

October 16, 2019 7:00 PM Eastern

My Story of How Getting A Speech Device Changed My Life

**Presenter: Todd Hutchinson** 

Moderator: Stephanie Meehan, Ph.D., CCC-SLP

Mr. Hutchinson has a personal non-financial relationship to the content of this course as he is telling his story as an adult with cerebral palsy who uses AAC devices. No financial disclosures to report.

Moderator has no financial or non-financial disclosures to report.

# Webinar Logistics

#### **ASHA CEUs – live webcast**

- Included for USSAAC members;
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- Participant form and instructions on USSAAC website
  - USSAAC Website->News & Events Tab->Webinars
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 NOTE: You need to scan and send participant form to smeehan8@ku.edu by

### **October 30th, 2019**

- Enter questions in the chatbox. We will answer as time permits.



## WHAT WILL YOU LEARN?

- The participants will be able to discuss how using multiple modalities to communicate is necessary for individuals with complex communication needs (CCN) to be able to express themselves in all environments.
- 2. The participants will be able to describe how the use of a speech generating device compared to a symbol book can significantly improve spontaneous and novel communication.

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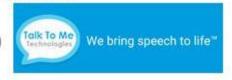
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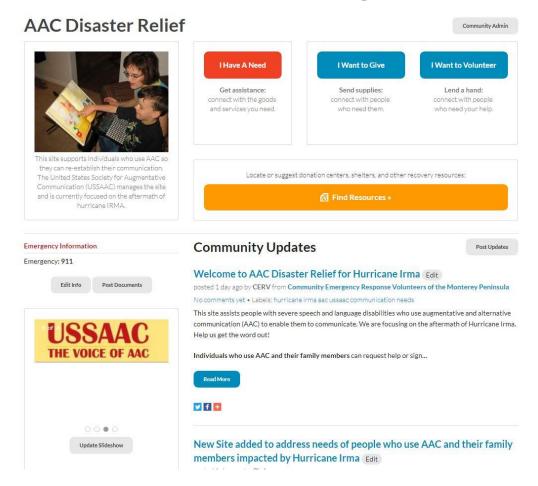






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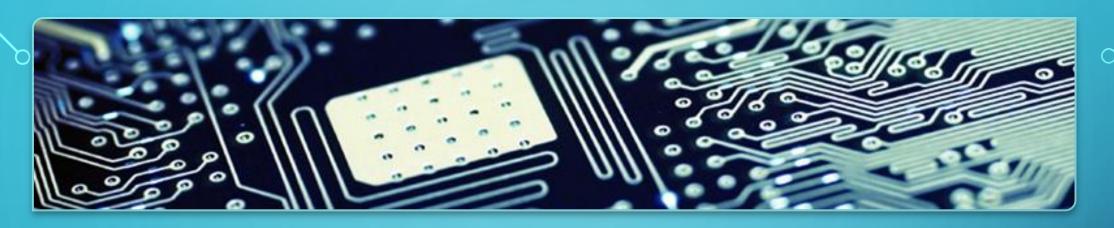
# MY STORY: HOW GETTING A SPEECH DEVICE CHANGED MY LIFE

TODD HUTCHINSON

ISAAC/USAAC WEBINAR OCTOBER 16, 2019

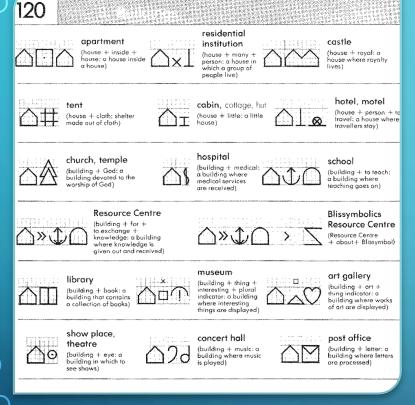
Hello, and thank you very much for giving me the opportunity to share my experiences on using AAC to communicate, and how technology reduces some barriers in my life. I am going to tell you a little bit about my life, before I had a speech device, and after getting one. My story also includes how all my life; I am seen as developmentally disabled in the eyes of everyone around me. You see, that's the first thing people think of when they see me, instead of, hey, that's Todd! At first glance, they see that I have a wheelchair, I can't walk, I can't speak clearly, and I need help being fed and getting dressed. My hope one day is that people will first just see me, Todd, the guy with a great personality, and the other stuff is just part of who I am!





During my life, I have used a range of low to high tech to help me communicate. Because of the evolution of technology, I now have access to communication in various ways. For example, everyone uses some type of technology to communicate today. Whether it be an email, text message, a post on social media, really, everyone uses AAC! For me, communication didn't start with a speech device or use of computers. Because I was born in the early 1970s, I didn't get my first speech device until I was 16 years old! That is a long time to wait! Today, I hope that doesn't happen to any child!

Before my first speech device, I used a communication board with Bliss Symbols from 4 until 18, and man, it wasn't easy for me! To communicate, first I had to point to a bliss symbol on the board, next a person would say the word or message. When I met new people, I showed my bliss symbol board, pointed to pictures, but people didn't say words for me, they didn't understand that's how I was communicating. It was very hard for me, because I was pointing to the same stuff, but a lot of different people were speaking for me or even worse, not knowing I was trying to say something! Despite my frustration, I kept working on communicating and hoped for the best.



At school, I was lucky to have some teachers who believed in my potential. Very soon, my speech teacher thought I needed more symbols to help me to talk. So we made a picture communication book. It was okay, but it was also a pain, because I had 50 pages of pictures. My speech teacher and I added more pictures to my picture book every week. At this time, one of my therapists thought I should use a head pointer because it was hard to see what I was pointing to. I didn't like it because I got a headache with it, and I just didn't like it. So they made me a hand splint, to help them see which fingers I was using to point. I called it my 6 fingers.

Soon after, I went from to classroom to classroom. Then one day the team wanted me to try a different classroom. Mr. Bees taught a harder class that worked on reading. When I went, I didn't know how to read, and it was very upsetting. But, Mr. Bees knew that I understood what was read to me, because I did so well on my first comprehension test. Mr. Bees wanted to help and he wanted to find a way for me to show my high I.Q. The next day, I went back to my speech teacher. Because of what happened in Mr. Bees room, she started to put words under each picture to help me learn the word that went with each picture. Without the picture, I could not read or spell. It helped a little, but sometimes, I didn't look at the word, because the picture was more meaningful. I realized that I thought with pictures.

Soon, I started going to a classroom with a lot of typewriters. I started to use a keyboard first with my head pointer, then with the hand splint. It was okay, but I didn't like it, because I was coping words off of a paper instead of writing my own. Then I saw something that the teachers were using. I could not help it, I had to go over to it, even if I got in trouble, because it was just too cool! Every day I went over to it when I was in that room to use the typewriters. Pretty soon, my teacher introduced me to an Apple System Computer. In two months, I learned everything about that computer. Every time I was around computers, I watched others use it, and I learned to use it without reading the book or taking a class. When they added a key guard to the computer keyboard, I could type with my hand splint on. I could only use the Apple Computer for word processing or to play games.

My teachers wanted to see how fast I was writing, but I was bored because I was just copying something from a book into the word processor. Suddenly, I found my favorite thing in the world; spreadsheets and numbers! Oh my God! This was the best thing the team did for me, because I saw how numbers worked! Even my own teacher began coming to me for help on how to use the computer and spreadsheet program. She was so amazed that I had picked up all of this information within such a short amount of time. My speech teacher heard about what I did with the computer, she thought of an idea that might help me more than the picture book.











When I was 16 years old, my speech teacher changed my life when she showed me my first high tech A.A.C. device. This device had voices in it, so that people could listen to me speak, instead of talking for me! My first speech device was a Touch Talker. One day, my speech teacher put this Touch Talker in front of me with my hand splint on. I didn't know what it was. It looked like a big box with a lot of holes on a key guard. This box also had a lot of different pictures on the screen. After using the Touch Talker for a few weeks, I thought it was a joke, and that this device was not going to assist me.



You see unlike how we made my communication book, one picture and pages at a time, the Touch Talker was already programmed. It was not similar to anything that I had used before. I had trouble remembering the new language program because all of the pictures had totally different meanings to me. At one time, there were 144 pictures equating to almost 10,000 words on this Touch Talker. To resolve the issue, I needed to have the pictures that had the meanings to what I had learned over the years. Remember, I started using Bliss Symbols at the age of 4! I am now 16! So we cleared out the page sets from the device. We built a language system specifically for me using the Bliss Symbols and pictures from my communication book because I knew these meanings and already communicated effectively with them. Then we came up with pictures that I could associate with words, and phrases, so that I would remember them when paired with a meaningful picture.



As we got started, the first picture I picked, was a picture of an apple. This picture to me meant, food, eat, hungry, and the color red. That's right, for this 1 picture, it meant 4 different things. The challenge was that I had a picture with a several meanings. I told my speech teacher that I would like to program like my communication book. I learned on my Bliss symbol board that green colored icons = verb, blue = adjective, and orange = nouns. Now, when I selected apple + orange key, "food" is the word that appears in the message window. If I select apple + blue key, "hungry" appears in the message window, and if I select apple + green, "eat" appears in the message window. But we cannot forget about additional word forms like: "eats", "eating", "ate", "eaten" and "to eat". Now 1 picture must represent 8 words. We continued to create word combinations with the symbols. As we added more pictures on the device, we added an end key because we did not want any key to mean itself. If I am using the apple picture, and I want to say the word apple, I push apple key + end key = "apple". While programming, the first mistake we made was that we didn't put a space at the end of the word. So in the message window the words were clustered together. If I wanted to say, "I am hungry", the message would cluttered together to be "lamhungry". Unfortunately, to fix this problem, we had to change each key. The process was a lot of work, and took months to complete, but it was my unique system, and I am the only person who understands it. Remember that everyone is different and thinks differently.





When the programming was completed, my AAC device was ready to go! I could not believe that I was actually going to be able to talk without help! I was in awe, and my speech teacher started to cry.



I was excited, because now I was going to have a voice, and people can now listen and hear me, but it was still very hard for me. When I used my speech device, I had to remember what all of the pictures meant to me. I also needed to learn when it was the right time to use it. I thought an idea to help me. I needed time to play with my Touch talker because that's how I learned. In order to have more time, I needed to take my Touch Talker home.

I had a long 50-70-minute bus ride each day. On the bus, I began to learn sign language, made friends, and met nice girls. To have my speech device all the time was important.



After a few months, our request was approved and when I was on the school bus, I used my speech device to communicate! My bus driver thought it was cool! About a week later, I started to turn down the volume so that I could just practice using it on the bus ride alone. This helped me because I needed a lot of time to learn all about the Touch talker, and what it could and could not do.

Like most technology, it can fail! A moment that I am proud of; because I understood technology, I knew how to handle tech bugs! A few times, I found bugs or issues in my speech device. One trick was to turn it off and wait a few minutes, then turned it back on, and it worked fine.

Once, when I was home, I found a bug in my device. The next morning, I wanted to find the bug before I reached school. I found it, and remembered it, and then I turned off my device. As I headed to the classroom, I turned my speech device back on. I asked my teacher if I could see my speech teacher. My teacher asked me why? Did you break it? What? I felt like she had no faith in me! Why would she doubt me? I finally showed my speech teacher and together we called the company. When we were connected, the company acknowledged there was a bug in our system, and that you found it because you are using the device a lot. My speech teacher clarified, no, I did not find it, Todd did!



Just because I have a speech generating device, does not mean that is my only voice! By 16, I used my voice for small words like "hi", my communication book, communication board, my speech device, plus I had learned some sign language! It took me a few months to use my Touch talker more than my communication board and my picture book. But one day, I was ready to use my speech device as much as possible. Using my Touch talker, I said please put my bliss board, and picture book in my backpack on my wheelchair. The teachers were happy, but I wondered if it was right thing to do? That is the question, I am going to answer a little later on.



Now, I was using Touch talker more, but my teacher Mrs. R. wanted me to use it even more then I was. She wanted me to just use my speech device, even though I knew that I can say "Good Morning" to her. WHY? I didn't want to say it to her, but I did say "Hi" to her with my voice. Well, she doesn't like that because I didn't use my Touch talker in front of her. She wanted me to use Touch talker 100% time! I asked myself, why? I can say "hi", "yes", "no", "thank you", and I didn't know why using my voice was not okay. Why should I stop to use my device, when I do have a few words that I can say? I chose to keep using my voice for a few things, but when people don't understand something that I try to say, then I will use my Touch Talker. Some people like it, but some people didn't. I don't care what they think! This is, my voice!

A new year and a different classroom, but my classroom was next door to Mrs. R. She heard me joking with my Touch Talker. It said phrases or words in funny ways, which made the students laugh, and they kept asking me to do it again and again, and I did, because everyone was laughing. I was laughing too, and having fun, but when I saw Mrs. R., I got in trouble? I don't understand why, because I was using my AAC device? My classroom teacher was present, and she was laughing too. Maybe, Mrs. R. didn't hear that everyone was laughing with me, but I learned that I need to be careful to say the right things at the right time.

Mrs. R. didn't like was how I liked to type out my entire phrases or sentences before I spoke. She wanted my device to speak each word, which drove me nuts! I like to think about what I want to say, and maybe even change it 5 times, before I say it! Because people speak faster than those of us who use a speech device, they don't want to wait for me to answer. When using my speech device, I need time to think, look at speech device, remember what a person said, then construct my response or my own question. I tried using the phrase, Please, be patient with me. Sometimes it worked, but instead, I just like yes and no questions because it is faster, and then they aren't waiting around for me to communicate.



When I started to take my AAC device home, I didn't use it, because my family knew me. Why should I have to use it? If I had to say something my family didn't understand, then, of course I did use it. My AAC device is now part of my life because it is the fastest way to communicate. I don't want to change my life, but rather than getting a speech device at 16, I have always wondered what if I started with a device, when I was like 8? I ask that question a lot! I love my speech device, but I felt and still feel that people look at it, not me! That is why I keep using my voice to say "thank you", "yes", "no", and "I don't know", because it is not words that I need people to listen to, it has everything to do with seeing and communicating with me! People lack compassion, and their negative attitudes towards me, make me think about how people treat others with disabilities, especially individuals who cannot respond verbally.

Now that I had been using my speech device more, new opportunities to use technology were heading my way! The Candy Lady, the teacher who always gave me candy, was working on something more for me. She knew I liked the computer. Now, she wanted me to use the computer through my AAC device! We worked on it for months. There were a lot of cables and a T, Tam that would help my device talk to the computer. When it was all working the right way, it was awesome! Oh my God, it was awesome! I could write a word faster than spelling it out. I can remember it like yesterday, because it made me different. Now I could use my speech device for writing, and I didn't have spell every letter out. I hated typing every letter, because it took me a long time! What used to take me 90 minutes now only took 30!





#### TouchTalker

#### Liberator





#### **Pathfinder**

ECO



Time to make more goals for myself! I knew that my speech device, and now computer technology would turn my life around! But we still had a lot of work ahead of us. Looking back, what if I didn't tell someone to put my bliss symbol board in my backpack? I knew if I hadn't, I would have used that board every day.

1988 was the last time that I used my board. While writing my PowerPoint for my Boston Speech in 2018, I was looking for a picture of bliss symbols, I found a picture of my old communication board. Wow, I looked at it for 5 minutes! I remembered it, and I was very shocked, it had been 30 years since I last used it. Then, I looked around me because since then, I have been through many speech devices that kept advancing with the rate of technology.

I started with the Touch Talker, then to the Liberator, the Pathfinder, and lastly my ECO2. The ECO2 was a huge upgrade that offered me a far more advanced communication device. This is my connection to the social world. Not only does it help me to speak to someone while I am out being social, but now I can connect to the internet from almost anywhere, text people from my computer, and I have access to use social media, like Facebook. I access my apple computer through blue tooth with my ECO2. I use my huge flat screen TV to project from my computer, which gives me access to communicate via email, use the web, and communicate with anyone while at home. Each speech device that I have purchased or I have, has helped me get everything that I need. Now, I can talk to people, use a computer, make schedules, and create and manage my budget, and write my speeches for events.

Now I would like to take you a small journey back to the summer of 2016. I was asked to do program at UB. I said sure, because over the years, I had helped their programs, and they also helped me to learn different things. This project was 5 weeks long, but 2 days in a week. Even though I had little to no support staff, I kept my promise to go there. I would sit at UB, waiting for 3 hours before and after the program, but I was happy that I did, because I met nice people, and I did awesome projects. Dr. H asked me to do this special project with him, because we had worked together for about 30 years. He asked me keep the journal each time. I agreed, but I had no idea what I was walking in to.

On the first day, we gathered in a big circle, there were O.T., P.T., Speech, Dancing, and Art students with no experiences. Additionally, there were other people participating that were not students. Supposedly, this was a project for all people to bring their talents together to make "something". At the start, students wanted the participants, like me, to share about ourselves. I did that, but then they needed us to write down information? I couldn't, so I asked a lady to help me. She agreed, but she said she had little a problem, she only had pink pen! I looked at her, laughed, and I said why not? So, we wrote our information in, pink pen! A friendship had begun.





Then a different lady was in back of me. I knew her, because she had done a project years ago with me, and she remembered me too. Today, we are still good friends. This first day, she asked me, what I wanted to do here at project participate? I told her that I wanted to take pictures by myself. I had never been able to take my own pictures, because I can't hold a camera. I wanted the chance to show people pictures through my own eyes.

The first 5 days of the program were BAD! You see, the students were not thinking about the different needs of people. As I wrote in my journal and shared with Dr. H and the project team, I believe things began to get better. With my help and ideas, the students rigged a mount to hold an iPad high enough, above my communication device on my wheelchair, so I could drive and look at the screen to take pictures.

With a Tecla shield or blue tooth adapter, a "Jelly Bean" switch, and the iPad set in Point mode, I took my first pictures! I drove my wheelchair around the project spaces, stopped and looked for a great shot. I ended up taking over 50 photos of the participants and students!

The best part was in the end when my friend with the pink pen, worked with me. I used the iPad to video a short skit of how we first met. On the last day, we had family to come to see what the whole group had accomplished. I showed my pictures and my first small movie about how I met "Pink Pen". It was awesome! In the end, the show, was a true testament that when people communicate, think outside the box, and work collaboratively, great things will happen!



My Alexa has really opened up doors for me, but not literally yet. Maybe, one day! With using my speech device, I can tell Alexa to turn on the lights, play music, tell jokes, adjust my thermostat, and much more. I wished I had this technology and a speech device when I was 8 years old because it might have changed my life sooner. I would have used my speech device more. It is a tool for me to use, it has power to do different things, and I have faith in the computer world to keep making accessible technology that will continue to change my life. After all of my struggling for independence, I now have the FREEDOM to do WHAT I WANT, and that is something I have dreamed of my entire life!

My experiences have driven me to work on something for me. I am writing a book. It is a story about my life. I am glad I have ECO2, because now I can go to the mall, and open the notebook and start writing. While I sit, people walk in back of me, and can see what I am doing. Sometimes, I laugh at them because they don't have any idea what I am doing.

I've always wanted to put my life into writing, so the best way I could think of was writing a book. I didn't want the entire book to be based on my point of view. I am writing multiple short stories based off of my real life experiences, along with experiences of my loved ones and friends. When I am done, I look forward to sharing my book with the world.





Some things to remember from my speech today: I may have some physical disabilities, but as soon as anyone hears the words "disabled", or "special", it's like they don't know how to act anymore. The majority of people categorize disabilities as 1 big group, even though not a single person is the same. This then makes it seem like we have the same brain activity, the same physical disabilities, like we are all the same. We aren't! It's very frustrating to me, because I am lucky enough to have full brain activity. I consider myself to be very smart, but it is upsetting that it only takes someone to look at me, and think that I don't understand anything. I think that there is a big misconception on people with a disability.

To reach the place where I am now in my life has been a tough, and a hard working journey. I know we all wish for, and dream of the things we want, and the people we want to become. All of those thoughts I've had in my head as far back as I can remember. I've pictured my lifestyle and the way I want it to look many different times. In the long run, I truly believe having dreams to follow is what gets you through life, and hopefully I will achieve all of my dreams someday.

# FREEDOM

In closing, you never know what someone is capable of, until you give them the opportunity. Also remember, to really look and listen when you are helping all individuals. Just because it works for you, or has worked for others, doesn't mean it will work for that person. Everyone is an individual.

If we hadn't recreated my language program, I definitely would not have the Freedom that I have today. I just really wish people could understand more about people that are labeled "disabled". Just like you, those that are so called "abled". After all, we are all human, with real feelings.

See me, TODD, not my disability! Please never count me or someone like me out, just because we do not fall into your opinion of "capable". Give me or someone like me a chance, and just wait to be AMAZED!





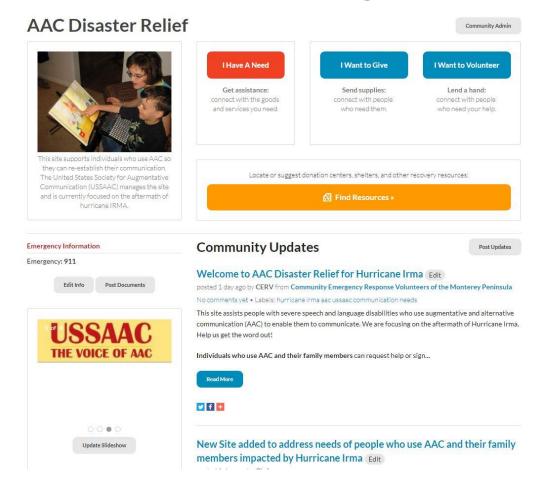


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#### **AUGUST 1-2**

AAC Camp, Pre-Conference Workshops, Executive and Council Meetings

#### **AUGUST 3-6**

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#### 1-2 DE AGOSTO

Campamento de CAA, Talleres Preconferencia, Juntas Ejecutivas y del Consejo

#### 3-6 DE AGOSTO

Congreso principal en el ICC de Cancún, México

Rodeado por la cultura maya y con fácil acceso a playas hermosas, tiendas, restaurants y tours tanto de Cancún como de la Riviera Maya, el congreso de ISAAC contará con eventos de CAA, perspectivas, lo último en investigaciones e innovaciones clínicas, talleres, seminarios, exposiciones de las compañías más importantes, eventos sociales y entretenimiento. Todo en un sitio culturalmente único.

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