

generation to generation:

the fight for language access continues

By Travis Zellner



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Obtaining appropriate special education and related services to establish the best educational environment—academically and socially—for our children is not only challenging but also downright daunting. Our decisions supporting our children, 6-year-old James who is deaf and 12-year-old Miia who is hard of hearing, are, in part, derived from our experiences growing up.

Both Pam and I are deaf. We were born into hearing families, both of us the first deaf individuals our parents had encountered. It astounds us that our parents fought for us 30 plus years ago, much like we are fighting now for James and Miia. They say they spent countless hours in their local libraries doing research. They begged for help from medical and educational professionals who had either poor answers or no answers at all.

I started my education in a small preschool program with other deaf children at a public school in Connecticut using both spoken English and American Sign Language (ASL) under a philosophy known as Total Communication. I moved on to a local public elementary school in my hometown where I was mainstreamed to fifth grade. I struggled socially and academically, often feeling frustrated and sometimes depressed. I actually told my parents, “I want to go to school with other deaf children.”

Wanting me to have both a peer group and role models, my parents worked to transfer me to the American School for the Deaf (ASD) in Hartford, an hour north of home. They hoped I would be happier among a larger group of deaf and hard of hearing schoolmates and learn directly from teachers who used ASL. They realized I needed ASL to establish friendships.

After some resistance from our town, my parents were successful and off to ASD I went, where I was indeed much happier. However, after extensive testing it was determined that not only was I intellectually ahead of my peers but also that ASD didn’t have the means, curriculum, or program to support the style of learning I had acquired from mainstreamed classrooms and living with my hearing family. Finally, a compassionate professional directed my parents to Clarke School for the Deaf in Massachusetts, an academically challenging oral

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program a bit further from my home. My parents found themselves with a much greater fight on their hands, but they were again successful. At Clarke, I found peers, academic challenge, and success, and I was very happy.

After eighth grade graduation, I was enrolled in a private hearing high school. I was the only deaf student. I started to struggle again. After a few months, I transferred to a very large public high school closer to my home with a small program for deaf students. This was not a good fit. The next year my parents and I were able to work out a new plan. I attended a public school for half of each school day and then went to ASD for the rest of the day. This worked well. I successfully finished the remaining three years of high school.

After graduation, I entered the Rochester Institute of

Technology (RIT), where I had support from the National Technical Institute for the Deaf. I graduated from RIT with a bachelor's degree in furniture design/woodworking. I continued my education at the Rhode Island School of Design, completing my master's degree in interior architecture.

Pam, my wife, didn't endure the same nomadic education. She started in a small deaf preschool program with other deaf children. She was then mainstreamed into her local public school system in Fairfield County, Connecticut, where she remained from kindergarten to graduation from high school. Pam and her family learned how to sign through an Easter Seals program when she was 3 years old. A "teacher of the hearing impaired" assisted her throughout high school. She, too, struggled socially and academically. Her parents also



fought to obtain support. Like me, Pam attended and graduated from RIT, earning her bachelor's degree in illustration.

We both remember struggles with communication, loneliness, and ignorance. Today we consider our first language to be English. However, we prefer to converse primarily in ASL. Pam, program manager at the Rhode Island Commission on the Deaf and Hard of Hearing, seldom uses spoken English. I, purchasing agent and materials coordinator at an architectural millwork company, utilize both ASL and spoken English. I volunteer as commissioner for the Rhode Island Commission on the Deaf and Hard of Hearing, where previously I was chairperson. I am also chairperson of the Board of Trustees for the Rhode Island School for the Deaf.

Services for Our Children

Miia, our first child, passed her newborn hearing screening but at 6 years old was diagnosed with mild to high frequency hearing loss and classified as hard of hearing. She was immediately outfitted with hearing aids. We established a 504 plan under the Rehabilitation Act to ensure equal access in education. The 504 plan fosters communication and awareness among teachers, school professionals, and parents to make sure

Miia does not miss out or fall behind. The plan allows for specific accommodations, such as ensuring media are closed captioned and audiologists are available.

When Miia was 6 years old, James was born. He did not pass his newborn hearing screening test and was diagnosed as profoundly deaf. When the audiologists broke the news to us, we were quite surprised. No one had been aware that our deafness could be a genetic trait.

As deaf professionals, Pam and I did not have any concern that deafness would impede James's development to his full potential. Unfortunately, this was not true of the other professionals who surrounded us. If we had 25 cents for every forlorn professional expression reacting to the infant they were discussing being deaf, we could be rich. We knew that James was born into the best family he could be born into—a loving family with experienced grandparents and understanding relatives. We are not only deaf but also experienced and knowledgeable about deaf and hard of hearing education and culture. We knew what to do.

Still Pam and I were shocked by the gloom that marked our first contacts in the medical industry. We had heard about this often, and now we were experiencing it. We looked at each other and thought of the inexperienced hearing and deaf parents who would not know what to do, where to go, or whom to trust. How would they handle being surrounded by these forlorn faces? These faces told us—two deaf professional parents—that deafness is a tragedy. We learned long ago not to be bothered by ignorance and to move on. Pam and I reached beyond the limited services initially offered, insisting that the first priority for our son must be exposure to ASL. Although spoken English is important, it is not the foundation for James's academic, social, and emotional development.

At 6 months old, James received his first hearing aids. We also reached out to Early Intervention (EI). We stressed that the most important service James required was access to language via ASL. Our EI person did not know anything about deaf culture or

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education, nor had she worked with deaf people. Ironically we were the teachers, not vice versa. We shared everything we knew, including information about implantable and biologically assistive technology. Soon EI hired another support person experienced in early childhood deaf education. This helped tremendously. We were told that we were one of the few families in the country to secure a certified sign language interpreter for daycare when James was 6 months old. We continued with the interpreter through the expiration of EI services.



When James was 2, we contacted the special education director. We wanted to be proactive. We knew it was impossible to establish James's needs within the normal two- to three-month time frame for transition of EI students to public education. Deep down, we feared we would have to relocate. Still, we were hopeful; perhaps our town would work out James's needs for education. By the time James was 3, we'd already had several tense discussions. Our town's definitions of *least restrictive environment* and *appropriate education* were about as similar to ours as apples to oranges—or apples to orangutans! We insisted that they contact The Learning Center for the Deaf (TLC), a well-respected school in Framingham, Massachusetts, to evaluate our son. We refused to rely exclusively on evaluations from the public school speech pathologist and psychologists—none of whom knew anything about deaf education or the idea that access to language for some students may best be promoted through ASL. Our town remained adamant: The foundation of their beliefs was that the only way for deaf students to succeed in academics was through spoken English.

We insisted that the town hire a full-time deaf teacher, retain consultation from a speech pathologist experienced in working with deaf children who knew sign language, and hire an interpreter certified in educational interpretation. We wanted James in preschool full time to prevent him from falling behind his hearing peers. We didn't get everything we wanted; James's preschool was only half day. We did secure a speech pathologist trained in working with deaf children and a good interpreter with a degree in early childhood education. After the school year ended, we requested that the special education director continue services for James throughout the summer. Unfortunately, James's first day of summer school found him in a class with children with severe developmental disabilities. This was not acceptable. We pulled him out the next day.

We decided to relocate. We put our home up for sale and secured a new home in Massachusetts. There, we talked with

everyone—from individuals at the Massachusetts Commission for the Deaf and Hard of Hearing to pathologists, psychologists, special education teachers, and other educational professionals in our new town. We felt reassured that, once there, we could enroll James in the program where we knew he would get a good education—TLC. We felt things were falling into place, and we thought the worst was behind us. A short time later, the town notified us that the “team” had determined that the local school—without one deaf child, one deaf teacher, or even one deaf adult on its premises—would provide an appropriate education and least restrictive environment for James.



This was a slap in our faces. As deaf individuals, deaf parents, and deaf professionals, our words, emotions, knowledge, experience, and professional testimony had been totally discounted. We were furious. We reached out to professionals in deaf education, speech pathology, and psychology. We contacted the Deaf and Hard of Hearing Program at Boston Children's Hospital, one of the largest and most experienced programs in the nation. We retained a highly regarded

attorney, formerly a hearing officer of the Massachusetts Bureau of Special Education Appeals. We were prepared to fight all the way. Still, we'd never felt so alone and frightened for our son. There was a lot of correspondence, many meetings, and a mediator from the Bureau of Special Education Appeals was assigned. A hearing was scheduled. Suddenly the town reversed its position and agreed that James should enroll full time at TLC. We collapsed and cried.

A Dream Becomes Reality

Now we are moving on. James loves his school. He and Miia are doing awesome. Both are well on their separate ways to successful futures.

Still, it infuriates us that so many officials have resisted my wife and me, experienced deaf professionals. We are even more infuriated for all those hearing parents who receive the news that their babies are deaf. We worry about the inappropriate, often inaccurate, and sometimes counterproductive counsel regarding their children's future and options.

Communication—not speech—is the primary factor in children's development. Sometimes we ask why there are so many overcrowded prisons with speaking prisoners. We ask why there are so many speaking American families struggling in poverty. Clearly if speech alone were the mark of success, this would not be the case. However, speech is meaningless without communication, education, and loving, active parents. Like so many others, that's what we intend to be for our amazing children.