

Communication Is a Wonderful Thing

by

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Using an Augmentative and Alternative Communication (AAC) device should be accepted by everybody because it helps people with communication disabilities participate in society and communicate our thoughts. I have been lucky because people who I know have supported my communication no matter how I get my thoughts across. Many people with communication disabilities are not this lucky. Educating the general public and fellow AAC users about the different ways to communicate is needed to gain acceptance.

Not being able to communicate is the most frustrating feeling in the world. This lack of communication ability can make people feel trapped in a body that will not cooperate. A lack of communication does not give a person control over his or her own life.

When a person does not have adequate communication, people usually assume this person does not have normal intelligence. This is not true. A physical disability can cause communication difficulties. We need to look past how we communicate and concentrate on what a person is saying.

Since I was born with the umbilical cord around my shoulder, I have brain damage that falls into the category of Cerebral Palsy. This birth accident has robbed me of the abilities of walking, using my hands, and talking understandably. I can think and feel like anyone else. I miss my hand use and talking the most because I cannot express myself easily and effectively.

Since my type of Cerebral Palsy is not characterized by an intellectual disability, I have not had to prove that I was not dumb. Of course, I had a few ignorant babysitters who enjoyed calling me, “dummy.” However, people did not realize how smart I was or that I had a talent for writing until I had independent communication methods. I put up with teachers repeating what I already knew because I couldn’t show what I knew. I put up with younger cousins talking down to me because I couldn’t express my knowledge. I had to listen to a teacher brag how smart a fellow classmate was because she could draw cartoons and use sign language to tell jokes.

I waited until I had the technology to enable me to communicate. Though I have had technology help for my communication since I was eight, just recently I received a device that enables me to use my eyes to type and speak. Before this, I struggled for every word that I produced. Despite my struggles with communication, I earned a degree from junior college and became a professional baseball writer. Now I feel as if I have the world by the tail. Although my current communication system needs tweaking to meet my complex communication needs, I feel I can use any word to describe how I feel. This is a great feeling.

Since I could remember, my family and school wanted me to be able to write independently. Though nowadays people want communication disabled to have a computerized voice, in the late 1970s and 1980s, the devices that produce verbal output were crude and extremely expensive. In third grade, I received my first low-tech communication board that enabled me to communicate with a trained communication partner. My teacher and aide did not allow me to use my own voice for anything, so my speech deteriorated until no one could understand anything else except yeah and no. My mother protested the exclusive use of the low-tech communication board because she wanted to have me able to learn to

speak understandably. She knew I would not speak normally, but she thought I could learn how to talk better.

Before I went into third grade, the school district bought an \$8000 scanning typewriter with variety of switches called the Possum. The school district had many children with trouble writing and a few who could not talk either. At first, I did not receive much opportunity to use the Possum though I could have benefited from the experience. Every student with a minor handwriting problem wanted to use the Possum.

As soon as teachers and students realized the Possum was slow and unreliable, I received more opportunity to use it. By my seventh grade year, the Possum was my communication device. I could use the chin switches easily, but my neck ached after thirty minutes. My communication was tediously slow, and the device was not portable. I couldn't see what I was typing, and it became a huge problem when I had to take algebra tests. Since the Possum was mounted on a low traditional typing table, I received bruises on my shins, so I wore soccer shin guards to protect me.

At the start of tenth grade, my special education class changed classrooms, and during the unsupervised move, my Possum toppled over and broke. It took weeks to get the school district to send out someone to repair it, so I could write independently. At home, I had no way to put any word on paper without my mother's help. Though I went through an extensive communication evaluation while I was in fourth grade, it did not show us anything that we did not already know. This expensive evaluation said that I could use a switch to scan and recommended I have a personal computer, which was new in 1980. However, it failed to tell anyone how to buy a switch and connect it to the computer. My grandparents and parents went together to purchase the computer, but no one knew how to adapt it for my use.

I had a headstick that I sometimes used it to paint. No one thought I had enough head control to use the headstick to type. In October of my tenth grade year, just after my fifteenth birthday, I was desperate to write independently without the Possum. Although my mother was going to a communication conference later that month, I wanted to learn how to use a normal keyboard as everyone else did. I felt more disabled than my special education classmates because I was the only one who had not learned how to use any keyboard. This was harmful to my self-esteem.

One Saturday in October, I asked my mother to push my wheelchair to my father's computer and put my headstick on my head. I began attempting to type with the headstick. One of my classmates communicated this way, and I did not realize how difficult it was until I tried it myself. I was lucky to hit a key a minute. I had three correct keys in ten minutes, and my neck felt like it was going to drop off. My sheer determination to learn how to write independently with a normal keyboard made me continue. Soon I improved enough to type three words a minute and finish the essay that I was writing. Although I received a B on the unimportant essay, it was important enough for me to learn how to use the headstick to communicate.

Using a headstick was never easy for me though I was able to use any keyboard without adaptations. After I graduated from high school, a computer seller told me about a program to hold down the shift, control, and alt keys until I pressed another key. His idea was to keep my adaptations to a minimum, so I could use any computer. I believe he was right for employment because employers are frightened of assistive technology because they do not understand it and feel like they will be asked to buy it.

The headstick enabled me to finish my junior college education. Eight years after my graduation from junior college, I, with the aid of a brilliantly written article about me by Bill Plaschke, was hired by Major League Baseball Advanced Media to write a column for the Official Website of the Los Angeles Dodgers. I hold this position still. Major League Baseball Advanced Media does not care how I write my articles if

I can. I included in my biography on the website that I use an AAC device, and I have received many positive e-mails about this.

A few weeks after the article appeared, I was contacted by the manufacturer of WordQ. I had not known that word prediction existed before then. I tried the program, and it lessened my fatigue, sped up my typing, and gave me a voice that everyone could understand for the first time in my life. I loved it.

A year after I was hired, my neck began to hurt. I realized that I needed to find another access method for my computer other than my headstick. I met the Dodgers, and I could not speak to them because I did not have understandable speech. I realized with help of a pitcher that I needed a speech device that would be mounted on my wheelchair so I could speak at anytime that I wanted. I asked Vocational Rehabilitation to help me to get evaluated and get the equipment that I needed for better communication. They agreed.

I was evaluated and given EZ Keys and a switch to scan. Nothing was mounted on my wheelchair. EZ Keys was not good word prediction, and scanning hurt my neck more than the headstick. With the headstick, I could type about six words a minute. However, with scanning, I could type at the most three words a minute. The evaluator tried an eyegaze system with me, but I had too much movement to use it. She also tried Tracker, but I could not get the cursor across the screen.

The next spring after the article about me appeared in Reader's Digest, I was contacted by a local occupational therapist who knew communication access. I began working with her. She wanted to get me a Freedom Lite, a small notebook computer with EZ Keys. Although I knew Words+ called it an AAC device, I thought it was their marketing slogan instead of the industry name for devices that helped people with communication disabilities talk faster. During the process of getting my Freedom Lite, I met Barry Romich who showed me his Pathfinder with a language system called Unity. I thought it looked interesting. This was the first time I learned a couple simple keystrokes could produce a word.

After I received my Freedom Lite, I began to detest my new device. It had a keyboard that I could not access with my headstick because it took too much pressure. I hated scanning and I could not use Morse code without making myself dizzy. I began looking at alternatives.

I saw the Pathfinder and was not impressed. Why do I type SHOE, SHOE, and HOUSE for baseball when I had abbreviated it as "bb" for years? The device had only DecTalk, and the women's voices sounded like they were longtime smokers. The PRC rep seemed to believe I was deaf, and she did not know Unity herself.

The DynaVox rep was nice to me. The poor man had to demonstrate his DV4 three times before I decided that I wanted to have the device. I was impressed with Gateway because it had so many words that I could select by a few hits. It had a normal sounding voice that everyone could understand. The touch screen barely took pressure to hit.

For two years, my DV4 met my communication needs. I knew I needed to perform soft resets frequently or I would need assistance. Although these soft resets were annoying, I could do them, and I knew no assistive technology equipment was perfect. Everyone could understand what I was saying. I programmed extra words and phrases that I used frequently. I purchased WordPower that gave me an excellent computer access keyboard. I thought my communication problems were solved, especially after I downloaded adult pages from the DynaVox 3100 because it had many multiple-syllable words that I used frequently and the health words that I needed.

After two years of use, my DV4 broke. I thought no big deal because I had a warranty that covered everything. I would miss my device while it was in for repairs. I sent it in with every confidence that

DynaVox could repair it. The device returned within two weeks and lasted two days before the same problem occurred. I was getting angry about it but sent it back for more work. It came back to me with a screen calibration problem that it did not have when I sent it back. WordPower would not scan, another problem that the device did not have when DynaVox received it. Of course, I returned the device to Pittsburgh, but the device could not be repaired.

I began looking for a replacement. I realized I could be a successful AAC user. Since I only heard of Wor3d+ and PRC besides DynaVox, I thought my choices were limited. I knew I did not want to have another device from Words+. I e-mailed Barry Romich and my PRC rep to schedule a demonstration of their new ECO-14. The rep was too busy to schedule a demonstration. Barry suggested that I join Acolog, a group for Augmentative and Alternative Communication users and people who care about them. He wanted me to know people who used Unity. I did. Everyone who used Unity loved it.

I was convinced that an ECO-14 was a device for me. My mother, who just sold the family house, bought this device without seeing it. Since PRC was overloaded, they wanted twelve weeks before the device could be shipped. This angered me because I had nothing to use to communicate. While waiting for my ECO-14, DynaVox loaned me the VMax. The VMax did not have good word prediction, but I liked the familiar language system.

The ECO-14 finally arrived. I began using it and learning Unity. I learned Unity quickly though it affected my memory for other things. For the first time in my life, I had cognitive overload. Two weeks after the device arrived, it broke. I returned it to PRC and I received a loaner. The loaner was fantastic, and I was communicating faster than I ever had.

Six weeks after I returned the ECO-14, my device came back. Though it was repaired, my device did not work as well as the loaner. The touch screen took too much pressure, so my neck ached. I could not update the software. The device was locking up frequently. I could not add a word myself because the program key was out of my reach. I convinced PRC to buy the device back.

DynaVox loaned me a VMax until I could get funding to buy my own. The headstick was becoming increasingly more difficult to use, so I knew I needed to find another access method. The company was coming out with an eyegaze system that would tolerate movement. Since I was an infant, I had used my eyes to point to the things that I desired, so I thought using eyegaze was a logical solution to my access issues. I scheduled a demonstration of the EyeMax.

I hoped that I could use the EyeMax, but the VMax did not have the particular scanning that I needed. If EyeMax did not work, I needed to search for another device. The day came, and I had been practicing moving my eyes without moving my head. The EyeMax was difficult to set up, and every time I moved my head, the device had to be re-calibrated. Though the rep thought I could use it, I did not think it would work for me.

I bought a used Vanguard II and Pathfinder from a friend. Though several people had recommended I use a Pathfinder, it did not work for me because I could not push the keys without knocking off the headstick. The Vanguard II was satisfactory, but I hated 84 Unity. When I was scanning, I had to choose a button to allow me to scan the word prediction list. To me, that was ridiculous because I use word prediction to save time and keyboard. That feature was costing me time and energy. I thought a newer Vanguard Plus would have changed that, but it has not.

I thought my only choice was an ECO-14. I had a new speech-language pathologist who recommended that I have a demonstration of the ECO-14 with its new ECOPoint. We scheduled a demo. While I was

waiting for the demo, a person from Tobii posted on Acolog how great their Sono Script was. Although I did not appreciate his attitude, I thought I better check Tobii out.

I googled Tobii Augmentative and Alternative Communication devices. I went to Tobii's website and saw a solution to my access issues. It had a video of a young woman from Germany who used her eyes to communicate while she looked alive. I read about the devices, and I got excited. Their computer components were much better than either DynaVox or PRC.

Though I have tried the ECO2 for a limited time and realize PRC is geared to promoting the Unity language system for school-aged children, I have found my most effective communication with Tobii P10. It has out-of-date computer components, but I can say or write whatever I want quickly. Using my eyes to communicate seems natural and effortless for me. Tobii does not have a good language system, but it has superior word prediction and abbreviation expansion.

I hope sharing my journey to find effective communication helps to teach people not to give up. We need to accept any communication method that a person uses. The AAC manufacturers need to support everyone's device, including setting the devices up. Increasing awareness and acceptance for AAC is needed for the greater good.