## **L&L S1E7**

Christy: [00:00:00] You are listening to the Love and Language Podcast where we inspire hearing parents of d/Deaf children and remind you that as long as you are giving your child love and language, you are doing a great job.

**Christy:** Hey, Beth. Hey Christy. How are you doing? Oh, I'm okay. It's been obviously a little crazy around here. We apologize for the last two weeks we were not able to do the podcast. My husband got shingles, it was very bad and like a varicella pneumonia situation.

**Christy:** And yeah. How's he doing? He's doing a lot better now. My husband also has blast trauma. So he has hearing loss and wears hearing aids because he's lost so much of his hearing from his job. Beth- I did not know that.

**Christy:** Yep. And so the shingles that he has, It got into his right ear. So hopefully, I [00:01:00] don't know, hopefully he doesn't get my gosh, any more hearing loss on that side so yeah, fun times.

Beth: I'm glad he is doing better.

Christy: How are you?

**Christy:** 

**Christy:** Just always have things

Beth: going on. I don't know, not enough time in the day, but all good things.

**Christy:** Good. Good things is good to be busy with. I appreciate them so much more right now, in this moment.

**Christy:** And then when we went to record today, we're laughing cuz we couldn't get the audio to work and we're like, it's so ironic that we're doing this podcast about hearing loss and we can't hear each other. Would love to be fluent on a s l to do an a s l. Podcast. That could be a goal of ours for sure.

**Christy:** So today we are just going to talk a little bit about what's been going on with our kids, cuz I know Beth had an appointment with Coop and it was his first one and I think. Eight months or

**Beth:** something like that. Eight. Eight months. Yeah. Yeah. We had to reschedule once or twice, so it was a little longer than that.

**Beth:** Six months.

Christy: We're gonna talk all about that because we mentioned this in [00:02:00] earlier podcast, how it feels like you're bringing an entirely different child to these appointments. So I can't wait to hear how we did in there. And then I'm gonna talk about Charlotte's kindergarten i e p meeting that I had yesterday and some tech issues we're having with her cochlears, we went, we got pretty far without them but here we are. So Beth, I wanna hear all about his appointment.

**Beth:** Yeah. So like I said, right now he's at the point where he's just going twice a year for the general like mapping. Check in, see how he is doing, make sure we don't need major changes.

Beth: And we had to push that off a couple times due to various things. So it was a little longer than normal. So I guess the last time he was there would've been August, I think. And I don't even think I took him, I think Brandon actually took him to that appointment, so I hadn't seen her audiologist in literally a year.

**Beth:** Like Wow. It was weird. I wasn't at that appointment obviously, so I don't recall the specifics of it. So it was just such a different experience taking in this like little [00:03:00] boy compared to a toddler who's not putting full sentences together. And he, number one, he is just a ball of energy all the time.

**Beth:** So the office waiting in the office is always fun. But yeah, once we, got in there, our audiologist was like, I heard him in the waiting room and I just stood there and listened for a while. Cause I knew that as soon as he got in here it wasn't gonna be like quite the same level of chatter, which is true.

**Beth:** But yeah we got in there and we sat down and just caught up a little bit. And then she started doing some of the booth testing where normally in the past I go in with him into the little, room where they do the testing just cuz he doesn't love, like not seeing us or not knowing why he's in this like little room.

**Beth:** And he just marched in there this time all by himself and sat down at the table and stayed in there with her for a solid half hour, 45 minutes. And just, it did Awesome. It was the first appointment that, I left with her saying I have zero

concerns. And that was like a really good feeling, not that she was like always super concerned before, but it was like

**Beth:** he was a little later to start putting big sentences together and [00:04:00] just your kids don't act the same at an audiology appointment as they do at home either. So if she never really got like the full scope of, what we were seeing and I think she, she did at this appointment.

**Beth:** So it was just felt really good to be like it's working, all the work that we have put in. And then to be able to give her a copy of my book too. My, the ABCs of inclusion was really cool. Oh. A weird like full circle moment that I never would've expected when we were first in her office three and a half years ago.

**Christy:** Wow. And so when he goes into the booth, how does he like to do his testing?

**Beth:** Honestly it's just depends on the day, which is a very toddler thing. So this time she was working with him too on just some of the like labeling and sounds and stuff that we haven't been able to do before by pointing to pictures and having him like repeat things.

**Beth:** And so that was different just because he is at that point now where he can do that. And then he's also at the point too where he like, He knows the TV's gonna go off to his right or his left during booth testing. So he is constantly like looking for both. So we have to get a little bit creative around that too, and make [00:05:00] sure that he's actually responding to sounds instead of just like knowing that they're gonna come

Christy: on.

**Christy:** Does he get like a listen and put something in a bucket or like a game like that?

**Beth:** In the past? Yes. Honestly, like I said, I wasn't in there this time. And the way that the room is set up, if I had been in a spot that I could see him, he could see me and then he would get super distracted.

**Beth:** I peeked in there once and he was like, mom. Yeah. So I just, I stayed outta the way and I obviously couldn't really hear what was going on either. Cause it's soundproof, yeah, I remember. I wish I had more

**Christy:** insight. Yeah. Hey, that's like the best insight Somebody needs to hear that one day your kid is gonna march into the booth and you don't have to be in there.

Christy: I haven't had that experience yet. I've still had to go in there with Charlotte and it is like, they're always more distracted when mom's in the room. And then, I remember feeling oh wow, they're trusting me to go in there by myself with her and do the things because it used to be me and then, an assistant that was [00:06:00] helping and then just Charly, then it gets to just you. So to think about, I even feel encouraged that I don't have to go into that booth and feel the distractions and, so that'll be really nice. What was he like at his last appointment? I wasn't at the last one. Oh yeah. So that's, so you, the

Beth: last appointment that you in August,

Christy: like what was the last appointment you went to?

Christy: How old was he and what was he like in it then?

**Beth:** It would've been the beginning of 2022. I don't think I was at that August one. I have no recollection of it, but I'm pretty sure Brandon brought him. So it would've been like six months before that. So he would have been. Two and a half-ish. So at that point, he was saying a lot of words and pointing and saying and that kind of stuff, but he wasn't really like connecting big sentences.

**Beth:** And then especially when we would get, to the audiologist and he would not necessarily get shy, but just he knew, he, he's always been one of those kids who's he's just stubborn, he knows he's supposed to do something, so he is [00:07:00] not gonna do it type of thing.

**Beth:** Yeah. And so that's why I felt like a totally different kid, because now he's making these multi word sentences with propositions and like directions, and it's just there's days where he says things and I'm just like, did that just come outta your mouth? When did this huge shift happen?

**Beth:** And I feel like I'm always saying oh, in the last two, three months things have really changed. And, but that's just when you start hitting that like uphill gain, it really feels like things are always building and changing. And so I'm sure, when we go back in October, I'm gonna be like, oh, he's totally different this time than he was that time.

**Beth:** So I think the main thing for her to see was just that engagement and like being able to answer questions and ask questions.

**Christy:** And I don't wanna breeze over the fact that. When he comes back in October, because for people listening who are just starting out, like these appointments do get space so much further when is his birthday?

**Christy:** September. September. So he's gonna go through entire summer. He's gonna go through all, more [00:08:00] holidays, start a whole new school year, have a birthday. Yeah. So many things happen between that appointment. And your next one. I still remember that our last appointment was probably like August. We're trying to get rescheduled and being like, oh, okay, I'll see you next year.

Christy: Like opening, like happy Halloween, happy new, Merry Christmas, happy new Year, happy Thanksgiving. It was wild. Aw, that's awesome. When he tests in the booth. Yeah. Does he still test as having any hearing loss or is he like, Does he test normal hearing levels?

**Beth:** I was just so like amazed at with him this last time that I did not ask all the questions that I usually ask.

Beth: I know. Just based off her saying she had no concerns and in the past, like from his education team, he is, doesn't qualify for a speech and language development delay at all. So as far as I know, he's responding to that full spectrum of sounds. She didn't say any differently. Normally she would point out if he wasn't.

**Beth:** So I think the only thing she really mentioned was that his eardrum and his left ear wasn't moving quite as much as the other [00:09:00] one, which, he went through that phase a couple. Months ago where he like didn't wanna wear them for a few weeks at a time, not a few weeks at a time, but was harder to get 'em on and off.

**Beth:** So she's it's possibly had an ear infection at that point. It's still just aftermath of that. So that's something too, I guess to keep in mind is like, they're always looking at their actual ears too, at these appointments, at least for us., which is nice.

**Christy:** Yeah, it is nice. And then sometimes things do click together and come together like that oh, maybe.

**Christy:** That is the reason why X, Y, and Z were going on. Yeah, Shirley, yeah. She was able to

**Beth:** see too that his tubes had moved. So I was like, oh, if he did, have an infection, that was probably part of it.

**Christy:** But do they have to take out his tubes or do they fall out?

**Beth:** How does that work? No, they were, they said they were just gonna leave him.

Beth: She said they were both just floating around in there right now.

**Christy:** I was like, okay. And that, and they just, and she just eventually would come out. Yeah. I always wondered about that. And then, yeah, would you,

Beth: they made

Christy: it like two years. Yeah. That's good.

Christy: I was trying to pull up Charlotte's last [00:10:00] appointment because, so she still tests in the like mild hearing loss in one of the ears. Mild to moderate, I think, which is interesting. Okay. But I think it might be because of her She has the mondini malformation. When they tested, I wanna say like they tested, like they did when they did the surgery. Look, do you ever feel like, what do I know about my kids hearing loss? Like both of us here? Like we, I don't really,

**Beth:** I know like when you're asking me these questions, I'm like, in the past I would've been asking all these detailed questions and now I'm just this is our life.

Beth: I know how he is doing day to day, so it's like that's what matters to me.

**Christy:** Exactly.

**Christy:** Wild to think about the journey. Yeah, and it goes by fast. It goes by fast. I had this week Charlotte's i e p meeting with her. Team and her kindergarten teacher, which is wild to me and honestly she's at, she could have started kindergarten this past year cuz she is fi, she's already five.

**Christy:** She turned five August 2nd, [00:11:00] so she'll be turning six. But we gave her that extra year just to let her language milestones catch, which was definitely the best call. And we're

**Beth:** in that same exact boat with the early September birthday. Are you gonna hold it back a year? Glad it was a good choice.

**Beth:** Yeah. It wasn't even, I am bored in early September and my parents waited and I loved being like the oldest in my grade.

**Christy:** Yeah, that's what I was saying. I was like, even if she didn't have hearing loss, we would've considered it anyhow. That's what we're looking at with my son too, cuz he's July 29th, so he is really tiny, but he also can, I, he's crazy smart.

Christy: Yeah. And he reads, he can read full books and also don't want him to be bored, but With her. It was, so our I E P meeting was with her teacher, Ms. Danielle, which I really was getting emotional on there with Ms. Danielle, Ms. Karen, who's our speech therapist at school. And then there's also the teacher of the d/Deaf and her new teacher, Ms.

Christy: Brewer, who she's gonna have next [00:12:00] year. And like Miss Danielle has been, Like Our Rock. We, and we were her first, like Charly was one of her first students. We were her first year at the school. So her and Charly and her does have a bond that's very special and she's been in her class since she was two and a half, three years old.

Christy: And now she's almost six. So it was like, it's gonna be hard for. Me,. I met her teacher yesterday and she's wonderful. Her kindergarten teacher. And looking at it was nice. What they did, this is the part that I took away and I wish I brought in the paperwork, but they have the whatever report card a kindergartner would get, and I don't know how they do it where you live, but it has AP for.

**Christy:** Advanced proficiency, P for proficient. Something needs improvement. I don't know exactly what the list is. I don't remember. But they graded her as if she was in kindergarten to let me [00:13:00] know where she was at, like right now. And she had. Aps in almost all the sections.

**Christy:** So they're like, she's more than ready. Oh, there was the one that she needed improvement on was like me, she has issues. And if they were telling me this is very common with a lot of cochlear kits, I'm curious if Cooper has an

issue with this as well, is memory recall? If you told her a 10? Cuz I didn't know how this test works.

**Christy:** So if basically they, they told her a 10 word sentence. I don't know if that's the exact amount of words, but what could she repeat back? So if you were like, the dog and the cat went running past a blue trashcan and she had to say, just repeat that, the whole thing. Yeah. It's like she, she gets the concept and she gets like the p parts of it, but to actually repeat that sentence.

Christy: Verbatim, I guess is difficult for her. So they're gonna work on that. And a few of her speech sounds, there was only [00:14:00] three sounds that they were concerned about this time. So I'm like, wow, that's just so reassuring for me to hear. It was so good. Yeah. And she, they let her and the other little boy in her class that she's been to school with at this whole time, and he's gonna be in kindergarten with her.

Christy: They let them go to the kindergarten class. Like a couple times a week and participate for a little while. And she said Charlotte's so good. She just sits there quietly and she raises her hand and answers questions and she's really just confident and comfortable. So yeah, we're gonna have a kindergartner and crazy.

Christy: It's wild. Yeah. And right now she's, because she is in the d/Deaf and heart of hearing program through Virginia Beach Public Schools, she is at a different school than my daughter.

**Christy:** They were saying in first or second grade she could probably qualify to go to her regular [00:15:00] school district. And I was like, wow, I didn't even know that was an option.

**Christy:** And I think a lot of people don't. That's interesting. Yeah, because at the school that she's at, so it's a totally different district. She's in the same school. Sorry,

Beth: lemme turn this, just a different elementary

Christy: school. Yeah. So she's

**Beth:** in Virginia Beach. Okay. So our, ours does that too, where they segment like all of the d/Deaf and heart of hearing kids go to, because we have five elementary scores, schools that feed into our middle and high school.

Christy: Then that sounds like about similar, but I always just assumed that she'd be at that elementary school till fifth grade because they do have, for every grade up to fifth grade, they have. Like the classrooms that are more accessible and have, like all the teachers have their mics and they don't have that at my daughter's school, but it sounds like by first or second grade, she might not need that for accommodations.

**Christy:** I don't know. It's just an interesting thing that I didn't even know was possible

**Beth:** [00:16:00] then you have the meeting going into the school year, and then how many do you have like throughout the year

Christy: for IEPs? Again, do I even know? I know, I'm like, I don't think I know either.

Beth: We have one coming up next week actually,

**Christy:** but I think we do one a semester.

**Christy:** Like I didn't, I know I did one over Zoom. A few months ago, so maybe, I don't know. Her goals aren't written, her goals are written until August, 2020 or April, 2024. So I know her goals are like out here. Okay. Which is crazy still to be like, oh, wow. Yeah. Yeah, been ready,

Beth: There's parents who like, have issues with the I E P meetings or have I had bad experiences and I guess we're just le or we as in like me and Brandon are lucky that our district has been so on top of things like I've never felt like we don't have the resources or we don't have realistic expectations I feel lucky in that sense, like to have a really supportive team.

Christy: Yeah. I always thought that [00:17:00] too, like the big deal with i e P meetings because I feel like maybe you only get people share more about their bad experiences than with their, I wouldn't even say good experience.

Christy: It's just a normal experience. I guess good regular experience, but. Yeah, I thought the same thing. And maybe it's just because we do have the programs that we have or maybe it's more of an issue when they get to middle school or I can't wait to have people on that can help us, like when, I don't know.

**Beth:** I think we're both pretty involved parents too, so it's just the fact that we probably know what's going on and know what to expect and know what's realistic.

**Christy:** Also maybe it's very obvious they have cochlear implants, so they're d, like you have to Yeah. Yeah. It's very, it's maybe it's a more obvious hearing loss issue with IEPs, but ours have been fine. But what I was gonna say earlier about equipment, we have like [00:18:00] issues with our coils for the first time. And no. Have you ever had any equipment issues with

**Beth:** Cooper's? Yeah, but we also have so many coils and so many magnets and so many batteries and so like I just swap 'em out upstairs.

**Christy:** So did we and I swapped out coils. It was not working well. Like we tried everything I got nervous because her one ear was fine. The only issue and we couldn't think if we had to send back, we had to send back the. ZOS a couple times for, yeah. Replacement, and I think that was more I think they just get more moisture in them, or battery.

Christy: I don't know what the difference is, but we never really have issues with her N seven s that aren't easily fixable. Yeah. But when you put it on, it was like you had to wiggle it into place. I'm thinking, is there something like if you wiggled it Yeah. And turned green, I'm like, oh God, is this an internal thing or is this an equipment thing, which.

Christy: And her I know two people [00:19:00] who are just right ahead of us in our journey in her school. And both of them had to get revisions on one ear done when they were five and a half. So I was like annoyed. And she was hearing, like when she was a little bit younger, she was telling me she was hearing like a motorcycle sound.

**Christy:** I was like, what the hell does that mean? I get tinnitus, but never hearing like that motorcycle. And then recently she was telling me It sounds like a sh like staticky.

**Christy:** And I was like, that's so weird if you're new to this journey with cochlear implants, you can plug them in and listen to see what they saw. Yeah. And everything sounded great. And then I switched out the coils. I was still doing it. And so I called them and we sent what we called them.

Christy: Did they have to send us a new one? God, I'm all my times are running together right now. My husband ended up getting new coils again sent because

then we were out of 'em [00:20:00] after trying them and this one worked and it hasn't been an issue, but I'm like, what the heck? So

Beth: it's just, do you guys not have a backup set events at sevens?

Christy: We have the ZOS are our backup. Okay. Okay.

**Beth:** Do you have two N seven? We have two

**Christy:** sets of N sevens. Okay, so we don't have a cans. Yeah, we when we did our options, we did the N seven S and the cans. So our backup is the ZOS and one of her zos, the one that we would need isn't working there's always something that can go on with their implants that you gotta be ready for and the actual like tech piece of it. Yeah. So luckily it was resolved and I was like frustrated a little bit I mean we've gone five years for a piece of tech to be Yeah.

**Christy:** Working as great as it has. Like we're lucky and was like, yeah, I guess you are right. And that, so is she almost

Beth: due for

**Christy:** an updated Yeah, so July [00:21:00] she can get the N eight. Which I'm excited about. Cool. So that's why I didn't stress it too much. It's all fine now.

**Christy:** I don't know what the deal was with our coils or what was going on, but just one of those things. But yeah, I can't wait for the N eight. Do you know anybody who's had it?

**Beth:** Yes, I know. I know one parent of a. Kiddo who has just implanted, but I haven't, been able to talk to her enough to really know.

Beth: Yeah, I'm curious

**Christy:** the difference there, like how big the differences are and whatnot. So yeah, I'll be excited for it. But today's gonna be a short one, guys, because I know Beth has to get going

Beth: both of our lives are just like,

Christy: yeah, it's crazy. It's actually crazy we are going to be getting together to record our.

Christy: Cochlear surgery series. But .

**Christy:** We're happy to be back. Thanks for being patient with us for the last couple of weeks. This is again, yes, we said this before. This is an act of love. We do this because we just really feel like it's [00:22:00] something that other parents need and it's therapeutic. It's like therapy for us. So we were saying too, to be able to have these conversations and talk about it.

**Christy:** So we try our very best, but sometimes life happens. Yep. As always, as long as you are giving your child love and language, you're

Beth: doing a great job. All right. Bye

Christy: everybody.