

Fall 2019 | Theme: Deaf and Hard of Hearing

Authors who are hard of hearing or live with family members with hearing loss describe personal challenges and how hearing loss impacts their experience in the church.

Cochlear Implants Pair ASL with Voice

by Allison Vriend

Sunnyslope CRC, Salem, OR

My daughter, Alena, is three years old, has bilateral cochlear implants, and communicates with sign language. But these are only small pieces of her miraculous story.

Alena was born at 25 weeks gestation and weighed one pound. On March 6, 2016, I was diagnosed with HELLP Syndrome and had an emergency C-section. Alena was rushed to the Neo-natal Intensive Care Unit (NICU) in critical but stable condition, the first of a 221-day hospital stay.

Alena was placed on a variety of breathing supports and required a tracheostomy when she was five months old. Through it all, our God was faithful, taking care of our little girl when there was nothing we could do, performing miracle after miracle to keep our sweet baby alive.

Before discharge, Alena failed a hearing test. A few weeks later, further testing discovered that Alena had profound hearing loss in both ears, which may have happened sometime during her stay in NICU.

When she was little over a year old, Alena received cochlear implants, which completely changed her life. She was blessed to receive implants so young, because she was able to adapt to them easily. She caught up on speech and language quickly.

My husband and I have been teaching Alena sign language, learning right along with her. Alena picks up new words quickly; her implants allow us to pair signs with vocal language. Alena loves to have people read her books and sing to her. Although Alena had her trach taken out earlier this year, it is unknown yet whether she will be able to speak because one of her vocal cords is paralyzed.

Since the removal of her trach, Alena has started attending church. Our church family has been a huge blessing throughout our journey with Alena. Everyone is quick to offer help and support when we need it. Many members of our church as well as many others follow Alena's story through her Facebook page (www.facebook.com/alenaraevriend). Knowing that so many people are following along and praying for us every step of the way is the biggest support and comfort we have been given.

Alena has gone through more in her life than any three-year-old should, but we serve a mighty God. The power of prayer is more than evident in Alena's life, and we know what a blessing her cochlear implants are. To God be the glory.

Longing for Communion with Others

by John M.V. Koole

retired CRC minister, Strathroy, ON

I was introduced to deafness at an early age. My father's mother was profoundly deaf. Soon after she began 40 years of widowhood with three children, she stopped attending worship. It was a four-mile walk with the children, and what would she hear? Her correspondence suggests she was not always the recluse I knew, but one wonders whether deafness was to her a disabler or an incentive to seclusion. For decades she never left

the property, never would get in a car, and saw her family only at her home.

My brother had mastoid operations (bone behind the ear), and as a teen I had a chronic mastoid infection. School tests indicated that hearing in my left ear was poor. The battle began to secure front seats in school and get my instruction right. When I finally got an aid for my right ear, people would seek out my left to whisper messages—the wrong ear. In a church pew, I would have no idea what was happening to my left. In choirs, I tried to hear the other voices, but anyone on my left could have been singing a different song for all I knew.

As a young man, I wanted little attention given to my poor hearing. But as I grew older, I had to admit that the whole neighborhood knew what sort of music I played on the radio. In church, when the praise team lines up behind its mics, I must turn off my aid. Although the organ is often loud, it does not distress. A row of mics, however, means that I will be tuned out of worship. One person with a microphone assists hearing, but a team will lose me, mics hiding their faces, obscuring the signals eyes and lips give, sound dissolving into cacophony.

My grandmother was not served well by the church. Perhaps there are questions we fail to ask of our seniors and people with disabilities about changes in worship style, architecture, and the like.

I thank God that I could live a full life, much fuller than that of my grandmother, and I am thankful that friends do not let me sit alone, a recluse, or an outsider. They prod me to a life still rich in communion with others. I pray God that I may be alert to the losses others grieve and give some solace in the Lord's name.

ASL, Not Just for the Deaf

by José Rayas

pastor, Valley Ridge Community CRC, Socorro, TX

Two of my children have cerebral palsy. However, they are unusual because their condition has been degenerating to the point that they now have a severe speech impediment. That is where American Sign Language (ASL) comes in.

As a group, my family as well as members of our church all took the time to learn ASL. At this point in time, we all can talk to my children, and they in turn have the language to communicate back.

The benefits do not stop there. Our church teaches an English as a Second Language (ESL) class in the evening. In that class, we

have started to use ASL to emphasize meaning. As a result, some of the students have taken the time to learn both English and sign language, which has not only opened different ways to communicate, but also has given them additional skills for work. When the students in the ESL class come to visit our family, there is no fear of not being able to communicate.

ASL has surely been a blessing from God to our family as well as the community.

Clear Communication Helps Me

by Cindi Veldheer DeYoung

Hope Church (RCA), Holland, MI

Most people perceive me to be a social person who engages others easily, and church is a great place for fellowship, making friends, and being connected to caring people. Why, then, do I escape quickly from fellowship time after a church service or avoid our church's monthly pizza Sunday festivities? I am trying to be a good steward of my energy. Because the cacophony of noise makes for a very difficult hearing environment, I might speak with a few people, but if someone wants a longer, in-depth conversation, I try to move us to another room.

I was diagnosed as hard of hearing when I was four years old and have worn hearing aids since my early 20s. Hearing aids are both blessing and curse. I hear some things very well. Kids screaming happens to be the pitch that my audiogram indicates I'm very strong in! Discerning the pitch of a complex hymn tune makes me wonder if I'm singing anywhere near the right sound.

I wish each congregant and pastor would understand two things:

- 1. Hearing and listening well take a great deal of effort. When I'm already tired, trying to listen well for comprehension and appropriate interaction can make me react more emotionally. Consequently, the harder I must work to hear when I'm tired, the less gracious I can be.
- 2. When I request behaviors that are helpful for hearing well (speak clearly and one at a time, face me, minimize interruptions), I appreciate others joining me in affirming these clear-speaking behaviors. When a committee member speaks while leaning her chin on her hand during a discussion, I work much harder to discern what's being said. When more than one person speaks, my brain cannot identify what I need to listen to because there's too much happening. However, when someone else speaks up on my behalf, it's a terrific boost to the hard of hearing person not to be the only one "nagging" others: "Hey,

let's remember to keep the conversation to one person speaking," or, "Please keep your face clear for speech-reading."

I'm relieved and grateful when people "get it" and follow me to another room for our conversation. I appreciate clear speech in meetings and good use of microphones so that my telecoil can help me listen easily and well. It's a joy when people remember to face me, tell me what needs to be said, and wait for my response.

By Enabling Hearing, Churches Lead

by David Myers

Hope Church (RCA), Holland, MI

Imagine yourself as a person with significant hearing loss. At worship, or perhaps in a movie theater, you struggle to carve meaning out of the spoken word. Given two assistive listening options, which would you prefer: To make the effort to locate, check out, wear, and return a special headset that likely is incompatible with your hearing aids or cochlear implant, and that delivers the same sound to everyone? Or to inconspicuously push a button that transforms your hearing aids into wireless loudspeakers that broadcast sound customized for your own hearing needs?

Option 1 is the prevalent assistive listening technology in North America. Option 2, assistive listening that is directly hearing aid compatible, is the common option in worship facilities in the United Kingdom and Scandinavia and, increasingly, in churches and other venues throughout the U.S. and Canada. To find looped venues in the U.S., see www.loopfinder.com. (If you know of a similar Canadian website, please let us know.)

Happily, the momentum is spreading. In many states and provinces, churches are leading the culture in making sound more conveniently accessible. Dr. Juliette Sterkens, an advocate for hearing loop systems, runs a website for her state, www.loopwisconsin.com. One Wisconsin parishioner recalls, "The first Sunday the loop system was activated in my church was one of the most memorable days of my life. For the very first time I was able to hear every word, and it was as if the pastor was speaking directly into my ear. As I looked around the congregation, other people who wear hearing aids had looks of wonder on their faces, and I knew they were experiencing the same thing. Some of us had tears streaming down our cheeks."

Sometimes, the church seems to follow the culture. In supporting people with hearing loss, the church is leading the culture. (For more information, see www.hearingloop.org or www.letsloopcanada.ca.)

Adapted from an article by David G. Myers, Breaking Barriers, Spring 2011.

Editor's Note

Be Quick to Listen

I've wised up since my youth when I went to ear-splitting rock concerts. Now I carry hearing protectors nearly everywhere. Years ago, I took my high-school-age son to a concert that was very loud and packed with teenagers. Between my age and the hunter orange hearing protectors, people stared at me, the dinosaur, but I left with my hearing intact.

People lose hearing for many reasons, and hearing loss is a disability few want to admit to. Although eyeglasses can make a fashion statement, hearing aids receive no such amelioration. Culture equates hearing aids with being old and decrepit. Perhaps this is the reason we had such difficulty getting articles for this issue.

Nevertheless, hearing loss affects more than 10 percent of the North American population, and that percentage grows with increasing age. On the Network (network.crcna.org/disability), we provide many ideas for making worship and other church

activities more accessible for people with hearing loss, including printed sermons, ensuring that everyone can see the faces and lips of those who sing or speak, using a microphone for anyone speaking in a public meeting or worship, and installing hearing assistive technology, preferably a hearing loop.

Most importantly, seek out, listen to, and act on the advice of people with hearing loss. John Koole's article in this issue makes a strong case for listening to someone with hearing loss, then finding ways to worship that don't shut out some of us. The body may not say to the ear, "'I don't need you!' On the contrary, those parts of the body that seem to be weaker are indispensable" (1 Corinthians 12:22, NIV).

-Mark Stephenson

Ways to Get Involved

Without monetary support for Disability Concerns, we wouldn't be able to share these stories. To help us make sure that "everybody belongs, everybody serves," would you please consider praying for us and making a financial contribution? It's quick, it's easy, and it's a gracious and beautiful act of obedience.

Give to RCA Disability Concerns:

www.rca.org/disability and click on "Give"

Give to CRC Disability Concerns:

www.crcna.org/disability and click on "Donate"

Upcoming Themes

Winter 2019—Medications

Many of us need to take medications—for pain, for rheumatoid arthritis, for seizures, and for other reasons. Medications can improve quality of life and can cause side effects. If treatment of a disability or mental health challenge involves medication for you or a loved one, please tell us your story (400 words) by **September 30**.

Spring 2020—Visual Impairment and Blindness

If you live with a visual impairment or blindness, please tell us about how you engage in the life of your congregation (400 words) by **February 3**.

Additional Formats Online

Additional articles about Deaf culture and hearing loss are posted online in the *Breaking Barriers* section of the Network website at bit.ly/NetworkHearing.

You can also find this issue in a variety of alternative formats (print-friendly layout, audio, Spanish, and Korean). Go to bit.ly/BBfall2019.

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