

An augmentative conversation

February 23, 2016 8:45 AM Benjamin Alexander
newwave@tulane.edu



Tulane student Benjamin Alexander, right, communicates with former New Orleans Saints safety Steve Gleason, left, using computerized technology during a meeting at Gleason's home. His father, Sam Alexander, assists him during the conversation. (Photo by Mark Berger)

It was a meeting between two men. Neither one could speak. They utilized modern computerized technology to convey their innermost words. One was a 38-year-old, former professional football player. The other was a 21-year-old college student, a nonverbal person with autism.

The former professional football player is Steve Gleason, an iconic figure who has come to represent the rebirth of a city from the aftermath of Hurricane Katrina. Gleason is known for his memorable blocked punt against the Atlanta Falcons in the

first game in the newly refurbished Louisiana Superdome following Hurricane Katrina.

His performance energized his teammates and the city of New Orleans. Gleason was a kamikaze on special teams. He now battles amyotrophic lateral sclerosis (ALS) and is confined to a wheelchair because of the neuromuscular weakness that is a result of the disease. The connection between this disease and football are intuitive, not scientific, but the specter that one caused the other hard to avoid. Scientific studies have suggested that there is a genetic component in addition to trauma to the brain that can predispose someone to ALS. In 2011, Gleason was diagnosed with the terminal illness of ALS, which has an average life span of two to five years, although there are reports of people living longer. Today, Gleason has lost his ability to speak due to ALS, but not his ability to think and communicate. A voice output computer program produces words based on his eye movements.

The other conversant was me, the 21-year-old Tulane University junior English major who is a nonverbal person with autism. For eight years, I had no means of communicating until by chance my parents placed a keyboard in front of me and the world opened its doors as I was able to attend neurotypical schools. The words have been flowing out of my fingers as I have expressed my innermost thoughts of how I feel about “being trapped inside my mind” by this fiend called autism. My writings have expressed to the world what it is like to have autism, which has been metaphorically analyzed by people with and without the disorder. Spatial metaphors to describe isolation have compared those of us with autism to be within a “container” or “being in a prison cell.” Autism creates isolation as demonstrated by the inability to communicate. The isolation of autism additionally makes it difficult to interact with others as we lack the cues for normal socialization.

I have known many people with autism and I have never met anyone who is nonverbal like me who can communicate in the manner that I do. Although Steve Gleason does not have autism, he too is dependent on computer technology to communicate. We have a similar voice. It comes out of a computer.

The meeting with Steve Gleason was arranged by our friend Mark Berger, whom I have known through the running community for the past six years. Berger put together a 3.7-mile run (37 was Gleason’s jersey number) for Gleason Gras, an event to raise awareness for ALS research. Our augmentative conversation was witnessed by Berger, Lauren Bowman (Gleason’s assistant in his foundation Team Gleason),

my sister Hillary, and my father who serves as my assistant.

We sat in Gleason's kitchen with our computers facing each other as if they were dueling. I broke the silence by typing, "Hi Steve! I really appreciate meeting you. I saw you play when I was little including, you know that blocked kick. Ha ha."

"Oh yea, that blocked kick. That is very funny Ben," replied Steve.

I introduced myself to Steve by saying, "I am autistic and I cannot speak. I am 21 and I am a junior at Tulane. I have never spoken out loud, however, like you, I communicate not with my eyes, but by typing through an augmentative computer program."

"Where are you from Ben?" asked Steve.

"I am from New Orleans," I typed. "Can't you tell by my accent?" I added, which brought out laughter from the witnesses and even an attempted smile from Steve. Although Gleason has little facial muscle movement, I could tell he was amused by the gleam in his eyes.

"I can be British as well if I change my voice," I typed with a loud laugh letting everyone present know that I am not just a stiff computer voice.

Steve responded, "I can too," in the voice of a British female.

Steve then asked me a question that I don't believe anyone has asked me directly. I have countlessly written about autism, but nobody has directly asked me this particular question.

"So Ben, tell me about autism as I know nothing about it," asked Steve through his computer.

The answer to this question could have gone on forever, but I kept it short and succinct. "I have this disease I guess that keeps me from talking, and socializing. I also have epilepsy. There is no known cause or cure. It sucks," my computer voice responded which seemed to make everyone in Steve's kitchen cringe who heard this straight-forward answer. Mark and Lauren could only stare at each other as it seemed that I had taken away their ability to speak. I believe that my statements affected Steve as it was like a punch in the gut because it also took him several minutes to even say "I am sorry."

I knew that this would be an emotional conversation for Steve and me but I did not expect it would be as strong as it was. After all, it was a sharing of thoughts between two men, both with the inability to speak out loud. Both who were aphasic. One who had the ability to speak and who lost it due to his neurological disease. The other was also aphasic, but who never had spoken language due to his neurological disease. It was their similar-sounding computer generated voice that allowed them to probe each other's minds.

I continued with my questions.

"Steve, I would like to ask you about your lost language and compare it to me. I never had language. Not more than a few words. My life has been extremely frustrating because words never came out of my mouth. Can you tell me how you stay so positive? How do you deal with frustration? How do you make your computer scream?"

Steve replied with the same voice as me, "This is a great question man, and I am not sure how to exactly answer it. I try to have projects that I am always working on. These projects help me to feel purposeful. I am not just talking about projects with Team Gleason, but personal projects as well. The project that makes me feel most purposeful is trying to be a father to our son Rivers. I am constantly trying new approaches to fatherhood with him. I type out questions for him when I pick him up from school. I am fortunate because he has never known another way for me to communicate. My project that helps me feel most purposeful is my journals to Rivers. I started these journals when I could still talk. The journals are my effort to share as much of myself with him as possible. I would also say that I try to keep myself on as level a playing field as possible while trying to stay as normal as possible. What I mean is, I try to stay in situations and surround myself with people that foster and support my communication speed. So, I spend a lot of time texting or chatting online with my friends. Finally, at all costs, I try to have outlets for humor. I am not always great at this, but try to be funny, even if it doesn't always work."

Steve's reply to my question made me think of the team of people who support me. Beginning at age three, student after student therapist tried various different therapies on me such as Applied Behavioral Analysis, Floor Time, Music Therapy, Physical and Occupational Therapies in order to bring me out of autism. All of these modalities, which are used to treat children with autism, were applied on me. In

retrospect, these modalities have helped me to develop my thinking processes and my writing skills. I was also very lucky to have had teachers who were willing to teach me as most instructors have little to no experience with children on the autism spectrum.

Just as Steve Gleason has his “Team Gleason,” I too have “Team Ben Alexander.” My team includes my parents, therapists and, in addition, the staff from the Goldman Office of Disabilities Services at Tulane University. The Goldman disabilities office introduces me to the various professors of the classes that I take and reassures the instructors of these classes that I can do the work that is required in a college classroom. This is so important because more people on the autism spectrum will be attending universities as the incidence of autism has increased to 1 in 44 children.

“I have another question for you Steve,” I said. “Are you angry about your situation? I am very angry about being autistic. I did not ask for it. I do not believe it is God’s plan. Unfortunately, there is nothing I can do about it, so I have to make the best of it.”

There was an emotional pause and Steve replied, “I understand your feelings about God’s plan. I think if people who experience tragedy can truly believe that God planned the tragedy, then that can be a good thing. I am more of your thinking. I don’t think God planned this for me. More than anything, I think that no matter what a person believes about God or fate or destiny, I think there is an inherent search for meaning and purpose inside most humans. So, I try to think about what opportunity I can find within the seemingly tragic circumstances we may be experiencing. What meaning and purpose can I find within these circumstances. I think that is why people say, ‘This is all God’s plan.’ But I think that, no matter what a person believes, the search for meaning and purpose inside of us humans is the most fundamental search we face. I think this is true even for people without autism or ALS. Ordinary people struggle mightily with meaning and purpose in their life. So in that sense, I think you’re very normal.”

Before I asked another question of Steve, I reflected on the last sentence that he said: “So in that sense, I think you’re very normal.” I have never had anybody say or think that I was normal. I have only dreamed about being normal. This normal is a vision of me speaking through my own mouth, not requiring an aid in school, or even being able to take care of myself with the routine daily tasks. Unfortunately, my normal is autism and the question is why? Why do I have this condition that is

trapping my voice inside my head and preventing me from being “normal”? I have no idea of what normal is, except that my normal is autism.

Continuing on this theme, I asked Steve another question. “Sometimes I feel that people talk at me rather than directly to me,” I said. “Do you feel this way? Also, some people are scared of me because of my autism. Do you ever think that people are scared of you because you are different?”

Steve replied, “I think more than being scared of me, I think people are misunderstood. Or they’re saddened when they see me. My best strategy for shaking them out of that is to try to make a very human comment or remark. Maybe make fun of someone, or make fun of yourself. For example, something that showcases your humanity so that people see you, instead of the autism. Does that make sense?”

That did make sense to me, I thought to myself. It made me think of a joke that I played on a professor that I had in my first semester at Tulane. My professor, Anne-Marie Womack, had never taught someone with autism and I had never had such an intense class before. My first paper I wrote had a theme on the various types of metaphors. No big deal! I figured my innate writing skills should carry me through this assignment. Writing always came easy to me as it was my only way to communicate since I could not speak out loud. Maybe, certain writing areas in my brain overdeveloped in compensation for my aphasia. Words made their way through my sealed lips only to be released by my fingertips so that the world would know the innermost thoughts of Benjamin Alexander.

A “D”. Yes, I made a “D” on my very first writing assignment in college. How can that be? I am a writer. Autism took over as I flapped my hands incessantly while complaining about my grade. “You did not follow my instructions, Ben,” said Womack. “If you did all of the classwork, then you would have had a better grade,” she continued.

The obsessive-compulsive part of me, which is a big component of my autism, took over and made me want to revise the paper as soon as possible. For someone with autism, order is a must. Nothing can be out of alignment and this D threw my universe out of whack so that there was a disruption in the force that was felt over the entire galaxy. The second paper for the class was a revision of the first with the addition of more research. This paper was better, but it didn’t live up to my writing

standards as I improved to a “C” grade.

The next paper allowed me to write about metaphors that would describe a subject of my choice. “What is your topic Ben?” asked Womack.

“I am going to write about a subject that I am very familiar with: autism,” I typed in a rapid pace that indicated my nervousness of speaking about this insidious disease which has haunted me all of my life. “I am going to find metaphors that describe autism. I have already started my research,” said the computer-generated voice of Adam from the Write:OutLoud program.

“I expect a very good paper from you Ben,” responded Womack. This is where the humor comes in as I replied, “I have found research that people with autism can’t understand metaphors.” Dr. Womack was speechless and had the appearance that she had seen a ghost. She was stunned as she put her hands over her mouth in disbelief. She could not speak. It was as if she was bitten by an autism devil. She had to think that she failed me for a subject that was impossible for me to understand because autism did not allow me to understand metaphors. Amusingly, I let her off the hook, as I typed while laughing my ass off, “I don’t believe it!”

“Here is my next question for you Steve. You are bringing out awareness to ALS. How can I do the same to help others with autism?”

Steve responded by saying, “I would try to start small. And, I think, helping others is the best way to begin helping yourself. You’re clearly very gifted, and have overcome a language and communication challenge. I am very confident there are other autistic people who need to see your example. So, even if it is one or two people. You may find meaning and purpose in it, Ben.”

I had one final question for Steve even though I would have loved to talk with him all day. I said, “Steve, on a lighter note, if you could have somebody else’s voice, whose would you have?” I said, “I would love to have George Clooney’s voice just because he seems so cool.”

Steve responded, “I am trying to get Master Yoda, from Star Wars.”

Ooh, I would not mind being his Padawan.

Benjamin Alexander is a junior at Tulane University majoring in English with an emphasis on creative writing. Steve Gleason received an MBA from Tulane in 2011.

“We have a similar voice. It comes out of a computer.”

Benjamin Alexander