

*Our Stories, Our Lives*

Georgia Libraries for Accessible Statewide Services (GLASS) Oral History Project

GLASS-007

John McCarty interviewed by Stephanie Irvin

With assistance from communications partner, Joan McCarty

December 7, 2018

IRVIN: Hello my name is Stephanie Irvin, and I'm going to have a conversation with Joan McCarty, the communications partner of John McCarty, for "Our Stories: Our Lives," an oral history project with the Georgia Libraries for Accessible Statewide Services, Georgia's talking book and braille library. Joan will be sharing John's story as written by him. It is December 7, 2018, and this is being recorded at the GLASS Atlanta recording studio in Atlanta. Thank you, Joan, for joining us today.

JOAN MCCARTY: You're welcome. Thank you for having us.

"I am going to talk about my personal communication history and how I am working on building community. I'm also going to talk about how Georgia Libraries for Accessible Statewide Services, GLASS, has helped me along the way. I have written this script for Joan to read.

"I'm twenty three years old now, and I've only been able to communicate effectively for a short time. I am an autistic, non-reliable speaker; I cannot use my mouth to say what is in my brain. In fact, my brain does not do a very good job of controlling my body. Because my brain does not do what most brains do, I appear totally checked out. My mouth and throat make noises that mortify me. I cannot smile like others though I am often happy and smiling inwardly. I cannot read to myself because my eyes do not work together, and I cannot track words on a page.

"Not too long ago I learned to do spelling as a way to communicate and learn. Before I could communicate through spelling, I did not have a lot of options or intellectual stimulation. I am, and I always was, part of the family life through chores that I did: emptying the dishwasher, taking out the garbage, putting my clothes away. I learned how to bake, and I volunteered at church organizing the books in the pews. I exercised mostly on the rowing machine but also on the stationary bike.

"I'm part of a large family and my mom always read to us. Even when she didn't know how smart I am, she made me listen to age-appropriate books--*Charlie Bone*, *Percy Jackson*, *The Hobbit*, *The Lord of the Rings*, among others.

"Then I learned RPM. The world changed significantly for me in late 2014. That is when we found RPM, Rapid Prompting Method. RPM was developed by an Indian woman named Soma who worked with her son Tito. My mom knew about RPM in the early

2000s when she saw a *60 Minutes* episode on TV. An organization called CAN, Cure Autism Now, brought Soma and her son to the U.S.

"Soma was able to figure out how to replicate what was working for her son with other non-verbal autistics. In general, the theory goes like this: There's nothing wrong with the language center in the brain--it's the motor. A lot of autistic people have difficulty with their motor functioning, particularly fine motor. Speaking is the fine motor function of the language center of the brain.

"Because gross motor is easier to train than fine motor, a person learning RPM harnesses and trains the gross motor function of the shoulder and arm to point to letters. Initially I used a pencil and poked it through a stencil while doing lessons. Eventually I moved to a laminated letter board. I now use a keyboard when I'm answering questions during presentations or doing my email. Using a letter board is faster and less exhausting than the keyboard because a keyboard takes a lot more motor control.

"My day of freedom came on November 8, 2014, when my mom learned to use the letter board. It was during an RPM therapeutic workshop over the weekend of November 8, 2014, that I attended with my mom and dad. The person running the workshop, Elizabeth Vosseller, is a speech pathologist from Herndon, Virginia. Elizabeth started some lessons with me, and then taught my mom what she, Elizabeth, had been doing during the workshop sessions with me.

"Elizabeth started simply. She said what RPM was and then asked me to respond to a simple question to which she knew the answer. In my hand was a pencil; in hers, was a stencil. She used gestures and her words to coax my body to do the next-to-impossible: to insert the pencil through the letters on the stencil. It was the hardest work I had ever done.

"Elizabeth and I worked intensely over six sessions during the workshop. As Elizabeth realized my control was getting a little better, she asked a question to which she did not know the answer: 'Tell me something you see in the sky.'

"Somehow I was able to get out what was in my head: 'The big dipper.'

"During our sessions, Elizabeth asked me about my interests, and I was able to spell that I liked books--in particular, books about history and the Civil War.

"My mom started getting me books on CD at the library mostly focused on the Civil War. I now had more interesting things to do. One day, when we were working on a lesson on cephalopods that included a video, I got very frustrated, but I was able to tell my mom that I could not track the movement on the screen. She took me to an eye doctor who said that my eyes did not work together, and my vision was distorted. The doctor signed the papers so that I could become part of GLASS.

"Using GLASS material is better than CDs; they play from start to finish and there is an incredible amount of material. Almost any book and many magazines are available, especially through BARD. Braille and Audio Reading Download. I have a GLASS profile that automatically sends me books, and I have enjoyed books that I never would have chosen for myself such as Michelle Obama's *In Her Own Words* and *The Autobiography Of Malcolm X* written with Alex Haley.

"Along with some of the others who have found RPM as a way to learn and communicate, we formed a book club. A recently acquired ability to communicate broadened our opportunities to participate in meaningful and age-appropriate activities. Our first book was *Life of Pi* which I hated. We have done a broad range of genres from memoirs like *The Glass Castle* by Jeannette Walls and *Angela's Ashes* by Frank McCourt to dystopian science fiction like *Station Eleven* by Emily St. John Mandel and *The Martian* by Andy Weir.

"Our activities through the book club led to a chance for those of us in the book club to take a class on the Perimeter campus of Georgia State University. The class was a remote Duke University House Course called "Beyond Christian Intentions: Colonialism, Evangelism and Reconciliation in Native American Communities." This was a six-week course that ended with a group project. From there, another class: physics. A retired physicist taught a University of Virginia course called "How Things Work."

"At home I was working on preparation to take the GED, and then I went to GED prep classes on the Gwinnett Technical College campus.

"Because I could communicate now, I was invited to speak to the Boy Scouts at our church. I presented with Darcy Elks during her meaningful day seminar about the value of social roles including my role as a book club member. I also presented to Creative Consulting Services direct support professionals. I have been able to have a positive impact on homeless families who have autistic kids by presenting a training for the staff at Drake House, a shelter in Roswell, Georgia, for homeless, single mothers.

"I presented my Wheel Power through the Sangha Unity Network Self-Advocacy Planning Sessions, which is a topic for another day. These sessions are expanding the influence of self-advocates throughout the state of Georgia, hopefully like this GLASS oral history project.

"I am honored to be able to share a small part of my history."

IRVIN: And thank you, John, for sharing your story and, Joan, for sitting with us today.

JOAN MCCARTY: Thank you.