

# Building a Hearing Loss Community





## A unique Girl Scout troop breaks barriers for young girls with hearing loss

BY JANNA ROVNIAK

As humans, we are wired for connection. It is through connection that we find belonging, understanding and support, which are critical for emotional well-being.

When you have hearing loss, it can be hard to connect with others, leaving you feeling isolated or misunderstood. This challenge is amplified in a hearing-centric world, where communication norms are built around those who can hear, so everyday social interactions can feel exhausting or even alienating.

This is why community among others who share similar lived experiences is essential. In communities, we find empathy and understanding—where frustrations, like struggling to hear in noisy environments and lighthearted moments, like saying, “My ear just died,” are fully understood. Shared lived experiences lead to the feeling of connection and belonging that is often hard to find in hearing-dominant spaces, for both adults and children.

Living in a hearing-centric or small town can make it hard to find a deaf and hard-of-hearing (DHH) community, especially for your children. Many kids are blended into mainstream classrooms, isolated from other students with similar conditions, and as a result, they often feel like they are the “only ones” at their school. There is no peer representation.

### Creating Community for My Kids

As a woman with lifelong hearing loss, and the mother of two daughters with hearing loss, I searched high and low for an inclusive DHH community in Orange County, CA. I posted on Facebook parent groups, attended events centered around hearing loss, found park play dates and even tried creating some events. But nothing clicked and I was almost ready to give up.

Then a chance social media post led to an opportunity that profoundly and positively impacted all of our lives.

A Senior Girl Scout who studied American Sign Language (ASL) shared on Facebook about an ASL troop with Girl Scouts of Orange County that she had just started. I reached out right away and got involved. We began with just three girls, and my older daughter was the only one with hearing loss. In time, our troop expanded through community and social media outreach, building on the Girl Scouts’ strong reputation.







The next step was integrating everyone's diverse needs into a cohesive community. When you see Girl Scout Troop 8542 now, everything seems to be in place—all the girls work together and know each other well. What you don't see is the journey it took to get here. Our troop didn't magically fit together from the get-go.

Some girls communicate using their voice while others sign, a few are bilingual or even trilingual. They use a range of different assistive listening devices, or none at all. We also have CODAs (children of a deaf adult) and SODAs (sibling of a deaf adult\*). At first, figuring out how to communicate with everyone at once was a challenge.

But as the kids and parents got to know each other, we'd discuss things like DHH family camps, conferences and other local events. Our girls started doing things together, figuring out their communication styles and learning more ASL simply from being in the troop. Any lesson learned from outside activities was brought back to the troop. The parents also found a safe space to share about schools, mainstreaming, individualized education programs (IEPs) and all things related to their children's hearing loss. Slowly but surely, our community solidified.

### Personal Parallels

My leadership experience with this Girl Scout troop has given me new insights into my own journey with hearing loss.

Growing up with hearing loss made me shy as a child. I believed that I was supposed to wear my hair down, cover my ears and conceal my hearing aids, so I could blend into the hearing environment around me. I believed that the only way to be accepted was to hide what made me different. The social stigma brought on feelings of unconscious shame where I knew that I was unique but couldn't understand why no one could see it. I didn't realize that I was hiding who I was, even from myself. Deaf students in my school who used ASL seemed to have confidence that I couldn't quite explain. Looking back, I can see the strong sense of community they had, which gave them an understanding of who they were.

At 13, I left home for the first time to attend a sleepaway camp. There was no place to hide; I had to talk about myself. Amid questions about "those things in your ears" were also, "What's your favorite music?" and "Which TV shows do you watch?" Sharing personal details with others helped me start to see who I was. It was my first experience with a community outside of my family, and learning to talk about myself was my first form of self-advocacy. It was a turning point in building my confidence. After that, I started to embrace my hearing loss. Once I accepted and learned that's what made me unique, I stopped hiding. Then everything got easier.

### Making Connections

When I was 25, I took ASL courses with other classmates who had hearing loss, and they encouraged me to attend deaf events and ASL socials. I discovered that we all had so many of the same experiences



and internalized dialogue. Many of us felt like we were in the grey area of space somewhere between a deaf world and a hearing world—not entirely belonging in either one. For the first time, I connected with peers through shared lived experiences and learned that I wasn't alone.

At that time, I knew that if I ever had kids who inherited my hearing loss, I would want them to have a DHH community from a young age.

## Keep Showing Up

As someone who enjoys meeting others, I often feel awkward the first time I attend an event in one of my communities, whether it's fellow graphic designers, people with hearing loss or my kid's school. I walk in, look around and see everyone talking and laughing. Some come up to introduce themselves politely, then return to their groups. At those times, I ask myself, "How do you become the person everyone knows?"

Over the years, I've discovered that the answer is to keep showing up. One step leads to another. Each person you meet can connect you to another. Such connections have led me to form a social media community and speak publicly about embracing hearing loss at conventions and corporate workshops. Now I am the co-leader of our unique Girl Scout troop, which has been featured in online articles and on our **local news station**.

The parents and kids in our troop have all continued to show up, too. We've grown over the years and today, there are 10 Girl Scouts in our troop. The girls are learning that not only is this an inclusive space for them, but they have peers with shared experiences. Their joy with each other continues to grow as their community and world expand. It's clear that having DHH representation in their peers, adults and leaders is building the girls' confidence.

Through our Girl Scout troop, we've created the community we were looking for. The bumps along the way were just another part of what has been a beautiful journey. One of my biggest joys now is seeing the girls just being themselves, forming friendships and building a strong, supportive peer group. I hope it is making a difference in their lives now and for the future. **HL**

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\*In accepted usage, a SODA can be either a child or an adult who has a Deaf brother or sister of any age.

Find out more about the Girl Scouts of the USA at [girlscouts.org](http://girlscouts.org)

