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AAC RESEARCH: THE POWER OF COLLABORATION

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The first word in accessibility is "access"

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ABSTRACT

This paper focuses on access challenges that I have experienced as someone who uses AAC, how my team and I have resolved them, and what challenges I face now. I use AAC and assistive technology (AT) to work, advocate, exercise, socialize, manage my healthcare, and participate in community-based activities. Over the years, I have used many different AAC systems, computer applications, and access methods as technology advanced and my needs and skills changed because of spinal muscular atrophy. Too often AAC is only considered as a speech prosthesis, rather than as a support for communication in all its forms to enhance participation in society. People with disabilities need access to functional communication, including not just speech generating devices, but also the Internet, phone, computers, and software for medical and health reasons as well as education, employment, and community participation. Researchers need to learn more about the challenges that AAC users face and how our access needs change over time. My hope is that they will develop a new generation of AT that will make it possible to integrate all my access methods so that I can use them in a wide range of positions and for a multitude of purposes.

This paper focuses on the access challenges that I have experienced as someone who uses AAC, how my team and I have resolved them over the years, and what challenges I face now.

I hope that researchers will learn more about the challenges that AAC users like me still face and how our access needs change over time. My hope is that they will come up with the next generation of access improvement and assistance that will make it possible to integrate all of my access methods, so that I can use them in a wide range of positions, and for a multitude of purposes.

I am 30 years old. And I have been using a high tech, speech output device for about 28 years. I am the President-Elect of the United States Society for Augmentative and Alternative Communication (USSAAC), a member of the LEAD (Leadership Education Advocacy Design) Committee for the International Society for Augmentative and Alternative Communication (ISAAC), and the Coordinator of Activities and Events and President for Bridging Communities Through Alternative Communication (BCTAC), an adult outreach program of The Bridge School in Hillsborough, California, US. I am also employed as a Senior Media Tech and the Media Tech Coordinator for St. John United Methodist Church in Anchorage, Alaska, US.

AAC and assistive technology (AT), in particular computers, are my tools. I use my AAC and AT for work; to participate and serve on several committees for people who use AAC; and to attend virtual, live-taught exercise classes, socialize, and participate in other community-based activities.

I experience Spinal Muscular Atrophy (SMA), which is a motor neuron disorder characterized by muscle weakness and atrophy that affects skeletal or voluntary muscles. It affects the muscles closest to the spine more significantly. There is a broad spectrum of disabilities related to SMA, including, as with me, swallowing and breathing. I mention my SMA not because I feel that I am defined by my disabilities, but rather to explain the source of my challenges to accessing the technologies that I need to communicate through speaking and writing, and to access the world around me.

Presently, I use eye gaze to access my speech generating device (SGD) when I am sitting up in my wheelchair (Figure 1, Supplemental Materials). When I use my computer, I have to use a trackball and I have to be positioned on my left side, in side-lying, so my monitor is set up on its side (Figure 2, Supplemental Materials). However, because of physical changes, using the trackball is getting to be more difficult for me. Due to my physical disabilities, and in particular muscle weakness, access to my AT, including my speech-generating tools and computers, has always been my biggest challenge.

Here is a bit of the history of my path toward accessing AAC and AT, mostly as related to me by my parents and my longtime speech therapist. When I was a very young child, I could sit up, holding my head up, if my lower body was supported (Figure 3, Supplemental Materials), but I never walked. I had very good fine motor skills, but I did not have a lot of strength in my fingers, and my gross motor skills were significantly affected by my SMA. So, I naturally used adaptive skills, for example supporting one arm with the hand on my opposite arm to play (Figure 4, Supplemental Materials).

Just after my second birthday, I was hospitalized with pneumonia and ended up having a tracheostomy. After my

tracheostomy, I was not able to talk using my physiological voice. According to my parents, even before my tracheostomy, my speech was very soft and limited by my breath support. And my speech therapist said that my expressive language skills were impacted.

I started off with a four square Cheap Talk[1] AAC device, but I could not push hard enough to activate the buttons. Even the button switches had too much resistance at that time for me to activate them. Shortly after that, I received my first high tech speech device. It was a Dynavox 2C[2]. The Dynavox was chosen for me because, at that time, it was the only device that had a sensitivity adjustment for the touch screen that could be adjusted to be sensitive enough for me to activate it. However, because of weakness in the muscles in my trunk, I could not lean forward to look at the Dynavox. When it was placed where I could reach it sitting up, I could not see it. When it was placed where I could see it, I could not reach it. And the Dynavox 2C was very heavy.

A few months after I received the Dynavox 2C, Sentient Systems came out with the Dynamyte[3]. It was smaller and lighter. And it had even greater sensitivity available in its screen settings. My speech-language pathologist (SLP), Cara Leckwold, managed to get one for me through the state Special Education Service Agency. I cannot remember if I started preschool with the Dynavox 2C or the Dynamyte, but I think that it was the Dynavox 2C at first.

When I first started preschool, I used low or no tech AAC at school (Figure 5, Supplemental Materials). And I used direct selection on the speech generating device with some limited success due to my access issues. When I was learning to read, I followed along by supporting and stabilizing my right hand by pulling on and holding my right thumb with my left hand (Figure 6, Supplemental Materials), but my parents were concerned about the long-term impact on my right thumb joint.

When I was 3 years old, my SLP, Ms. Leckwold, met us at a tiny computer store (literally, the guy only had 3 boxed computers to sell, but eventually he built his business up to being the largest Mac[4] store in Alaska). He worked with us to set me up with a Mac G3. I tried accessing it with a mouse, but I could not move or unweight the mouse. So, the man loaned me his trackball, because I could pinch the edge of the buttons to activate the right click button. And eventually we located and bought a similar trackball, but it only worked with a Mac computer. I was able to operate the computer to play educational games somewhat while sitting up, but it was tiring for me. And it was hard to breathe because I had to sit up so straight to be able to see the monitor.

At that time, I was not using a ventilator yet, even though I had a tracheostomy.

I am mentioning my experience with accessing computers because it helped to improve my access to my speech generating device. Just before my last year of preschool, we found a clear trackball that was not limited to use only on a Mac. It was so cool-looking. You could see all of the electronics inside of it. And it was PS/2[5] and USB[6] capable. I got it to go on a Disney Cruise. My parents had contacted Disney and found out that the computers in the computer lab could accept an external pointing device. Disney let me connect my trackball to the computers in the computer lab. And Disney also relaxed the age rules to allow me into the lab, with my parents as aides, even though I was not old enough. I used the trackball on the Disney computers while I was reclined, and lying on my side in my wheelchair.

When we returned home, my parents shared about my computer access experience with my SLP (Ms. Leckwold), my preschool teacher, and also Sharon Steed, an excellent speech-language pathologist who worked for the school district and was assigned to the Assistive Technology (AT) Department. My parents discussed the fatigue I experienced trying to use the trackball and computer sitting up, and that I could not really push the ball against gravity. They described how they positioned me on my left side to use the computers on the cruise. My mother asked if I could be positioned in that way to do my schoolwork. So, from then on, I did my art, and most of my other schoolwork, lying down.

Sharon Steed called us one afternoon, very excited. She said that she had been sitting in the grocery store parking lot eating a salad in between school visits, and she remembered that there was a port on the side of the Dynamyte for a peripheral device, and that the settings in the Dynamyte could be changed to allow for selection using the trackball. She asked my mom if we still had the clear trackball and told her where to try to attach it to the Dynamyte (Figure 7, Supplemental Materials). That changed my life because it gave me access to direct selection on my speech generating device and speech software while in side-lying, without having to touch the screen.

Later, I had a much heavier speech generating device (SGD) than the Dynamyte. It was ruggedized and it was a Windows-based computer, running the Dynavox speech software, and other educational software, including Math Pad Plus[7], Inspiration,[8] and Kurzweil 3000[9]. It was mounted on a

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[1]CheapTalk is a very simple speech generating device available from Enabling Devices at https://enablingdevices.com/.

[2]The Dynavox 2C was an early version of a speech generating device manufactured by what is now the company known as Tobii-Dynavox; it is no longer available.

[3]The Dynamyte was another early version of a speech generating device manufactured by what is now the company known as Tobii-Dynavox; it is no longer available.

[4]Mac computers are manufactured by Apple; the Mac G3 is an older model that is no longer available. See https://www.apple.com/mac/.

[5]The PS/2 port is a 6-pin connector used to connect keyboards and mice to a computer.

[6]USB or universal serial bus port is used to connect peripheral devices to computers.

[7]MathPad Plus was a software program from Intellitools, designed to enhance numeracy skills, particularly for students requiring alternate access methods. It is no longer available.

[8]Inspiration software provides a tool for creating concept maps, diagrams, graphic organizers, outlines, and presentations. See https://www.inspiration-at.com/.

[9]Kurzweil 3000 is an AT platform that allows users to read out loud the web, PDFs, e-books, their own writing, etc.; users can access dictionaries, highlight and color-code, write sticky notes, and circle text to support learning. See https://www.kurzweil3000.com

monitor arm which was clamped to a therapy table. The monitor arm allowed for the SGD to swing away when I was not using it, so that I could see the teacher and the whiteboard (Figure 8, Supplemental Materials).

Since those early years, I have used a trackball, lying on my left side, to access my computer for schoolwork and also for my employment. At work at the church, we use two monitors to run the slideshows and videos, and to have a view of what is being shown by the projector (Figure 9, Supplemental Materials). Because my speech generating device would get in the way of me being able to see those monitors, I am unable to use it at work running slideshows at the church.

In 2014, I added eye gaze to my toolkit. After years of trials, I finally found an eye gaze system that worked for me. Being able to access my SGD by eye gaze enabled me to use it in positions other than just lying on my left side. And for the first time, I was able to access my SGD sitting in my wheelchair, and when positioned on my back and on my right side.

My current system is an Eyegaze Edge[10] SGD, the company formerly known as LC Technologies and I use their Eyeworld and also Text Talker in Grid3[11].

Being able to access my computer and the Internet has allowed me to continue to work, exercise, and minimize my exposure to COVID 19. I attend adapted fitness classes, through a virtual platform, that are taught live and in real time, by instructors who are thousands of miles away. But I cannot control the meeting software by eye gaze when I am sitting up and participating in the classes. So, I have to transfer from my wheelchair for the discussion portion of the classes.

Because I am not able to turn my body and my head, even when I am sitting up, I need to use the same device for communication and controlling the virtual meeting software during meetings and events. I split the screen so that the communication software is on one side and the virtual meeting software is on the other (Figure 10, Supplemental Materials). However, I am limited to using my trackball lying down for accessing the meeting and communication software at the same time, because I cannot calibrate the eye gaze to only one side of the screen for speaking, and separately to the other side of the screen for the meeting. So, I cannot use my eyegaze for meetings and speech at the same time in either side-lying or a seated position.

I would benefit greatly from the ability to use eye gaze to access both sides of my split screen, separately. Then, I would have access to more positions in which I could participate in virtual meetings and work, and I would be able to change my position to relieve pressure and for comfort.

It would help reduce wear and tear on my body. Because of physical changes, using the trackball has become more difficult. I now control the trackball with my knuckles, which has caused a significant callous on the knuckle of my thumb. And I would also be able to control the meeting software and my speech software while sitting up in my wheelchair. Unfortunately, that option is not available to me at this time.

Over the years, I have also used various mainstream software programs and some software, designed for people with disabilities, for my education, socialization, and work, and to help adapt activities for the groups that I lead. For example, I have used Kurzweil 3000, including its text-to-speech features, a range of educational software, Microsoft Office and Teams[12], Doodle poll[13], Google software and services[14], Web Ex[15], Zoom[16], Audible Books[17] and Kindle Books[18], just to name a few. I consider the computer and software and apps to also provide me with access to education, work, community and communication beyond just speech.

People with disabilities, and in particular people with severe speech disabilities, need access to computers and software, Internet and phone service, and virtual meeting platforms, for medical and health reasons. In this day and age, we need to be able to download, store and read our medical records. We need to be able to access the secure patient portals of our medical providers to make or request appointments, or to review messages from our medical providers, and to communicate with them. And for some AAC users, that might be less complicated, and more independent than trying to do so by telephone. We need to be able to complete forms required for us to receive medical care, including providing health histories, insurance and personal data. And we need to be able to participate in telehealth visits, which help resolve the accessible transportation and/or travel issues and staffing deficiencies that many of us face just trying to travel to an appointment. And it can help us to have access to medical services despite inclement weather that causes unsafe travel conditions.

Many of us also need computer functionality and software, Internet and phone service, and access to virtual meeting platforms to participate in education and employment.

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[10]Eyegaze Edge is an SGD that can be accessed through eye gaze. It is available from Eyegaze, Inc., the company formerly known as LC Technologies. Eyeworld supports chat, mail, phone text/calling, computer control, environmental controls, etc. See https://eyegaze.com/products/eyegaze-edge/.

[11]Text Talker is a grid set in Grid3 designed for literate AAC users, that allows us to quickly generate messages in the moment and also to prepare in advance. It has quick phrases, message generation, message banking, chat history, etc. It is available from Smartbox; see https://thinksmartbox.com/text-talker/.

[12]For further information on Microsoft Office and Teams, see https://microsoft.com For information on Microsoft accessibility features, see https://www.microsoft.com/en-us/accessibility/.

[13]Doodle poll is a web-based app designed to support scheduling; see https://doodle.com/.

[14]For further information on Google products and services, see https://about.google/ For information on Google accessibility features, see https://belonging.google/in-products/disability-innovation/.

[15]Web Ex by Cisco supports web-based conferencing and videotelephony conferencing; see https://www.webex.com/.

[16]Zoom is a videotelephony software program that supports online meetings; see https://www.zoom.com/.

[17]Audible Books offers a large library of audiobooks and podcasts; see https://www.audible.com/.

[18]Kindle Books are e-books available for purchase and reading on Amazon's Kindle devices and apps; see https://www.amazon.com/kindle-dbs/storefront

We need to be able to do written work. We need to be able to participate in virtual meetings, gatherings, classes and more, just like our nondisabled peers. The benefits of such access and increased opportunities for education, employment and social interaction can help with mental health and well-being. However, too often AAC is only considered as a speech prosthesis, rather than as a support for communication in all its forms (e.g., face-to-face, written, and telecommunications) to enhance participation in all aspects of society, including education, employment, healthcare and community living.

Without Internet service and access, we are cut off from being able to update the speech and operating system software on our SGDs. Without telephone or Internet services, the only way for a person with speech disabilities to communicate with others would be in person and face-to-face. And for many people who experience severe speech and physical disabilities, that would require access to accessible transportation and support staffing.

These days, society uses technology to communicate. Without Internet and phone service, we are unable to function, participate and communicate in ways that people who do not experience such disabilities are able to function, participate and communicate. It is wonderful that SGDs are more widely accepted, available and supported. But I respectfully submit that focusing on only functional speaking needs (i.e., audible/verbal speech) is insufficient to meet the communication needs of people who experience severe speech disabilities, many of whom are also unable to use handwriting for communication. The focus should be on functional communication in all its many forms. Service providers and funding agencies should not limit AAC to just that which provides functional speaking. It is important for academic research, product research and development, funding, and direct services, to support innovations for access to SGDs, telecommunication, written communication, and the full array of computer applications.

I believe that AAC users would agree that it is not easy to communicate through AAC, even for the most skilled AAC users. It takes a lot of energy, work, perseverance, patience, and dedication. And continuing to improve access can help lessen the load and challenges of communicating through AAC. I am fortunate to have the opportunity to write this paper to reach a global audience of academicians, researchers, developers, clinicians, AAC users and other stakeholders. And I appreciate their dedication to helping to improve access to AAC.

Author note

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