

Powering Potential Podcast

Season 2, Episode 2: Dear Parents

Jayden: I would tell them that ... Don't give up on your child 'cause you could look at the possibility of their kid's, of their child's future, and he can live a normal life like anybody can.

Dr. Caraway: Jayden's family knows a lot about seeing the possibility in a child. Seven years ago, his parents traveled to an orphanage in China and adopted Jayden and his sister. From the moment they met him, they've been propelled by an unwavering determination to give him a better life. It's that same determination that has helped Jayden go so far on his journey toward listening and speaking.

Welcome to Season Two of *Powering Potential*, a podcast from Hearing First where we explore the unique joys and challenges of growing up with hearing loss. I'm Dr. Teresa Caraway, your host, a mother, and a speech-language pathologist specializing in Listening and Spoken Language. In Season Two, we'll get to know six incredible teens and young adults who are learning to navigate the hearing world as individuals with hearing loss.

If you're a parent of a child with hearing loss just beginning the journey, I want to tell you that you are not alone if you struggle with the unknowns along the way. The diagnosis often comes as a complete surprise. The majority of children with hearing loss are born to parents who have typical hearing. We can't predict all of the inevitable ups and downs on the journey, and that can be stressful. But we know one thing for certain: If you're a parent who's

chosen a Listening and Spoken Language, or LSL, outcome for your child, your involvement in their journey is absolutely critical. LSL is truly a team effort. Your child's speech-language pathologist, other members of the hearing healthcare team, and you, the parent, all work together to teach your child how to listen, speak, and thrive. No two families on the journey incorporate LSL into family life in exactly the same way, and that's okay.

In this episode, we hear directly from our young friends about their biggest advocates: their parents. I hope that through their stories, you hear how the emotional and practical support you give your child every single day will pay off now and in the future.

So, the thing with Listening and Spoken Language intervention is that a parent is always involved in the session. And so, then you'd go home, and what types of things do you remember that your mom did for you to help you?

Zach:

Well, I know that she would try to replicate, you know, the therapy session. She would get me to talk as much as humanly possible, ask me, you know, more questions than I was asking her, you know. It's just pretty, pretty insane for a kid, you know, getting me to talk as much as I can and stuff like that.

Dr. Caraway:

Yeah. So, in fact, you know, what happens with moms and dads is that they become some of the best speech-language pathologists, Listening and Spoken Language therapists. They just need to have a degree conferred on them because they've lived it 24/7.

Zach's mom did exactly the right thing. She asked him lots of questions and talked, talked, and talked with him some more. We like to tell parents to become a radio commentator for their child's life. A constant stream of language helps them associate words with their meanings, and reinforcing the games and lessons learned in weekly LSL intervention sessions is an important part of learning to listen and talk. Peter's parents took the same whole-hearted and hands-on approach to his LSL journey, even incorporating a homemade hearing test into their routine.

Peter: They threw themselves into my hearing loss, which I feel like is very important and probably the single most important reason that I'm as successful as I am today.

Dr. Caraway: Yeah.

Peter: I do know that my mom and my dad always tell me that, like, kind of their homemade tests that they would do is that ... So, they would take me up to the top of our driveway the first Saturday of every month while I had hearing aids, and see if, like, if I would respond at all to the tornado sirens, and I never did. So that was kind of their indication that something—

Dr. Caraway: That hearing aids weren't going to be powerful enough to give you access to all the sounds of speech.

Peter: Exactly. I found I was really good at English, like, writing, which is surprising. I feel like that goes back to all the therapy that I had as a kid. And I remember one of the things, I forgot about this, one of the things that they said in therapy was to read. Because if you read, and you identify words, and you get them in your

brain, then you can hear it and you'll be like, "Oh. Hey, that's that word." So, like, my parents made me read a lot, and I got to read whatever I wanted. And I was a weird kid. I never read, like, Junie B. Jones or Harry Potter or anything like that. I was reading books about sports and history, and I feel like that's probably why I'm really good at history. And I was reading way above my age level. I was reading, like, college books in middle school, but that's beside the point. Anyway, so I was really good at English, so I really enjoyed that class 'cause like, we get to read these classic books.

Dr. Caraway:

What did your parents do that gave you that foundation?

Peter:

Oh, okay. Yeah. I feel like what they did was ... They would read to me before I could read. Like, every night they would read me a story. So I was exposed to that process very early on, of listening and understanding and comprehension. And they would stop and ask me questions and everything like that. And they did a tremendous job of that. And that's, I feel like, what propelled me to be a great learner and listener today.

Dr. Caraway:

And then they read, read, read, talked, talked, talked.

Peter:

I remember that we would always watch the news every single night; we still do. We'd watch the national news, so I'd be exposed to these big words because big words happen in national news—well, at least to, like, a child, big words—

Dr. Caraway:

Yeah.

Peter: Happen in national news—and so I'd be exposed to this and then they would pause [the news].

My mom's a political science professor at UCO and my dad was a political science major in college, so like, we talked politics. And politics is full of large, difficult concepts to understand, so I feel like ... They would pause it on the news and, like, we would talk about what was happening, and I was a 5-year-old kid. I mean, I don't know what gerrymandering is, or anything like that, and yet, I would be able to participate.

Dr. Caraway: But that's interesting Peter because what I hear you saying is they didn't just use words that they knew you understood.

Peter: Yeah.

Dr. Caraway: They got out of the rut and they had lots of conversations—

Peter: Yes.

Dr. Caraway: About topics that—

Peter: And that's crucial. You've got to expose ... I feel like exposure is so, so important as a parent of a kid who's got hearing loss. You have to expose them to the real world. Because like you ... I know as a parent, you're going to want to protect them. You're going to want to shield them from every bad thing that happens in the world. Because, I mean, as a parent you're afraid that your kid's going to be bullied, teased, made fun of, all that kind of thing because they're different; they have a disability. But you have to stomach the fact that you're not going to be able to protect them

forever, and the earlier you expose them, and the more that you expose them to, the better.

And I feel like one of the key things to do is, like I said, to put them in school, where they're exposed to kids that have normal hearing every single day. But, like, you can't just stop there. You have to put them into situations, whatever it may be. It could be sports; it could be music; it could be dance, whatever it is. But you've got to put them in an environment where they're being exposed to sound from all directions and sounds that they're not familiar to. Because I know personally, there are voices I can understand, like they're mumbling, like, completely horrible, nobody can hear other than me. Like I can ... I know what they're saying, even though they're mumbling terribly.

Dr. Caraway:

It takes courage to do what Peter's parents did. They treated him exactly the same way that they would treat a child with typical hearing. Their courage has helped Peter become the high-achieving young man he is today. So, what other qualities are important for a parent of a child with hearing loss to have? I asked Connor this question. We met him in the first episode. He's the pediatric audiologist who has profound hearing loss and understands what it's like to be both a patient and a professional.

Connor:

Perseverance ... You know, there is a lot about hearing loss that we still don't know, and you have to ... You know, I feel that everything happens for a reason, you know. And whenever you have a child with hearing loss, you are going to have a lot of things come at you all at once. And I think if you can help persevere through that ... You know, your kid is going to see how you handle this from a very early age, and if you can help persevere

through that, that will help. Patience ... You know, when those kids, when those hearing aids keep getting ripped out, just keep putting it back in. They're doing it because they're liking the ... they're liking the attention that you're giving them. If they take it out, don't pay attention to them. Don't give them the attention they are [seeking]. I cannot tell you of a single baby that I have fit hearing aids on, that has not attempted to rip hearing aids out.

Dr. Caraway:

So how did your mom ... What did your mom do that showed perseverance and that showed patience? Can you talk—

Connor:

Sure.

Dr. Caraway:

A little bit about that?

Connor:

My mom ... I was talking to her about this yesterday and she said that she, whenever ... Right after I got identified with the hearing loss, she had clipped an old newspaper clipping out. It was ... Was it Dear Mary, or—

Dr. Caraway:

Dear Abby.

Connor:

Dear Abby.

Dr. Caraway:

Oh, wow.

Connor:

Yeah, yeah.

Dr. Caraway:

Okay.

Connor:

[It was a] Dear Abby newspaper clipping. It was actually about hearing loss. And somebody had written in and said something like, "The best thing that you can do for somebody with hearing loss is not make a big deal about it, to not, you know, make that a

central focus in the kid's life, not make that a defining feature in the kid's life.” Because honestly, they're still a kid. It's just a feature of their life. The best thing that you can do is just, just live life, and that's it.

Dr. Caraway:

Not making hearing loss the central focus is great advice for a family on the LSL journey. Hearing loss doesn't have to define your child's life. It's just one aspect of who they are. Kane and Zach's parents took the same approach.

What is it that you think your parents have done that has supported you the most?

Kane:

Well they've done, I mean, everything that like ... I wouldn't be able to hear like I do without them, so I'm very thankful for them. And they've never given up on me, which I love. And like I ... I may have a bad day where I won't hear just anything, where I'm just, like, tired, and they still won't give up on me. I mean, like, again, they're, like, my parents. They're hard on me because they know [it's good for me.] Like, if I want to play, like I'm going to play because I'm not going to let [hearing loss] define me. So they treat me like everybody else. They don't just treat me like I'm a special kid, and then all the other kids are just normal. They treat me like everybody else, [like I'm a normal kid too].

Dr. Caraway:

So is that a tip you'd give to other parents?

Kane:

Oh, yes, I would.

Dr. Caraway:

Yeah. That, not to, not to—

Kane:

Yeah. Don't just be, don't just be babying them because of their hearing loss. I mean, be hard on them and give them discipline. And then,

just let them know that no one, no one's perfect, and no one's ever going to be perfect. So just take that, just put that in mind. And that's really the only advice I could give them.

Dr. Caraway: Yeah. Expect high expectations.

Kane: High expectations, Yes.

Zach: Make sure you get them on hearing aids as fast [as] possible. Don't try to do anything else, like, sign language and all of that. Get them into speech therapy, you know, as early as possible too. Don't treat them like they have a disability. Because if you do that, they're going to live their life thinking that they're disabled. And my parents never did that. They never, never made me seem different. And I don't, I don't feel different.

Dr. Caraway: Kane's gratitude for his parents is not uncommon for children born with hearing loss who had the opportunity to learn to listen and speak. In 2018, leading audiologists and researchers, Drs. Stacey Lim, Don Goldberg, and Carol Flexer, conducted a survey of young adults with hearing loss who learned to listen and speak. Ninety-five percent of them responded that they would do it all over again. Like Kane, many express their gratitude for the dedication of their parents.

While parents play an incredibly important role on the journey, they're not the only ones who have impact. Teaching a child to listen and speak is truly a family affair. Involving siblings, aunts, uncles, grandparents, and others enriches a child's access to spoken language. We see this all-family approach with Harper, who has a close relationship with her grandmother.

And what did you think your grandmother did that helped you?

Harper: Well, my parents both work, so my grandma's always taking me to, like, the places I need to be, like theater and games. Or she's always coming to my games too. She always wants to be there for me. And she probably ... she's probably wasting more gas on me than on herself.

Dr. Caraway: Yeah.

Harper: She also knows, like, how to do tape or ... and if I ever, like, don't have extra batteries in my backpack, or, like, I forgot them that day, then my grandma, she'll bring me something from home.

Dr. Caraway: Like Harper's grandmother, family members on the LSL journey often go the extra mile for the children in their lives. Jayden's parents went more than a few extra miles to get him to where he is today.

Tell me where you were born and how you came here and about then getting implants and all of that stuff.

Jayden: So I don't really know where I was born, but how my life started was when ... So my grandpa and I were going to my grandparent's house up there in the mountains in China, and then we were on the way. And on the way, I asked him if I could go get a snack [from a store] because I was getting hungry. And then when I went in to get a snack, when I [came] out [again], he was riding a motorcycle up the hills. And so, I went back [to] where we were before I went into the store, and I waited for him to come back, but he never came back.

So, I started walking around everywhere, and before I knew it, I was lost.

Dr. Caraway: Yeah. And how old were you then Jayden?

Jayden: I was six.

Dr. Caraway: Six years old. That was pretty scary. Yeah. So, then you started walk, wandering around—

Jayden: And then I was by myself three days and three nights and then a police [officer] came, picked me up, and took me to the police station. And they fed me noodles. And then after that, they took me to the orphanage, and I stayed there two years. And then after two years, that's when my mom and dad decided they were going to adopt me. Before they adopted me, they adopted my sister, older sister Maylee, who's in 12th grade, and she's 18, I think.

Dr. Caraway: Okay. So, they decide ... They come to China, they adopt you, and then what happens?

Jayden: So they adopted me and then we flew back to the U.S.

Dr. Caraway: What have your mom and dad done that's made a difference for you?

Jayden: They have taught me great things. They helped me not to give up on [the] things I like to do, so ... They usually just help me with everything I get frustrated at or things I have hard times with.

Dr. Caraway: So you don't go to therapy anymore, but your family continues to help you.

Jayden: Mm-hmm (affirmative).

Dr. Caraway: What kinds of things do they do to help you at home?

Jayden: When I say something incorrect or, like, a definition that didn't make sense, they usually correct me and help me with those words, and make it make sense. They have been amazing parents. They help me get through [the] tough times and hard times, you know, when I had ... [like the times] when I was in China. And they helped me [learn] how to overcome those times.

Dr. Caraway: And how does your mom help you? How does she support you?

Jayden: She helps me [know] how not to be scared or [afraid]. She usually helps me [know] how to, just, how to not be scared.

Dr. Caraway: How does she do that? Does she talk with you? Does she—

Jayden: She usually talks with me [about] how I can, you know, just shake it off and just go [out] there and try my best, and then, you know, before you know it, it's over. She usually give[s] me instruction [on] how to relax and just take your time and everything; just don't push yourself [too hard]. Just relax and try your best.

Dr. Caraway: Yeah.

Jayden: Just give your best effort.

Dr. Caraway: As Jayden points out, children who are learning to listen and speak need not only the practical and logistical supportive parents, but also the emotional push and cheerleading that parents provide so well. His family's story of overcoming immense challenges to thrive in

the hearing world makes it seem like anything is possible. I'd like to close this episode with Harper who is wise beyond her years.

What do you think is important for families to know and to do to help a child with hearing loss?

Harper:

Think of, like, the future, not, like, what it is right now—also think of that—but, like, farther into the future, what their life's going to be like later because of the decision you're making right now. And put your child in speech, definitely.

Dr. Caraway:

Harper's advice to play the long game is spot on. Parents of children on the LSL journey have the opportunity to build a solid foundation for their child that will last the rest of their life. As our young friends have demonstrated, the determination, perseverance, and patience of their parents have paid off immensely. If you're a parent struggling on the journey, I hope you remember their voices and stories, and the full, rich lives they lead today.

Check out episode three of *Powering Potential*, where we'll hear from our young friends about their experiences attending mainstream schools.

Announcer:

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