

**Rick Creech**  
**Testimony before the**  
**United States Senate Special Committee on Aging**  
**April 27, 2016**

Chairwoman Collins, Ranking Member Casey, and other members of the Committee, thank you for inviting me to speak before you today.

There can be no social engagement with others without interactive communication.

As someone who was born with cerebral palsy and was without the ability to speak in the accepted way, I grew up lonely and isolated – except for my parents and grandmothers. It was not until I received my first vocal output communication device that people began know that they could speak to me and I could speak to them, well, at least, some people did.

I was born in 1954 in Smithfield, North Carolina. Back then babies like I was were not expected to live, and if we did live, we were not expected to be out in public, we were not expected to be educated, and we were certainly not expected to become independent adults. However, I had extraordinary parents who trusted in God, and not in all the doctors, the therapists, the social workers who said I would never do that, or that, or certainly – not that.

My father told me once, and I never forgot this, that he wanted me to learn math, so that I would be able to manage my own money. He wanted me to read, so that I would be able to read and understand anything that someone might write about me, and what should be done to, and for me. And he wanted me to be able to communicate, so that I could have control over my life.

My parents presumed competence in my ability to learn to do those things. They insisted that I learn. Boy, did they push me. When it came to teachers, I would always prefer to have my mother because with her, I could slack some. With my father, the Baptist preacher, there was no way I could slack. He was more demanding than God was with Moses. However, they taught me that I was competent. I was competent enough to go beyond their goals – and their dreams – for me. This is what great parents, great teachers, and great schools do.

Supporting individuals who need to use AAC – is not simple. The person may want to communicate, however, the person will have to be taught how to use an augmentative and alternative communication device for his or her, expressive Communication. The vocal impaired person will not know how, what, when, or why to express thoughts, feelings, ideas without being encouraged, without being pushed.

I am speaking from experience. Initiating a conversation and carrying on a conversation is the hardest thing I do in life. To put it simply, I am no good at chit-chatting. I believe that there is an optimal age to learn communication skills. That age being as young as possible. However, I was 28 when I got my first voice output communication device, and, although I still have deficits, I can expressively communicate my ideas in conversations.

I had to work extremely hard, and I work long hours to learn to communicate with an AAC device. I used to read passages from the Bible and newspapers aloud to practice with my AAC device. My point is that we cannot provide a person with assistive technology or AAC, and expect people to use it.

I recently got the Amazon echo to help me to control the lights in the house. Sometimes I am ready to throw Alexa out the window, and I will not tell you the names my wife has called the thing. Amazon Echo is simple compared to AAC devices. I started telling people many years ago that assistive technology without training is not assistive.

Even today, as proficient as I am with my AAC device, I cannot talk to some people because they are too much in a hurry, or too caught up in my Accent1400, saying things such as, what can you say?, can you say my name?, or they are hollering at me as if I'm deaf, saying "it – is – good - to – meet – you, what – are – you – doing?" I get tempted to reply, talking to an idiot, but my parents taught me that if you cannot say something nice, say nothing at all, so I don't.

As I get older, I feel my body slowing down. My bones snap, crackle and pop – like Rice Crispies. My muscles hurt. Right now, I have my best friend and my protector, my wife, but she is almost my age and has a bad back, arthritis, and diabetes. I know that I might not always have my wife by my side. One day I will probably be in the care of a minimum wage worker, who will have 24 other patients all requiring less time and care than I. The only way I have to individualize myself to my care takers will be through my ability to communicate with them, so that they will be able to see me as a person rather than just another patient.

Of course, if that does not work, I could always call one of my three 250 pound sons, and say, son, I need help.

I would like to thank the Committee on Aging, for giving me this opportunity to speak here, although I do not think I am that old. I would like to thank the Association of Assistive Technology Programs for sponsoring my trip here. Before I started working for Pennsylvania Training and Technical Assistance Network, I worked with Pennsylvania Initiative on Assistive Technology. I started PIAT's Short Term Loan of assistive technology to adults nearly 30 years ago, so, maybe I am that old.

The communication device I use, the Accent1400, costs in the neighborhood of \$10,000. It is one of the more sophisticated AAC devices. However, even simpler augmented communication devices with speech output cannot be found for less than five thousand dollars. The AAC devices with eye tracking, so that people can speak with them using only their eyes, cost in the neighborhood of \$20,000.

All of assistive technology, my AAC, my van converted for a powered wheelchair passenger, my smart home equipment, all cost upward of \$200,000. Still, ladies and gentlemen, that is cheap, compared with a life time, of taking caring of me in a nursing facility.

For my work at PaTTAN, Pennsylvania Training and Technical Assistance Network, I help managed its Short Term Loan of assistive technology program that provides assistive technology to school therapists and teachers, statewide, to try with their students. Each year the Pennsylvania Department of Education generously provides around a third of a million dollars for equipment. To a poor North Carolina country boy, that sounds like a lot, but we have constant waiting lists of students, And at the end of every year, there are requests that I have to cancel or delay until next school year because we don't have enough inventory to meet the requests. These students needs appropriate assistive technology to receive education so that they can grow to be productive and independent adults, who can be social members of our society.

I want to leave the committee with this thought. Living without being able to communicate, is like being behind four glass walls. You are able to see others, and people can see you, but you are ignored, or worse, talked down to, until you stop remembering who you are and why you are important.

Thank you,

Rick Creech  
Have a blessed day