

MY LONG JOURNEY TO AUGMENTATIVE & ALTERNATIVE COMMUNICATION (AAC):

AAC, Aging, and Telephone Relay Access Technology

Many people with speech disabilities use voice output computers referred to as AAC. Although they may exist, I am unaware of other consumer reports about voice volume deterioration and the gradual implementation of AAC in its place. While it took Moses thirty years to lead the Jews out of the desert, my journey to AAC has taken longer than that. One reason that my journey took so long is that AAC was presented to me as a substitute for speech rather than as a supplement for speech. Had I realized its use as a supplement to speech, I might have adopted it much earlier. My impression is that AAC is generally marketed as a substitute for speech. Marketing it also as a supplement to speech might increase the number of potential customers, especially among people with deteriorating conditions who still have some speech. Many such customers may be elderly as I will discuss later. This situation is analogous to the development of telephone service for people with hearing loss. TTY relay is useful to many deaf people. Alternatively, many deaf people could speak and needed other technologies, such as voice carryover and closed captioning. These technologies opened telephone use to many more people.

My long journey to AAC makes me wonder how others came to use AAC and if a chronicling of such experiences might lead the way to better approaches to presenting AAC to potential users. We need to learn from current users what the obstacles to AAC use are and find ways to remove these obstacles for future users. We could have an essay contest asking current users to identify the obstacles and use that information to facilitate to the removal of those obstacles.

One of my obstacles was the difficulty in learning and using the AAC devices. For example, the first device that I saw in 1979 required combining syllables into words which made communication very slow. The recent advances in ease of use make AAC devices especially user friendly.

I was unaware of my voice deterioration until my senior year of high school. Until then, my cerebral palsied voice was probably a normal volume as I was always able to participate in the loud discussions common in Jewish families (stereotype unintended). I first became aware that there might be a problem with my voice during a talk I was giving that year, when suddenly the words would not come out aloud for a few moments. I was thinking the words, but when I spoke nothing came out and I did not consider the possibility of whispering. In retrospect, the aging of the muscles which bring my vocal cords together to produce voice had begun. Several years later in graduate school, I often went for a brisk walk before giving a talk as that made it easier to speak loudly.

My parents noticed the problem during my senior year of college and sent me to a neurologist. About that time, the medication Valium was beginning to be used in cerebral palsy and physicians were hopeful that it would benefit that population. To paraphrase Karl Marx, neurologists wanted to make Valium "the opium of the Cerebral Palsied." I was not able to tolerate the Valium so it is unclear whether it would have improved my voice in the long run. The Valium necessitated other medication which made my thinking slightly less clear and graduate school more difficult. In retrospect, my neurologist would have been better off to tell me not to talk so loud when voicing became difficult, but neurologists do not get paid to give common sense advice. Such advice would not benefit the pharmaceutical companies that spend millions of dollars sending mini-skirted representatives to visit male doctors to promote such drug dependence worldwide.

Over the next twenty years, I used a wide variety of hand held voice amplifiers for both speeches and face-to-face communication. It was easier to use an amplifier after I acquired a wheelchair so that I did not need to carry the amplifier. I am grateful that technology has led to smaller amplifiers over time. In twenty years, the amplifiers will probably be so small that I will need a magnifying glass to find them. I have discussed an amplifier implant with my physicians but the technology may not be available yet. Currently, I am exploring the use of an amplifier which will be built in to my denture. I am lucky that I am old enough to need a denture.

Amplifier repair was often a problem and I was forever tracking down repair people in distant cities because the airline had done creative baggage handling with my amplifier. Another problem with amplifiers was moisture. I was rarely stuck in rainstorms at home because I went from the house through the garage to the van and parked close to my office during my working years. Unfortunately, I was not able to protect my amplifier while traveling and often needed emergency repairs.

I tried an amplifier called "a speech enhancer" which was quite effective. Unfortunately, to protect the patent, the manufacturer scratched out the part numbers so that the equipment had to go back to St. Louis for repairs. That would have been fine if I had some other reason for going to St. Louis, but I am not a Cardinals fan.

Talking on the phone was always difficult after my voice had significantly softened. There were no good amplifiers for telephone use available to the public and I resorted to a TTY machine and relay for communication. It was through using the TTY relay that I came up with the idea for Speech-to-Speech or STS. The TTY relay operators were mostly young women with excellent hearing who had no trouble understanding me. This gave me the idea that such people could relay calls for dysarthric and low volume speakers. After a series of trials, and ten years after conception of the idea, STS became a state-wide service 24 hours a day 7days a week in California and in 2001 became nationwide. You can read about STS at www.speechtosome.org.

As my voice degenerated over the next five years, I requested my Blue Cross PPO to provide me with a Pathfinder. After a legal battle, with help from an AAC industry lawyer, I obtained my AAC device in 2006. Consequently, Blue Cross changed its nationwide policy to provide AAC devices as part of its durable medical equipment options.

Currently, I use AAC partly to communicate with people who cannot hear or understand my speech and also over the telephone with a speaker phone using Speech-to-Speech. This includes strangers and people over 30 who have lost the hearing ability of youth. When I was a young man in the 1960's, I could not trust anyone over 30. Now only people under 30 can hear me. Obviously, I can say a lot more to people who can hear me than to those who I communicate with using AAC. Therefore, I speak whenever I can and choose environments with limited background noise given my degenerated whisper. I will continue to structure my life so that I can speak as much as possible because faster communication facilitates other goals, like participating in a group discussion or communicating with people who are in a hurry. My use of AAC for communication will increase as my vocalizing decreases. As I age and my companions age, their ability to hear me will also decrease, also increasing my dependence on AAC. Speech Language Pathologists (SLP) may want to study adults who have had lifelong speech disability to see if the decrease in vocal ability is a common problem and if AAC may be useful to this group. This may be an untapped market for AAC sales.

My second use for AAC is to increase my typing speed. Recently, I have acquired sufficient Unity (AAC) vocabulary to write email. As my typing speed decreases with age and osteoarthritis, I expect AAC to become more useful to me on the computer. The first lesson I learned with that device was to keep the shoulder strap around my neck while sleeping on airplanes because the first month that I had the device, it broke when it fell during a rough landing at LAX. I have found my device useful in a variety of specific situations, particularly if there is any background noise or if the audience does not have perfect hearing. As time goes on, my voice has become even quieter and I require an audience with increasingly better hearing to be understood without an AAC device. Currently, most people over thirty-five cannot hear me and people under thirty-five can only hear me in a very quiet room. My device became increasingly necessary after I moved into an apartment complex for the elderly, as it facilitates socialization with people who have less than perfect hearing. As I no longer speak loud enough to be heard by the Speech-to-Speech operators* consistently, I combine speaking and AAC to communicate with them. The operators introduce my calls and educate my callers about how to communicate with an AAC user. This prevents my callers from getting confused and hanging up. I am working with the Attainment Company to make a video demonstrating the use of AAC with Speech-to-Speech.

The time consuming nature of learning to use AAC software has been a challenge. Over the last few years I have learned a variety of increasing complicated AAC software. Fortunately, I can use the same software to increase my word processing speed this software allows me to combine keystrokes into words rather than typing one letter at a time. My osteoarthritis combined with my spasticity and uncontrolled movement reduces my typing speed to 8 words per minute without AAC. Using flashcards, I have acquired a AAC vocabulary of 300 words over the last month. My goal is to acquire a vocabulary of 2,000 words. I understand that I may be able to increase my typing speed above 30 words per minute with AAC.

One of my challenges to learning AAC was the lack of a teacher. When I learned Hebrew, Latin, Spanish, and French I went to daily classes, where not only the teacher, but also the students reinforced my learning. The AAC manufacturers may want to develop a series of online videos to teach Unity. I was also dismayed by the icon structure of Unity. Moving from a Word based vocabulary to an icon based vocabulary was difficult for me. I was more comfortable with the Word based structure of AQLS.

As an aside, because as a sociologist, I look at whole segments of society and have speculated on ways that AAC could help the older generation. With the baby boomers moving into old age, some of them will acquire age related speech disabilities and need AAC. It may be easier to teach AAC to these consumers with a Word based vocabulary than with an icon based vocabulary. The challenge to the linguistic programmers who develop such software will be to find ways to provide as large a Word based vocabulary as currently available in Unity without increasing the number of keys drastically. The opportunity to make AAC useful to this ever increasing geriatric population may justify the research and program development necessary.

Accountants and actuaries with knowledge of the projected population of potential geriatric users over the next few decades could estimate the profit that could be made by making AAC more user friendly to this population. Judging by the training material available on the Web, the AAC industry appears to target children and teenagers. Attempting to serve a geriatric population will require a change in perspective which could present a significant business challenge from both a management and sales perspective. The SLPs who do this training are geared to a young population and it may not be easy to motivate them to work with elderly people. Another obstacle may be the availability of insurance reimbursement for both devices and training for this population. From a societal perspective,

it is not as productive to provide AAC as a tool for elderly people who may only use AAC a few years rather than a younger population who may use it for many decades. AAC manufacturers, actuaries, SLPs, and the few Sociologists, like me, who are interested in this topic, will all look at it from different perspectives. This phenomenon is a bit like the story of the nine blind men who examined different parts of an elephant and each described the elephant in a different way.

While this paper appears to be the first chronicle of the decline of speaking volume and subsequent substitution of an AAC device, I hope that it will motivate others in similar circumstances to chronicle their experiences to build a knowledge base.

*Speech-to-Speech (STS) is a telephone relay service for people with speech disability. For more information please see www.spechtospeech.org