

The Importance of Augmentative and Alternative Communication to a  
Non-Verbal Person. A Look at My Life.

By

Sarah Lever

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Thank you so much for allowing me to speak at this prestigious conference.

My Name is Sarah Lever. My home is in Charlotte, North Carolina. My degree is in Internet Technologies. I have a strong interest in technology, especially assistive technology for people with special needs.

We will look at my life. I will share with you the impact of not being a verbal communicator. This presentation will cover social, educational, and mental health issues. I will also tell you of the positive changes that took place after becoming an effective augmentative and alternative communication (AAC) user. I have always used devices from Prentke Romich Company because they meet my needs and their support system is great. I am an ambassador for this company.

As an infant I had much difficulty breast-feeding. My mom had to put small amount of baby cereal in with my milk. Then she would cut the nipple on the bottle slightly to make it easier for me to pull the mixture from the nipple into my mouth. When I began to eat table foods, all the food had to be put through a grinder. Otherwise, I would get choked.

When I was six months old my mom prayed that I would be able to call her mom. The next morning she was in another room when she heard me call "mom". That has always been an easy word for me to say.

When I was three years old I began going to a mainstreaming preschool. I loved being around other children. It was difficult when I tried to say "Let's play", and no one could understand me. As time passed my frustration grew. I would have periods of extreme anger: banging my head, hitting, biting and so on.

One of the recommendations I have heard over the past few years is that age three is a good time to begin a non-verbal child on AAC. At age three I was not in a wheelchair to support an AAC device. Most of my time at preschool was spent on a little horse I used to get around. Mom and I worked all the time trying to develop my oral motor skills. She would count with me. I would say each number after her. She would sing children songs and leave out words for me to say. I could say some of the numbers and words. Not many were clear, but did sound similar to what mom was saying. We read a lot of books and got new ones nearly every week. I would point to the pictures of the words she was reading. In our garden she would ask me where are the peppers? Where are the squash? I knew the names of all the plants. My receptive language was high, but my expressive language was not that hot. I went to speech therapy to work on my oral motor skills two times each week for five years.

My mom was caring for another non-verbal girl whose mother was a speech pathologist. Her mother had made her a word board. So, my mother made a word board for me. It had five hundred words; everything was color-coded. When I was in kindergarten my friends couldn't read yet and that made me feel like I was going crazy. I used to get very angry with everyone because they couldn't understand me. I used that kind of communication system for about six years off and on. It was hard on my mother and me because the vocabulary was so limited, just having the words my mother put on the boards. I couldn't experience that needed development until much older. Sometimes we used to get so upset because she couldn't understand me. We would lay on the floor for hours trying to get what I was thinking across to her.

We got an AAC device. It was nothing like the Liberator, Pathfinder, or Pathfinder Plus. I won't say the name of that device because it would give out my age. Just say it stayed broken. I had to use my low tech board a lot. If I had been using a Pathfinder at that time I would been a happier child. I can't stress how important it is for a child to be able to communicate using words at an early age.

The teachers and staff didn't have enough time to read what I was saying on my word-board. I was fortunate to have a secret weapon in the form of my best friend, Allison. She was beside of me as much as possible. Her reading skills were high and she always had the time to read my word-board. She would tell the teacher what I was saying even if they didn't want to know. She got mad whenever the teachers didn't wait for me to communicate. Once, I needed to go to the bathroom. She told the teacher five times. They never took me. When my mom came to pick me up from school the teacher told her, "Sarah wet on herself". Allison explained to my mom what had really happen. Allison and I did everything together. We were in the same Girl Scout troop. On Saturday mornings my mom usually took us somewhere: like a movie, the zoo, out to eat, or just play at my house.

When I was in the third grade they moved me to the hospital school where I got the physical therapy I needed. I didn't like leaving my home school but, it was the only choice they gave me. Really, it was not great because I had done the school work in the second grade. But, the teachers gave me time to communicate when I needed to say something and I needed that to work on my language skills. I don't think I liked it there. One day our class went on a field trip. When we got back to the hospital school I refused to get off of the bus. They called my mom to come and get me. The teacher was always saying, "I am pulling my hair out".

I got to go to a grade school in fifth grade for a half of the day. I was with my peers. The children didn't know me because that was not my neighborhood and I wasn't on grade level anymore. Really, a non-verbal child should stay on grade level for their mind-set. My emotions fell downhill when I figured out I wasn't on grade level anymore. That was the worst thing the school system could have done to me at that time. The mainstream experience is so important to a non-verbal child. Looking back, mainstreaming is the

way to go if it is possible to have all the supports in place. These supports should include a personal assistant in the classroom and a team made up of a physical therapist, an occupational therapist and a speech language pathologist. The professional team should be available to give recommendations to the teacher and personal assistant.

In the sixth grade I went to that school full time and I was in the mainstream classroom for a half of the day doing the science and history classes. They made me do all the work and the teachers called on me. I needed that for my mental health. I got to go on the class trip to Washington DC. I took my personal assistant. She was a neighbor and great friend to my mom. She acted like there was no disability and we traveled a lot on weekends while my mom worked. That is the way to act with a child who has a disability.

When I was in the sixth grade a speech language pathologist recommended that I get a Touch Talker and a computer. My uncle gave me the money to buy a computer. Mom and I went over to the Children's Hospital in Durham, North Carolina to see Karen Casey who is a speech language pathologist. She selected the Touch Talker for me. This was my first effective AAC device, but I didn't have long term support, because Children's Services of North Carolina only allowed me a few months of training time. I had to learn the device on my own, very slowly. At home I had friends that I played with all the time and they liked me to use the AAC device or the board.

The middle school age is important to any child; especially if the child is an AAC user. There are teenager problems from wanting to be liked to acne. One thing that I had going for me was my Girl Scout leader. She was extremely hard on everyone. She made us do homework each week. We called her Aunt B. She kept us busy and out of trouble. She made me to feel like a regular girl. When it was raining and I had to be outside selling Girl Scout cookies, she came down and helped me. She made me communicate on my Touch Talker a lot, and pushed me to work on the same things like the other girls. She brought in a person with no arms to teach us about disabilities. When the girls where talking about going on their yearly

trip, she asked mom if I could go. Two of my best friends were standing there saying, "please, please". I got to go on the yearly trip. It was to the home of the Girl Scout's, savannah, Georgia. It was a great time for everyone.

My first year of middle school was not that bad but, we had a couple of bad episodes like they weren't going to let me go on the zoo trip. We had to call our lawyer. Well let's us just say I went on the trip. The following year was a nightmare I had a teacher who said she had worked with orthopedically impaired children. I can say that she may have worked with orthopedically impaired children, but the school put her in a cross categorical class and it was just too much for her. I had a speech therapist and my communication was slowly getting better.

In the ninth grade, my mother and I couldn't take anymore of this craziness, so we moved to Charlotte where my grandparents lived. I can tell you that was the best move we could have ever made because I had some good years in public school. The Charlotte City Schools had much better special education classrooms for the orthopedically impaired. I had an extremely good teacher for my ninth grade year. By the afternoon of the first day I knew everyone. Also, the teacher and staff allowed me to talk on my Touch Talker. I was mainstreamed for my economics class and received a honor society metal. My grandmother was more nervous than me. It was a great year for me before high school. I got into a great Girl Scout troop that year.

After moving to Charlotte, I met Dana Scroggs at Charlotte Institute of Rehabilitation. When I met Dana, I knew only one-third of the vocabulary in the Touch Talker and my language skills weren't that hot. Two years into working with Dana my vocabulary increased to about five thousand words, and my language went from total concrete to abstract. Dana taught me the Word Strategy by giving me thirty words and I had to make sentences with each one before the following appointment. We took each group of words and learned them. At this point I felt that I was truly an effective AAC communicator. In 2000 we

moved me to the Unity when I got the first Pathfinder but, I learned the Unity by myself quickly.

Minspeak works on the same system through all the applications.

When I began high school, I got a teacher who was into computers and assistive technology. My mom called her in the summer and told her about my Touch Talker and training about this device. We invited her to go to the training, and she said she would love to go. Under her direction she got me to the point where I could use my augmentative communication device with a computer. She also put me in one regular classroom.

My last year of high school I had another great teacher who loved technology. She worked with me for many hours on end teaching me six years of school in ten weeks. I passed the North Carolina State Competency Test, and graduated from high school with a diploma.

It is extremely important for a non-verbal person to be an effective communicator before arriving at college because you must communicate to people without parents. After high school, I began college at our local community college. But, I loved it. When a person with a disability is trying to get into a place of higher education he or she might find it difficult to get the needed supports. This is when you need to be a great communicator. You must know what your own needs are, so you can tell others how to help you. I want to say learning how to advocate for yourself is very important because prejudice does still exist. Yes, I have had many experiences with advocacy, but I know I couldn't speak as an advocate for my rights without my communication system. There was a time; I didn't have a voice output. It used to get so frustrating because I couldn't be an advocate for myself. I knew people were pulling my strings; I didn't like that at all. I wanted my rights like everyone else. I didn't have the equipment to express my needs. When I got my first augmentative communication device, I began speaking out for all my rights. At my college I had a great support system the computer department. I had to make up a lot of my high school classes because my high school years were mostly spent in self-contained classrooms. Then I started on my degree program. I graduated with a degree in Internet Technologies and I am now a web master.

Thank you for your time. Does anyone have question?