

A PARENT'S PERSPECTIVE

A Deaf Child from China to the Voice of Apple TV's *El Deafo*: The Power of Families



Rosie Finigan

Rosie Finigan is a parent member of ACI Alliance and serves on the CI CAN network. Her family is a model for parent ingenuity, resourcefulness, and the power of the human spirit when we allow a child to learn and excel in ways that best meet their unique needs.

Editor's Note: Try to get through this wonderful narrative in one gulp. If you don't have time now, it's also posted on our website here: www.acialliance.org/page/storiesaboutchildren

2022 was special for our family in a few ways. It marked the ten-year anniversary of my daughter Lexi receiving her cochlear implants. By today's standards, she is considered a late-implantee, receiving her first cochlear implant at 27 months of

age, and her second implant a month after her third birthday. My hope is that by sharing her story it gives hope to other families, especially those that feel they might be getting off to a late start.

Adopting a Deaf Child from China

In early 2011 we were a family of three. We had already adopted a little girl from China five years prior, who was six years old at the time. Both myself and my husband are close to our siblings, so we wanted our daughter to have that same experience, and we felt that our family had a lot of love to share. We have many family members here in our community, and several who have a built their family through adoption. We were hoping to adopt another child, but adoption from China at that time was mainly through their special

needs program, and there was no guarantee that we would be matched with a child.

After a few years of waiting, we received a file for a little girl with hearing loss. We knew very little about hearing loss. In addition, we live in the Florida Keys, which is rich in beauty but short on services—especially specialized services for children. We were able to consult with an audiologist who confirmed, with the limited medical information we had, that she likely had a profound hearing loss in both ears. We did a lot of research, weighing the fact that we have no deaf community here and no audiology services. I wondered if we could meet her needs as parents, and if our community could provide what she needed to learn, grow and reach her potential.

Finding People and Resources to Help

I remember looking for a sign. I received many. I reached out to an audiologist who had tested my hearing a few years prior, and she was kind enough to read Lexi's audiogram and offer her expertise. I reached out to parents who had adopted children with hearing loss, and I even was able to speak with parents who adopted children from Lexi's orphanage. We were blown away by the kindness of strangers and how many people were willing to help and share their experiences and advice to a couple whom they had never met. So, despite the many unknowns in adopting a toddler with several identified medical issues, my husband and I decided that what Lexi needed most was the love of a family, and we would just have to figure the rest out. After all, becoming a parent is such a leap of faith in just about every way.

Once we decided to move forward

with the adoption, we set out to learn as much as we could about hearing loss, the options available, modes of communication and where we could obtain services to help Lexi catch up. We also needed to consult other medical specialists for what Lexi may need, as well as how to best foster attachment with a toddler. I realize that in choosing to adopt a child with hearing loss, we did not have a grieving period, and I can only imagine all of the difficult emotions that many

University of Miami had a Children's foundation to help children with hearing loss. I reached out to them and they met with us, (before we even had Lexi!) to tell us about all of the options to help Lexi hear. They kept in touch and once we finally received our dates to travel to China, they were able to schedule us a couple days after we returned home. Lexi was two and a half years old when we adopted her and she had no language other than her ability to give a thumbs up. I often worried about how to soothe her when she couldn't hear, and how confusing this time must be for her. Surprisingly, communication was not as difficult as I had feared. She watched what we did, would lead our hand to what she needed or would point to what she wanted. It certainly helped having our daughter Mia with us, who was six years of old at the time. Lexi attached to us pretty quickly and seemed so eager to learn. She compensated very well for her lack of hearing. It was clear that although she had been in an orphanage for most of her young life, she was well cared for.

not yet be candidates for cochlear implants until they are older, or their hearing loss was not identified until later, or in other cases the loss has been identified but the parents have to battle their insurance company for coverage.

The next couple of months was a whirlwind of appointments. The staff at medical offices came to know me pretty quickly because I would call every day to see if there were cancellations in order to move up appointments. As a working parent who was off on maternity leave, I felt like I was in a race against time as well. Persistence pays off as does having a competent team. After a short hearing aid trial, Lexi received her first cochlear implant about two months after we returned home. We had already begun participating in AVT, and this was good preparation for the work we would need to do at home.

The team at the University of Miami was fabulous and although I felt like I had done enough research to complete a dissertation, when they turn your child's implants on and give you a suitcase of supplies, it is overwhelming. Chasing after a very spirited toddler trying to keep the processors on her ears is a feat that I am sure every parent can relate to. Of all the support we received from the fabulous team at the University of Miami, the one moment that had the greatest impact on me is when the director of the program looked me in the eye and told me that I can do this. She already knew what we slowly came to realize: we are the expert when it comes to our children, we are the team leaders, we are the teachers and facilitators. I am quite sure that as professionals they knew that the most important role to achieve a successful outcome for the CI child belongs to the family and the family environment in which the child develops. Studies show that



parents experience when they are told that their child has hearing loss. International adoption has many challenges but in between the paperwork and the fingerprints we tried to prepare for every possible scenario the best that we could.

During this time, we learned that the

Moving Ahead Quickly to Develop a Team

Two days after we returned home from China, we were in a sound booth at the University of Miami testing her hearing and getting fitted for hearing aids. I remember feeling like we were in a race against time since she was so behind in her language. I was surprised to learn that kids are often implanted after the age of two. There is a ton of research that supports the benefits of early implantation, especially before there is a substantial delay in spoken language. As a results of the research, the recommended age for receiving cochlear implants has been lowered. However, many kids have progressive hearing loss and may

the relationship between the family and the auditory-verbal development potential of the CI child is strong, even if the exact mechanism that contributes to success are not clear.

Lexi's CI Turn-On and Maximizing the Opportunity

It was obvious to us that Lexi was eager to hear and speak. I honestly believe that she didn't want to miss out on anything. She is a very outgoing, strong-willed child who was eager to learn.

She started to pick up on sounds. One of the first ones was hearing our coffee percolating. We pointed out sounds constantly, narrated everything we were doing, and minimized background noises. She started pointing out new sounds almost every day. She was a tireless child so I just tried to bombard her with as much language as I could. The University of Miami was a three-hour drive for us, so I needed to find ideas for how to best help Lexi at home. We used TeleRehab with an AVT from Central Institute for the Deaf in St. Louis, which was a newer concept at the time. In no way could Lexi sit at a computer for 30 minutes but I quickly realized that these sessions were to teach me as her parent how to best foster her listening and spoken language. One of the silver linings of the COVID pandemic is that it has broadened the availability of teletherapy for AVT and speech services, making them more available and affordable for the families that desperately need these services. I also found so many resources online.

We participated in the John Tracy Clinic's distance learning program for children with hearing loss and attended their international summer program the following summer right after Lexi's fourth birthday. This

program serves to educate parents on how to best help their child learn to listen and speak. I think many parents, including myself, don't realize that we must become strong advocates for our children with hearing loss. Many parents at the time blogged about their experiences and I learned so much from them. We used games, picture cards, toys, essentially anything we could to introduce novel words and push the language in. Lexi's older sister Mia, read many beginner books to her which benefited them both.

Advocate to Set the Bar High

In the Summer of 2012, we enrolled Lexi in pre-school. At our first IEP meeting, it was suggested to us that Lexi be placed in a special needs classroom. Another professional suggested that Lexi could use an iPad to supplement her communication. Lexi had just received her second implant so I asked them why on earth would we set the bar low when as far as I was concerned her potential was enormous. We would not let her struggle but we needed to set the bar high and give her a chance to reach for it, while providing her with the services to do just that. I told the team that she has a physical disability not a learning disability; therefore she needed to be in an environment with kids who could model good spoken language. I often wondered what would have happened had I not educated myself to be a strong advocate for Lexi. A month later she started preschool. Although her language was still very limited, I knew that she needed to be immersed in a language rich environment. We taught her some vital words in sign language, and she seemed to be understanding more and more spoken language each day.

During those early years I found it

very helpful to journal the progress that Lexi was making, keeping track of the words she was saying. I often use the CASL inventory form to keep track of her growth and shared it with her audiologist and AVT when we had follow-up appointments. Because our services were so limited in our island community, we looked for additional summer programs and found ones that provided both of my daughters with fun, engaging opportunities to learn. I saved up so I could take FMLA from work for a month each summer. One summer we went to the Atlanta Speech School's day camp and another year Lexi participated in a day camp at The River School in Georgetown. I always have believed that each therapist has a different approach and perspective from which we could learn.

Catching Up Lexi's Language

Each year in elementary school Lexi closed the gap a bit more. Her love of reading was a huge factor in teaching her new vocabulary and helping her catch up in her English language skills. By the time she was in third grade she was essentially caught up if not ahead of her peers in several areas. This created yet another challenge to keep her on an IEP. However, I continued to be a gentle but persistent team leader, armed with research and my child's best interests, prepared to make sure my daughter was able to get what she needed at school in order to be successful. There are so many resources available for parents today, such as the ACI Alliance, Hearing First, AG Bell, and the Face Book group: Parents Children with Cochlear Implants. The parents on this Facebook group are a vast wealth of information and happy to help others who are earlier in their journey. I have also found other helpful FB Pages, such as Lynn A Wood, LSL, AVT. She

is always posting great ideas and activities to foster language growth.

The good news is that as a parent of a child with hearing loss, you are not alone. Even if your child was implanted late, like Lexi was, there is still so much hope. A study in 2020 suggested that post-op performance of auditory perception and speech intelligibility of CI kids implanted prior to age five was significantly related to the family environment, as well as the educational level of the parents. With so much research about the most successful outcomes being for kids implanted before age two, I was glad to see this study. I think the correlation with a child's success and the educational level of the parents has so much to do with access to health care and resources, as we have seen with so many other health issues in our country. We need to continue to demand insurance coverage for our kids and expand services to those who really need it. For the parents whose child was implanted after age two, know that there is hope and plenty of potential for your child.

Parent Engagement Makes the Difference

Narrating everything you are doing with your toddler, engaging in more interactive conversations with your child, and becoming an advocate comes more naturally to some parents but the good news is these are skills that a parent can learn. More importantly, there are resources to help your family—you just have to look for them. In many areas of life, we sometimes find ourselves needing to compromise or lower our expectations. For our implanted kids however, I think we need to set the bar high and provide them with great opportunities to be in language-rich environments as research shows that this input during the first years

after CI implantation strongly predicts later language outcomes.

Casting Call for EI Deafo Lead Character

In January of 2020, the director of the University of Miami Children's Hearing Program passed on to us a casting call from a talent agency. They were looking to cast a deaf girl for a voice role. Lexi auditioned for the role and got the part of Cece/EI Deafo for the animated series on Apple TV based on the graphic novel "EI Deafo" by Cece Bell! After a delay due to the pandemic, the recordings were finally completed in 2021 and the series was released in January of this year. While the whole process was an amazing experience for Lexi, I don't think Lexi truly understood the impact until I read her the comments from parents and kids online. Parents who wonder if their child can succeed with cochlear implants. Parents like me who just a few short years before wondered if my child could gain the skills to listen and speak, catch up with her peers, attend a school in our community and thrive in a hearing world.

Becoming an Advocate for Herself and Supporting Other Kids

Lexi is now a teenager navigating the middle school years. She has become a strong advocate for herself. Her school district was finally able to hire a teacher of the deaf a few years ago. Lexi has learned to be the team leader, telling the IEP team what she needs to be successful. As a girl who is Chinese, adopted, and deaf, she is learning how representation is important in her life, as well as how it can positively affect others. Lexi recently had

the opportunity to talk to a group of deaf children across the country on Zoom. It started off with her answering questions about the voice role but then the kids just talked about how they each handled the various challenges in their everyday lives. It was such a positive experience and each of our kids were able to see that we all have challenges, and that they are not alone. Last month we attended an event sponsored by the University of Miami children's hearing program. Lexi was able to meet with and encourage young kids with CIs early in their journey, telling them that they can do anything they set their mind to.

I often reflect on my daughter's hearing loss journey. I think many other parents would agree that although it is one I never knew I would be on and there were certainly many days and nights of worry, battles with insurance and school team members, it has been an amazing journey. Through this process I have met the most wonderful people, some of whom I have yet to meet in person and others who have become lifelong friends. It has taught us important lessons and even shaped the path of my older daughter as she plans to go to college to become a pediatric audiologist. As a family, we have witnessed the miracle of modern medicine and what the support of a strong family can do. It's a powerful combination. So don't underestimate your ability as a parent to help your child reach their potential. Reach out for help when you need it. There is an entire community of parents who are ready to help and want to pay it forward. Set the bar high and look for the blessings in the journey.

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