

Transcript of a DVD video and AAC-RERC webcast of

**How Far We've Come, How Far We've Got to Go:
Tales from the AAC Trenches**

by Michael B. Williams

Presented as part of *Building and Maintaining Social Networks by Strengthening Communicative Interactions* by Sarah Blackstone, Ph.D., David Wilkins, Ph.D. and Michael B. Williams, M.L.I.S. at the California Speech-Language-Hearing Association's 2006 CSHA Annual State Convention in San Francisco on April 1, 2006. Based on the Eighth Annual Edwin & Esther Prentke AAC Distinguished Lecture of the same title presented by Michael B. Williams at the Annual Convention of the American Speech-Language-Hearing Association (ASHA) in San Diego on November 18, 2005. Copyright by Michael B. Williams, 2006.

Thank you Sarah.

Title slide

Before I begin my formal remarks today, you should know I developed much of the material in this talk for the Edwin and Esther Prentke Award Lecture, which I delivered at last year's ASHA Conference. Here are the Prentkes:

photo of Prentkes

I want to thank ASHA for bestowing this honor on me, and the Prentke Romich Company along with Semantic Compaction for their generous help and support, which enabled me to transform my wispy dreams of a presentation into a concrete reality.

Good afternoon, ladies and gentlemen. It's a real pleasure to be here this afternoon. When I was considering what I might say to you today, I started thinking about the word lecture. The word lecture has many meanings, right? There's the lecture you get when you are five years old, and you're out in the backyard with a friend, bashing the heck out of each other with sticks that look like good-sized tree branches. Your mom, in order to preserve her sanity, and in an attempt to uphold public safety, sticks her head out the window and yells, "Stop that this instant before you put somebody's eye out."

Then there's the lecture you get around November, when you're in fourth grade. The teacher walks in and goes, "Now class, today we're going to learn about the first Thanksgiving." You're sitting there, bored out of your skull, thinking, "Geez, Louise, not the old Pilgrim and Indian bit again."

And then there's the type of lecture you get in graduate school. You hear stimulating stuff like, "strategic asset allocation in inefficient markets." Boy, I can't wait to hear that one.

And then there's this lecture. Don't worry! I'm not planning on being a scold, a purveyor of pap or a pedant.

In preparing this talk, I went through files that hadn't seen the light of day in decades. Among the interesting things I extracted from those files was the date of the first talk I gave using synthesized speech. It was May, 1980, twenty-five years ago this year. So I have been involved with AAC for over a quarter of a century. I'll get back to that first speech in awhile, but first I must digress.

Although I am well known today for my work in AAC, I didn't just spring whole from the head of Dennis Klatt one day. I had a rich and meaningful life before I even heard the term augmentative and alternative communication.

I've always been willing to give a girl a ride:

photo of me with girl on tricycle

A first grade picture:

photo of my first grade class

They gave me this my senior year in high school:

high school service award

Two years earlier, the powers that be didn't even want me in their damn school. The final decision on whether I got in or not was left up to the school nurse. The school nurse! Can you believe it?

I graduated from college in 1961, and like many people in my generation, I was smitten by John F. Kennedy.

Photo of JFK

But I didn't sit idly by and watch the JFK train chug along the tracks. I didn't want to miss out on all the excitement, so I joined the local chapter of the Young Democrats. I should add here that this was my ambulatory phase of life. I could lurch my way along from place to place in my spastic imitation of walking. Of course, I fell on my face a lot, but I didn't care. At that point in my life, I was living by the motto: no pain, no gain. If I had to walk long distances, I would grab hold of somebody's arm and move at a good clip.

So here I was, this severely disabled guy, with lousy articulation, trying to blend in with this bunch of mostly up-and-coming professional people, the majority of whom were superbly groomed and decked out in sharp looking clothes. Sorta like an ASHA convention.

Have I told you yet how I communicated with people during this phase of my life? I learned early on that idle social banter, the verbal caffeine that fuels most societal interactions, was an activity in which I couldn't easily participate.

Fleeting social niceties, jokes, slices of juicy gossip, all were swept under my mental carpet so I could concentrate on conveying what I considered the really important thoughts in my mind. I did this using the most laborious method possible. I drew the letters of each word in the air with my finger, while my would-be linguistic interlocutor winked, blinked and performed all manner of mental gyrations trying to figure out what the hell I was saying.

My really, really important thoughts were typed on my standard manual typewriter at home, carried to the place of conversation and presented to my listeners with the gravest solemnity, as if they were the Ten Commandments. Needless to say, with communication methods such as these, one has few friends.

But I digress.

So I am in with this bunch of Young Democrats...remember them? They think I'm a creature out of a fifty's horror movie, and I'm as nervous as a vegetarian at a cattlemen's convention. It's not your ideal social situation. But ever so slowly, we learn ways of working together. Somebody discovers he can decipher my air writing, and I demonstrate I'm not the blob incarnate. Somebody else offers me rides to and from meetings, thus removing my parents from the transportation equation. Then it's discovered I can write—well! This turns out to be a seminal event. I am assigned to write key articles for the Chapter newsletter, which wins an honorable mention at the next State Democratic Convention. I am flabbergasted.

I find I like writing so much, I volunteer at the local Pacifica radio station, KPFK in Los Angeles. I write news copy off the Associated Press wire service for broadcast on the evening news. The job is so pressure-filled that I soon realize this isn't my cup of tea, but it's okay, because I enjoy the atmosphere of the station and decide to just hang around. It was a fortuitous move on my part, because semantic lightning was about to strike me right between the eyes in the form of another station volunteer named Art.

I am in my mid-twenties during the time this story takes place. And to my twenty-something eyes, Art looks ancient—about fifty. I notice another thing about him. He's a post-polio guy with long leg braces who drags himself around on a pair of Canadian crutches. Art and I often have short conversations with each other. He can decipher my air writing pretty well, but he always walks away after a few interchanges. One day, he comes in and throws something at me. “Here, try this,” he says in an irritated voice. I look at what's on the table beside me. “A checkbook cover? Why is this old fool giving me a checkbook cover?” I wonder to myself. Art deigns to endure my blank stare a few milliseconds. Then he comes over to the table, grabs up the object in question, opens it and slams it back down in front of my face. “The next time you talk to me,” he snarls,

“use this!” Then he calmly walks away.

By this time, my heart is pumping harder and faster than a Thompson submachine gun in full cry. “Damn,” I said to myself, “what have I done to deserve this?” Slowly, I pull myself together and look at what's on the table. Yep, it's a checkbook cover all right. But instead of the usual check pad and register inside, I find the letters of the alphabet neatly pasted in rows.

Now, some of you older moviegoers will remember that long opening sequence of Stanley Kubrick's *2001* when the apes discover the concept of tools and their ability to make them. This is exactly how I felt looking at that rudimentary letterboard. Holy Batman, you mean I could use this instead of air writing?

Remember this all happened in the mid-1960s. And now that I'm armed with my wondrous new communication tool, I'm going to fast-forward the tape of my memory to August, 1969. My best friend, Jim, and I have just arrived back in the states from Europe. And right on cue, here's proof that I indeed was on the continent:

photo of me at Eiffel Tower

Why, I think I look absolutely marvelous in that photo. The past two years had been hectic. Both my parents died. I sold the family house. I moved from a stultifying suburban neighborhood into the heart of Hollywood. I learned the painful ins and outs of living alone. And, oh, yes, I partied a lot, too.

But I digress.

So here I am, freshly returned from Europe. My best friend, Jim, is getting ready to go to graduate school in Berkeley. I decide I will move up to Berkeley, also. I am tired of all that ersatz glitz and glamour that is Hollywood. And then there is all that urban sprawl of Southern California. Los Angeles is the only place I know where you have to get in your car just to go to the bathroom.

I am attracted by Berkeley's politics and counterculture. I also think it would be nice to live near a large university. I have no idea that Berkeley is also the hub of a nascent political and social movement that will radically alter my life.

I never think much about disability. I have spent the first thirty years of my life stumbling around, pretending I was passing as a normal person. I see no reason to change my attitude about that. My Berkeley apartment is great. It has a bedroom, a huge kitchen with a pantry, big wood-paneled dining room and a large living room with a bay window facing the street.

Oh, did I mention this apartment is up a flight of stairs?

photo of my Berkeley apartment

So I'm in this swanky abode, which I'm essentially a prisoner of, but I don't worry too much about getting out in the wider world, because I've decided to really concentrate on my writing. To that end, I've set up my desk and typewriter in the bay window so I can observe what's going on outside my door.

And, by the way, I should tell you I have a six-foot-tall, handmade, papier mâché owl standing in my living room, a parting gift from one of my artistic friends in Southern California.

So here I am, sitting at my desk, watching the passing parade float past my window, when I notice a most unusual sight. There is this person in a wheelchair going down the street, and he isn't being pushed by anybody. I am dumbfounded! I've never heard of a motorized wheelchair, much less seen one. In the days following, I sit in my living room and watch many more people using wheelchairs whiz past my window. "What's going on here?" I thought to myself, "There must be some kind of hospital or rest home around here."

A couple of months later, somebody suggests I visit this guy Ed Roberts and his mother, Zona, who live a few blocks from my place.

photo of Ed Roberts with Willy Winokur

Upon learning Ed was disabled and in an iron lung, the guy who runs my interior monologue starts yelling in my ear. "Yeah, yeah, yeah, Michael, this is something you really want to do—waste a perfectly gorgeous afternoon chatting up somebody in an iron lung AND his mom." But I went, of course.

I still remember my first meeting with him as if it were yesterday.

I'm going to digress again to tell you something about Ed. You would enter his house from the back, because that's where the ramp was. You'd come into the kitchen and begin to hear a faint hissing and pumping sound. This got louder as you proceeded through the dining room. Finally, you saw it: the pumping, hissing, metal monster of an iron lung that was ensconced in Ed's tiny living room. This is Ed's office, bedroom and den. It's also the Ed Roberts think tank, where dreams of disability rights are strategized into reality.

So this is what I encounter when I first enter Ed's domain.

I'm really nervous and scared to death at the same time. There's a chair next to the iron lung. I sit down, trying to avert my eyes from the small windows in the side of the machine that reveal parts of Ed's body. "So you're new in town," a voice says. I realize Ed is talking, but I don't know where to look. If I turn my head sideways, all I see is the side of Ed's head. Finally, I try looking up, and there, over the iron lung, is a mirror with Ed's grinning face and twinkling eyes reflected in it.

photo of Ed in iron lung

Our two-hour chat seemed like minutes. Ed had a very laconic style. He could thoroughly interview people without appearing to do so. I realized this soon after I came home from that first visit and started playing back my mental tape of the afternoon. I was shocked to discover that I had been enlisted in the Ed Roberts Disability Army.

Ed changed my life. For instance, he talked a friend into loaning me his old wheelchair so I could try it out. I quickly learn that the phrase “wheelchair-bound” is a damn lie! Within a month I have my own motorized wheelchair and am tooling all over Berkeley, acting like a teenager at age thirty-three. I start to become involved with my community for the first time in my life.

Sometimes I want to go places further than my wheelchair will take me. Somebody tells me about a collective taxicab service that uses old cars painted in psychedelic colors to shepherd people in various states of altered consciousness around town. I figure if they can handle someone whacked out of their skull on LSD, they certainly can handle the likes of me. And I'm right. However, I have a slight problem. How do I call a cab when I need one? Well, I have a speakerphone and a tape recorder, so I get somebody to tape a prerecorded message that will send a taxi to my place. I dial the number, hit the play button and the dispatcher hears the following:

sound of male voice directing a cab to my address

By the way, the guy who made the tape for me is a famous linguist in his specialty. I've known him since he was a fifteen-year-old kid, hanging out at KPFK. He attended UC Berkeley, and here's a citation of his dissertation:

Okrand, Marc 1948-
Mutsun Grammar by Marc Okrand
1977
Dissertation

And here's a picture of Marc lecturing to a group of people about his field:

photo of Marc Okrand lecturing

Anyone know what it is yet? Well, I've strung you along enough. Marc is better known for this:

cover of Klingon Dictionary

He creates all the Klingon language stuff for the *Star Trek* movies. Actually, that's just his avocation. In his day job, he is director of the National Captioning Institute in Washington, DC.

But I digress.

Ed Roberts also hooked me up with the collective who put out the local radical counterculture newspaper. I start writing a column on disability which covers both personal experiences and the emergent disability rights movement.

Quasimodo newspaper clipping

I know I have arrived when I write a negative column about rock promoter Bill Graham and get a call a few days later from one of Mister Graham's henchmen, who tells me where I can go and what I can do. I laugh hysterically as I hang up the phone. When the Center for Independent Living opens its doors under Ed's leadership, I start hanging around the place on a daily basis.

photos at CIL

Because CIL serves a diverse group of people with disabilities, I am exposed to a wide range of disabilities and see an exciting array of communication and mobility strategies. I am also exposed to a multiplicity of technologies. I am smitten by some gadgets deaf people use, like this portable TTY:

the MCM by Micon

This is the MCM, which was manufactured by the Micon company. As you can see, it's very compact, and I can tell you it weighs next to nothing.

So I buy one of these devices and use it as an electronic letterboard. I find it makes communicating much easier. People appreciate not having to assemble words in their heads as I point to letters on a board. I am really cooking with my communication now.

Things are heating up at CIL. The first federal disability rights legislation has been stonewalled by several presidential administrations. Now Jimmy Carter is elected president. Disability rights leaders throughout the nation decide to turn up the heat on Carter's fledgling administration in an effort to get it to sign these 504 regulations.

Mass demonstrations take place at federal buildings in key cities across the country. When the buildings close for the night, the demonstrators refuse to leave. They remain in the buildings for several more days until authorities remove the disabled protesters from all sites except one—San Francisco. We remain in the building a month.

Because I have a press card from KPFA in Berkeley, I can enter and leave the Federal Building without much hassle. This helps greatly in gathering firsthand information on the demonstration for a special issue of the CIL magazine, *The Independent*, which I now edit. When a small group of protesters from the federal building is selected to go to Washington, DC to exert more pressure on the Carter administration, I travel with them. And here's a picture from that trip:

Photo of me at 504 protest

Do I look like a protester, or what? I was a very tired protester when that photo was taken. Ultimately our efforts are successful and the first disability rights legislation, Regulation 504, is signed.

But I digress.

One unfortunate side effect of my DC trip is my MCM device goes missing—from a church, no less, and I go back to communicating with a letterboard.

Although I continue to edit the CIL magazine, I'm now living with my future wife in the suburbs and commuting to Berkeley twice a week. The pace is hectic, and I have no time to keep up with the CIL gossip like I used to. This becomes apparent when out of the blue I get a call from somebody who says he's John Eulenberg at Michigan State University. He claims to be the director of something called the Artificial Language Laboratory and says he's doing a sabbatical at Stanford. Then he tells me he's teamed with CIL and a company called Telesensory Systems on a grant to explore the viability of speech synthesis for people with dysarthria. He says he's read all my writing and he thinks I'm a wonderful communicator. Then he asks me to participate in the project. Well, I've never heard of this guy or this grant. I've heard synthesized speech a few times and decided dysarthria isn't so bad after all. I think this guy is a nut job. And yet, I agree to meet him.

Photo of John Eulenberg

John is a heavy-set guy, but his size is offset by his soft, slow speaking voice. It's not the voice of a person who is trying to be patronizing. No, it's the voice of a person who wants you to hear every word he is saying. And then there are those eyes. They're not the eyes that attempt to pierce your soul. No, they're the kind of eyes that gently tug at your spirit and draw you into anything John is doing.

John tells me what he's been doing at the Artificial Language Laboratory. Most of it sounds fantastically fantastic and impractical, like people with dysarthria independently ordering pizza over the phone.

I ask myself, do I really want to hitch my wagon to this eccentric's star? My inner voice gives me an immediate answer. "Oh, why the hell not Michael. Do you have anything better to do?" So off I go on the Eulenberg Express.

One of the projects in the grant is a field test of the first commercially available speech-generating device. Three people participate in the field trial. This is the device:

photo of HandiVoice 120

It's the one on the right. Behold the Handivoice 120, manufactured by HC Electronics.

You'll notice the numeric keypad and the really tiny display. The guts of the device had a Votrax speech synthesizer. There were a thousand items burned into read-only memory: words and phrases, plus forty-eight phonemes and some other stuff, like a space, comma and period. So how did we make this beast talk? Well, look at this:

page of HandiVoice 120 vocabulary code set

This is one page of the vocabulary set of the HandiVoice 120. Each word has a three-digit number associated with it.

close-up of HandiVoice codes

So, if you want to say the word “down,” you would use the numeric keypad and enter “three-eight-eight” and push the talk key. Or if you want to say the sentence, “I’m ready for something,” you would enter “four-zero-nine, three-nine-zero, four-zero-eight” and then push the talk key. One had to have the patience of Job and the heart of a lion to say something of any substance with this device.

Here's what the HandiVoice sounds like:

sound of Rick Creech on HandiVoice 120

Did you notice those clicks after every sentence? That is the sound of Rick's tape recorder starting and stopping. If you want to make a speech with this device, you have to build it one sentence at a time, taping each sentence after you key it in perfectly.

Much later in the grant cycle, I have an opportunity to fool around with some prototype equipment being developed by Telesensory Systems. It's a text to speech system that uses TSI's own speech synthesizer called the Prose 2020. Here's a soundbite from a talk I gave using this equipment:

sound of me talking on TSI prototype

Sounds good doesn't it? Unfortunately, the equipment covers the entire surface of one of those carts you put microwave ovens on. I push it from room to room whenever I want to use it, but it's a portent of things to come.

Now it's time to go back to that point twenty-five years ago when I'm about to give my first talk using a voice output communication aid. I am very nervous. My palms are sweating and my stomach is doing cartwheels. I want to go home. But I step on stage and enter the future.

Unfortunately, I couldn't locate any audio of this event. So I want to read the first and last paragraphs of what I said that day.

Say the Word and You'll Be Free

presented May 22, 1980
text from *Communication Outlook*
Vol. 2, no. 3, August 1980

The message is as relative now as it was then. Here's the first paragraph:

“This talk is dedicated to Albert Sheely. Al is a thirty-seven-year-old man with cerebral palsy. He has been moving from one institution to another since the age of ten. He has never been taught to read and write. He has no speech. His principal means of communication is nodding yes or no to questions people ask him. People never ask him many questions.”

And here's the last paragraph of that talk from 1980:

“Let me conclude by quoting a few lines from two of my favorite poets, Lennon and McCartney. ‘Say the word and be like me / Say the word and you'll be free.’ We must not rest until everyone can say the word.”

“We must not rest until everyone can say the word.”

Ladies and gentlemen, we still have much work to do. Thank you for your time and attention this afternoon.

Thanks

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