

Fall 2021

BREAKING BARRIERS

everybody belongs ■ everybody serves

THEME: SPEECH DIFFERENCES

Our stories in this issue feature people living with speech differences and the challenges they face, adaptations they have made, and the power of listening and being heard.

What? Is the Question

by Elizabeth E. Schultz

The Church at Benjamin's Hope, Holland, MI

According to Google, on an average day, women speak 16,215 words and men speak 15,669. I was born with cerebral palsy, use an electric wheelchair, and my speech pattern is irregular. Let me assure you: I speak every word of my 16,215-word daily allotment! It helps that most of my conversations are with people who have learned my speech patterns, but sometimes even they ask me the *What?* question—*What did you say?*

It gets wearisome constantly repeating myself. Yet it is better than the alternative—people trying to guess what I want or need. For me, *What?* is a signal that someone cares enough not only about what I am trying to say, but also that I am valued as a person. I'd rather hear 1,000 *What?* questions to one, "I can't understand you!" When that's the response, my body tightens up, making my speech even more difficult to understand.

With these ongoing challenges, one might think I would shy away from speaking, but I have enjoyed and excelled at public speaking since I aced public speaking class in high school. I taught a monthly class at the local Community Mental Health department for 13 years, which led me to check out the local chapter of Toastmasters International, a worldwide public speaking and leadership organization. In 2019, I earned my Distinguished Toastmaster's Award, a designation that fewer



 Elizabeth Schultz

than 2 percent of the worldwide membership accomplishes.

My advice to you—don't put a person in a place of submissive discomfort. A good mantra to follow instead is: Be patient, and don't hesitate to ask the *What?* question.

Interrupted, Ignored, and Isolated

by Chris Klein

Victory Point Ministries (CRC), Holland, MI

While the social isolation due to COVID-19 was a new experience for many people, for those of us with a complex communication disability, it wasn't. We are regularly passed by without being talked to. We are routinely interrupted because we communicate differently. Because it takes us longer to communicate, people tend to walk away before we speak.

I know this because I live with athetoid cerebral palsy, meaning my muscles never stop moving. This affects my ability to communicate with my mouth, so I communicate with an augmentative alternative communication device (AAC). AAC changed my life because it lets me express my thoughts. It gave me access to language, which gave me access to be in regular classes, which allowed me to graduate from Hope College. Yet my communication style still presents barriers for me.

I am talked to slowly and loudly because I communicate differently. One person came up to a friend who was with me and asked her how many words I knew. She was so stunned by the question that she didn't know what to say. This is a common problem for people who use AAC.

This is also why many people who use AAC don't feel comfortable in some large group settings. We struggle with social isolation, prompting many of us to stay home. I wish churches would be more welcoming; however, many don't have the awareness needed to support or include an individual with a complex communication disability.

At church, people don't know how to engage me, and if they don't know me, they don't communicate with me. Since many don't understand that it takes me longer to answer a question, they walk away before hearing my answer. Poor acoustics in churches also contribute to the problem, making it difficult to hear my AAC.



Chris Klein

This is why I have started a Bible study called Device Verses. It is open to people of all abilities, but it is especially for people who have a complex communication disability.



Additional Formats, Award Update

You can find this issue in a variety of alternative formats (print-friendly layout, large print, audio, Spanish, and Korean) in the *Breaking Barriers* section of the Network website at bit.ly/bbfall2021.

In addition, find back issues of *Breaking Barriers* and editions in Español and in 한국어, plus a link for electronic subscriptions, at either the CRC website (www.crcna.org/disability) or RCA website (www.rca.org/disability).

This newsletter and the Disability Concerns blog (network.crcna.org/disability), co-published by CRC and RCA Disability Concerns ministries, are recognized for excellence annually by the Associated Church Press.

This newsletter and the Disability Concerns blog, co-published by CRC and RCA Disability Concerns ministries, received three awards from the Associated Church Press recently for work done in 2020:

- For the Best in Class-Newsletter category, the Award of Excellence (first place) for *Breaking Barriers*.
- For the Reporting and Writing-Theme Issue category, the Award of Excellence (first place) for *Breaking Barriers*, Spring 2020, on visual impairment and blindness.
- In the blog category, the Award of Merit (second place) for the Disability Concerns blog on the Network.



 *Norah Libolt*

Therapy Connects Speech Pathways

by **Janna Libolt**

Third CRC, Lynden, WA

At age 3, our daughter Norah was diagnosed with severe childhood apraxia. Apraxia is not common and is a motor planning disorder that mainly manifests in Norah's speech and gross/fine motor skills, like someone who has had a stroke and has lost the ability to speak or loss of motor skills. Whereas stroke survivors use therapy to re-strengthen the motor planning pathways, these pathways were never connected in people with apraxia. Extensive therapy is needed to make these connections.

The doctors at Seattle Children's Hospital told us that Norah would need therapy sessions four to six times per week to see improvements and that this regimen would give her a chance at leading a "normal" life. At age three, Norah began to receive speech therapy at Lynden School District two times per week for 30 minutes, and Norah continues to receive these services on site to this day.

We also enrolled Norah in the speech program at Western Washington University (WWU). Norah completed 16 consecutive quarters at WWU, attending two times per week for 45 to 60 minute sessions, year-round. Norah went from not being able to speak at all to being able to have full

conversations with at least 90 percent intelligibility.

To help her gross and fine motor skills, we enrolled her in occupational therapy, swimming lessons, horse riding therapy, and educational tutoring. We were told early on that activities that require her to cross her midline would be extremely beneficial for her brain to make motor planning connections.

Norah is now 12 years old and going into seventh grade. Running her around is a full-time job and such a blessing to see how she is making *huge* strides. Norah has not complained one single time! This girl is the hardest and happiest worker! She thrives off attention, and it has compelled her to work all the harder. We are so proud of her.



Upcoming themes

Winter 2022—Young people with disabilities. In Canada and the United States, about 13 percent of people ages 15–30 live with a disability. Are you one of them? By **December 1**, please tell us a story (up to 400 words) about living with a disability when nearly 90 percent of your peers do not.

Spring 2022—Acquired disability. How has your disability—acquired through stroke, accident, illness, aging—affected you, your relationships, your work, your spiritual life? What have you lost, and what have you gained? Please tell us a story (up to 400 words) about your acquired disability **by February 7, 2022**.

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 Carma Smidt

Restored through My Eyes

by Carma Smidt

Sibley CRC, Sibley, IA

Shakespeare wrote, “The eyes are the window to the soul.” In the last couple years, my eyes have become more than just the window to my soul; they have become my lifeline and means of communication with my family and friends.

Living with spinal muscular atrophy for 40 years, I have learned to adjust my life when abilities would slowly diminish and eventually disappear. I have always been thankful to God for giving me a positive personality in spite of my progressive disability. But, a couple years ago when my disability affected my ability to speak, I was not so willing to relinquish my voice and adapt my life.

I *needed* my voice! I had no use of my arms or legs, and I couldn’t move my head. I needed my voice to instruct others on my care, to operate my voice-activated computer so I could continue my online teaching position, to interact with my family and friends. With my voice diminished to a whisper, I inwardly pleaded with God to restore my voice. His answer of restoration was far different from what I expected.

While God didn’t restore my ability to speak, he did provide me with resources to obtain a speech generating device. This device is a computer that I control completely with the movement of my eyes. I can browse the internet, play computer games,



Editor’s note

A Countercultural Practice

This issue of *Breaking Barriers* introduces you to several people living with speech differences. Here’s one more.



My friend Cecil lives with Parkinson’s disease. He is a perceptive, informed thinker and conversationalist who keeps up on current events. He does this in spite of extreme hearing and vision loss that makes telephone conversations, reading text digitally or in print, and seeing and hearing TV difficult. His mobility is compromised, and his speech can sound labored. At 91, it’s best to schedule time in advance with Cecil and to sit close in a quiet environment, but visiting with him is delightful.

Cecil has always enjoyed interaction and engagement. He is outgoing, thoughtful, and interested in people, but his world is closing in. He now depends on the patience of others to speak and give him space to ask questions and hear what he has to say.

Not all speech differences require a slower pace, but several do, as both Chris Klein and Elizabeth Schultz illustrate in their articles. Like many disabilities—I’m also speaking from my own experience as a disabled person—practicing a slower, more deliberate pace is a countercultural discipline, but it’s also a gift that serves everyone well.

—Terry A. DeYoung

and type documents with my eyes. The computer will also verbalize whatever I type with my eyes. It allows me to express my needs and thoughts without much effort.

While a wonderful device, it is slow and has limitations. When communicating with those who know me well, I have found my most efficient and effective way of talking is with my eyes. I have been told that my eyes speak volumes even when no sound is uttered. I’ve learned that God has given me big, expressive eyes not only for seeing, but also for speaking. God has taught me to adapt to this life where he restored my voice through my eyes!