A glimpse of assistive technology in daily life

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Abstract

Robitaille (2010) wrote 'if all technology companies have accessibility in their mind then people with disabilities won't be left behind.' Current technology has come a long way from where it stood decades ago; however, researchers and manufacturers often do not include people with disabilities in the design process and tend to accommodate them after the fact. In this paper we share feedback from four assistive technology users who rely on one or more assistive technology devices in their everyday lives. We believe end users should be part of the design process and that by bringing together experts and users, we can bridge the research/practice gap.

1 Introduction

"i am hungry." types 21-year-old Augie on his augmentative and alternative communication (AAC) device. Augie is one of many people who uses a switch to access a communication device. Similar to the switch, there are several other assistive technology (AT) devices that can be deemed as capability enhancers ranging from reading glasses to brain-computer interfaces (Robitaille, 2010). These devices help an individual overcome some of the limitations due to their disability and continue major life activities.

Despite the advances in the technology, factors such as affordability, access, learning curve, usability and pandemics (e.g. COVID-19) can limit who gets to use these AT devices (Madara Marasinghe, 2016; Alabbas and Miller, 2019; Rasouli et al., 2021; Naghavi et al., 2022). We believe involving the users early on in the process of design will help us bridge the gap sooner and better (Shah and Robinson, 2007; van de Kar and Den Hengst, 2009). Largely, researchers and manufacturers tend to obtain a generic survey of features from a pool of users or involve few users to some depth in the design process. Many of these approaches lack in-depth diverse involvement of users. Additionally, due to various reasons the information obtained remains within the reaches of the group that is central to the collection. We need an open platform approach to bring together users, scientists, and manufacturers.

Many existing platforms are scientifically oriented, and we observed that users may not necessarily have scientific evidence to hypotheses to actively participate. Therefore, their involvement gets limited to an attendee or spectator or panel member. The goal of this paper is to provide users an opportunity to get involved and actively participate by sharing how some of these AT devices have empowered them. We also share some of the unmet challenges that exist in the current technologies.

We crafted seven questions that were answered by four users (also co-authors) via email using their respective devices. These simple questions were formulated by a product engineer and a speech-language pathologist who have worked for approximately 5 years with various users of AT, and were designed to elicit responses that would highlight the user experience to the forefront of researchers' minds. The questions range from asking users about their experience obtaining their AT device (since many devices are not easy and quick to obtain due to their funding process) to how easy or difficult it is to use it (many devices have a complex learning curve.

In the next sections we share the feedback from each user word for word as typed using their respective devices. Therefore, there may exist typographical and formatting errors. Please note, this paper does not intend to analyze any AAC device or a company's product.

2 Amy Diego

1. What assistive technology (hardware or software; low-tech or high-tech) do you

use? I use an Eye gaze Edge communication device.

- How difficult was it to find the solution or device you use? It was not difficult to obtain. We got the referral from UCSF.
- 3. How difficult is it to use your solution or device? My eye gaze device wasn't hard to use initially. We have a great person who helped us get up and running and we have her to touch base with if I have problems . Also, on the device there are videos for all kinds of trouble shooting problems.
- 4. What are two important problems that your device or solution solves? ALS is a debilitating disease that has robbed my ability to move and speak . The Eye gaze Edge has solved problems of communication and entertainment . I can speak freely to my family that no alphabet board can do . I can get in touch with my friends and I love being able to communicate independently . Entertainment - wise, I can watch Netflix on it, shop on Amazon, connect on Facebook and Instagram, and use the web for anything.I love it!
- 5. What are two important problems that your current solution or device does not solve? Two problems that the Eye gaze doesn't solve are minor issues . When I am texting friends, I often need to say the same thing to many people . I can't do group texts . Also, I receive texts that have a link but I can't open the link.
- 6. How do you think improvements could be made to one's Assistive Technology experience? There isn't much that the eye gaze doesn't solve. The above mentioned issues would be worthwhile to look into. I'd love to see the pictures and links from texts without asking my husband. Overall, the device helps tremendously in keeping me independent and in touch with my family and friends.
- 7. Tell us a little bit about your background (could be school, work, or interests or hobbies). Having grown up with a dad who was a lifeguard Captain, I have always loved the beach. I miss watching my kids in the sand and my hubby running around with the

dog. Love the sound of the waves and the taste of saltwater on my lips. I left the best job ever when I got my diagnosis .I was teaching K/1 at the same school with my kids. My daughter would have lunch in my classroom with her friends. I loved my "littles" and would be excited to go to work everyday. My other hobby that I miss are drum lessons. I've always loved music and there isn't a memory that I have that isn't connected by a some song. When I started playing drums, it was fun to try and learn these songs.

3 Augustine Webster

- 1. What assistive technology (hardware or software; low-tech or high-tech) do you use? I use a PRC Accent 1400 with two "bluetooth" freedom switches. One scans and one selects. The scanner is mounted to the left side of my head and the selector is at the back of my head. both are mounted on a whitmyer headrest. I also say yes by looking up and no by looking to the side.
- 2. How difficult was it to find the solution or device you use? I cannot use my fingers to type. it was challenging for therapists and my mom to figure it out. From age two to seven I had a dynavox with 4 boxes, but I couldn't hit it accurately with my hands. During that time my mom found different therapists who experimented with switches by my knees, elbows, and head. The Switch It games helped me get the scan/select system down. The PRC device worked well with 2 switches, the Dynovox did not. I have tried eye gaze without success ad the ablenet orange and white switch for the i pad but i cant remember the pattern.
- 3. How difficult is it to use your solution or device? It is easy for me to use my device, when it is charged and working, and when the batteries work in my switches. Some people say I play it like a piano. I know some patterns by heart. like "i am hungry." The switches use CR2032 lithium batteries 3 volt and last about 1 week. My switches wear out about every six months. I could use wire switches and I did for years, but my athetoid movements often disconnect the wires. And when I did use wire switches the internal ports wore out bc i often

yanked the switches out by accident due to my crazy body. I really like the wireless switches but it is expensive to replace them and their batteries.

- 4. What are two important problems that your device or solution solves? I can express my wants and needs, make jokes, and communicate.
- 5. What are two important problems that your current solution or device does not solve? I cannot access the internet at all. I cannot read long texts when texting. A very smart person has to pair my phone to my device and not all my aids or school team knows how to do that.
- 6. How do you think improvements could be made to one's Assistive Technology experience? I am going to see a new therapist Monday to see if I can manage a 1-switch system to surf the internet. I cannot email or surf You Tube, I have to ask everyone to help me. I want to be able to navigate an I Pad or computer all by myself to go where I want and email who I want and be on social media. I will have to look at a blue line that moves horizontally on the screen click when it gets to what I want and then follow a vertical blue line to stop where I want. then the device goes at the crosspoint. This kind of system has been hard for me but there is a new one so I am going to try it.

My body moves too much so eye gaze doesn't work for me. also i have blue eyes and my retinas are pink and not always picked up be the infrared eye gaze systems.

I would like 1 device that is my Accent and have it be an ipad and phone that I can control to communicate with the synthesized voice and surf the internet to watch cooking shows, do research on restaurants, and connect on the social media channels. I have 100s of pages that my mom and teachers have programmed over the past 14 years...it is like my library..i can't imagine not having access to it. But I think I might need 2 devices. my accent and an ipad mounted to my chair. I love youtube and probably wouldn't need an aid all day if I could navigate it on my own. I'd like to have some switches in my bed to play music when I wake up.

- 7. Tell us a little bit about your background (could be school, work, or interests or hobbies). I am 21 years old. I like to go out to eat, go to concerts, and visit with friends. I love to tell stories. I write them and then my mom programs them into my device so I don't have to type one word at a time. I have attended Fairfax County Public Schools since I was 2 years old and received a lot of help with assisitive technology. I am an assitive technology ambassador for FCPS and have shown many kids with mobility challenges how I navigate. One boy's mom found my mom on Facebook and thanked her for braving the world of "Augie"mentative communication. He was 6 when I showed him how and now he uses 2 switches and writes book reports. I like jokes and puns. I like to talk about NFL with my dad. I remember all the books my mom reads and remind her of them when she can't remember. I hope I can find a job in 2023 because that is when school ends for me. I would like to work at Jills House, a respite program for kids. I would choose the menus and movies and talk to the kids. My favorite TV show is Speechless. My favorite movie is Major Payne. My favorite restaurant is Social Burger in Vienna. My favorite band is Peter, Paul & Mary.
- 4 Angela Wilson
 - 1. What assistive technology (hardware or software; low-tech or high-tech) do you use? Jaco Robotic Arm
 - 2. How difficult was it to find the solution or device you use? It was easy I saw it on you tube and on Instagram and I asked my occupational therapist about it and she had the company fly out to my house and let me try the arm out.
 - 3. How difficult is it to use your solution or device? There's definitely a learning curve. There are sixteen different directions and four different modes to learn. With time it gets easier to use.
 - 4. What are two important problems that your device or solution solves? If I drop

something on the floor I can pick it up. I can also open doors and push elevator buttons without assistance from someone.

- 5. What are two important problems that your current solution or device does not solve? I can't use it for two handed things. I can't feed myself with it because I use a syringe so you need two hands for that. I also can't open jars and containers because again you need two hands.
- 6. How do you think improvements could be made to one's Assistive Technology experience? I think it would be better if the hand was more realistic. Also if it had five fingers. Instead of three. Also if would be cool is if came with something to hold objects in place while you used the arm to open the lid.
- 7. Tell us a little bit about your background (could be school, work, or interests or hobbies). I was born with a rare form of muscular dystrophy called Spinal Muscular Atrophy. It's similar to ALS, basically my muscles get weak over time. My life expectancy was the age of 3 and today I am 40 years young! Life is relatively normal for me and I use many devices throughout the day to help me do everyday tasks. I just recently decided to go back to school . I'm pursuing my masters degree in Criminal Justice. I'm obsessed with crime documentaries so I decided why not get a degree in something that I'm really interested. In my free time I enjoy volunteering at Muttville in San Francisco. They are a wonderful senior dog rescue. I also became a foster with them and I have successfully helped 3 dogs find their forever homes!

5 Doug Sawyer

1. What assistive technology (hardware or software; low-tech or high-tech) do you use? My high-tech solution is a system called EYEGAZE EDGE .It is a Tablet-based product that utilizes an IR-based camera to track eye movement. The software runs on Microsoft 10 OS.

My low-tech standby solution is a simple letter board piece of paper with a matrix of letters.

- 2. How difficult was it to find the solution or device you use? My hunt to find a solution was not that difficult. Children's Hospital in Massachusetts has a department dedicated to helping individuals find the proper communication-assisted technology for their needs. During my visit to the hospital, I was able to try various products from different manufacturers to find the right solution for my application.
- 3. How difficult is it to use your solution or device? The device is straightforward once one master's eye control. The layout of the software models causes a little difficulty during online meetings, and the inability to engage three keyboard keys at once causes a problem.
- 4. What are two important problems that your device or solution solves? My device's first and most obvious solution is communication in general. This allows me to work and maintain some level of dignity and self-worth..
- 5. What are two important problems that your current solution or device does not solve? Because sunlight interferes with IR cameras, my device will not function in direct sunlight. Also, the camera on my device can get out of focus. Without assistance from another individual to adjust the camera, I am stuck without communication.
- 6. How do you think improvements could be made to one's Assistive Technology experience? Enable the user to go outside and enjoy the sunshine. Provide full functional private phone capability.
- 7. Tell us a little bit about your background (could be school, work, or interests or hobbies). I have an MSEE and MBA. Work full-time in new product development. I love the outdoors and watching all sports.

6 Discussion

The shared direct-from-user responses show that existing AT solutions have helped users perform some of the tasks they could not do otherwise, enjoy some of the activities they would have been deprived of, and above all given them back their autonomy and dignity. However, we also recognize that many of these solutions are comprised of multiple incompatible components, not providing an overall solution to their needs and in some cases quite difficult to use thereby limiting the usage.

Although there are many centers and clinics that offer ways to try out the devices, obtaining a device becomes little difficult due to the expertise involved in finding the right to solution for a given individual e.g., User 3, Augie had to consult with different therapists and needed some experiment before finding the right device. Additionally, many of these devices require at least some level of training for the care-givers or aids at home, school, or workplace. Likewise using these devices to do what an individual would do on their computer or phone has improved over the past few years but often the available features and usability is specific to the type of AT device or manufacturer. For example, User 1 Amy who uses an Eyegaze Edge can access internet without much issue whereas Augie currently cannot access internet at all. In most cases the respective devices need some kind of intervention by a caregiver or family member e.g., User 4 Doug's device would go out of focus and then he is stuck without communication until another individual provides assistance. The responses shared above certainly highlight the positive features of current AT devices and how they improve everyday lives. Some of these improvements are that users can now access internet, their phones and computers, smart home devices etc. using their AT devices. However, these improvements seem like afterthoughts. Accommodation for the disability population happens after the actual device or technology has been designed and become mainstream.

Participants experience a range of ease-of-use with AT products, ranging from "easy-to-use" and difficult or complex. All participants were able to identify features in their technology that improved their lives and allowed them to communicate or access communication platforms. Participants were also able to identify limits their AT devices had, with a majority of participants identifying real-life scenarios where their access to communication or participation were limited. Responses also identified challenges with AT not always being durable and long-lasting, expensive and requiring assistance from others to set up or maintain use over time. Each participant was able to suggest solutions to solve these problems. These themes highlight that AT users experience real challenges that spark ideas for possible solutions; also 100% of participants expressed current solutions made possible by the AT they use. From these interviews, we would suggest researchers look at asking similar questions to a larger sample size across a wider specrum of AT devices (communication, mobility, computer access) to ask and understand, "How can AT manufacturers collaborate with AT users to innovate functional design? What are ways to improve AT ease-of-use, durability, and increase access to communication in text and spoken forms?"

We acknowledge not all the issues presented in the user responses are directly related to Computational Linguistics or Natural Language Processing e.g., a robotic arm looking and feeling more realistic or an eye tracker that would work in the sunlight. However, we believe many of these challenges are multimodal e.g., existing AAC devices used via touch/headmouse/switch/gaze are used for communication with another human, with the computer or phone, with the internet. If we could bring AT users, NLP experts, Computer Vision scientists, clinicians, engineers, caregivers, policy-makers and others together we could bridge the research/practice gap sooner and more efficiently. The sample size we present here is small, but we find it significant that each participant was able to share the current limitations of their device and suggestions for improvements; this is where a 'a gap to be bridged' is illustrated by these interviews. We hope this paper is a step forward in bringing the users to the design table and work toward solutions that give them back their autonomy and dignity.

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