

Pierce and Jaide's Story



Pierce

My son's name is Pierce and my name is Jaide. My son was diagnosed at almost 4 years of age; we did not know about it until he failed the hearing screening at Head Start. He was actually born at home so to find out he may not have had that hearing screening was a huge blow to me. We still do not know if he had a newborn hearing screening. That's a big punch in the stomach because you are supposed to do all that stuff. As a mom as a parent you tell yourself you do all these things to protect your kid and make him right and if I would have known about that what if we would have found out when he was a kid so there is all that what if., if he had had that hearing screening may be he would have been, had the hearing aids sooner or we could have stimulated his hearing sooner, so all that what if was obnoxious like gut wrenching because maybe I could have done something more before 4 years of age. Had we not have been in Head Start, we may have never found out that he had a hearing loss. His language, the way he says his words, his articulation is so high that no one even noticed. The audiologists were even stumped because he had mild to moderate loss, at the higher pitches, his speech was so intelligible, and we didn't really know if he needed to be fit with hearing aids when he was first diagnosed. The grieving was kind of sad because you knew there was one to be one extra element of unknown. You have this perfect infant baby when you take him home, and he was smart, then to find out he has a hearing loss. They are supposed to be perfect, he looks perfect and he has always been perfect and then there is this thing you do not know much about and how much more am I going to have to do and how much time because I have three other kids. What's this going to do to him when he is in school, are kids going to tease him, all these things go through your head. I mostly dealt with it by crying, getting those feelings out, and also talking to other people that have gone through that was really helpful. I also wrote my feelings out a few times just to get the negative feelings out and then

be able to move on and look at the good things that can happen from it. Part of the grieving process was talking to professionals and learning more, understanding more. A lot of times if I had certain questions they would direct me to other parents and they also had meetings, family support groups for kids at Sound Beginnings so I got to know those parents and any time something comes up you have that support group to talk to.

You have that denial piece; I still have that piece like does he really need hearing aids? I have this to this day because he says all the time "I can hear everything, I can hear so good, I do not need them". The good is that he is at school, here at Sound Beginnings where he has other peers that are deaf or hard of hearing or have hearing aids. He is just one of the kids with his hearing aids. I have heard from a couple of different audiologists that kids with mild to moderate loss stump them. They say they are the harder cases they say because it is not black and white. Kids with profound hearing loss, obviously if they choose to hear, then that's what you do. However, with someone who is getting some sounds the hearing aids may block them or different things like that. For us it is a struggle, they had to tell us that all kids could benefit from sound amplification. So when they told us that, it was like OK they make it so that it won't hurt his ears.

I felt at a loss for relating to people because he went to a school where most of the kids had a profound loss. It is like, how do I relate to some of the information that is coming in, talking about IEP's and this and that and he does not qualify for them. I really did not have any body that I knew or I did not know where to find anyone that had a child with a mild hearing loss so I could have it be more relatable. I feel it is pretty important to have a support group that can relate to when you are going through something like this, no matter what stage it is. A mild hearing loss just does not seem like a huge thing to have grief about. But I kind of feel like it has resulted in some of his shyness and social inadequacies. I could get hung up on that. It was more about like what are the amazing resources that we have and the wonderful parents that I am surrounded with and the wonderful professional that are helping us advocate and helping us get the information we need. Just looking for all the positives and still fighting the battle of advocating for my son. Gathering all the positives and seeing down the long road that he will be able to advocate for himself. If I had had access to parents that ha a mild to moderate hearing loss with their children, but even still we have been able to use the resources that we do have to make a good impact on our choices and because there is always going to be some questions like does he need a 504 or does he need an IEP so just having people to talk to, knowledgeable people. I think having the deaf educators and the listening and spoken language educators around to ask them

questions, and people with teenagers, that's always really helpful.

There is going to be some major need for recharging your battery. I have four kids and just one of them has a hearing loss. It is more a time to breathe, anyway you can breathe and think yeah everything is OK. I like to go out in nature a lot. I started taking water coloring recently and I was creating something for me is really, really energizing. Whether you are doing crochet or creating a picture on the computer is really reenergizing. Even if they are in the room creating something and taking that time to breathe. You have to take care of yourself as an individual to take care of others. No matter what.

Family support has been huge. My whole family is two three states away, a 14-hour drive away. My mom is an educator in the public school setting so I want her to know. But it is almost like "I do not even understand this". So I've really have to go and talk to the professionals' time after time, talk to different ones, may be ones that spoke my language a little bit better and just grasp for whatever I could get from them that was really important to me so that I could tell my family a little bit. They will ask questions over the years like mild hearing loss getting worse? Sometimes I am like I do not even know, thank you for asking that and then I go back and ask the professionals. My family has been really easy to deal with. They have always been part of the support but they are always very far away and they do not really know much about the hearing loss, so I really rely on my hearing loss family for that support because they understand more. It takes a village to raise a child and I totally get that now because this is my village here. My recommendation would be to find at least one person that is your village.