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# Deaf Plus: A Mother Reflects on Her Son's Experience

*By Ukawia Johnson*

The day that we both fought so hard for was here. He did it! We did it! After 12 years of ups and downs, uncertainties, hard work, determination, and tears, my son James graduated from high school with a regular diploma.

James's accomplishment was a truly special milestone on a journey that has certainly not been smooth. He was born with cerebral palsy and has scoliosis along with a number of other health concerns, some of which have necessitated four surgeries between the time he was born and the time he entered high school, with more surgery still to come. When James was a newborn—only 3 months old—he was diagnosed with auditory neuropathy, a condition in which the inner ear successfully detects sound but has a problem sending sound from the ear to the brain (National Institute on Deafness and Other Communication Disorders, [www.nidcd.nih.gov](http://www.nidcd.nih.gov)). As a parent, I had all the emotions that I now know are common: I was scared, upset, and in doubt. *How could he be deaf? I am not deaf; my family has no history of deafness. What if the test were wrong?* I knew my child heard me; he responded to my voice. The first few years were learning years for us both. I did not know what to expect, and I did not know what to do. It turned out that James had a moderate hearing loss in both ears that later progressed to a severe loss. Most of the medical focus was on James's physical disability resulting from the cerebral palsy; the doctors seemed less focused on his hearing loss.

When James was about 3 years old, I was informed that there was a preschool for deaf children in our city of Mobile in Alabama. Prior to my learning about the preschool, James had only attended mainstream daycare. I toured the school and James began shortly after, attending the preschool for about two years. He started kindergarten at the Regional School for the Deaf, and a year later he transitioned into the mainstream public school system. It was recommended that James repeat

*Photos courtesy of Ukawia Johnson*



kindergarten because, they said, he wasn't as mature as the other kindergarteners. Not really sure what that meant, I accepted the recommendation. We embarked on another year of kindergarten, and James received his first hearing aids.

James's Individualized Education Program (IEP) stipulated that he have a paraprofessional aide to help with daily school activities. As a result of cerebral palsy, he needed assistance holding his lunch tray, using scissors, and writing along with other motor tasks. First grade passed smoothly. His teacher was sensitive and helpful; his speech pathologist was great. In second grade, however, everything changed—and I boldly became an advocate for my child.

In speaking with James and his paraprofessional, I learned that James was not receiving the services that we had been promised. These included a reading coach and some one-on-one class time. Worse, he was made to sit in the back of the classroom, and he was not called on when he raised his hand. Further, while the other students moved from discussion to discussion, he remained isolated. Instead of participating, the

teacher allowed him to color. When I asked the teacher how she could so deliberately isolate a student within her classroom, she said she did not call on him because she could not understand his speech. She also refused to wear the FM microphone that was connected to his hearing aid and would have provided him with clearer hearing. This was not what I expected when I sent him to school, and this was not what I was going to allow. After that first talk, I thought things would improve, but daily conversations with James revealed nothing had changed. I attempted to speak with his teacher again, but she refused to meet with me. I asked to talk with the principal. There was no reply. I sent letters to the school board, and again there was no reply. It wasn't until I retained an attorney that I received a response. Still, it was not what I had hoped for. In fact, I, who had never considered myself

**Left, clockwise:** James as a toddler and young child; leaving James (age 14) at ASD to embark on a new school journey; James pictured with Representative Napoleon Bracy, Jr., after receiving the 2017 Youth Leadership Award; James's senior year at ASD.

anything more than a concerned mother who wanted a good education for her son, now found the school board considered me an adversary. Some members of the IEP team accused me of “wanting special treatment.” I did not want special treatment; I wanted my son to have the reasonable accommodations promised by the law. Faced with the threat of legal action, the school board allowed James to have reasonable accommodations and a chance to participate in class activities. Unfortunately, this decision came at the end of the school year. James’s entire second grade year was spent fighting for fair classroom treatment.

Things finally improved slightly and James continued with his education, moving through the elementary grades in mainstream classes. He was somewhat of a loner. James is normally very social. In fact, he is “Mr. Personality,” excited to engage others in laughter and conversation. Sadly, many people, most important the other students, only saw

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his disability. The way he felt and the way he was treated presented a constant struggle for him—and in some ways a constant defeat. He was unable to participate in sports due to physical limitations. My son, so wanting companionship, wasn’t happy.



**A Life-Changing Decision**

We knew that an alternative to public school was available. We toured the Alabama School for the Deaf (ASD), part of the Alabama Institute for Deaf and Blind, when James was in seventh grade. He had attended summer camp there. After rejecting the decision for many years, we began to reconsider. Should we allow James to go to ASD, where his peers would be more like him? We live in Mobile and

**Left and right:** James’s senior photos at ASD.  
**Far right:** James on graduation day with Dr. John Mascia, president of the Alabama Institute for Deaf and Blind; a proud mother, a successful son.

ASD is in Talladega, over 270 miles away. We ultimately decided to allow James to attend the school, and he began eighth grade at ASD.

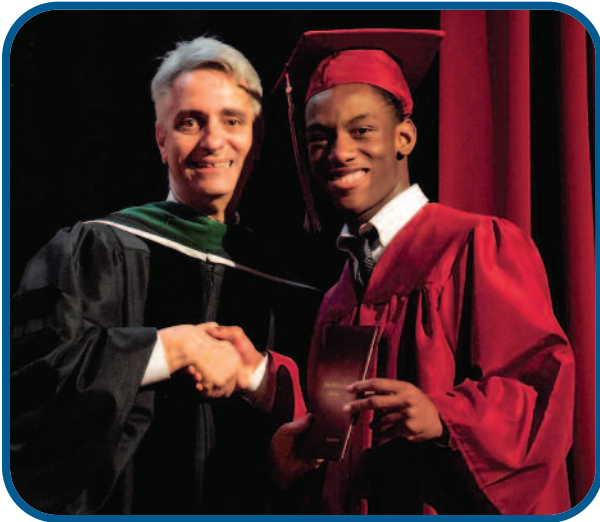
Although the first month was a hard adjustment for our family, we eventually got used to the change. At our nearby public school, James had been accompanied by an adult throughout his school day, and after school he was often alone. This all changed when he went to ASD. James, who had learned signs in preschool but refused to use them, began signing again. He made friends. He became very involved in school activities and organizations. In fact, he was dorm president, vice president of his class, a member of the Student Body Government, and a member of the leadership council. He participated in various leadership camps,



and in 2017 he received the Youth Leadership Award from the Mobile Area Governor’s Committee on Employment of People with Disabilities.

At ASD, James was evaluated on his strengths and needs, and the school individualized a plan for him. He participated in work experience activities, and we attended yearly career fairs at his school, where we met representatives from various colleges and businesses. Each provided valuable information as well as described the





program in which he would learn to self-advocate, become ready for a full-time job, live independently, and continue his academic work. His goal: to attend Troy University, in Troy Ala., and major in counseling.

**Looking Back, Looking Ahead**

It has always been important to me that James received a

steps to complete the application process. At our final gathering—the IEP exit meeting—James, his teachers, counselors, administrative staff, and I discussed his future. James wanted to attend college, but his ACT scores were not high enough for the college he chose. We discussed alternatives, and James decided to attend a transitional

quality education and an opportunity to be involved in social and academic life. I was determined that he understand that his hearing loss and health needs did not make him any less valuable than other people.

I wanted James to believe in himself and not let his disabilities define his future. Instead, his future should be determined by his skills and determination.

Asked how he feels about having a disability, James responded, “I feel my disability has been a blessing. I have been able to participate in and experience things I may not have had the chance to if I didn’t have a disability.” He once told me, “I could feel sad, I could be angry, but I am still going to have a disability. I just need to accept it and be



an example ... to help others deal with their disabilities as well.” As James’s mother, his advocate, and his biggest supporter, I am grateful to ASD—and I am **so proud** of my son.



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