Living with Hearing Loss And Being An Advocate for Your Child with Valerie James Abbott, Mary Clare and Bridie

Alaine: [00:00:00] Welcome to Raising Deaf Kids. I am excited to bring you this conversation today with author Valerie James Abbott and her daughters, Mary Claire and Bryony. Bridie was diagnosed with hearing loss at the age of three years old. And today I got to sit down and chat about living with hearing loss in your house, being a sibling of a person with hearing loss, advocating in school for your child.

Alaine: And we even go into tips that will help parents navigate college services and help their adult kids you know, get those. Things that will help them be more comfortable living alone. These three women are such a fun family, and they also have so much insight to help younger parents like myself navigate the sometimes uncertain waters of hearing loss.

Alaine: I know they're going to be an encouragement to you as well. So let's get started with our chat.

Alaine: [00:01:00] Hey mama, welcome to Raising Deaf Kids. Do you want more ease in your daily life? Do you want to help your child learn language faster but have no idea where to start? Do you find yourself searching for how to learn sign language and best ways to practice speech goals? Hey, I'm Elaine. I'm a mom of three littles, two of whom are deaf.

Alaine: I remember when I received the hearing loss diagnosis for our child, there were so many decisions and information overload. I lacked clarity and confidence and yearned for ease and balance in our lives. It was then that I discovered strategies to support our kids language development at home and I even helped them learn language faster.

Alaine: I can't wait to share it all with you. So put down that to do list, close out that ASL app for now, and let's get started!

Alaine: Did you know that I have a free community of women just like you, busy [00:02:00] moms who want to help their kids learn language faster while still getting all of the things done in the house each day. In the community, we share strategies to help our kids learn language faster and lean on each other for encouragement and support in this up and down journey of hearing loss with your kids.

Alaine: If you haven't found your community yet, then welcome home, mama. Come join us at facebook. com slash group slash raising deaf kids.

Alaine: I have a question for you. Do you want to be on a podcast? Of course you do. And it just so happens that I'm looking for guests for my new season of the Raising Deaf Kids podcast. I'm looking for professionals in the field of hearing loss, especially professionals who work with parents of kids with hearing loss, artisans, people from the deaf community, and regular parents, just like you and me, who want to share your story and help encourage other parents of kids with hearing loss as well.

Alaine: If that sounds like fun to you and you want to have a really fun chat with me and I cannot wait to get to know you, [00:03:00] send me an email at hello at raisingdeafkids. com to let me know that you're interested and I will get you all set up to be one of our guests. Okay, I can't wait to meet you. Bye.

Alaine: Welcome to Raising Deaf Kids. And today I have very special guests. I'm so excited to talk to you guys. I have author and speaker Valerie James Abbott here with her two girls. Welcome to the podcast everyone.

Bridie: Hello. Hello.

Alaine: Hi. Hi. Do you guys just want to go ahead and like introduce yourselves? And maybe even chat kind of a little bit about who you are, your background, your background.

Valerie: Sure. I'm sorry. Sure. I'm Valerie and I'm a mom and I live in Richmond, Virginia with my two girls and my husband, Chris. And this has been quite a journey and I'm now the proud mom of 2 college age kids. So this is an exciting time in my life.

Alaine: You made it. Yeah. [00:04:00] You made it through what all the rest of us are trying to get to.

Alaine: So congratulations. Thank

Mary Clare: you. I guess I can go next for age order. I'm Mary Claire. I'm 22. I'm a rising senior at Hollins University, the older sister. And my name

Bridie: is Bridie. I'm going to be a sophomore at Longwood University and I'm the hard of hearing one. So yeah.

Alaine: Awesome. Do you mind sharing just a little bit about kind of your story with hearing loss? Valerie, you can chime in too for the parts she may not remember.

Bridie: I really don't remember a lot of it but I have an XM26. We don't know who, which parent I got inherited from. That's about all I know. Yeah, you were finished.

Bridie: Do you

Valerie: remember? Do you remember a time? Because there was a time. Do you remember a time before?

Bridie: No.

Valerie: No. [00:05:00] Yeah. So Bridie was, diagnosed just before her 3rd birthday, and it was because of some wonky language that she was speaking this other version of English that we now know was a very distorted version of English that she was fluent in speaking.

Valerie: And we were all pretty adept at understanding her. And it was when she was enrolled in preschool that the preschool teachers were like, what is this? And they recommended a speech evaluation. And that's what led to figuring out that she had lost her hearing. Mysteriously.

Alaine: Okay, yeah, that is definitely and, you know, I feel like this is where school step in and can be so helpful to us as parents too, because I feel like that is true.

Alaine: I have a three year old who actually speaks really well, but I remember when the kids were little and you. That, you know, while they're learning language, they do kind of call things different things [00:06:00] and you do kind of get used to it as a family. And I think until you get that outside you know, voice and information, you kind of don't know what you don't know.

Alaine: You know what I mean? Cause I know that a lot of parents, and maybe you can speak to this, Valerie, a lot of parents who have kids with like, A little bit later on site hearing loss they get really down on themselves because they didn't recognize it at first, or they went too long without getting aided or without support.

Alaine: And the parents are like, I just didn't know, maybe like you, they had older kids who didn't have hearing loss. And so it wasn't something that they were looking for. And then parents who I've talked to get really down on themselves about not recognizing that. How could I not recognize this in my child?

Alaine: What would you say? Valerie to those parents who are like, I can't believe we didn't do this sooner. I can't believe I didn't know.

Valerie: So that is for those of us that experience whether it's late onset, hearing loss in 1 of their children, or [00:07:00] just late identification where it's not identified until far later than the typical child with congenital hearing loss, which generally that's pretty early on in the process.

Valerie: That the best way I know to describe our our grieving process was a backpack full of panic and guilt panic because no one could tell us how this happened when it happened, why it happened, what it might be connected to and the other piece of it being guilt on how on earth did we not notice this.

Valerie: And granted, we were a very busy family of 4, you know, Mary Claire was 5, 6 at the time, right? So, you know, she was a busy body and then we've got this preschooler that's running around and both of my both of us were working. So. The idea that we missed this, and it was looking back, very obvious that guilt stayed with us for a long, long time.

Valerie: And I think that's very [00:08:00] normal. It's very painful, but it's very normal. And I do feel that after she turned around and her language skills improved pretty dramatically because we invested. All of us invested time in helping her acquire language, that feeling of guilt softens them.

Alaine: Yeah, definitely.

Alaine: And I mean, I think the way that you described it is like a backpack of like panic and guilt is so true. I see a lot of parents facing that. It was a little bit different for us because our kids. Yeah. Were born with hearing loss. And so they were identified by about like two months of age. So we like started the process kind of from the beginning with the hearing loss.

Alaine: You know, but I can imagine, you know, coming on later in your child or being late or identified in your child kind of having that guilt. And I think you said it really great that it kind of over time dissipates. And I think, you know, you and I have talked about this before I [00:09:00] really like to give parents permission to kind of feel those feelings and work through them because I think so much, and maybe you could talk to that a little bit, is true.

Alaine: We're all busy families. We all have kids. When your kids are identified, they are probably little preschoolers, you know, or toddlers or even babies. And it's a busy time having the little, little ones, you know, everybody's working, everybody's doing stuff. And sometimes I think parents don't take the time to feel those feelings.

Alaine: You know what I mean? I feel like I didn't at the beginning,

Valerie: they feel guilty for feeling guilty. You know, it's, it's layer upon layer, they feel guilty for feeling guilty, or they feel guilty for being, for saying, I don't want this. I don't know how to do this. I don't want to do this. There's a lot of, a lot of in, in those early months and years, there's a lot of unexpected emotions that we're wrestling with.

Valerie: In addition to trying to raise a family and, You know, 1 of the [00:10:00] things looking back that's so clear to me now that was completely not clear to me is the incredible benefit we had in our family of having an older sibling. And that is because she was a great language role model and we had no idea what a gift that was.

Valerie: But it's clear now. 1 of the reasons why. Bridie turned around as quickly as she did was because as a whole family without being told. All right, this is the way we're doing things. Now. You need to, you know we need to be maximizing language acquisition 24 7 that being a family of 4 was a benefit for us because we had an older sibling with a really great language foundation.

Valerie: That was the bar that we were reaching for with Bridie.

Alaine: Yeah, yeah, I love that. And I think that is true. A lot of parents don't realize kind of what a help the older kids can be if they have older kids and their younger kids [00:11:00] have hearing loss. I kind of wish I had had that with my kids to know that you're saying that because it was my two oldest that have the hearing loss.

Alaine: So we did that first. And now my third one. She's three. She doesn't have the hearing loss. And she, she, although she is still kind of a language model for her brothers because they're still a little bit behind. And she speaks very well because she had hearing from the beginning. So she, even though she's younger, she's still a little bit of a model for them as well.

Alaine: And she's becoming such a good little advocate for them. Which I didn't expect and didn't really tell her to, but she'll come tell me when. They're, they both wear cochlears, their cochlears are off or when they like throw their headbands off because they do sometimes she'll like come bring them to me.

Alaine: And it's so kind of cool to watch because no one, I didn't really like specifically explain that to her. I think she's just watched us doing that. Which I would love to hear from Marie Claire about, [00:12:00] you know, how you felt growing up with a sibling with hearing loss. Was there any differences in your family or?

Alaine: You know, kind of like, how did you feel and navigate that?

Mary Clare: Yeah. I would say, I mean, I don't know what it's like to grow up with a sibling that doesn't have hearing loss. So I can't really say I have that experience, but I do remember around the time of her getting diagnosed and getting hearing aids.

Mary Clare: That was kind of a several month process. The things that I remember from that time. In my mind had nothing to do with her hearing loss. Like my first sleepover with a friend was the night before she had a procedure to go in and check, right. The yeah, the sedated AVR. Right. So I, you know, to me, that was my first sleepover, not, Oh, my sister's going in really early in the morning for a test.

Mary Clare: And I, you know, my parents can't wake me up at 5 AM. So I remember spending a little bit less time at home during that period, but it was all like, Oh, I'm [00:13:00] going to hang out with a friend. And quite frankly, I don't think I view Bridie any different than I would if she did not have hearing loss. I, all throughout, you know, her childhood and growing up, I would forget all the time that she did.

Mary Clare: So yeah, I don't view her as, you know, Oh, she's this person with hearing loss and I have to treat her any differently. My little sister and I argue with her and get along with her.

Alaine: So,

Mary Clare: yeah.

Alaine: They're sisters. Yeah, that's really great to hear because I know that I hear from a lot of parents who have kids who have hearing loss and have kids who don't have hearing loss. And I know there's a lot of concern and maybe even a little bit of fear with parents that. The sibling that does not have the hearing loss is going to feel like the sibling with the hearing loss is getting more [00:14:00] attention because naturally they would just need more.

Alaine: They would maybe need more therapy appointments. It depends on, you know, the hearing loss in the situation. We have people from all types listening here but they are really concerned about the hearing siblings actually feeling like left out or feeling like the other one is getting more attention.

Alaine: But it doesn't sound like that you had that in your family, which is great. Maybe you guys, the girls and Valerie can talk to, you know, were there any things that you did in your house to help Bridey? Get language better, get language faster. Maybe they incorporated the whole family. Maybe you guys can give some tips to parents about incorporating the hearing and the non hearing siblings together.

Valerie: Well, let's talk about the Ling 6 sounds.

Alaine: Perfect. Great place to start.

Valerie: Right. Right. And so we were not familiar with the Ling Six Sounds. We were just told that every morning, you know, kind of when she was putting her hearing aids in [00:15:00] that we were, we were supposed to be doing this to check for understanding and without saying.

Valerie: Anything suddenly that became your thing where you would

Mary Clare: yeah, a lot of the like therapists that would come to the house or that we would go and see incorporated me into the practices that we would do at home. So, it was very much a. Both of us thing. And I felt like I was being helpful, which is an older sister.

Mary Clare: That's what you want to feel. So oh,

Alaine: yeah, I'm the oldest. So I get it. Yeah.

Mary Clare: Yeah. But yes, we would do the checks and I would cover my mouth. And speak, do you remember that?

Bridie: I don't remember what we said.

Valerie: Yeah. So so then somebody else in our house changed the link 6 to a different version of the link 6, just for fun.

Valerie: And then 1 day, somebody who shall remain unnamed [00:16:00] over here shared our 6, which was.

Bridie: My dad started saying Guinness, Beamish, Murphy's, Irish Stout,

Valerie: which for those of your listeners who aren't aware, those are Irish adult beverages. And so again, we just kind of incorporated this. Her new thing in our family into our life.

Valerie: And it was a little bit of an embarrassing moment when, you know, she goes in and demonstrates her knowledge of the Abbott family, Ling six, which was Irish adult beverages. Yeah.

Alaine: To the therapist. That sounds fun. Yeah, Bridie. I'd love to hear from like your perspective to what [00:17:00] was it like, you know, being I guess the person with hearing loss in your family.

Alaine: Did you feel any different? What do you think your family did well for you?

Bridie: I don't really feel any different. And if anything I just use it to my advantage. Yeah, I agree with that. Yeah. , like, my mom asked me to clean my room, like I did not hear you say that or dishes didn't hear that. It's not my fault.

Bridie: I can't really argue with me on it. . But I mean, I don't really remember them. I remember some speech therapist sessions. I just remember making a sticker book and somehow that worked. So I appreciate that, but I don't really remember much of learning how to talk, but because I was always talking, it just wasn't always English or a word at all.

Bridie: But yeah, no, I never really feel any different. I just do this to my advantage. And I kind of feel bad for them that they don't have that so

Valerie: we did have an interesting recent thing. Can [00:18:00] I share the genetic testing? So we had the opportunity to go through genetic testing again. So, 15 years later, science has changed knowledge of genetics has changed.

Valerie: And so I had the opportunity to go through genetic testing again for connects in 26 to see if there was anything else in the mix. And and that didn't change the results of that were identical to the original test. And that's and the kind of the report that came back was almost spitting image of the original 1, 15 years ago.

Valerie: But what that did do was make Mary clear now. Eligible for free genetic testing, which you had been wanting to have genetic testing for a while. Yeah,

Mary Clare: I always knew that, like, prior to having kids of my own that I would go through genetic testing to test for connects in 26, not because it would change any thought of having kids, but just so that if I knew I was a carrier that I would kind of keep a closer eye on that, or have regular testing for them.

Mary Clare: And [00:19:00] so I qualified to have the genetic testing done for free, which was great. And I did it and they said, okay, the results should be in, in like 2 weeks and the genetic counselor called me and told me that I did not have connects in 26. and so I texted, I think I tried to call Bridie, but she didn't answer her phone and so I texted her and I was like, hey, I got the results back of my genetic testing and I don't have connects in 26 and you said something I wish I had my phone.

Mary Clare: I would pull up the screenshot, but you were like, Oh, well, that's kind of disappointing. And then you were like, well, maybe not like disappointing, but I mean, yay. Congratulations. Conversation. Yeah. It's not a bad thing to have it, but it's

Bridie: not a good thing. Like it was just, it is what it is. Yeah. I mean, little baby hearing aids.

Bridie: So

Mary Clare: how

Valerie: did you feel about that? How did you feel when the counselor was like, So the results are in and you, you don't have this in your genetic makeup.

Mary Clare: [00:20:00] In a way it was kind of disappointing just because I do think from a Like i'm a big planner and i've You know, I've known my first born's name since I was like 12.

Alaine: Oh my gosh, you and I, yes, we are like the model oldest children. My family would say that too. They would say like Elaine at age 6 had her entire life planned out. Like, I get it. Me too.

Mary Clare: So, like, I don't know that disappointed is the right word, but I did think, like, if anyone on planet earth was going to be a carrier or, you know, have a higher risk of having children with hearing loss due to connexin 26, I felt like I was more prepared than the average person walking around having watched my parents go through that and, you know, being raised with a sister with hearing loss, like, you know, if they were Pull a number out of a pot for someone to have, you know a child with hearing loss.

Mary Clare: I felt like I was would have been a good candidate, I guess, but that would have been kind of [00:21:00] neat. So what they did say was. There is technically a higher chance of me having a kid with hearing loss than there is anyone else because of Brody's hearing loss. But in terms of it being connection 26, that that risk is the same as anyone else walking around the earth.

Mary Clare: So yeah, there was like a little bit of, oh man, like that. I always kind of thought that that was a possibility. But

Bridie: the same of Bitcoin though. Yeah.

Mary Clare: So yeah, I am, I'm probably saving some money that way, but.

Alaine: Yeah, no, I love that reaction because I feel like that is not a reaction that people get often that they were like, Oh man, I was kind of hoping for the baby hearing aids and stuff because I mean, most parents are shocked and have never had this happen before.

Alaine: We certainly were hearing, hearing losses never been in our family except for in our two boys. You know, so most parents and most people have like a very different response, but I feel like. Growing up with another deaf person in the [00:22:00] household or, or hard of hearing, I'm sorry that kind of like demystifies kind of the process of hearing loss, what it's like having hearing loss, because I think at the core of it, parents are just scared because they don't know what the possibility is for their kids.

Alaine: Like, you know, when your kids are identified, when they're babies or they're young, they haven't gone, they don't have older kids like you are. You know, they haven't gone through the process and they don't know. Because our kids are so young, like, what the possibilities are for their kids, that their kids are really going to be okay, that deaf and hard of hearing people and people with hearing loss who are adults, like, walk this earth every day, they have jobs, they are very successful, they, you know, navigate Starbucks perfectly fine, that this is possible, but when you're sitting there with your baby, you don't know this yet.

Bridie: And

Alaine: so it's really great to hear [00:23:00] how your perspective is a little bit different and the process of hearing loss is kind of demystified for you and like not as big of a deal maybe because you grew up with a sister with hearing loss and you kind of know what it's like and you know that it's fine. And, and it's not a big deal for you.

Alaine: Would you say that that would be

Mary Clare: Yeah, I think a lot of the kind of panic or fear feelings that parents have, and obviously I'm not a parent, but but I imagine my parents had and other parents who are not familiar with the deaf or hard of hearing world. And, you know, all of a sudden have this diagnosis that they're not really sure what to do with.

Mary Clare: I don't think that the same feelings of panic and fear I would have, like, if I, you know, were to have a, a baby in it to their diagnosed with hearing loss, I, you know. I have watched a successful story of someone with hearing loss who's. You know, thriving. So would I still be, you know, a big advocate and, and worried about some things?

Mary Clare: Sure. But it [00:24:00] would not be the same, like, oh, gosh, what's going to happen now? And, and whatever. I, I've seen it work fine, I guess, is the way to put that. Like, Bridie's a normal kid. So yeah.

Alaine: Yeah. I love that. And Yeah, I was just wondering, Bridie, if you can tell, so a lot of parents who listen to this podcast are a little bit newer to hearing loss with their kids so Bridie, and even Valerie, you can jump into what, so if parents kind of like just found out that their child has hearing loss, what is something that they can start doing now, or what should they start doing at the beginning to help, you know, their child, like, their adulthood, I guess.

Bridie: I mean, I don't know about start doing, I think that's more for my mom to say, but I would say, like, you don't need to worry as much as you probably are. I'm, like, I think I'm not really supposed to be able to hear the violin, and I've played the violin since I was five, and I played the [00:25:00] upright bass.

Bridie: That's the lowest, so I can't hear that. I can also hear the violence, but like, the our world is not over your world's not over. And they might be lying to you when they're older, and they said they didn't hear you, but you can't really blame that on them. But my mom can tell you what to start doing.

Valerie: You 1 of the things that we did very, very early on was my husband and I, we faked it until we would make it and we felt very strongly that. We somehow figure out a way to be as positive about this experience as we could. And and our process for figuring out what was going on went actually very quickly.

Valerie: And so 1 of the things that we did was when she 1st got her hearing aids that 1st time and we picked them up and we got the molds. We had preordered color coordinated cupcakes and we had a little party a hearing aid party. [00:26:00] With the neighbors and a couple of friends and they got to come up close and look at them and they were pink and they had like edible sparkles.

Valerie: And and we did that every time she got new molds for a very, very long time. Like. Maybe 6 or 7 years. I mean, it was a long time. We ate a lot of cupcakes in the beginning.

Alaine: That sounds great to me. I bet my kids would agree.

Valerie: Yeah. And and it was an opportunity for us to say, okay this is for my husband and I to say, okay, we are still unsettled.

Valerie: We are still not sure what to do about this. We're still not sure how to feel about this, but we are going to celebrate the fact that we figured out what's going on. We are going to celebrate the fact that there's technology that can be helpful. We are going to celebrate the fact that this is just a part of our of your journey of your yourself of our families experience.

Valerie: We are going to celebrate everything we can think of to celebrate. Frequently, and be reminded frequently that we need to be as positive about this as possible. And for us, [00:27:00] color coordinated cupcakes with other people may talking about them. Normal celebrating them. Normal asking questions about them.

Valerie: Normal. And I really do think that that mentality is part of why variety love them. I mean, I mean, she still loves them. We never had an issue getting them in her head unless she really didn't want to hear my voice. And then she really didn't want to put them in.

Bridie: I'm not ready yet. What? I'm not ready yet.

Valerie: Yeah. I'm not ready yet. She would say I'm not ready yet, which really meant I'm not ready for you. Yeah. I'm not ready for you. I'm not ready for all the things you need to tell me I need to do. So I think that, you know, for the families who are just beginning this experience, whether it is with using technology, whether it is with using American sign language, cute speech, what a mixture of these things, a combination celebrating.

Valerie: In whatever way makes seems to make sense and doing so frequently because some of us need to fake it [00:28:00] until we make it and then we realize actually there is a lot to celebrate. There is a lot to be excited about. And would you change anything if you could go back?

Bridie: Continuing the cupcakes for a little longer,

Alaine: I

Valerie: think

Alaine: that's

Valerie: right. I think most people would also be surprised to hear that bride. He doesn't I mean, I don't know. Do you still feel that way? Would you if there's a some kind of miracle cure out there and they could restore your hearing typical? What are your thoughts on that?

Bridie: No, I probably wouldn't just because like I had gotten so used to I guess living like this because I don't really remember not living like this, but like I get the most peaceful sleeps like I can't hear thunderstorms. I have a strobe light in my room for emergencies, so that works. It's gone off before.

Bridie: But I don't, I would not really change anything. I kind of like it. I've never that I can recall really been bullied for it. [00:29:00] And if I have, I'm like, wow, you have like nothing better to do with you. It's like, you're born with glasses. I'm like, okay, like I can just turn it off and then not hear you. Like I can do more things than the average person can.

Bridie: But I do like, if like your child does wear hearing aids or cochlear implants, I've always been kind of horrible about not going with the skin colored or the nude hearing aids or cochlear implants. So I've always had. Lots of colors and sparkles and sometimes like I have another kid in the neighborhood who had clear molds.

Bridie: And he saw that I had colors, and he was like, wait, you can have colors? And now he has colors all the time. That's what happened with another little girl. But even like, cochlear implants, I work at a camp for kids with hearing aids and cochlear implants, Baha's, all of it, and all of them are decked out.

Bridie: Like, one of them had Ninja Turtles stickers on their cochlears. Another one had unicorns. Like, I wouldn't try and hide it. [00:30:00] Like, you're gonna notice them either way, but a lot of kids don't really, like, bully your kid. I know that was probably a big worry of yours, but I never had really any issues with that.

Bridie: And if I did, I was like, I mean, if that brings you joy, then I'm glad I can Really don't care what people say. Which I think my parents played a big part in, like, it's normal. It's like, if you're wearing glasses, like I really don't think it different. Like, I forget that I wear them all the time. I don't feel them in my ears.

Bridie: Like it's not painful. So, yeah.

Alaine: No, I love that insight, Bridie. And you are actually the second person who has talked to me about not doing the skin color. So I talked to a couple of weeks ago, the author of the mighty Mila books, and she was talking about her daughter, Mila you know, who is younger than you guys.

Alaine: And how they have. Two sets of cochlears. They have one set that does like blend in with her hair and one set that's white that does not blend in because she has like brownish hair. [00:31:00] And then they let Mila, like, choose what she wants and she her mom was saying that a lot of times she goes with the white one which completely stands out and she's like so proud of it.

Alaine: Like no problem. Every now and then she'll choose the, you know, brown one that blends in more, but mostly she goes with the one that stands out. And I think that's so important for you guys as kind of like older kids, young adults, older adults, older than like kids my age. to see, you know, adults having, being so proud of, you know, their hearing aids, their cochlears, wanting them to stand out instead of hiding them.

Alaine: I think that is such a good example for the younger kids that are coming through. And the fact that you work at a camp with kids with hearing loss is really fantastic. I would love for my kids to kind of have like older kids like that or you know, older. People, adults to [00:32:00] look to that kind of show them, this is how you do this.

Alaine: This is how you do that. It's no big deal. You can be proud of them. I think that is so powerful for the generations coming up to kind of have that mentor ship. Whether or not you realize you're doing it or not.

Bridie: Yeah.

Alaine: What would you guys say besides maybe like the lean six thing, which was pretty funny, what would be like your funniest thing that like Hearing loss growing up in your family.

Bridie: I

Alaine: have a response to

Bridie: this.

Alaine: Or weirdness or whatever. Yeah, because I mean, I definitely have them with my kids.

Bridie: Yeah. Well, starting grade school, I was in kindergarten. And I used the FM system so that I could hear the teachers. And make sure that I'm actually hearing them and it travels, doesn't really have a far distance where it doesn't break down or break up [00:33:00] because it's so far.

Bridie: So it reaches the bathroom and my kindergarten teacher went to the restroom one day. And. She was wearing the FM system and she started singing the ABCs. I think that's what happened. And like, there's been a lot of bathroom incidents at the beginning of the year. Like, I always tell them, I'm like, I will pretend I didn't hear anything, but like, I can hear you in the bathroom.

Bridie: So please take it off. But one time my fifth grade teacher had, I thought, an important phone call. She took outside and she said, okay, I'm on my way home right now. And I thought, like, one of her kids was dying, like, I was, like, crying in my fifth grade classroom, like, I hear her conversation, like, her kid's going to the hospital, her kid just had strep, but, yeah, I tell them if it's important to take it off, like, I heard a lot of things I shouldn't have.

Bridie: I think it was good for my language. [00:34:00] This

Mary Clare: is not just you as a kid, we have this. still where Bridie will say like a term or a word that most of them have now become like family inside jokes, but she will say it with full confidence as the correct word for something or term for something. The most recent one has been the part of where people like keep their owner's manuals in a car, the glove compartment, which we have started calling the department.

Mary Clare: So, yeah, there's been a lot of words over the years that our family now does not say correctly, but it was because, I mean, it's been like recently that she will say things, you know, like, what? I'm like, the glove department. Yeah, the glove department. It's in the glove department. And we're like, what?

Mary Clare: Yeah, we have no idea what you're talking about, but now we call them that because it's kind of funny.

Bridie: Yeah.

Mary Clare: But we come across those words pretty regularly, even still that she'll say. Like, it's the normal word, because [00:35:00] you don't realize that it's not, and then, like, what are you talking about? Like, I don't know what you're saying.

Mary Clare: Yeah, those are funny.

Valerie: Yeah, some of the because she has had the same pediatric audiologist since the very beginning. So, for about 1516 years and doing the, you know, the annual test and, you know, they go into the booth and they repeat baseball and softball or whatever ice cream and some of the responses that brought when she was younger, when she would get bored of those words that she would give back.

Valerie: You know, instead of, you know you know, they'd say, you know, baseball and she'd recite something back like home run really

Bridie: smart. Yeah. Yeah. Yeah.

Valerie: And so those kinds of things, like, it really has become just a part of you know, who she is and who we are, and we're not. You know, post your Children for how to do it.

Valerie: We've just we've just taken one day at a time and there are things we do differently. Sure. But there's a lot that we're proud of. [00:36:00]

Alaine: Yeah. Well, that was my next question. What was your proudest moment?

Valerie: What was my proudest moment? I would say, honestly, it was her high school graduation.

Bridie: You didn't think it was going to happen?

Valerie: No, I didn't.

Alaine: See, you can see. It's hard. It's hard getting your kids through school. It is,

Valerie: you know, the my proudest moment was when she, Graduated from high school and kind of walked across the stage and got her diploma that wasn't really in there because they kind of

Bridie: pretend

Valerie: it's in there and then you get it later or whatever.

Valerie: It was recognizing just how hard she worked from K through 12. Going from starting with an IEP, then going to a 504 plan, then going back to an IEP you know, school was hard. You know, it was, it was, it was hard. It was hard for all of us, but it was really hard. Parts of it were hard for you and so [00:37:00] seeing her walk across the stage on time with an advanced diploma, which is a thing in Virginia that not many states don't have and knowing that she's college bound and that she.

Valerie: Is a really, really good egg that was, that was really an incredibly proud moment for me for saying we, we made it. She made it. We made it.

Alaine: I love that. And you're right. It is school. It's a long process from kindergarten to 12th grade. And it's a lot of work with your kids with hearing loss. You know, I always.

Alaine: Say, you know, my kids are having to do like twice, at least twice the work of their hearing peers you know, and pull outs and my five year old communicates with ASL. So he's on, like, a completely different curriculum in school. And yeah, it's a lot. And I think parents feel that as well. And it's a very big part of your child's life [00:38:00] is being in school.

Alaine: And I think as a parent. You really want to like get it right for your child. You really want to give them that educational foundation. You want to get the right services. You know, you want to get it right for your child because this is Kind of like their whole life. It's kind of like the foundation of the rest of their life really.

Alaine: Well, I would love to talk about, I'm always encouraging parents to be in the schools more and kind of be more communicative with their IEP team and just kind of be a presence in the school. And so I would love to talk to you about Valerie, about. How much if you were, but I think you were in the school with your kids advocating for them educating other parents and you know, how can other parents kind of start, you know, getting into more of like a leadership role in their communities.

Valerie: So, we, when Mary Claire started kindergarten, I [00:39:00] kind of jumped into the in part, because I wanted I was nosy and I wanted to know what's really happening. Not just kind of through the grapevine what's happening. And met a really great group of parents that were equally concerned about education and maximizing the experience for their child.

Valerie: And I do think that 5 in Virginia, that helped a lot because when. When Bridie was entering the school system they already knew who I was. They already knew I had a big mouth and that I would share what was on my mind. And so it was kind of getting her services and having those services implemented really worked well, K through 5 that we didn't really have a whole lot of issues with K through 5.

Valerie: and I do think that's in part because I was very involved not from the. You know, mom, or the you know, the, the hovering mother of a child with a disability, but just as a, as a parent volunteer in general that [00:40:00] changed a lot with with middle school. We moved middle school is also different because you've got multiple teachers and things.

Valerie: But I do think that being involved in general. Was a benefit for us and not just being involved with that or her classroom. Although, you know, I was to the extent again, a working mom, you know, has a lot going on. So, just I think getting involved in the school in general, especially K through 5 can only reap positive things.

Alaine: Yeah, I definitely agree. And I think like I'm in my kids school all the time, or I'm talking to parents all the time, especially like birthday parties. I, you know, get my kids to go to the birthday parties because I want to see, you know, other kids to see that, you know, my kids with hearing loss do all the regular stuff.

Alaine: Like, I really am trying to like normalize it for, you know my kids like classes that they're in and [00:41:00] going to those birthday parties also gives me a really good opportunity to talk to parents, just like parent the parent. And I really open myself up for answering questions. Because I'm very open to no problem.

Alaine: I'm happy to talk about anything. I'm happy to talk about answer questions, especially if it can, like, educate parents more and they can, like, help their kids understand more. And so just kind of, like, being friendly with parents at, like, birthday parties or, like, school events and going up and asking about them and seeing how they're doing, they start naturally asking you questions about, like, what is hearing loss?

Alaine: You know, what do the cochlear implants do? You know, can James, my five year old. Really talk or does he sign or, you know, what is this like, and I'm able to kind of do that education with the parents. And that kind of like filters down to the kids too. And I think right now they're in [00:42:00] my James, my six year old, now six year old.

Alaine: He's going to be repeating kindergarten. And then my older one is going into third grade this year. But they have such sweet relationships with the kids in their class now which is really great because we started from kindergarten and they've like moved up with these kids. You know, just using ASL in the classroom, we, along with their teachers, like let The other kids, I let some of their friends take their mini mics around on the playground and like

Bridie: Yeah,

Alaine: we like get the kid other kids involved to like normalize hearing loss and just say like this is you know, no big deal but also me along with like the teacher the deaf and stuff kind of show other kids like different signs they can use and how to kind of support people with hearing loss without making that person act.

Alaine: Just kind of doing it normally and we had a really sweet. So my six year old just turned six and we had his birthday party [00:43:00] over last weekend. And, you know, we were opening presents. One of the kids had to leave and James was so and he was just busy opening presents and, you know, wasn't looking at him and he went up and said, bye James and his dad told his son, Hey, make sure, remember that James is looking at you and you know, that he's paying attention to you so that he can hear you.

Alaine: And he said that without me having to say it. So this like education does work and I found that parents and kids, especially younger kids, they're just curious. And they're really open if you come at it in like an open educational way. Would you say that you found that to be true as well?

Valerie: Absolutely. And what's really, I guess it's not weird, but it does seem a little bit weird is Mary Claire's done that as the older kid in school too.

Valerie: So she'll see, you know, a kid that or, or a younger student with that's wearing cochlear implant. And she knows that. [00:44:00] It's perfectly okay when, especially if it's Mickey mouse, that's on there, you'd be like, oh, my gosh, cool. I love Mickey too. And, you know, there's a reason why Mickey mouse is on there because they're a Mickey mouse fan.

Valerie: And so, of course you would, you know, and so there are times when all of us. You know, have educated other people in the school, whether it's parent to parent, student to student. Parent student, student parent we've seen that just being active people in our schools that we've been able to educate and advocate in, in just a very delicate, nice, soft evangelical way.

Valerie: Would you agree with that? Do you have any

Mary Clare: thoughts? I think a lot of people are curious about, like, they have questions and it's, it comes from a place of curiosity and wanting to, I think. You know, if somebody had a question about Friday's hearing aids and came to me and asked me about them, I think it would come from a, oh, I want to interact with your sister.

Mary Clare: Like, oh, I want to get to know your sister better. Not like, oh, [00:45:00] this bad place and being a safe place for people to ask questions. I think and being approachable is important. So, yeah.

Alaine: Yeah, and I think that's great for parents to hear because sometimes I know I hear from parents. There's a little bit of like education fatigue Where they're like people asking questions all the time, but I I mean, I don't have that I guess I just like talking to people a lot and Well, I always feel like the more education the better like, you know As long as someone is coming at me with like, you know, true curiosity, which everyone is I've personally never had a bad experience That may not be everybody's You know, story, but everybody that I've come to have talked to just been curious, but you know, you don't just want to walk up to someone with hearing loss and just ask them.

Alaine: I mean, you have to ask the right people. And that is true. So just opening yourself up As like you were saying, Marie Claire, that safe place that people can come and ask questions and you will answer them like [00:46:00] truthfully and honestly. And with grace, I think is the best way to kind of like spread the information throughout the school.

Alaine: And then the great part is like if parents like talk to their kids and then kids also come home and like talk to their parents about it too. And so you're really educating the entire family is. You know, it sounds like that's your experience, too. Yeah.

Valerie: Yeah. And 1 of the things that we, as a family, I have kind of embraced is we don't get caught up with the terminology and I know that, you know, that the language and terminology and words matter.

Valerie: And and some, some families feel very firm and in different words that are used to describe. Their children or themselves and so when, you know, someone asks me, you know, when did you, you know, when did you find out that brought he was deaf? I don't I don't say, well, she's not deaf. You know, I might say, well, you know, we learned [00:47:00] that are hearing loss was whatever.

Valerie: And I just kind of keep going. So, for us. You know, we don't people use all different term. People use the term hearing loss. People use the word hard of hearing. People use the word deaf. We, we kind of just go with that, keep going with that conversation versus trying to instill what, you know, the terminology that we think is right.

Valerie: And part of that is because we want people to keep coming to us to answer questions to ask questions and to have a conversation. Do you have a thought on. You know, do people tell you that you're, or ask you, like, are you deaf or?

Bridie: That didn't really happen until college. And then some people like kind of made it my personality trait, like, Oh, here's my friend, Bridie, she's deaf.

Bridie: I'm like, this is just so weird. Thanks. I mean, one, like I've always called myself hard of hearing if I brought it up, but I never bring it up. Like, if I meet someone, I'm like, hi, I'm Brian, we're hearing aids. Like, they kind of just figure it out on their own. Or if I say what a million times, I'll be like, oh, it's because of this.

Bridie: They're [00:48:00] like three years into the friendship. They're like, wait, what? But that, I really only had that in college. And then I was like, all right, guys, like, that's not the only. Thing about me. Interesting. I hope. And you're like, oh yeah, no. And so now, well, yeah. Now it's just, here's Bridy. I'm like, thank you,

Bridie: It was just, yeah, it's just like, I've never been introduced as, oh, this is my friend Bridy. She's deaf. I'm like. I am, but like, that's not that. It would be like, you can kind of tell who's been around somebody who's like, never seen someone with hearing aids or cochlear implants or like whatever it is.

Bridie: And I'm like, that's not that deep. Would you introduce your friend? Oh, this is my friend Bridie or she wears glasses. Like.

Mary Clare: Like she's Irish.

Bridie: Yeah. She's, they'll figure it out for themselves. I'm sure. Yeah. I mean, I've never been offended by anything or like if somebody says something and they're like, Oh wait, I meant I'm like, I'm not offended by anything else, but some other people might be offended.

Bridie: So I [00:49:00] would use this term or something, but I don't take it. I don't think anything offensive. I'm like, it is what it is.

Alaine: Yeah, and that's great. I appreciate that you come at it like that because you're right, you know, I think back to like, before I had my kids, I would not have known what to say because I had no experience with any hearing loss.

Alaine: I really never met any deaf adults, adults with hearing loss ever before I had my first child who, you know, is profoundly deaf at two months old and got cochlear implants at 11 months old. I would not have known the correct terms, right? You would just, I would have probably just known the terms, like whatever popular culture said, you know, like whatever I would have heard.

Alaine: And so I tried to think about that. It sounds like you're kind of on the same page as like, I probably would have used the wrong term too if I hadn't known and I just like know [00:50:00] now because I'm in this world because of my kids, but if I wasn't in this world, I wouldn't know. I probably wouldn't know how to, you know, interact with adults with hearing loss or kids with hearing loss.

Alaine: I wouldn't know about hearing aids, cochlear implants, Baha's that there are all these different things. And so that's why I, you know, like you guys tried to educate. Openly and not get so caught up on the vocabulary. I think that's a really important thing that you guys are talking about, just so people will feel good about coming up and asking you questions because you're right, if you kind of like shut it down and they're like, Oh, we can't come and you want to keep like educating.

Alaine: You want to keep because I think it makes it better for the kids coming up and for, you know. Thank you. all of kids, all of other, you know, adults with hearing loss, if we can just like educate and get that out into each of our communities. And it just kind of makes it better for everyone. And I am curious, Bridie, [00:51:00] how is college going?

Alaine: You made it through. It was

Bridie: pretty good. A little rough at some point, but it was pretty good overall. I made some good friends. And I'm really excited to go back to see my friends, but not the school part, but you know what

Alaine: you're studying

Bridie: yet. My major right now is kinesiology to be like a sports physical therapist.

Bridie: So hopefully that works out. Yeah, it's going pretty good. I like it. It's a very small town. It's okay. It's only an hour and a half away from home. I put surprise my parents a couple times like, Hey,

Valerie: we're supposed to be empty nesters and they keep returning unannounced.

Bridie: Can I do my laundry? I don't want to pay 6.

Bridie: But yeah, but I like independent. I've always been a very independent person. And I think I like it being more independent next year. I'll be in my own apartment. So I'll get to like cook for myself. I'm just like, I'm excited. I [00:52:00] love college. Being independent. Love being home too. Home a lot. But

Alaine: yeah. Can I just tell you that I live near my mom too and I'm 37 with three kids and I still have my mom come over and fold my fitted sheets because I cannot

Bridie: do it.

Bridie: I don't know how to do it. But

Alaine: every time she comes over, I literally if I know she's coming over, I just save them for her. And I'm just like, Hey, can you come fold these things real quick for me? So It literally doesn't end. And I prepared for that with my own kids too. She still, and now she helps me with my kids.

Alaine: So it's, it is being a mom is lifelong. I am learning, but I would love to, yeah. Talk Friday a little bit. I know that parents it's a summertime parents are getting ready to send their kids off to college. They're nervous about it because You're not under their house anymore. How did you feel about [00:53:00] being in college, having to, you know, advocate for yourself, which it sounds like you're already, you know, pretty comfortable with you know, did you need any supports in college, in your class, what are things that parents and they're kind of like rising college students, you know, might want to think about before they get to college in August.

Bridie: Yeah, well, all through like grade school, I was I think I've been like every single 504 IEP meeting. And once I got to like middle school, I was kind of leading them myself and my parents were just there. That's great info in, but I would, I would pretty much always kind of advocate for myself, which I think was really beneficial.

Bridie: Once I got to college, because my parents are like, you're kind of like, you're on your own for advocating. I'm not going to call my mom up to talk to my professor for me. But my school does have a program called arrow, which is accessibility resource office. Something like that? I don't know. It's for, it's nothing like specific, but you can get certain [00:54:00] accommodations.

Bridie: So, I had a few, but in college, like, you pick where you sit. So, one of my accommodations in school was towards the front of a classroom away from a door or air conditioning. But I do have accommodations at school, like extended time or written down due dates so that I can't say that I didn't hear it. But yeah, I do have a lot of that.

Bridie: And then my professors, I would always walk out, give them my paper and then just tell them that I'm hard of hearing. And usually it went pretty good. And they'd be like, Oh, I speak kind of soft, but you might want to fit in this seat. Because I usually stand right here. But I mean, like, your professors are trying to help you.

Bridie: It's rather than like, public school or whatever grade school you went to, like, your professors are, their goal is for you to pass. Most of them, but I think they're all my professors were pretty good. And then at the end of the year, they would just forget and they'll be like, Oh, I totally forgot you had hearing loss.

Bridie: Like, I thought you just had these accommodations for something else, but yeah. Yeah, [00:55:00] I think that's

Mary Clare: do you think, like, a little bit to add on to that? Bridey and I go to, we both go to small schools, but hers is a state school and mine is private and the kind of rules around what accommodations you can get at a private school versus a state school or a public school are different.

Mary Clare: So. You can correct me if I'm wrong, but I think 504s are supposed to follow you through college and at a private institution. That's not required. So had she gone to a school like mine while I love my school, and they're pretty accommodating of things that other students need. You're not they're not bound by those same requirements and some schools are great about that private schools and and things, but.

Mary Clare: Because of the rules about them, not having to follow that. I think it can be a little bit more challenging, but long, what I think has been, yeah, they

Bridie: have a lot of resources so that you don't really have any excuses to not after class, but they do their, they do their best. And I think it works pretty well.[00:56:00]

Bridie: Yeah, so,

Valerie: yeah, from a parenting perspective, I do think it's important for families of children with any disability. to kind of have something in place that's already existing when they're seniors in high school.

Bridie: Even if it just has like a guideline in college, like even if you can't bring it to just say, Hey, this is what I need.

Bridie: Like, how do I get this? Like, that's what I think we call the school. And they're like, Oh, we have this. And then I got to move in like a week early with the program and meet other people in that program. Different things they needed, and I got to move in early, which was great.

Valerie: So the form that we had to fill out for Bridie had questions like, does your child have a current plan?

Valerie: We provided a copy of that. The questions were for each accommodation, how did you use it? And so, again, if you're walking into college without an or a plan, I would imagine it would be harder to to get. And so, again, if you're walking into college without an or a plan, I would imagine it would be harder to get.

Valerie: Accommodations, because you don't have [00:57:00] something that's kind of this is what we've been accustomed to. This is what we're used to. And this is how it's benefited our student. So that's something for families of of high schoolers to consider is if you're thinking of dropping your 504 plan prior to senior year, you might want to rethink that.

Valerie: Only so that you have, even if you end up having a 504 plan with accommodations that your child advocates, I'm not going to use those today. At least they're present when they're graduating to bring as an example into college.

Alaine: Yeah, that's a great. Yeah, that is great advice for our parents to just keep kind of keep that in place and to give their kids options.

Alaine: Like you said, the kids can always refuse. They don't want to use them. That's fine. They don't need them. But having that option is great because I can imagine maybe some classes you would, some classes maybe you wouldn't. It might depend on the room. It might depend on the teacher. you know, whoever. So they might change their mind.[00:58:00]

Alaine: Also you know, get through like first semester and they're like, Oh, actually like this would be helpful. Yeah. So that's great advice. Thank you. And Bridie, I know that parents would probably also want to know, do you use any like technology to help you like to help you wake up in the morning? Like, what are some things that parents can help their kids put into place?

Alaine: Maybe like, Start doing it during like middle school, high school earlier to like help kids be more independent and learn to be more independent.

Bridie: Well, once I stopped waking up to my regular alarm in the morning, my parents got me a bed shaker called like a sonic bomb. Like, it was kind of, that's what

Alaine: I have for my, yeah, for my rising third grader.

Alaine: That's what I have. It works really well. Although he's a very deep sleeper, and

Bridie: I had to stop eating it because my sister's room is right next to mine. And I would wake up earlier than the whole house. Yep. So after that, I have an Apple watch and that [00:59:00] just like vibrates in the morning and that eventually wakes me up at some point.

Bridie: But, yeah,

Valerie: there's eventually,

Bridie: yeah, for like an hour, but that's just me.

Valerie: She also has a an addition in her room to help her with emergency things

Bridie: earlier. I have a strobe light in my room because we did a test on, like, the fire alarm or the alarm in general, like, without my hearing aids on, I was just sitting in my room and then my parents came up like, 30 minutes later and I was like, when are we going to start?

Bridie: And they were like, It's already over like we've already tested it and they're like, oh, you can't hear it at all. Even when you're like waiting for it, then we got a strobe light. And then 1 day

Valerie: and we, and we moved the the siren. So there's 1 right outside of her room, which is also right next to

Bridie: wake up.

Valerie: Yeah. So, but

Bridie: our alarm did trip 1 day and it went all. It's the same for like a burglary, a fire, like any emergency is all the same. And I was like, I don't know whether to run or [01:00:00] hide under my covers, but, and then I'm, so I decided I was like, I'm just going to hide here if I smell smoke, I'll jump out the window.

Bridie: But, and then I'm like, my eyes are like closed, but not really. Cause I'm like, is somebody going to walk into my room and like murder me? And someone did walk into my room and then they look over me and then they left. And I was like, Oh my gosh, I just like escaped death. And then I hear my mom, you know, it's my mom.

Bridie: I was like, mom, you have to wake me up at that one. I was sleeping. So the strobe light

Mary Clare: went off

Bridie: and you didn't wake me up, but I was not actually sleeping. Like I was fake sleeping. Like you should wake me up. And I don't think I was so terrified. It's like, stop breathing. Yeah. Yeah. It works. I was just really confused.

Bridie: It was like three in the morning. Yeah.

Valerie: Yeah. It was very, So, we still even now are still figuring out technology and how to use it to protect our children, educate our children. Yeah, never ending

Bridie: woke me up. But maybe next time someone can just tell me [01:01:00] what it is. Yeah, but I do, that's all I really use.

Bridie: Okay, yeah, yeah, that's

Alaine: I mean, that's helpful for parents to know about and I'm assuming that you're probably. As you're like getting an apartment going to be implementing like these things into your.

Bridie: Yeah,

Alaine: that's going to be the bigger conversation, not having the things, but like,

Bridie: if

Alaine: you have apartment mates being like the thing they go off is really loud.

Bridie: Yeah. And I did have a roommate or two roommates in the beginning of the year, I ended up with single, but in the beginning of the year, I told both of them, I was like, Hey, like all I already know is to like. Bang on our door and like unlock our door if there's ever an emergency. But like, just so you know, if you don't wake me up, like, could you do me a favor?

Bridie: Wake me up. And they were both like cool about it. We never really had, we never had any emergencies. I have one drill. I heard it and I was like, I [01:02:00] would never have woken up to that. It was like during one of my classes. And it just says, there's an emergency, leave the exit. It's not even like an alarm. I was like, okay.

Bridie: Don't want that within a single hour. Make sure my RA was like, please wake me up if something happens, but yeah. But there were accommodations in my dorm. It was like a doorbell that says hard of hearing or like blind person in for those. I Dorms, but I wouldn't put in one of those, but I guess there was a strobe light in there.

Bridie: Yeah, or a noise for the visually. I'm not, I only know my hard of hearing terms, but

Alaine: yeah, yeah, no, that's great. These are really great things for parents to start like thinking about and helping their college students like. Start thinking about and start getting. And how did you feel, Valerie, about sending your girls off to college?

Alaine: Did you feel like they were [01:03:00] ready? Did you feel confident? I felt confident.

Valerie: I mean, yes, they're, you know, they're really, really good girls with some really great heads on their shoulder. You know, but just like any parent that's sending their child off to go really start navigating the world.

Valerie: Without you right there frequently. It is an, you know, there is an anxiety that goes along with that. But I am grateful that they do, you know, they're, they're smart girls. They're kind. Brian is a friend, making machine. Mary Claire's a friend, making machine. So Socially, I knew that they would both do well.

Valerie: So it really and they also chose some fairly safe places to go to school. So, we, we really did a lot of research into what school would be best for both of them. And with Bridie, we asked that extra question about accommodations for students with disabilities. And there were some schools that had a better track record and offerings than others.

Valerie: So [01:04:00] it was, you know, I, I'm excited that this, they're, they're here, they're, they're college students. They're living their best life and it, but it's been a journey and it's a journey that continues.

Alaine: Yeah, I love that. I love that perspective. I know a lot of parents are nervous about it, especially their kids with hearing loss, because it does come with a little bit more you know, and even.

Alaine: How their kids are going to do, you know, advocating for themselves, talking about their hearing loss, you know, getting other people to understand, but. Yeah, it sounds like you guys have done such a great job, and I love it. I know we are at the end of our time, but I didn't want to leave without just letting parents know about your most recent book.

Alaine: I would love to know the girls, how do you girls feel about your mom's books? Everybody else loves them. I talk to parents, I talk to parents all, I mean, all the time that love your books, but I would love to talk a little bit about your [01:05:00] newest book, how that one came about.

Valerie: Yeah, so we published in the thick of COVID, Pat a Pillow, which is based on our family's experience with discovering hearing loss and coming to terms with that.

Valerie: And it was a family project. What are your thoughts on it, girls?

Mary Clare: I like to tell people I'm the star of it because it's written through my eyes.

Valerie: Yeah,

Bridie: yeah,

Valerie: they're not shy about that. So so the story is narrated by a snarky older sister who sees all the things that the parents didn't notice. And what I love about that perspective is it does remind I think readers that.

Valerie: Siblings have a seat in the car of this you know, where we're all in it together. And so from her perspective I just love the way that it's that it really get gives the story through the lens of an older sibling that is watching all of this unfold. What do you think about it? Bratty?

Bridie: I mean.

Bridie: I'm glad that it's out there. [01:06:00] A lot of people are like, Oh, it's a book about you and like your experience, but I really don't remember any of it. And I'm, I'm sure I put a lot of work and to get to where I am today, but I kind of consider it more my parents story. Like, they're the ones that kind of went through the quote unquote bad parts, even though none of it's really bad.

Bridie: And the tough parts, I was just kind of there. So I, I mean, it is like me about me and like, I'm the one with the hearing aids, but I don't really consider that part my story. I think it's good for other parents to see that too. That's not the end of the talk.

Valerie: Yeah, it was written, you know, as a tool to help families uncover and tap into some of the emotions they might have been struggling to come to terms with.

Valerie: It is an emotional, a little bit of an emotional roller coaster where the, you know, the, the disbelief, the denial, the testing of the hearing with stuff you have at home. I mean, all of these things that we did. Are part of that. But [01:07:00] then at the end you know, we see a, a, a snarky older sister who doesn't really have a lot of empathy for her, her younger sister, who's really annoying.

Valerie: All of a sudden you see her becoming protective and excited when she sees her her younger sister developing language skills that weren't there in the, in the first place. So there's a lot to unfold, but Pat Pillow has really, I think, helped to highlight. The topic of late onset hearing loss and late identification, and the fact that children can lose their hearing at any age at any stage, and it can have pretty significant impacts on their language development.

Valerie: And and that's really the mission that our family is on. It's educating the world that we need to be on top of children's language all throughout early childhood. And when in doubt. Check out hearing, because if that if that is part of the equation ignoring it is not going to do anything to benefit the child.

Valerie: We need to we need to know a child's current hearing status and then make [01:08:00] decisions based on that.

Mary Clare: I do think it's. Kind of a slight side story. I think that the book has become a part of all of our kind of lives beyond just like when we're home. At school this past year as a junior at my school, we go through ring night where you like earn your class ring and Part of that is what are called call outs.

Mary Clare: So someone on campus will say, like, something and you're big creates them. And 1 of my call outs this year when I was earning my ring was if someone across campus said, look, Mary Claire, it's a paterpillow that my response had to be that is not a paterpillow. So, like, even my friends at school know the book and know the story.

Mary Clare: But I think it's become part of, like, all of our lives beyond just. When we're home or on, you know, book events or book tours.

Alaine: Yeah. And I love that the whole family can like read this together because it kind of speaks to the child with the hearing loss and the siblings and kind of like brings it all [01:09:00] together.

Alaine: So it's a really great kind of together family book to read, you know, to your kids to kind of understand both sides, honestly, to it. I love it. Where can people find your book and you?

Valerie: Yes, so the easiest way to find me is online at Valerie James Abbott dot com. And my personal email address is Valerie James Abbott at gmail dot com.

Valerie: So that's we kept it pretty easy. And Pat a pillow can be found in most bookstores and certainly on Amazon. So Barnes and normal Amazon for a while. It was in target, which is crazy to think that our book was available through target. Yeah. And it's also available in Spanish. We, which is absolutely wild, but yes, the paterpillow is also in Spanish.

Alaine: Wow. That's so fun. Well, thank all of you for coming on the podcast today, chatting. I had so much fun getting to know you guys. You are [01:10:00] such a fun family. If you can, and this is open for anyone or everyone, leave parents with one last, like, piece of advice for raising their kids with hearing loss, what would it be?

Valerie: To remember that children with hearing loss, children who are deaf, children who are hard of hearing, or really, children with any disability are children first. They're children first. And to enjoy enjoy this time, especially of early childhood with them as much as possible, but that they're children 1st.

Alaine: Love that writing. Marie Claire. Do you guys have any thoughts from your perspective?

Mary Clare: I kind of agree with that. I would say also don't set limitations on what you think your kid can do. I think my parents thought that they had limitations or assumed that Bridie couldn't do some things and [01:11:00] Bridie was like, watch me and went and did them.

Mary Clare: So your kid is, with hearing loss is just as capable of anything as you are.

Bridie: I would say probably it's not their personality trait, whatever is going on. Like my mom said, we're kids first and to kind of also embrace what it is and make it normal in your own household. And that it's really not that deep.

Bridie: It's just something that's going on. Yeah, I don't know. It's like normal in my life because my parents made it so normal around the world. I don't know like. I don't know. My mom, like, used to explain it to me like, Oh, she wears glasses. Oh, you wear hearing aids. I'm like, Oh yeah. Okay.

Alaine: guys so much. I appreciate you coming on the podcast today and thanks for your words of wisdom for the parents. I know that they're really going to appreciate it too. Thank you so much.

Alaine: Hey mama, I hope you enjoyed today's episode. If so, would you take [01:12:00] 30 seconds and subscribe to this podcast? I never want you to miss an episode and to be without valuable information to help you and your family. Also, please leave a quick written review for the show on Apple Podcasts. It lights me up to know this podcast is helping you.

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