

One Family's Journey

Amelia's Story:

ANSD and Cross-Country Move

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Making a move for your deaf child could mean many different things. It could mean moving to a different program or a different school district or even a different state. Last year, it meant doing all of these things as we moved from New York to Seattle away from family, friends, and church. This much change is probably never easy for any family, especially when siblings are involved. "When my parents talked to me about the move, I didn't really want to go. But I knew it could really help Amelia," said Nicolas, our daughter's big brother. He gave up his school and friends to move so that his little sister could have a better chance at learning.

Early screening and ANSD

Five years ago, Amelia failed her newborn hearing screen. At the time, Nicolas was eight years old. We weren't sure if she had a hearing loss or if something else was wrong. A month later, she was tested by a pediatric audiologist who diagnosed her with profound bilateral sensorineural hearing loss. Soon after, we learned she had auditory neuropathy spectrum disorder (ANSD) in both ears. ANSD varies with each child, but it can mean there is distortion and fluctuation in hearing, making it difficult for the child to understand sounds. Our lives, as we had imagined, were changed forever. When we told Nicolas about Amelia being deaf, he asked, "What does that mean?" It dawned on us that we weren't sure yet, ourselves. Amelia was only seven months old and we knew nothing about deafness. When we learned through her MRI that her auditory nerves were underdeveloped, we were told that she wasn't a good candidate for cochlear implants (CIs).

After researching the condition and doctors who specialize in challenging anatomy, we met a physician who told us that it was hard to determine with 100% accuracy whether or not a CI will work. He had seen many children be successful with CI's despite expectations. This gave us the hope we needed to schedule the surgery, and Amelia was bilaterally implanted at 13.5 months old.

Change of Plan

By age three, we saw that Amelia was struggling to learn and communicate. Her peer group was disappearing as she couldn't understand or respond to what the other children were saying to her. I was seeing my daughter, who was naturally social, start to withdraw. She was enrolled in a total communication (TC) class that used ASL and speech.

We were learning ASL through a local college. We had people come over to our house to help us practice. But was it enough? A fantastic speech-language pathologist encouraged us to follow our instincts when we saw that our plan was not working for Amelia. We needed a change.

We took her for another opinion. We were still hoping she would develop speech but knew it was unlikely. We had her evaluated by The Moog Center in St. Louis, where they have an onsite team of audiologists who work hand-in-hand with the teaching staff to get immediate feedback on a child's hearing. They were not afraid to try different techniques with Amelia's cochlear implant MAPPING to help maximize her hearing. We learned from this Amelia's quality of hearing would mean she would not hear well with her CIs.

Betsy Brooks and the team at Moog spent a lot of time with her and learned that she benefitted from a simultaneous communication learning environment with a great amount of structure and verification through feedback from Amelia. We learned that she was at least two years behind her hearing peers. Because of her ANSD, she would have good hearing days and bad hearing days, which meant the teacher needed to know what each looked like to continue teaching her. We knew we needed to change our current TC approach as it did not seem to be working.

What we thought was Amelia "getting it" was really Amelia becoming proficient in copying other kids. We also learned that although the teaching used a TC approach - ASL and speech simultaneously, the kids could choose what they preferred to use – ASL, speech or both. Most of the kids could speak and chose that mode to communicate which left Amelia out. We felt like we were failing her.

The team at Moog worked with us determine the best approach for Amelia. We will forever be grateful for Betsy's honesty in helping us to readjust our goals with regard to Amelia's communication abilities, and for the realization that an accessible learning environment was the most important focus. In our own experiences growing up, language proficiency and literacy had been keys to college and careers. We wanted this for Amelia so that she could have options and choices in her future. We had to find the best learning environment for her that met our criteria: a highly structured simultaneous communication environment that could teach her English language proficiency, continue with sign, and provide a strong peer group for our social butterfly. We wanted Amelia to learn but also feel like she was a part of a community.

We began searching again, talking with professionals and parents and exploring the Internet. We found Signing Exact English (S.E.E), a method of signing along with speaking that gives visual access to grammatically-correct English. We visited two schools who used it, but it was Northwest School for Deaf and Hard of Hearing Children (NWSDHH) that seemed a fit. Here, everyone signed to each other when speaking. Students were pushed to sign and speak to the best of their abilities. They also had great tools to measure progress, which would allow parents to verify at home what they say she is learning in school. With almost 50 children attending the center-based school, she would meet many signing peers.

Back to Learning

Amelia started at NWSDHH last September and is thriving. She loves school again, has friends, and her language has taken off. She is a sponge with learning. We feel like our daughter can now be the happy five-year-old she was meant to be. What have we learned through this journey so far? Set the bar high and don't let anyone tell you that your child can't do something because they are deaf. Don't be afraid to push and keep pushing your child to their potential. If you feel like something is not right, then you're probably right. No one knows your child like you do. It's okay to try something else. Seek other families out, listen to their stories, and remember that every child is different. Your child's story will be different.

Amelia is spontaneously forming sentences, handles herself with confidence, and has a best friend. She understands that all the "little words" (articles, conjunctions, pronouns) along with the structure of English is needed. She tells us when her processors are not working and she is now starting to question the sounds she hears around her. Her personality and interests have blossomed—she is as inquisitive, communicative and energetic as any five-year-old. We are all excited for Kindergarten and seeing her learn to read and write proficiently.

And her brother? He can finally communicate with his sister! They engage like any other siblings now. He includes her because he can. When you can't communicate with someone, it is really hard to include them in what you are doing. He knows that he is part of the journey. We have truly grown closer as a family.

Washington Hands & Voices wishes to thank the Fagundo family for sharing their story.

If you wish to share your story please contact info@wahandsandvoices.org