The First Word in Accessibility is ACCESS
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[Patrick Regan]

Hi. My name is Patrick Regan. I am 29 years old. And I have been using a high tech speech output device since I was about two and a half years old.

I am the president elect of USSAAC. I am on the LEAD committee for ISAAC's People Who Use AAC and a frequent moderator of the AAC user chats. I am the coordinator of activities and events for bridging communities through alternative communication, an adult outreach program of the Bridge School, and also the co-president of that group. And I am employed as a senior media tech and the media tech coordinator for St. John United Methodist Church in Anchorage, Alaska.

So, you could say that AAC and assistive technology, in particular computers, are my tool. I use eye gaze when I am sitting up in my wheelchair, and when I am positioned on my back, and on my right side. My current system is an Eye Gaze Edge speech generating device from Eye Gaze Inc., the company formerly known as LC Technologies. And I use the Eye World and Text Talker users in Grid 3.

Because of my physical disability, and in particular muscle weakness, access to my environment, including my speech generating tools and computers, has always been my biggest challenge. I would like to tell you a bit about my access challenges, how my team and I have resolved them over the years, and what challenges that I face now. I am hoping that someone in this room 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. Here is some of my background.

When I was born, my disabilities were not obvious. I have a neuromuscular disorder called Spinal Muscular Atrophy, or SMA. SMA is a motor neuron disorder. It affects my skeletal or voluntary muscles, including my intercostal muscles that assist with breathing. And it makes the muscles closest to my spine weaker than my distal muscles.

SMA is divided into types, with type 1 being the most severe, and people with type 3 and 4 SMA experiencing more mild symptoms. And being able to walk, for at least part of their lifetime. I have SMA Type 2.

When I was a very young child, I could sit up holding my head up, if my lower body was supported. But I never walked. This is a photo of me sitting in a wooden chair, with my feet on a footrest, and my thighs held in place with foam. By the way, my PT had the adjustable footrest made through a program at one of the jails here in Alaska. The inmates did very nice woodwork. Can you imagine teaching useful skills, and putting people to work to make things for others in need? Awesome.

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. And even before my tracheostomy, my speech was very soft and limited by my breath support.

I started off with a 4 Square Cheap Talk, 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 device. It was Dynovox 2C, and I still have it. But I don't think it works anymore. The Dynovox was chosen for me because at that time, it was the only device that had a sensitivity adjustment for the touchscreen that could be adjusted to be sensitive enough for me to activate it. But, because of weakness in the muscles in my trunk, I could not lean forward to look at the speech generating device. 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.

Shortly after I received my Dynovox, Sentient Systems came out with the Dynamyte. It was smaller and lighter, and it had even greater sensitivity available in its screen settings. My SLP, Cara Leckwold, managed to get one for me. I can't remember if I started preschool with the Dynovox or the Dynamyte, but I think that it was the Dynovox at first. When I first started preschool, I used low or no Tech AAC at school, and I used direct select on the speech generating device with some limited success due to my access issues.

When I was three years old, Cara met us at a tiny Mac computer store. Literally, the guy only had three boxed computers to sell. But eventually he built his business up to being the largest Mac 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, and I was kind of able to operate the computer to play educational games while sitting up. But it was tiring for me, and it was kind of hard to breathe because I had to sit up so straight to be able to see the monitor. At that time, I wasn't using a ventilator yet, even though I had a tracheostomy.

The reason that I am telling you about my computer use is that my experience with accessing computers helped to improve my access to my speech generating device.

Just before my last year at 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 PS2 and USB capable. We 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 it 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 wasn't old enough. And I used the trackball on the Disney computers while I was reclined and laying on my side in my wheelchair.

When I got home, my parents shared about my computer access experience with my speech therapist Cara, my preschool teacher, and Sharon Steed, who is an awesome speech therapist and audiologist that worked for the school district and she was in charge of AT. My parents discussed the fatigue I experienced trying to use the trackball and computer sitting up and how they positioned me on my left side to use the computers on the cruise. And my mother asked if I could be positioned in that way to do my school work. So, from then on, I did my art, and some of my other school work lying down.

Here is a photo of me at work at the church. We use two monitors to run the slideshows and videos. And for physical reasons, I am not able to use my speech generating device while I am working. And here is a photo of me using my wheelchair mount to do my work in a hotel while I was traveling.

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

Presently, in addition to being employed, I participate in several virtual communities of people who experience disabilities and some who do not. And I lead some virtual groups of adults who use AAC. 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. Computer and internet access has helped me and the people that I interact with online stay connected and improve our mental and physical health and well-being. Being able to access my computer and the internet has also allowed me to continue to work and minimize my exposure to COVID-19.

This is what my screen looks like when I am in a Zoom meeting. I split the screen so that the communication software is on one side, and the virtual meeting software is on the other. But, I am limited to using my trackball for accessing the meeting, and communication software at the same time because I can't calibrate the eye gaze to only one side of the screen for speaking and one side for the meeting.

That brings me to something that I want to mention. People with disabilities need access to computers and software 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 patient portals of our medical providers to make or request appointments or review messages from our medical providers. 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 participate in telehealth visits, which help resolve the accessible transportation issues and staffing deficiencies that many of us face just trying to travel to an appointment.

And also in this day and age, many of us need computer functionality and software to participate in education and employment. We need to be able to participate in virtual meetings, gatherings, classes and more, just like our non-disabled peers. That helps to maximize our independence and can help with mental health and well-being.

The reality is that high tech speech generating devices ARE computers. They have to be computers in order to provide the text or symbol-to-speech capabilities, and touchscreen and alternative access capabilities that people who experience speech and physical disabilities need. And because they're already computers, it should not cost any more to fund them with their full functionalities as computers left intact and unlocked.

The policy that speech generating devices should not primarily be computers because computers can be useful in the absence of injury or illness is not focused on medical necessity. It is focused on what non disabled people can do. Respectfully, that is food for thought and reconsideration.

I am grateful to have this opportunity to be here with you all today through the internet and virtual access all the way from Alaska. And I am grateful to have the tools to make this presentation.

And now my big ask is for those of you who work in academic research, product research and development, funding, and direct services, to continue working on and supporting innovations for access to speech generating devices and computers. I believe that the AAC users in the room 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 communication through AAC.

I would like to acknowledge Dr. Lori Geist and her team, who are working on models to assist in the development and improvement of assistive technologies and assessments. And in particular, I would like to thank them for inviting my input on a model for a keyboard that may provide more ease of access, and listening patiently to my concerns about the need to improve the interface between speech generating devices and closed captioning.

Thank you again, Dr. David McNaughton and the planning team for the Future of AAC Research Summit for inviting me to speak.