Ep 12 with Emilee Segura

Alaine: [00:00:00] Hey guys, it's Alaine, host of Raising Deaf Kids, where we get weekly encouragement, education, and feel empowered to raise our deaf kids as hearing parents together. So grab your coffee and let's get started!

Alaine: Hey everyone, welcome back to the show. Today I had the absolute pleasure of talking with Emilee Segura. Emilee Segura was born Deaf and she received a cochlear implant when she was 18 months old, which I'm sure is the story for a lot of parents out there, it was actually the story for my two boys as well.

Alaine: Emilee is bilingual in ASL and English. She works as an Early Intervention Specialist for the Utah School for the Deaf and Blind Parent Information Program. She visits families [00:01:00] that have a deaf or hard of hearing child and performs language assessments, teaches language strategies, and helps answer any questions the family has.

Alaine: Emilee has a huge passion for helping deaf and hard of hearing children succeed. As a deaf person, Emilee has personal experience with the importance of early intervention. She's incredibly grateful for PIP, which is the program that she currently works for, and the deaf mentors that helped her family when she was younger, and now has come full circle to help other families with deaf and hard of hearing kids.

Alaine: Isn't that so cool? You guys, the program in Utah, the Utah School for the Deaf and Blind Parent Infant Program, or PIP, she is now working for that same program that helped her and she is helping so many other Utah parents go through the same things that her parents went through with her.

Alaine: And I think that is just so [00:02:00] cool and Emilee shares about her life as a deaf person on social media. And let me tell you, there's a lot of things on social media. A lot of things you don't want to follow. Emilee is one that you do want to follow. I love following Emilee on social media. She is upbeat and she is so fair to parents.

Alaine: On her social media, she loves to share her stories, her experiences, her frustrations. She shares lots of tips for parents and she is constantly answering parent questions. And you can follow her on Instagram at Emilee Segura and on TikTok at Emilee Segura and she's also on Facebook and YouTube all at Emilee Segura and we will link all of her social media in the show notes

Alaine: just sit back and get a notepad because she has so many tips for parents. Like I said, Emilee is so gracious in sharing her experience. She's also very fair and open to decisions that [00:03:00] parents are making for their children. So without further ado, let’s get to the show.

Alaine: All right, welcome to the raising deaf kids podcast today. We have Emilee Segura on the podcast. Hi, Emilee. Welcome.

Emilee: Hi, thank you for having me.

Alaine: Of course. We're so excited! I think you're just going to just be so great for our parents. Just a wealth of information. And I really appreciate you taking your time to come do this for us.

Alaine: So usually I like to start out with just asking the guests you know, what is their background with hearing loss?

Emilee: Okay, yeah, so I was born with a bilateral profound sensorineural hearing loss, which just means that I cannot hear anything out of both ears. My parents found out through the newborn hearing screening, and then they got further testing and got my diagnosis and started an early intervention.

And they started learning American [00:04:00] sign language. And then eventually, when I was 18 months old, I got a cochlear implant on my right side. And while I am deaf in both ears, I only got one cochlear implant because at that time, the technology was so new, and they weren't sure how successful it was going to be.

So they only implanted the one side, but I am deaf in both ears. And then I started to, I did speech therapy for about 5 years, so I could learn how to hear and talk. And then, yeah, I lived a very normal life. And then I got my bachelor's degree in communication disorders and then my master's in deaf education, and I now work in early intervention.

And I visit families that have a deaf or hard of hearing child and I help them navigate this journey. And I help answer any questions they have. I do language assessments and teach strategies to make sure that their child is reaching age appropriate language. And I absolutely love it. And I feel like I've come full circle.

My parents received early [00:05:00] intervention. They're so grateful for their mentors. And now it's now my turn to continue to help parents that have a deaf hard of hearing child.

Alaine: Yeah, I love that. So that is definitely, that's exactly the diagnosis that my two boys have. And, you know, your journey and, you know, your parents journey with you is exactly, you know, what we did with our children.

Alaine: You know, yeah, we found out they failed the newborn hearing screening you know, and then we started with the same steps and both of mine got their cochlear implants when they were about 11 months. Of age, and then start all the things.

Emilee: Yes, that's good because the earlier is better at that time.

Emilee: Utah had just approved 18 months and that was the youngest I could get it. But now it is just showing that the earlier you get it, the better.

Alaine: Yeah, and it was really interesting. I mean, I remember and I was talking to someone else about this too. You know, so my 1st child was like a complete [00:06:00] shock because we have no, like, hearing loss in our family that we know of you know, so knowing our family, our extended family, we're hearing parents so we did not, you know, expect to have not a deaf baby, a non hearing baby you know, and but by the 2nd one, it was really interesting.

Alaine: So both of my boys were also like NICU babies. And you know, so we did all the things and went all through it with my 1st one. And then. My second pregnancy was exactly the same as my first one. And so we kind of knew from the second pregnancy like this baby probably has they both have a genetic syndrome That caused the hearing losses some other light special needs as well, which also has never shown up in our family And also only 12 kids in the world have been diagnosed with this light syndrome.

Alaine: So it's like a very rare syndrome But all of the kids have been diagnosed Have cochlear implants that is the 1 thing that is a common. They all have, like, the hearing loss. And I remember being in the NICU with [00:07:00] my 2nd baby, which, like, we've done, you know, done this before my babies were fine. They were just born small and so they just need to, like, grow and I remember, like, talking to the NICU nurses and telling them, we think this baby stuff, we've already done this and they were.

Alaine: Yeah, I think they're trying to, like, make us feel better. All this. This was our 2nd baby. We didn't care at this point because we already knew the process. We knew the steps you know, and, you know, they were trying to tell us things like, well, you know, little babies. My baby. My 2nd 1 was 4 pounds when he was born.

Alaine: No, 3 pounds. He was 3 pounds. The 1st was 4 pounds. And, you know, they were like NICU babies. You know, a lot of babies don't respond when they're a little or, you know, he failed the newborn hearing screen twice, which we expected him to, and we even told them, yeah, he, I mean, I was going to do the test, but we're pretty sure that he can't hear because we feel like he has the same, you know, whatever at the time.

Alaine: We didn't know it was a syndrome. We didn't know the [00:08:00] diagnosis until I had the second one and we could get, okay. The testing for, like, all 4 of us, you know, and compare our DNA, which was helpful. So, you know, we didn't actually, like, know what was causing it, but we knew something was causing it. Yeah, and we just kept telling them and then we ended up being right, but I think they were trying to be helpful, but I'm not sure that it was helpful.

Alaine: I would love to talk. You know, that's something that parents talk so much about is like. Providers, like, minimizing the experience and, you know, I think providers a lot of times are trying to be helpful and encouraging to the parents. And I think they were trying to be like, well, wait and see. You don't know.

Alaine: Maybe the child is hearing. Maybe they're not. You know, responding because they're little or, you know, trying to, like, make up things and, you know, my husband are like, no, really, he's probably deaf. Our 1st one is we've done this before and it's okay. Yes, we are. We know the process [00:09:00] and truly the process with our 2nd son happened a lot faster because we were already plugged in.

Alaine: I mean, I immediately, when I had this baby, went to our speech therapist and was like. All right, his brother's deaf. We're starting with you. You know what? And immediately called the E. N. T. Like, I just knew, you know, everything happened faster for him. But I would love to talk about your thoughts on, you know, experiences with providers and their reactions to people being deaf.

Emilee: Yes, absolutely. Working with families. I hear a lot of the same situation, some similar story where the provider is telling them something like, it's probably just fluid or yeah, and. They are just trying to be helpful. The parents and that moment feel shock. They feel overwhelmed. They feel like, what does this mean?

Emilee: And I feel that the providers, instead of just trying to say, Hey, like, it's going to be okay. It's probably just fluid. It's [00:10:00] probably not what we think it is. To just tell them the steps say, okay, we're going to get you started in early intervention. You're going to go get more testing. These are what you can expect in the future.

And we'll just go from there. So that way, parents just know that, okay, this is what we're going to do. And if along those steps, they realize that the child, it actually was just fluid. Then great. They were already doing the steps. They were already in the process and now they can just stop early intervention.

But I feel like most cases, it's not always fluid. And. Yeah, they're already doing those steps in early intervention. They're already going. They have support from the early intervention team who can help them process their grief, who can help them, you know, understand what the hearing loss means they can help them figure out the next steps.

They can help them visualize the future. And so I just think. Providers should just focus on early intervention and not do that wait and see because hearing and language is so important early [00:11:00] on and so if providers can just be positive about early intervention and getting them started with that. I think that's the biggest way that things can change.

Alaine: Yeah, no, I love that. And, you know, when providers are talking to, I mean, you know, people look to the provider or the doctor, absolutely information because you don't know. I didn't go to medical school for a reason, you know, and, and you as a provider set the tone, absolute parents a lot. And you give them, you know, I don't want to say like false hope.

Alaine: But, you know, telling them things like, well, it could be fluid. Your kid can hear instead of just being like, yeah, Honest and supportive. Yeah. Your child might have hearing loss in like, here's the support, like it's going to be okay, you know what I mean? Instead of just trying, trying to convince you that they don't actually have the hearing loss and they're going to be fine because then it's almost feel like harder, realize, Oh, like there is a problem and [00:12:00] they weren't. Preparing like emotionally for it.

Emilee:100%. I agree. And yes, I love what you said. How the, the families trust the doctors, they, that's who, and yeah, I just wish that doctors and providers were more positive on early intervention and just getting started and just going through the steps and going from there.

Alaine: Yeah, and I would love to mention, you know, we're starting talking about starting this up. I've actually heard from a lot of parents lately and talk to a lot of parents lately who are just starting the process and they have no idea what to do, which I mean, it is I'm, you know, 7 years in with, like, 2 kids with it.

And, you know, I remember being at the beginning. I have no idea what to do, especially when you're hearing yourself. Because we're, you know, as parents are hearing, we're raising children who aren't going to have the same life experience that we have. And that's a little bit scary. [00:13:00] And I believe that most parents want to do the best that they can for kids.

We just don't know what we don't know. You know what I mean? So, I mean, I cried when I found out that my first baby was definitely deaf. I was like sobbing on the phone to my mom and I would love for you to talk about that. And I love to normalize for parents that there is like a grief process. And it is okay to do that.

Emilee: Yes. And it is 100 percent okay to grieve. It is something that is shocking, new, overwhelming. You're not a part of that community, the deaf community. You're, it's so new. And it's, and when you have a baby, like you just want to enjoy that new baby. Having that fear of the unknown of how, how is my child going to live?

Emilee: How are they going to? What's their life going to be like in the future? All of those is just, it's just consuming. And then with just hormones and just the emotions of having a new [00:14:00] baby, like, it is just a lot. And I tell kids all the time, take time to grieve. Take time to process your emotions. Think about how you're feeling.

Emilee: Ask questions, meet other people, meet other people that are in the same shoes as you, but further down the road. So meet parents that have a deaf child, but maybe their child is now one or five or 20. They can help you understand the process. And Oh, there was one more thing I was gonna say, I was just talking about grief, actually in my training the other day.

Emilee: And we're talking about how grief doesn't we always think of grief as something associated with something like losing a loved one or death in the family and grief. Happens to us every day. It's the loss of something unexpected. And so when you were pregnant and you were thinking about this baby, you weren't [00:15:00] thinking that they were going to be deaf.

Emilee: And so you had this like vision of what it was going to be like, and then all of a sudden it comes crashing down and it's like, wait, it's going to be different. And it is scary and it is overwhelming and. Every parent goes through it, and it's just a matter of, okay, what are the next steps? Let's figure out.

Emilee: Let's process it. Let's what am I feeling? Why am I feeling this way and trying to move forward?

Alaine: Yeah, and, you know, I love that. That was something that did help me was connecting with, like, local parents who had kids. You know, a little bit further along than me, even who are like, 2 or 3 years old, because mine were like, newborn who had like, been through cochlear implant surgery, or I got hearing aids and we're starting to talk and just talking to them was encouraging because you can see like, okay, there is like a process and there is like an other side to it. And honestly, I still appreciate it because my kids are little talking to [00:16:00] parents who have teenagers, especially teenagers with hearing loss, because there's so much coming up for me. And I'm curious about it. You know, especially when you're talking about. Older kids and helping them like advocate for themselves and it's just like, you know, and then saying them off into the world, which, you know, mine are little so I can imagine right now you know, but I'm interested in, like, knowing what's coming.

Alaine: And so, even like, those parents who have older kids and who have been through the stages I've been through are still helpful to me. I still ask them questions. So you're right. And honestly. Following accounts like you, people who are deaf and people, you know, whether they have cochlear implants, have hearing aids, are not aided at all, just to see that, like, our kid will have a normal life which is not, I mean, I didn't think that they weren't going to have a normal life, but like I said, as a hearing parent.

Emilee: You just don't know you don't know anything. It's hard to know. And, and [00:17:00] you don't need to feel guilt for not knowing, right? It's, it's something that is totally new. And there's resources out there to help for sure. My parents, I actually talked to them recently about their grief. And I said, you know, what were your first thoughts when you found out that I was deaf?

Emilee: And they, they were very sad. They were, my mom said, I was saying. My mom were, she said, you know, I was worried, like, she would never hear music, or she would never be able to watch Disney shows, like, hear Disney shows, and there were just a lot of things that they were like, wait, she's not going to be able to do this, and this, and this, and this, and this, when they, they weren't thinking about the things that I would be able to do, because all they could think about were, oh, she can't, she can't, she can't, she can't, but then the thing that helped them the most was meeting other deaf people, so they started just meeting people in the community through early, early intervention, and And those people help them see that they are going, but I was going to live a very normal life that I was going to go to [00:18:00] school.

Emilee: I was going to get married. I was going to all of these things, and that was really comforting for them and that helped them push forward through that grief and figure out what was possible and just get started. Yeah, no, I. Love that and I love hearing from your parents perspective to now that you are older and they've like been through the process with you to what they were like, thinking back then as well.

Alaine: Yeah, so I would love to know when we're talking to parents that, you know, they've just found out what is like. A 1st step that they can do you know, maybe okay, we can say grief. They've gone through the grieving process. What's like. The next step in their journey that you can say, okay, you start here.

Emilee: I think parents just don't even know where to start. You know what I mean? Okay, I'm going to start back at the hearing screening and just kind of go through the steps there. So after the hearing screening, the next most important step is to go to the audiologist and [00:19:00] and have that appointment and have a confirmed hearing loss, have a diagnosis and then they should send over in a referral for early intervention and someone should contact you about early intervention services.

Emilee: And you'll get that set up. You have what's called an individualized family service plan and IFSP. And that's just a meeting where all the providers come in. So I will go into the home and I will say, do you want my services? How often do you want my services? And what can I help you with? And you'll set up goals.

Emilee: So I have families who say, I just want to learn more about my child's hearing loss. That's the goal. And so I'm bringing in resources, educating them on the hearing loss, going over the audiogram. so much. Some parents have a goal of, I want to figure out what hearing aid devices are appropriate for my child.

Emilee: So we talk about, is it a hearing aid? Is it a cochlear implant? Is it a Baha? Are they not eligible for a hearing device? And we go over all of that. And then as we go on, the goals will change. You feel okay, I'm confident in this, but now I'm [00:20:00] nervous about this. I don't know how to deal with this. Maybe I'm nervous about how my child will communicate.

Emilee: Which approach should we do? So I talk about American Sign Language. I talk about listening spoken language. And I just give them all the resources and they can help and I help them make a decision that's best for them and their child and their family. And then we just keep going from there. We make, okay, now we feel confident.

Emilee: We've chosen spoken language. Okay, how are we going to accomplish that? How are we going to help your child make sure that they get spoken language? And you just keep going, you just keep creating new goals and your early intervention provider will help you with strategies and you can know how to help your child.

Alaine: Yeah, I love that. Which brings up a point. Language is such a big thing for parents is so hard. I don't know if you find that with parents. Yes, language, so both parents feel pressured from, like, social media to, like, when we do, but, like, [00:21:00] what if. You know, their child does have cochlear implants and. It does have, like, really good hearing.

Alaine: Do they need to do sign language? Cause I've met parents. You know, and I support parents, you know, on whatever their decision and I've met parents have kids with cochlear implants who do chewing. You know, parents with cochlear implants who do do some sign language. Some have kids with cochlear implants that they.

Alaine: You know, just communicate with spoken speech because they didn't feel like they needed it and they're able to communicate in the home. My personal experience is my seven year old communicates with spoken speech. He can hear very well with his cochlear implants. That's like his default. My five year old is still like hard of hearing even with his cochlear implants because he has a small cochlear nerve.

Alaine: So he actually uses sign language, which we are. That's a process of us learning it. I'm still, we are learning it. And he actually does not really speak. So

I have 2 kids [00:22:00] in my house the exact same diagnosis and 2 completely different ways to communicate. So I would love to talk to parents about.

Alaine: Is there a better way? Should you feel pressure to go one way or another? Because I know parents also have talked about they, you know, if they don't teach their kids with cochlear implants sign language, like people out in the world get upset at them. Even people who are hearing, like, aren't even part of the deaf community get upset with them because they're like, you should teach them sign language.

Alaine: And they're like, you don't even have, you're not even part of the deaf community. Like, you don't even know. Yes. How do navigate through the language? Because the language. Seems to be like the big thing. Everything else you can handle is the language. Like, is my kid going to talk or communicate which has parents look worried.

Emilee: Yes. Oh, that. Yep. Everything you said. I'm like, yes. Yes. I love that you are able to share your experience with your two kids about how it's the same diagnosis, but they are completely different because that is my main message is every [00:23:00] kid is so different. Every family is so different. Every family dynamic, the situation. is so different and you cannot compare you. It's hard not to, it's so hard not to compare, but you, you just have to not compare because every kid is so unique. And I love that you show that of my one kid loves to talk, is able to talk and hear. And my other kid, same diagnosis has cochlear implant and prefers American sign language and that is okay. When I educate parents on the communication approaches, I often have to remind them that you have to do what's best for you and your child and your family and nobody else can decide that for you. I can't I can't say you know what you have to do spoken language you know what you need to do American language.

Emilee: I have, that is not my job, my job is to help parents navigate what is best and figure out what is best for them and they have to be the ones that make that decision now that can feel overwhelming and be like, [00:24:00] I don't know what my child the you just want someone to be like, this is what it is. But really, it's, it's what the family needs.

Emilee: So oftentimes when I tell parents You know, I tell them all about American Sign Language, I talk about spoken language, and I also talk about cued speech, and I'll give them all of the options, and then we just talk it through. We say, you know, is it possible for you guys to learn American Sign Language?

Is that something you are interested in? And I often have parents who are like, you know what, that's just not going to be a reality for us because both parents are working full time. We just don't have the time to do American Sign Language, and I respect that, and, but I also think it's important to know that if you choose to go the cochlear implant route, it's just not a matter of, okay, we're putting on the cochlear implant so they can hear.

Emilee: It's going to take just as much work. It's going to be speech therapy. It's going to be, you know, wearing a mini microphone so they can hear you. It's, it's, It's a lot of work. So I do caution parents on that because sometimes [00:25:00] they feel that spoken language can easy way out. And it's that's this is not the case when you have a deaf or hard of hearing child, it's not going to come as easily as a hearing child. And let's see is that helpful?

Alaine: Yeah, no, that's definitely helpful. And I was just thinking also, you know, to help out parents who are thinking about this. Number 1, it is hard to choose because now we're getting implanted or aided so early that it's like, we're choosing this when our babies are like, literally 3 months old or, you know, 11 months old and they're not even talking yet.

Alaine: And you're like, I don't know, but. Also that it can change. Everything can change. If you think you don't want to learn sign language now, that's fine, but like, you can learn it later. And that's been our experience, like, our experience. So, like, with my first child, we got him implanted. You know, we've always done speech therapy.

Alaine: He's, he, my two children still get speech therapy, like, in school now. And. We started with him just with, like, individual ASL signs [00:26:00] to just bridge the gap in communication. And so that worked really well with him until he started learning to talk. And then he actually kind of, like, like, the signs kind of fell away as he, like, started to talk and communicate, you know, a speech, so we started out with a little bit of like ASL signs and then move to speech as he like, developed his speech better. And then with my 5 year old, we always knew because he had that small cochlear nerve that he would need some sort of like visual with his implants. So that's always been the recommendation.

Alaine: So we, we started out trying cued speech for a while. He didn't like it. I mean, like, he just didn't catch on to it. So I learned it. I went to like a whole class and I learned it. And we tried it for, like, a year, and he made, like, zero progress on it. And so we were like, okay, this isn't, you know, working for him.

And his speech is, like, also at that point, like, not really improving that much either, because he, there's probably a lot that he still can't hear. So then we started incorporating ASL [00:27:00] signs, and he started picking those up right away. He loves it. He learned signs so quickly. So you may, you know, you may try like one way and your kid may not like pick up on it or may not like it.

Alaine: And you're like, oh, this isn't working. So you can try the other way, you know, and now my 5 year old, he, you know, is 5. He's in a really great school. He has a, I guess a teacher of the deaf with him. Who's with him all day long. And he's with her. She signs with him. You know, and he's like. Signing songs now, crazy.

Alaine: Yeah, which he's not doing at home because like, I'm mom and he won't do it to me. So we're, we're working at home, but it's at school. She's like sending me all these years. He's like signing. Along with songs. He knows like the days of the week. She just has built up such a good rapport with him. You know, he's doing all this communication in sign language.

And so what I wanted to encourage parents with is that it can change.

Emilee: [00:28:00] Yes, I love that you hit on that point. And it's changed for me throughout my entire life. So for my journey. I, my parents started doing American Sign Language because I didn't have access to any sound for the first year and a half of my life because I wasn't able to get a cochlear implant until later.

Emilee: So they started with ASL. That was my first language. And then once I got the cochlear implant, a lot of providers, audiologists, speech therapists told my parents, you need to stop signing with your child or else she's never going to learn how to talk. And my parents were just like, that doesn't make sense to us.

Emilee: This is how we communicate with her. We're not just going to stop communicating. She, she can't hear yet. That's a whole other process. She's got to learn how to hear. And so they continue to sign and I, I'm so grateful for that because I truly believe. That American Sign Language helped me learn spoken language because it was like a bridge.

Emilee: My, I remember my, my parents always loved to tell this story. We were on a walk and I heard a bird and I pointed to my ear and I was like, what is that? And my parents were able to [00:29:00] sign. It's a bird. They signed bird. And then they also said bird, you know, that spoken language. And I already knew the sign for bird. And so then I was able to make the connection to the spoken language bird. And that was just, that was my process of learning spoken language was I already had a strong language foundation and it just carried over. And then when I was about five or six, I told my mom, why are you signing? I can hear you.

Emilee: And my mom was like, okay, she prefers spoken language. And my mom was sad at first, right? She goes, I have spent these past six years learning a language for you. But even though I didn't continue using it, that I'm so grateful that my mom learned. Well, she did because Again, it gave me a strong language foundation.

Emilee: And then she continued to sign every time I could, when my implant was off, you know, swimming at the beach at night. If it broke, I was able to still understand ASL. [00:30:00] I just never expressively used ASL. And so I think that's also important for parents to know is even if your child doesn't. Express themselves in ASL it can still be beneficial because if it's loud, if we're at a restaurant and I can't understand my mom, she can sign and I'm able to understand. And so that I'm grateful for. And then high school, I took American Sign Language again. So then my expressive was coming back. And then in college, college was hard.

Emilee: It was, you know, lots of people are socializing. It is a loud environment. And it was like, this is just exhausting. And I found a good group of friends that were deaf and they had cochlear implants or hearing aids. And they used both ASL and spoken language. And so I. Dive back into the deaf community again and develop my spoken, my ASL skills again.

Emilee: And so it has been a journey. It hasn't just been my parents decided this from day one. And that is how it's been my whole life. It has been, it has changed all the time. And then [00:31:00] now I say, I probably use probably half and half. I use I love using American Sign Language with all my deaf friends, my husband, I made him learn it.

Emilee: I have it off all the time, my cochlear implant, and then, but I also love to talk. I love being able to socialize with hearing people as well. So, I often tell parents that too, that it does, you don't have to make one decision that's going to be, that's how it is for the rest of your child's life. It is going to change, it probably will change, and that's okay.

Emilee: And we're just gonna go, and we're gonna follow the child's lead and figure out what is best for them.

Alaine: Yeah, I love that. And that is actually so I've noticed as we've actually incorporated more sign language for my five year old, his speech is actually picking up. Yes, you know, it's nowhere near like a five year old level, but he is like saying more words and like trying to say, you know, more words you know, as we're doing the sign language too.

Alaine: So, yeah, there is absolutely. A language connection [00:32:00] between the two just giving someone like access to language, which way or another will often help develop like the other one, which is crazy, you know, until parents language built on language and they're just going to support each other for sure.

Alaine: Yeah. Do you know how your parent, have you talked to your parents about how they learn sign language? Because I think a lot of parents don't want to start because it seems really overwhelming. And it is to, like, learn a whole new language and that's kind of like, where we, where we are to, we are learning it and, but as I'm learning it, I'm realizing, oh, there's like a process to this and, you know, I'm starting with, like, individual signs, but I can't really put the, I mean, I put them together.

Alaine: But I know very few signs and just like, am I ever going to learn this enough to, like, communicate with my child? So I think parents just get overwhelmed when they're like, oh, I have to learn another language. And then they're imagining like I [00:33:00] failed like high school French or, you know, like, they're like, everything comes up of like, you know, I, I don't know how to learn a language or I don't learn a language well. And then they like, are afraid to start. Does that make sense?

Emilee: So, my parents, they started their ASL journey with a deaf mentor, and I know this is not a resource that is available for all early intervention, but it is worth asking and it's also worth trying to fight to see if they could, you know, maybe incorporate a deaf mentor into the program.

Emilee: But my parents and they had a deaf mentor that came into their home every week and taught them sign language. And then the other, I think the biggest thing though, was my parents started getting involved in the deaf community. So they went to a deaf church and that is really where their signing just took off because they were signing with other deaf people.

Emilee: They were practicing their skills. And a lot of times people feel overwhelmed, like, well, the deaf people are going to feel like. You know, I'm going to be a burden or, you know, I have to sign slower. And [00:34:00] I would say a lot of deaf people, not everyone, but the majority of deaf people are going to be very patient and they're going to appreciate that you are learning.

Emilee: And so they're going to be more patient because they want your child to be able to have American sign language. And so they are going to be. More willing to help you and to sign slower and teach you signs, but that really is the biggest thing that helped my parents was being involved in the deaf church that they were able to just socialize with other deaf people.

Alaine: Yeah I love that. Hold on real quick. Let me go get my two year old.[00:35:00]

Alaine: Sorry, I think she's getting a little fussy. Also, I think my five year old is bothering his sister. But yeah, I would love to pick back up since you mentioned church something that I'm really interested in talking about It's how churches can reach out to the deaf community better and what services or [00:36:00] things can they provide to help make deaf people feel more comfortable.

Alaine: Because I think this is, like, really big, like, I guess, question of my, I, the churches are really getting this wrong and they're really not, like, reaching out to the deaf community which is really a shame and I think it's the language barrier because there'd be no other reason, right? And, you know, That's something that I am, you know, really passionate about, like educating churches on about, you know, how to reach out and make people feel comfortable and supported who are deaf because I even looked like recently because I was interested in, like, attending a deaf church because I would like to at our church start welcoming more deaf people.

Alaine: And I'm not just exactly sure. What I need to make sure is in place at our church to help them have access to the language and the sermon and also to help them socialize [00:37:00] with other people at the church who aren't deaf. And so I looked locally to see if there's a deaf church that I could just like, tend, even though that's like, very out of my comfort zone, because I don't know very much ASL, but I was really interested.

Alaine: And I wanted to take my five year old who signs and there's like. Almost zero deaf churches, like, in I'm in North Carolina. I think there were like. 1 or 2, maybe 3, 1 church specifically was doing it really well and they do this, like, maybe 2 hours away from me. And they, you know, make a lot of efforts to blend you know, their congregation.

Alaine: The people who go to church that are deaf and the people who are don't and they have like a lot of programs to try to blend the two. I think they are doing a great job and I might even drive the two hours to like go attend their service because I'm really interested in it. But yeah, I think this is something that the church is getting really wrong and doesn't know how to fix.

Alaine: So [00:38:00] how can churches be more welcoming to the deaf community and what can we put in place? you know, to help deaf people feel more comfortable being in church.

Emilee: That's a really good question. I would say first off the churches need to be willing to provide an interpreter for their services. That is the number one thing is being able to actually provide an interpreter so that deaf people can access the service.

Emilee: Another thing that I've seen that I think is really awesome is inviting those deaf people to come and teach a class, teach an ASL class so that other people in the church are able to learn and then then they'll be able to communicate with the deaf people and start a relationship with them and be able to serve them.

Emilee: And so I think that's a really unique way. To involve deaf people is to say, Hey, we would love to learn American sign language so we can communicate with you. Can you come and teach a class one evening or whatever and start a weekly ASL class? And I've seen that work and I've seen a lot of [00:39:00] amazing things come from that.

Emilee: So I think that's, those are two things, get an interpreter and ask deaf people to come and teach an American sign language class for the people at that church. Yeah. I love that. And can we talk about why? An interpreter and just like adding captions or just saying, well, they can like read the Bible, you know, because, you know, we write down like what the scripture is, why that's not enough because I will say, you know, like my church, you know, when we're singing, they have like the words on the, you know, prompter.

Emilee: And so a lot of churches think, okay, well, if we're like captioning it you know, and then they can read along in like their Bible. Yeah. Then like that's providing access. So, you know, I'm, am, you know, curious and would like to talk about why that's not like the full picture. Yeah. A lot of deaf people have delays with written language.

Emilee: And so that just be hard because either it [00:40:00] takes them a little bit longer to read. And so even though they may be able to read. Reading it that fast might not be possible. And another thing is a lot of people don't think ASL is a real language. And it is. And that is deaf people. I just gave a side eye here, like, in the picture.

Emilee: Okay. Because Okay. That is how deaf people communicate, is American Sign Language. And they don't communicate by writing back and forth. They communicate by a visual signed language. And that is what they need. They don't just need yeah, the captioning. Because It's just not the same. Yeah, when I, you know, think and tell me if, you know, I'm right or wrong on this that you miss, like, the nuances of the sermon.

Emilee: If you're just like reading the Bible. Okay, that's fine. But you're. You know, you're missing the tone [00:41:00] of the sermon and. You know what it's about, or, you know, that can be translated through American Sign Language, American Sign Language, give that tone, give the facial expressions that match the tone.

Alaine: And yeah, I love that point.

Emilee: Oh, another thing I was going to say is your five year old might not be able to read, right?

Alaine: Yeah, that's true.

Emilee: Oh, like, yes, maybe you're accessing it for adults, making it more accessible by captioning for adults, but Little Children also need that access and they might not be able to read and so they can't read that Bible and understand they need that visual signed language because that's their language.

Alaine: Yeah, no, I love that. Thanks so much for that input. I'm always whenever I have someone to come on to help churches or tell them what they need to do. I jump on that because, like I said, that's something that they're getting really wrong. I'd like to help them get right better. But something else I love to talk about is you.

Alaine: Parents talk a lot [00:42:00] about, like, school. What do my kids need in school? What do my kids need on the IEP? I mean, I myself have gone through iterations of the IEP. We're now in a really great school. I've been in a school with, like, my five year old when he was in preschool last year in the county. He did okay. But they didn't seem to understand how to really educate him. They seem to understand how to educate children like my 7 year old who have cochlear implants, but have spoken speech and have like, full access to hearing. We didn't really understand how to. You know, help my child very well who uses sign language and who doesn't hear as well, but he has a cochlear implants.

Alaine: Yeah, but you can't hear as well. We did like a whole IEP meeting just explaining and like, showing them the audiogram and like, saying like, he can't hear like cochlear implants doesn't mean that they can still hear everything. There's a lot, you know, to do [00:43:00] with that and you know, so I struggled a lot with the IP with him.

Alaine: I had a lot of IEP meetings. I felt like I was educating, like, the people were supposed to be educating me, to be honest yes, which is hard. And I'm going to say I used to be a teacher. So before I was a mom and did all this, I was a high school teacher. I was not a special education teacher, but I still, like, understand the public school system, at least in my state, like a little bit.

Alaine: But I imagine it's really overwhelming for parents who are not teachers and don't really understand how the educational system works. And they're always asking. So, I would love to know, even like, your experience in school because it sounds like you maybe even had, like, a better experience than someone that I just interviewed didn't find out that she was hard of hearing until she was 40 years old. She had always been but her parents and, and she struggled with this a lot. We talked about this in an interview. Her parents said that they basically didn't do anything about it. They said they knew she couldn't [00:44:00] hear very well by the time she was in first grade.

Alaine: And they just told the teachers, put her in the front of the room. And that was it. And she had an awful time in school. Like it was just, she had like teacher, you know, she was labeled as like, Misbehaving because she couldn't hear. So she, you know, they say she wasn't paying attention. Even up through like high school and, but she was doing her work and, you know, she was like passing all of our classes.

Alaine: But she said she was like, miss, like, most of the lectures, you know, she couldn't hear to like, writing them down. I mean, she had teachers like, throw erasers at her. She's a bit, she's like in her 40s or 50, like a bit older than us, but to like, get her attention, just really wild stuff. And she, so it was really emotional about her experience in school.

Alaine: She had a really hard experience. It's like no one wanted to acknowledge that she had a hearing issue and that that was like the cause of stuff. So but it sounds like your parents took a few more [00:45:00] steps. So you have like a completely different experience. So I would love to know like what your experience was in school and what you would tell parents, you know, what are some things that you should think about?

Alaine: Like maybe putting on the IEP for your kids.

Emilee: Okay, so my parents sent me to the deaf school for preschool kindergarten and a little bit of first grade. So first grade, I started going to the deaf school. It was like a little trailer right next to an elementary school. And so half the day, I went to the normal, just public mainstream elementary school.

Emilee: And then half the day I went to the deaf school. And then in second grade, I Transferred completely to a charter school and my parents chose a charter school because it was a little bit smaller, like the classroom sizes were smaller. I was able to have more one on one with a teacher and then high school.

Emilee: I was mainstream just at a normal public school and then college on. But for an IEP. I'm trying to remember. I think I [00:46:00] qualified for a little bit, but then after a little bit I didn't qualify. 'cause in order to qual qualify for an IEP, you have to have a hearing loss and an academic, like you got like for an academic support and I was doing fine academically and so I didn't qualify, but then I qualified for a 5 0 4 and on the 5 0 4.

Emilee: My parents just made sure to include that the teacher needed to wear a microphone, like an FM system. So the teacher or microphone and it connected with my cochlear implant and that was helpful because classrooms are. loud and being able to hear the teacher with that microphone was really helpful.

Emilee: Another thing was preferential seating. And I say preferential because sometimes the front of the classroom isn't always the best. For me, I liked being more, actually, I liked being in the front, maybe like second, third row back. And then also on the Left side of the [00:47:00] classroom. So everyone was on my right side because I only have access on my right.

Emilee: So I needed to be not in the middle, but on the left side of the classroom. And I like sitting in the front or a little bit back because then I could see everyone's lips. Because I depend greatly on lip reading and so being able to turn and see my classmates that was the hardest thing was hearing my classmates and another thing was making sure that all videos and movies were captioned.

Alaine: I mean, 1 thing yeah, sorry. I mean, 1 thing that was suggested by the other person that interviewed was that she thought it would have been helpful to have like. Typed out like notes. Or at least, like, an outline of, you know, what, like, I guess, you know, as you get into, like, high school or college, like, an outline so that you didn't miss [00:48:00] part of the lectures.

Emilee: I love that and my parents also just really made sure that every time I got a new teacher, they would. Meet with them before the year started and just laid out expectations of you need to do this because of so and so and so and it can feel like I'm sure you feel overwhelmed and you know this burden of like, I have to do everything because you don't know anything.

Emilee: But that is just the way it is. And yeah, parents are their child's biggest advocate. And I applaud and admire and support parents 100%. And I, when I see all that, my parents, all the families that I work with, the parents, what they do, it is just. Incredible and mind blowing. And I just want to say to parents, like you are doing an amazing job.

Emilee: Every parent that I work with, they are doing the best they are doing, like they're doing the best they can. And I really [00:49:00] admire that. So my parents were just really good advocates for me and telling the teacher what I needed. And then as it's shifted to elementary high school, it was putting that, and, you know, helping me be able to advocate for myself and tell teachers what I needed. Another one I just thought of was making sure that the teacher faced the class when talking. So instead of turning and writing on the board or whatever and talking, making sure that They faced me so I could read their lips and also teachers like to roam the classroom and that was always hard because if they roam farther away, then I'm like, I can't hear you and so while still like letting them roam, maybe not roaming so far away from me was helpful.

Emilee: Another thing that was helpful was repeating everything like repeating the question or comment that the my peers said. So if my peers and they would say, that's a great question. The question was, and then give [00:50:00] the answer that was so helpful because sometimes A student would say something, ask something, and I would be like, what, what are, what is she answering?

Emilee: I don't even know what that is. And so I loved, loved, loved, loved when teachers repeated the questions and the comments as well. I love that. That was something that I haven't thought of just because like my kids are, you know, like not quite at like that level yet. That was a great idea to ask the teacher to repeat.

Emilee: And that's definitely. You know, something that, yeah, I encourage parents to do, too, is just talk to the teachers because, like, the teachers may have not ever had, like, a deaf or hard of hearing kid in their class before, and so it may, I feel like a lot of times it's not that they don't want to do stuff, it's just that they don't know what to do until you tell them.

Emilee: Oh, one other thing, I actually work with the The, the district should have an audiologist. I, I would really hope that all [00:51:00] districts have an audiologist and educational audiologist, and they should also have either like an SLP or a teacher of the deaf and those can be a really big. Resource because then it just doesn't fall all on the parent.

Emilee: The audiologist can talk to the parent about the importance of wearing the microphone, the FM system, and the importance of making sure that the child's device is actually on working and yes, they can go in to the classroom. And another thing that the educational audiologists do is they look at the environment and they, they test this, this, this signal to noise ratio. So they see how loud it is for the, like the speech signal compared to all the background noise. And they can encourage things like putting tennis balls, like on the edges of the shoe of the, sorry, the chairs. So that, you know, that noise is lessened. They can talk about adding rugs and curtains and things to dampen that like reverberations of sound.

Emilee: And so the educational audiologist [00:52:00] is an amazing resource that parents can utilize and say, Hey, I need you to talk to this teacher and help me with this because it's not getting through with just me. I need extra support. So utilize an educational audiologist and a teacher of the deaf.

Alaine: Yeah, I love that. I didn't even think about the educational audiologist. I'm glad that you brought that up because teachers are also busy too and they're trying to like do with the classroom and you know sometimes they also just miss stuff or don't know what to do or you know they've got like 20 other kids.

Alaine: I just know from being a teacher myself and so having someone else who during the school day can go like check on your child so you don't feel like you have to constantly it can help them. You know, with technology, I mean, you know, just today I'm gonna have to call clear probably because my 7 year olds mini mic, which we use at school and they're really great at it.

Alaine: It's like, not streaming. I don't know why it's like, turning blue and it's turning green again. And it just like, keeps turning off and on for no reason. You know, but, you [00:53:00] know, things like that sometimes like technology malfunctions. And then I'm like seeing on the phone or, you know, on like the text message trying to like help the teachers, you know, figure it out so that my kid can hear and, you know, having someone else at the school to help try to like figure out the technology to help the teacher really works because like, unfortunately, if technology takes too long, a lot of teachers are probably just going to leave it and like continue on with class because they have like a class that they have to continue on.

Alaine: And then unfortunately, the kid. You can't hear it's going to get left behind for the day, just because, like, they couldn't figure out their technology. You know, which is really hard. So having that extra person to help them figure that out is great. It would be helpful. And there's a great resource for parents to kind of lean on.

Alaine: One other thing I would love to ask is I talk to a lot of parents who wonder about transitioning kids to college. Yeah. Which I feel like [00:54:00] is, you know, we talk a lot and I talk a lot about little kids because that's the stage that I'm in, but I feel like parents who have kids who are deaf and hard of hearing who are in like high school and even middle school get less support because you're kind of looked at is like Oh, you've like been 13 years. You should like know what to do. You know, you've been in school this long with them or you should know what to do and different stuff from what I understand talking to parents comes up at those ages. Like now, now they're out socializing on their own. Now they need to advocate for yourself themselves.

Alaine: Like they're out with their friends and now they're in college and it's really. Working towards now like independence, which is scary when you take care of this kid for 18 years, and you're like, bye, like, you're on your own. You know, can you talk about, you know, anything that you remember from, like, transitioning from high school into college, like, advocating for yourself, advocating for yourself in, like, college classrooms or [00:55:00] anything that would help our parents who have, like, high schoolers who are getting ready to leave and, like, get out to college within at least the next four years.

Emilee: Yes, I love that question. And it is important to, you know, start in high school that turning over the advocacy so that in college, your child feels confident that they can do it versus like, okay, you're in college now, figure it out, you know, that can be overwhelming.

Emilee: So starting early and helping them learn how to advocate for what they need is important. But all colleges and universities should have an accessibility center, Or it's called different things. I've seen like a, an accommodation center and accessibility center. And that is a, an amazing resource. And it is for people with all sorts of disabilities or special needs or anything.

Emilee: It can be for people who have ADHD, anxiety, depression. Deafness, vision loss, wheelchair accessibility, all of that stuff. So they, at my college, at [00:56:00] both of the colleges I went to, they had an accessibility center and they had a. person that was just over deaf and hard of hearing. Like that was their full job to focus on the deaf and hard of hearing students.

Emilee: And they offered lots of different resources for me. So they offered someone who could take notes, a note taker. So what they do is when the class, before the class starts, they email out all the. The students in that class and they say, Hey, we have someone in the class who needs notes taken for them.

Emilee: Is anybody willing to volunteer and submit your notes and if they don't ever share the person's name, they just say this, there's a student in your class that needs help. And then the, the student who volunteers sends the notes to this accessibility center and they send the person that notes to the person so that's kind of nice because sometimes I feel like people don't want the attention on themselves.

Emilee: Okay, me. I didn't want anybody knowing that I was deaf in college. I was like, it's, it's just a, I don't know. It's a hard thing to navigate. You just [00:57:00] want to be, you want to blend in at least for me. I just wanted to feel like I was like everyone else. And so it's a note taker. They had ASL interpreters that could come to your class and interpret.

Emilee: They also had transcribers. So they would send someone into the classroom with you know, two people, and they would usually sit in the front and they would type everything that the teacher said and the students. And so I utilized the transcription, sorry, transcription services in college for my bachelor's degree.

Emilee: And I absolutely loved that resource because I felt like Again, I didn't need to be like I didn't stand out because the people were just typing away and then I pulled out my laptop and I would just follow along if I needed it. So because I have a cochlear implant, I am able to access a lot of the spoken language.

Emilee: And so A lot of times I could hear the professor, but let's say the professor wandered over here and I couldn't understand him as well. I would just look at my [00:58:00] transcription and I would just follow along and, you know, catch up where I missed or if a student that was really the biggest thing is if a student said something that my class sizes were, you know, 800 plus sometimes.

Emilee: And if a student is way over there and I can't hear him. This person was typing everything. And so I heard the question, I heard their comment and that was amazing. And I also was able to do it on my phone as well. And so I could just, you know, it's just so subtle. And I loved that. That was, that saved me in college, honestly.

Emilee: And then in, for my master's degree, it was during COVID times and people were wearing masks and I just couldn't do it, I could not understand people. And the transcripts. I've heard that so much. Yes, I've heard that so much from people who are deaf or hard of hearing that COVID was awful with wearing masks that they just like could not like they may as well stay at home is wild.

Emilee: Yeah, so I wasn't able to lip read because I couldn't see their lips because of the masks [00:59:00] and I just was having a really hard time and they actually sent in. It was actually at a different university and they sent in their transcribers through Skype and I'm not sure if it was just because of COVID times that they were sending in through Skype, but it just the.

Emilee: It just wasn't working because the transcriber couldn't hear the people in the classroom because of the mass like the sound wasn't just getting through like it normally would. And so it was funny because like the transcriber would like be typing and I'd be like, Hey, I can like understand that and then anytime that I couldn't understand the transcriber also can understand and they would like put in parentheses like unintelligible can't understand and I'm like, That's, that's, look, you're typing what I am experiencing, like, this is not helpful.

Emilee: So I went in and I asked her to switch to interpreters. And so for my master's degree, I utilized sign language interpreters and I had to swallow my pride and I had to, it was hard. It was a hard transition for me to go, okay, I'm using something and now everyone's going to know [01:00:00] that I'm deaf. And you know, and eventually I realized, you know what?

Emilee: It's not as bad as I thought it was like, it's okay. And a lot of people don't even care, like. They didn't think anything else. Like it was like, Oh, this person uses this interpreter. Cool. And the nice thing about the sign language interpreters was they are there for whatever you need. So that was something I had to learn.

Emilee: I had to learn that they're there for me. And if I don't want them to do something, I can tell them, or if I want them to do something, I can tell them. So I told them, I prefer to use my own voice to communicate. And so you don't need to voice for me. I will just talk. I just need you to sign what everyone else is saying.

Emilee: And. Then they were also like, where do you want me to sit? Do you want me to sit? You want me to stand? Do you want me to be on the corner? Do you want me to be right next to the teacher? And I was able to voice, you know what, I'm fine if you're just kind of like off to the side, like, I don't need you like right there next to the teacher.

Emilee: But some people do want that. And so just to realize like, I'm in control, I can say whatever, like, I can express what [01:01:00] I want, and that's okay. That was really empowering for me to realize that like, Oh yeah, I'm using ASL interpreters, but like, they're there for me, and I can have them do whatever I want them to do.

Alaine: Yeah. Yeah, you're describing a really interesting experience, because on the one hand, like, You didn't want to be known as being deaf and now like they're here with you and so like obviously everyone's going to know and you spend all this time just trying to like not be that way and like blend in but then at the same time it really empowers you to like being also be in control of it which is a really interesting like dichotomy and I really appreciate you like sharing that.

Alaine: With us, it's a transcription in real time. Like, if you're like, looking, oh, very cool. That is helpful. Yes. I love that.

Emilee: Yeah. The person was like, the professor will be talking and the person is just typing away and it's just real time just showing up on my computer screen or my phone.[01:02:00]

Alaine: So helpful. That's great. So I guess it sounds like what you're saying is the key when you're talking about like your high schoolers going off to college is really giving them those advocacy skills.

Emilee: Yes, like, talking to them about like, okay, like, you really need to. Like, tell the disability office, because they're also not just going to send people if you don't tell them to send people, right?

Emilee: There's lots of students in the university and you have to actually go to the office and yes. And then you like, I need this help. This is the help that I need. And you like have to initiate the process. Hopefully your parent will, but you know, not as a case. Sometimes kids are 18 and have to go do that.

Emilee: And so building those like advocacy skills. My mom joined that first meeting with the accessibility person and, you know, You know, she was right there with me, but then every semester after that, you know, at the start of the new semester, you got to get. Okay. New, you got to send your schedule. You got to make sure that someone's going to be there.

Emilee: And I had to do that. And so, you know, my mom was for me and then, you know, I was able to [01:03:00] support myself for every semester after that. So and then another thing I would say is just building a relationship with the accessibility. Person that's over the deaf and hard of hearing that that director, I developed a really good relationship with him and I felt that I could go to him for anything that I needed.

Emilee: So I actually had one professor who refused to let me have my laptop open for my transcribers. Like she just had a general rule that I'm transcription like that. Nobody could have their laptop out. And I was like, well, I have an exception. Like, I, I'm okay. through the accessibility center, like I have approval, here's the letter, all these things.

Emilee: And she was like, nope, that is not allowed. And you know, I'm in like tears, like she's saying this in front of your people. And I am like, I can't understand you or everyone else if I don't have this laptop, and she just didn't get it. And I was I was like, Oh, okay. So I texted this guy, like my person and I'm like, Hey, I'm trying to advocate for myself, but it's hard [01:04:00] and he was able to come and talk to her and say, you know what? Nope. This is, you know, explain everything. Not during class, but the rest of the semester, everything was okay. And so having that person in that relationship to know that like, it doesn't always have to just fall on me. I can, I have a support system that I can say, Hey dude, I need you to go talk to this lady because I tried and she's not listening to me and I don't have the emotional capacity to fight back.

Emilee: And I just need someone else to step in. And so that was really helpful too. And that's fantastic that he was able to do that for you. And that's for like building the relationships with the office because they are there to help you. Sounds like they just have to know that you're, that you need to help and you're there and that you can call on them anytime.

Emilee: I met so many people on campus that were at that cochlear implants and it was just so cool because I was like, Hey, like you're like me. Like I just saw their device on and. I don't know, we would start talking [01:05:00] and they oftentimes did not know that this was a resource and they were like, wait, that would be so helpful because they, a lot of times they didn't know America sign language.

Emilee: They just thought like accessibility center means an interpreter. And I was like, no, like this whole thing called transcription and you can have a transcriber come and you just pull out your laptop and like nobody knows. And they were like, wait, that would be so helpful. They just did not know. So I am.

Emilee: Big on advocating for that and just spreading awareness. Like, Hey, there's a thing called the accessibility center and every college or university. Yeah. I love that. That that, and that's so helpful for parents to know, to be able to like, tell their kids, Hey, like, go here. And you don't have to know sign language.

Emilee: If you don't, that's fine. They're still going to help you. So you don't have to suffer through your classes and not understand, you know, half of the lecture because how, like, how are you supposed to learn it? You know, if you can't understand what's going on.

Alaine: Yeah, and so, and when I know that our time is getting a little bit low and I want to respect your time, I really appreciate you coming.

Alaine: [01:06:00] Whatever thing I know that parents have like questions about and feelings about is exposing their kids to the deaf community. And I think a lot of parents, you know, if their kids like, are deaf and are not aided. That maybe is, like, an obvious choice. I think kids who have cochlear implants or have hearing aids, especially ones like my seven year old who can speak, you know, and like you, who have, like, regular spoken language I think a lot of parents just wonder if it's so important and Why?

Alaine: Because my kid can talk, right? So if my kid can hear via the cochlear implant, my kid can talk. Why, you know, do they need to be a part of the deaf community? Why do they need to be exposed? Aren't they really just kind of hearing? You know, I think a lot of parents think that way. So I would love to just talk a little bit because you said that you got more involved in, you know the deaf community more when you got to college, which is fantastic.

But what are some reasons? Why or why not, or whatever that, you know, our kids, even [01:07:00] if they can talk, even if they can hear with devices should still be exposed to the deaf community.

Emilee: I love that question. Growing up, I, so I have a deaf cousin and she also has cochlear implants and. That was probably so once I told my parents like I can hear you like stop signing, we kind of, we stopped going to the deaf church, and we kind of, I didn't really see a lot of, we weren't super involved with the deaf community anymore, but I think I had my deaf cousin, and that was that she was my community, I had someone else.

Emilee: That was deaf who was like me, and that was super helpful. So because I have her I feel like I was okay, but if I didn't have her I wonder, like, if I would want more to be more involved in the deaf community or just have know someone that was deaf. And that was like me. But as I got to college, I just realized.

Emilee: It was so nice to have people who understood what it was like to be deaf, like my family, like [01:08:00] they, they know, like they can, they can see what I go through, but they don't get it like they, they just don't. And to be able to have someone that I can say like, Oh, I wasn't able to hear this person today and it was so annoying and I was so embarrassed and they, the person goes I know what you're feeling like I went through that yesterday and just having that connection of like, I'm not alone, that other people are also deaf or hard of hearing and they also go through similar struggles is so beneficial to have that connection and so growing up my that was my cousin, I was call her all the time and be like, I had the worst day today.

Emilee: Like I just could not hear or I'm so tired. And you know, she'd go, I get it. Or I would go to a mapping appointment and it would sound really weird afterwards. And I was like, I hate this. And she's like, me too. And just having that support person was so helpful. And so I think that's, that's where that can come in the Jack community is having those people that say, Hey, [01:09:00] I get it.

Emilee: I know what you're going through. You're not alone is so beneficial. Yeah, and I love that. And just like validating your experience. Because you're right. I mean, we don't as hearing parents, we don't understand the experience to the back to like, why it's difficult at the beginning to like, raise kids who are deaf when you are not deaf, because you weren't expecting it.

Emilee: And you don't really understand and you can't really understand. And so having that exposure to someone who can validate their experience, like, you're not crazy or what, like, This is happening. Your experience is real is, I think, really powerful and definitely really helpful.

Alaine: That's what I'm hoping. I mean, I think the benefit in my house, I have two kids with cochlear implants is that they are will hopefully see that for each other. As well. And also maybe, okay, I just have a question and this is probably just my family. My like, did you ever question with your parents? Like, why you were [01:10:00] deaf? And like, they weren't because my boys have not, my boys do not seem to like, they know, obviously that we don't wear cochlear implants.

Alaine: They know that their sister doesn't, they know, like other people in their classroom, but they don't seem to like, okay. Be concerned about what I mean, which is fine and I'm open to any conversations, but they have like never asked even my seven year old, like, why are you and dad not wear them? And why do we, I just find it curious that they.

Alaine: I don't know if it's just because they've had them since they were babies and this is just the way they are and they don't know any different, but they've never, like, so far haven't asked me, like, why do my teachers not wear them? Why are you not wear them? Why is no one else in our family wear them except for us?

You know what I mean?

Emilee: Yeah, that's actually interesting. I've never thought of that. I've never been like, why am I the only one that wears them? I don't know. I feel like it's, maybe it's just you and my parents have always just been like good at [01:11:00] explaining like, oh, you're deaf, you have a cochlear implant.

Emilee: And I've just kind of been like, yeah, like I know that I'm deaf and everyone else is hearing like that's why they don't. I don't know. That's a good point.

Alaine: Yeah, I'm just curious. I'm not like worried about. Yeah, I think I'm just curious why they haven't seemed to like, you know, notice, but maybe, you know, he said, maybe they just don't care.

Alaine: It's just like how they are. It's just how we are. And, you know, whatever, which is kind of how we approach it to in our family. So maybe that's the reason

Emilee: I have also, I have asked my parents, like, why me? Like, why was I born deaf? Like, yeah, this is hard and this sucks. Why me? And so I have asked those questions, but I don't think I've asked like, like, I don't know, like, why doesn't someone else wear a cochlear implant?

Emilee: I don't know. I've just, I have been like, why me? Like, why did I have to get this? And my parents have just been like, you know what? Everyone has something. And this was just your, your thing. Everyone goes through something. And that was helpful just knowing that. Yes, like, even though [01:12:00] someone might not be deaf, they also have, you know, maybe they have anxiety.

Emilee: Or maybe they have depression. Or maybe they have ADHD. Or maybe they can't walk. Or, you know, there's so many things. And this was just my thing.

Alaine: Yeah. Yeah, no, I definitely understand that. I actually have a neuromuscular disease, which I was diagnosed when I was three. And now as an adult, it's pretty much like in remission and I don't, and maybe I just answered my own question about my kids because I've never considered it to be like a big part of my life.

Alaine: It's just like something in my life. It doesn't like dictate my life. I have my Sonia Gravis, which usually is like an adult onset. But I had the really rare type that I was diagnosed when I was three years old. So I've had it my whole life and I definitely, I mean, I questioned that same thing. I didn't question like why other people didn't have it, but I definitely, especially like middle school, high school, because it gets where it gets a little bit worse as like your hormones change.

Alaine: Yeah. So middle school and high school, [01:13:00] right? So it got better when I got into college and then as I've had like pregnancies, it's fluctuated. You know, but I'm like seeing a doctor and it's always been under control, but fluctuated with hormone changes. And so I definitely understand that because I, you know, definitely questioned that at times too, when stuff was hard and I couldn't do stuff and I would get like out of breath faster than everybody else.

Alaine: I couldn't like physically do as much as like, you know, other people. And like high school such like a time that you want to be like everyone else, you know, it's a hard time to stand out. And that's just like, kind of how the ages. And yeah, I, I also like will question same thing. Like, why me? Like, why do I have to deal with this?

Alaine: Like, no one else in my family has to deal with this. And yeah, same thing. I mean, it was just like, this is your thing. Everybody else has the thing. Like, my sisters are both ADHD. So like, that's, you know, I'm not in everyone. No one has like a perfect life. Everyone. Whether you know it or not has something something at some [01:14:00] point in their life.

Emilee Yeah. Yeah, that's true.

Alaine: You need a wrap up.

Emilee So, yeah, anything else? Yeah, absolutely.

Alaine: Just 1 more thing. If you could leave parents with 1 last tip or 1 last piece of encouragement. Keep going. You're amazing. And you're doing the best you can. And I admire that. And just find your support people.

Emilee: I think that's a big thing is find your support group, find who you can lean on when things get hard, and that you can ask questions to and just feel like you're able to keep going because it is It is a lifetime thing, and it is exhausting, and it is hard and overwhelming, but you are not alone, and there are lots of other people going through the exact same thing, and so finding your group of people, I think, is the most important thing you can do.

Alaine: Thank you. Thanks so much, Emily. [01:15:00] You have helped so many parents. You're so open about your experience and me as a parent, I am really appreciative of people like you who can talk about your experience and just like help us parents better. So thank you so much for being open and so kind and giving space for parents to ask questions you know, and get any information that they need.

I really appreciate it. Thank you so much for coming on the podcast today.

Emilee: I'm so happy I was able to come. Thank you.

Alaine: Wow, guys, wasn't that such a great episode with Emily? I just love talking to her and hearing everything that she has to say. She is so open about her experience and also so helpful to parents. And I hope you got so many tips from Emily today. If you've been a listener to this podcast for a while, go ahead and push that subscribe button so that you never miss another podcast episode.

Alaine: If you're feeling generous this holiday season, go ahead and leave a quick review and a quick rating for the podcast [01:16:00] wherever you're listening to the podcast right now. Rating and reviewing our show helps more parents find this podcast and all of this great information. I hope you have a great holiday season and I'll see you next week.