: Yes.

Dr. Caraway: And then they provide the FM technology, which is the technology that puts the teacher's voice directly into her ears.

Mercedes: Exactly.

Dr. Caraway: Does she have friends over to play? Does she—

Mercedes: She does. She actually does. She's really happy to be there, and [I'm] telling you, she's very smart. She's a leader also, I could say ... I could mention this. Since she was little, she was telling everybody what to do, how to play.

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So that also has been really nice for me to see that.

Dr. Caraway: Because of her spoken language skills, you can see her leader skills coming out, right?

Mercedes: Right. Exactly. Yeah.

Dr. Caraway: That's great.

Mercedes: And she advocates for herself. And being at school, you see her standing up and tell the teacher, "I can't hear you." So she could, whatever, move the FM system because she was... The microphone and the FM system unit and she'd tell her, "It's off." She had to tell her, "Oh, it's off. You— can you turn it on?" With the gym teacher, the music teacher, she says, "O.K., can you please turn on the FM system?" You see, she advocates for herself.

Dr. Caraway: That's terrific. Even at a very young age, she's not fearful or afraid to tell people how to use the technology to help her have access to the teacher's voice or to the instruction. That's great.

As much as we would like to be, we can't be with our children 24 hours a day to make sure they have all the tools they need at every moment. But what we can do is equip them with the confidence to stand up for themselves just like Mercedes has. We can teach them that it's their right to speak up when they need help and to encourage them to be self-advocates.

One way to help a child become a self-advocate is to develop a positive collaborative partnership with their teachers. For example, meeting with their teachers before school starts

and letting your child show them how to use the FM or remote mic system can make a world of difference. In the previous episode, Ketty told us about how hard it was to find the right speech therapy for her daughter Nura. It took perseverance to get Nura into a school that had specialists in Listening and Spoken Language or LSL.

Ketty:

I was very blessed that I found the right place. Nura was completely ready for mainstream. You see, when you find programs that specialize in spoken language, oral-auditory approach, and your child doesn't have [another] type of diagnosis that require other type of services. The approach is so strong and so well-targeted that the purpose is to mainstream our children in the educational system, and that's what happened with Nura. She just went to her regular kindergarten, The Zone School.

She was very excited, because she had spent two years in a group environment, and she loved it. She loved the fun, she loved learning, so she felt very grown up. "I'm my own person, I'm in charge." But that was the first time that I had to deal with another aspect of hearing loss, and it was other children looking at her ears and seeing the hearing aids and questioning. There were not many other children that were not close friends who would ask questions or point at her. She didn't go through bullying or anything like that at the beginning. I remember that we were at an activity in the park in the school, and one of the children comes running, and she says very loud, "What is that in her ear? It looks like a machine."

And Nura didn't cry, didn't lower her head, but she was startled. She just had this blank face,

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didn't know what to say, because Nura at that point didn't have an issue with having hearing aids. So I say, "Oh, it's called a hearing aid. It's the coolest thing ever, because she cannot hear so well in that ear, and she can hear you perfect with it. Do you want to look at it? It's really fun." And the kid says, "Sure." I said, "Come, Nura, come." And we show him, "Look. It goes through here and here, it's so amazing. And look at the color, it's so nice." They were colorful and she puts it back. And the kid says, "That is actually very cool. Bye." And he left. That's how I always approach it with her, because I said, "Well, this is sort of, like, the first time she's going to be dealing with this. I have to teach my daughter by example that there's nothing to be ashamed of. You shouldn't let anyone put you down for it." So it's just like it's an everyday thing, because it is for her.

Dr. Caraway:

So I think that you modeling the first time that a child runs up and talks about her... The hearing technology, the hearing aids, and how you modeled it so that you could teach Nura, do you know of a time when you saw Nura then do that same thing, where she took and she provided the answer?

Ketty:

Yes, she has done it a few times. Interestingly enough, she has had a couple of friends who didn't realize she had a hearing loss, and when they find out they're like, "What is that, Nura?" And she said, "Oh, I have a hearing loss." "Really?" And she's like, "Well, do you want to see [what] it is?" And she takes them off, and she explained how it works. "I cannot hear without it." And she lets them see it, and try it in their ear, it's very loud, right?

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And she explained herself like, "Well, I don't hear it the way you do. It's not that loud in my ear. And that's how I hear you perfectly. So if sometimes you see that I seem distracted, check it out, because maybe I don't have them on, so you can make sure I heard you. It's not that I'm ignoring you." She does use it as a conversation piece.

She's more comfortable with family, of course. With family, she does more of the, "Oh yeah, look, I got my new hearing aid. Oh my gosh, it's brand new. It doesn't have the outside mold anymore. It's like a grown-up hearing aid behind the ear, and look how small [it is]." And so she does that more with family. And talking about modeling, I would like to go back a little bit about support and family.

Ketty:

Family, they have good intentions, and they can become very opinionated. You need to use tough love with your family sometimes and be very grateful for their support and tell them, "You don't know what it means to have your support. Sometimes I feel a little bit lonely in this process." And explain everything to them. Invite them one day to therapy. "I want you to see what it's done." Engage them.

It is very important because if the whole family has the same approach for your child, that's the first group that can show your children the true meaning of acceptance, the true meaning of belonging. And if they have that there, they truly are stronger and more confident. And when they have to go out there with people who really don't know... I always tell my daughter, I say, "Nura, people are not acting that way necessarily because they want to bully you." I always tell her, "Ignorance is the greatest evil. Ignorance drives you to make the

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wrong comments, to do the wrong things. Only you can make it different for yourself. Educate people. When they say something mean or they point at your hearing aid, or they're like, 'Why is that with that?' With that face like, 'Oh,' like, [a] not very accepting face, educate them, be the model of how they should be. Be nice about it. Don't be offended and say, "Oh, it's just that I cannot hear so well. Just like you cannot see so well or I cannot see so well, and so I just put it in, it works really great, not a problem." In your own confidence in yourself and you're telling them what's happening, you might that day have to do something new to this person and help them become a better person that day, because you chose not to be offended, you chose to be accepting so they can learn to be so too." I know she's only 12, but these conversations are very important.

Dr. Caraway:

But that also builds empowerment in her.

As parents, we're our child's first and greatest teachers. When a child goes out into the world and begins to understand their place in a community, it's so important that we teach them that they're valued, they have amazing potential to realize their big dreams, and they are not defined by their hearing loss. There does come a point where every child just wants to fit in. By encouraging self-confidence and self-reliance from an early age, they'll be better able to do just that.

In the next episode of *Powering Potential*, we're going to explore the idea of fitting in and what normal looks like when life feels anything but.

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