

Coming Full Circle: Teaching Others to Overcome Learning Disabilities

Eureka! Helping my nephew helps me discover my vocation

MY SISTER TOLD ME THAT my ten-year-old nephew, Michael, was having some difficulty in school. She wondered if I would be willing to talk to him and see what was going on.

So we sat down together, Michael and I, and I struck up a friendly conversation. He was happy to talk to me. But when I brought up the subject of school and classroom work, his demeanor changed and he stopped making eye contact. Instead, he looked at the floor. Some stress was happening here. I concluded that he needed not only help with the classroom material, but also a way to deal with his underlying stress in perceiving his schoolwork (and himself).

I decided to start by communicating in a way that didn't raise his stress level. I asked him to get me a drink of water. That way, while he was in the kitchen, I could be sneaky and quickly review his schoolwork without getting him too uptight. I started to see a pattern. While Michael could read and write, he got some of the letters in the wrong order. I was getting a better understanding of what we were dealing with.

When Michael returned, I wanted to lighten the mood and get his mind off of the stress I caused when I asked him about school. So I did a little Elvis impersonation, deepening my voice and drawling, "Thank you, thank you very much." It got the desired effect: A smile was forming on his face. I then commented, "I drink a lot of water. Your mom thinks I might be a fish." Now Michael was chuckling, and I took that as a positive sign.

I deliberately pushed the schoolwork aside and sat there drinking my water. Michael looked at me with great surprise. But when I eventually drew his school papers closer, he looked down at the floor. I did this a few times and then I started talking. "You know what? I think that you are doing very well. School is not easy." Michael, I noticed, was listening. I continued. "Did your mom tell you that I have a learning disability also?"

Michael looked skeptical. "Yeah, mom told me." But he didn't elaborate, and I was not sure he believed it.

"Michael, every word your mother told you about my learning difficulties is correct." Michael began to look at me more intently. "You may or may not believe this, but when I was your age, I could not read or write half as well as you do. My handwriting was so bad that I couldn't read it."

"You couldn't read your own handwriting?"

“I only could if I took a lot of time to write it very neatly, which meant I was the last one done writing. By the time I graduated from high school, I could read like a third grader, and write like a first or second grader.”

Michael was amazed now, particularly by the last comment. “How did you get past that?” he wondered.

“That is a wonderful question. I had to stop comparing myself with my classmates at school. It was hard, but it’s easy to be hard on yourself about what you don’t do well. It’s much harder to enjoy and appreciate what you DO do well. I hope you understand what I’m trying to say. I had to stop worrying about what others wanted or thought of me. There will always be people and kids who will talk and say things that aren’t nice.”

“Yeah, that’s right,” Michael commented.

“I think of my life as a game. You follow the rules, be nice, help out when you can. Enjoy who you are as a person.” I could see Michael liked what I was saying but wasn’t sure how that idea would work for him. I went on, “The biggest thing I realized was, we are all strong in some way. We all have a gift nobody else can touch. Once I started to know that I am just as important as the next person, the whole world began to open up for me. I began to think about what things I like to do and who might like to do those things with me.”

Michael was smiling now, from ear to ear. That was cool. We still had work to do, but we had succeeded in shining a light on the complex part of his learning difficulty, which was his own perception of his personal value.

Michael and I now discussed which parts of schoolwork were hardest for him, and we identified reading as a problem. I asked him, “Can you read words ok, even read sentences ok?”

“Yes.”

“Okay, good. Now, this is the weird thing. Do you ever have trouble locating a word or keeping track of where you are on the page?”

Michael was amazed. “Yes that’s right, how did you know that?”

I explained, “I have the exact same difficulty when I read.” I asked him was it easier to read out loud, or quietly to himself? Michael identified that he liked to read to himself, but understood better if he heard the words out loud.

I announced, “I have a plan. Let’s think about the words on the page when you are reading.” I took a sheet of empty paper. “Point to the spot on the paper where you might have trouble finding the words.”

Michael looked confused. “Not sure what you mean.”

“My fault. See? We all make mistakes.” I drew two lines on the paper, dividing the space into four quadrants. Once I had gone to more effort to explain myself, Michael could see exactly what I was asking. Even better than that, he could now answer my question.

“I have more trouble keeping track of the words on the top part of the page.” He explained that once he got past the midline, he had an easier time reading on the lower portion of the page. I advised him to lower the book or paper when he began reading something new, and to keep his finger on the side of the page where it could track his progress. We used a paper from his class and he

practiced what I was describing. He thought it seemed weird at first, but was surprised that when he lowered the page, he could see the letters better.

Then he asked, “How should I track my words with my finger?”

“That is a great question. Try using your finger to track, but don’t get distracted by your finger.” This took a little practice.

I asked him then, “Do you have trouble with reading comprehension?” He rolled his eyes. I confided, “I know, I hear you. Here is what you do. Before you read any story, think to yourself: I wonder what this story will be talking about? Set up some possible questions in the back of your mind. Read a little bit at a time. You are the judge about how much. Read only a few sentences. Say to yourself, What did I just read? What is going on? Who am I reading about?” Michael seemed impressed at this advice. To be quite honest, I was somewhat surprised myself at how I was articulating a plan of action for him.

As we continued to meet together, I asked Michael, “How do you feel about reading? Are you tired? Do you want me to read for a while?” During each session, I discussed not what I thought was important, but what was important to him regarding learning. I believe this approach took a great deal of pressure off Michael’s shoulders and also reinforced the idea that people can help you, but you have to set your own personal direction. Eventually, Michael generated his own reading format. He no longer struggled with reading or associated his personal identity with his difficulties. Today, Michael is all grown up and works at an auto dealership. He has a wife, a child, and a home. I am proud of what we accomplished.

Michael gave something back to me as a result of our time together: He helped me to identify what I wanted to do with my life. My wife and I were considering what I could do to “give back” to my community. “Do something that uses your experience,” she urged. I immediately remembered my tutoring sessions with my nephew, and how I surprised myself with my ability to express educational concepts to him in a way that he could appreciate and understand. In doing so, I created a personal learning environment that let Michael feel safe while sharing his difficulties.

I realized I wanted to use those abilities again, this time in an adult environment. I had discovered an adult-education program in East Brunswick, NJ. It was geared toward individuals with forms of intellectual handicaps. I became a volunteer tutor there. My fondest memory is my work with a gentleman named Frank (for details, see page xiii). This opportunity allowed me to explore a vocation—teaching—that I had never considered before. My volunteer work eventually led to a paid staff position. Working with adult students one-on-one gave me a strong sense of personal achievement, and watching my students improve let me experience the joy of success that, for me, was a long time in coming. I worked in school environments for the next twenty years.

Taking it on the road: transporting autistic students by bus

My education background led me to a job with a bus company that transported individuals with mental impairments. One day, the company’s president approached me with a situation. “Nobody else can deal with this assignment like you, R.V.” Often he would lament, “I wish I could clone you!” (It had been the company’s habit to give me the more difficult bus runs.) This assignment involved

picking up twelve passengers to transport them to a work program. I had been coached beforehand so I would know what I was taking on. All twelve personalities on the bus classified “very dynamic,” meaning every single person had some kind of behavior that had to be watched very closely. For example, “Jeff” enjoyed tapping others on their heads; he would become very wound-up and sprint back and forth on the bus. “Marian” was sweet and nice most of the time, but stay out of her way when she was in a bad mood (she yelled). “Della” was nonverbal, and occasionally left her seat and walked around the bus. “Carol” complained about how hungry she was, often eating her lunch. Everyone on the bus enjoyed getting as much attention as possible.

I was the fourth bus aide to be assigned to this run in six months. My driver, Jim (an ex-Marine), was the third driver in six months. On my first day, I met Jim and our passengers, and it didn’t take long for them to show their true colors. “They were not kidding, this is a tough run,” I thought. “But I will get this run into shape.”

After that day, Jim and I had a meeting and I made a plan. We established my authority. I was in charge of the bus and it would not move unless I said so. Jim would pull over at my signal, if trouble occurred. Jim said, “I like it.” Next, I instructed Jim to react to bad behavior on the bus by slowing down and proceeding down a different road. Initially, he protested. But I explained, “They are used to a particular routine. The moment we go in another direction, they will feel less secure and their behavior will come back in line.” “Wow,” Jim marveled. “You know your stuff! Anything else?” “We need a code word when one or both of us will want to stop the bus.” With all this settled, we were ready.

The next day was much better. I made a point of sitting with “Della,” and I got the group to sing songs together, which worked like a charm. After that first week we had an occasional eventful day, but we handled it. In return, I received a wage increase reflecting my great performance.

Helping a nonverbal seventeen-year-old boy who loved soda

Months later, a different and even more challenging assignment arose. A six-foot, two-inch 200-pound young man with profound autism needed to be transported from home to a school called Douglas, which was connected to Rutgers University. My passenger’s name was Aaron, and he was nonverbal. The trip was thirty miles long, and Aaron was the only passenger. I would find that everything I had learned up to this point in my career would come into play for this new assignment.

Aaron liked soda, and his mom provided it. The first time he boarded the bus, he held a can of soda his mom gave him for the trip. I thought, “You have got to be kidding me. Giving a young man with profound autism a drink with sugar and caffeine for 30 miles, nothing can go wrong there...” Once we got under way, Aaron demonstrated that he was not happy at all. He rocked violently in his seat. I guessed that he was not comfortable with the new bus, driver, and aide. The good news was that he was not violent, and wasn’t attempting to leave his seat. But the rocking and agitation were increasing.

I knew I had to take command of the situation. I noticed that every so often, Aaron drew a picture on a note pad. I observed how he drew the picture, and then hit the pad with his pen three times. I began to pick up my own pad and pencil and draw something. After a few seconds drawing, I hit the

pad with my pen two times, so my plan worked very well. In a few minutes I could tell that Aaron was a bit more relaxed. He was no longer rocking intensely. The storm seemed to be over. After that day, I began to understand better what was going on in Aaron's mind. Being nonverbal, he used his drawing to help him find a calmer place. The tapping was his way of communicating. Three firm taps told me "This is my bus, my home." I got that. I must have gotten something, because overall we had a good four months working together.

One day, Aaron was in a mood. In addition to the soda he brought on the bus, additional soda had been rather badly hidden in his bag by his mother. After finishing the contents of the first can, he wanted the rest. I knew I was in trouble because Aaron was verbalizing now, in full sentences. He would say, "I want soda" and, remarkably, do it unprompted. He was speaking on his own with very good pronunciation and diction.

Years earlier, I worked with another autistic individual, Acea, who was nonverbal. He made no attempts to verbalize, except when he saw a piano. Then he said, in a very polite yet firm manner, "MAY I PLAY THE PIANO PLEASE!" He could not be diverted. I let Acea play the piano, stayed out of his way for the first minute, then slowly encroached on his personal space while he was playing. (I knew he would not lash out because he was doing what he wanted to do.) I also tried to create even louder sounds elsewhere in the room, making his concentration difficult, until he got up from playing and just walked away.

But on this day, I had a strong feeling that Aaron would not give up on his demands for soda. He knew the soda was in the front seat. Suddenly I felt a strange, bad sensation as Aaron hit me in the face with his large open hand. My glasses were broken on my face. I guess Aaron didn't know the rule about not hitting someone with glasses! I was unhurt but saw spots and experienced ringing ears for a while. (Needless to say, we gave Aaron the soda!)

Despite this incident, Aaron and I found ways to communicate. He would sometimes hold my head to smell my hair. We would draw and tap together. During our last month together, we developed our own communication. I would learn that he could not start a conversation, but he could answer questions. Later, Aaron's mother told me that he did not like to talk very much, so if he made a genuine effort to communicate with you, he really liked you.

I loved working with Aaron. He was able to convey to me his warmth and high intellect, and would not let his nonverbal status stop him from communicating. Aaron might have been nonverbal but he had a wonderful, strong voice. I learned from Aaron that communication comes in all forms: You just have to be willing to listen.

Working with Jessie, a nonverbal six-year-old

In 2000, when I was 38 years old, I had already been working quite successfully as an educator for ten years. I had worked for three schools and one bus company. My next job was at the Freehold Boro school system, working with pre-K to grade 8. By this time, I had worked with every grade level including high school. My time at Freehold sharpened my skills of communicating and instructing students to be better learners. Each student and I created a plan of action to help him or her develop

strategies to compensate for learning difficulties. I found myself paying very close attention to how students needed to think about information, then used that knowledge to develop a plan.

I had the opportunity to work in a pre-K class with autistic children one year. How super is that? It was super because I had the chance to work with children who demonstrated the exact same personal issues I had dealt with 35 years earlier. I could see myself in these children. I felt a wonderful rush of powerful, positive feelings wash over me. As a child, I remember feeling alienated, like I was the only one who had these behaviors. Throughout my life I sometimes felt like an alien who was dropped off from another planet, hoping that maybe someday I would find “another person from my planet” who saw what I saw. Now an adult, I felt a strong desire to show these children that they were not alone.

One year, I found myself on an anti-bullying committee at the school. We coordinated a school assembly about preventing bullying. I had an idea. I would dress up as an alien from another world. I would look mostly like myself, only blue. My wife did a wonderful job on the costume. I wanted to show the kids that even though I am blue, I still have arms and legs, a mom and a dad. I would also talk about the differences in my pretend world. Even though we are sort of different, we are all the same. Being a little different is okay. The children loved the presentation.

The interesting thing about the preschool class was that it provided essential learning skills solely for children diagnosed with autism. The teacher, Pat, created a dynamic approach for very young autistic children. She wanted the child to better understand how they organized and expressed information from their environment.

The class used five modules: Cognitive therapy (integrating information, following directions), Occupational therapy (improving coordination skills, balancing their weight without falling, obstacle courses), Behavior modification (scheduling, knowing what will happen next, earning rewards, multitasking), and Academic proficiency (incorporating better comprehension and vocabulary). Combinations of these modules were also used, such as learning to follow a speaker’s voice directing a child through a jungle gym, helping them to isolate sounds while simultaneously moving and climbing.

A fifth module called Manding was a combination of cognitive instruction and academic instruction. Manding involves rewarding a child when they have performed a specific task by identifying a



In 2008, I did a presentation at a school assembly dressed as an alien.

command with a personal action or task. A “mand” is a request or command (“I want or need from you”) to evoke a positive response.

A six-year-old nonverbal student in our class named Jessie was a very withdrawn little boy. He made very little effort to interact. Pat knew that Jessie would be transferred out of the class soon because of his age (this class worked with ages three to seven). Pat felt that a verbal program was needed to inspire Jessie to want to learn and express new words.

I wanted to be the one to work with Jessie using the (then) new methods of Manding. I felt a bond with him almost immediately. When I reached the age of seven, I could form words only with great effort. My difficulty with speech was caused by disorganized thinking combined with difficulty understanding sounds. My mental organization was only part of the problem, as I also felt alienated and unable to communicate the way others did. If I had not had the close friends who took the time to walk with me and talk in the same manner without making eye contact (see “Childhood Friends and Play,” page 73), I doubt I would have the language skills and the dynamic personality I have today.

I also felt a close tie with Jessie because he was African-American. He reminded me of many African American adults in my life growing up who helped me navigate my personal insecurities and welcomed me. These friends and coworkers lifted me up and gave me tools of self-confidence. Working with Jessie would bring this full circle for me, as I would be the adult who would help this time. I could give something back to the community that did so much for the quality of my life.

The first day I worked with Jessie, I found him at a cubicle that would keep him from being distracted by other activities in our classroom. As we talked, he would quietly say every word that I would say. He repeated words, but did not offer words independently. I was beginning to find this frustrating, especially as Jessie did not seem to be motivated by the toys in the room. I finally found some Legos and was relieved to see him eagerly respond to those. I thought, “Now we got this.”

I put the Lego near Jessie but he was not allowed to touch it. I would then show another toy. I would say the toy’s name and Jessie was to say the same name once without repeating it. It seemed to me that Jessie had the potential of a high intellect. He demonstrated excellent focus and concentration. His facial expressions seemed to show that he knew the meaning of each word.

I was so pleased that Jessie could now say the word presented to him without repeating it. However, I felt there were elements of the new Manding program that did not move fast enough to retain Jessie’s attention and keep him from staring out. I knew that game only too well and I was now feeling cocky. (I remembered how I, too, would want to just stare out and not talk or do anything. I learned to maintain attention by doing something like nodding, flicking my fingers, anything to give my mind another small activity. It had to be small so that I could avoid becoming stressed by too much stimuli). I looked at Jessie and said to myself, “You want to stare out? Ok, that is fine with me. I have my own plan.”

I suddenly knew how to fix the difficulty with the program. Once I knew Jessie was able to articulate certain words, I wanted him to express those same words in quick, rapid-fire fashion. I knew I had to introduce the word differently. My plan was to have Jessie see the toy he liked, then he would have to copy my sign language while at the same time saying the word I presented. When I tried this,

I said the word while signing. After a few minutes had passed, I stopped my verbal cue. The only way Jessie would get a cue would be from my signing. In a half hour's time, I had Jessie say "cookie," "toy," "boy," "girl," "eat," "candy." He said the words well, and only once. Not bad at all.

After our session concluded, the entire class stood up and applauded me for my great work. Jessie had expressed some words. Pat commented to me, "Great job, kid." She had never before seen anyone get a response like that from a nonverbal.

It makes me think: autism then and now

It was so interesting to me to watch the students in Pat's class manifest the exact same behaviors that I did when I was the same age. I would see things like refusal to change from a current situation, constant rocking, projectile vomiting, difficulty with articulation of spoken words, overstimulation with sights and sounds. It struck me just how rooted I am in the autism community, in ways that I would not have thought possible. I began to piece together in my mind that children with autism could really be taught how to create better coping strategies. Many of the techniques I saw working that day were similar to what I had experienced as a child with my occupational therapist, Dr. K.

Until 1973, behavior resembling autism was classified as "childhood schizophrenia." My parents felt, perhaps rightly, that classification of childhood schizophrenia would create a stigma I could never have escaped, possibly even resulting in institutionalization. They may have been correct in accepting an unclear diagnosis, even waiting until the assessment criteria evolved in case a better measurement of my cognitive potential was around the corner. But watching these children in Pat's class, it was becoming clear that whether or not I had autism or even schizophrenia was not the issue. The issue was figuring out the best way to get things done.

On the wings of autism: a simulated airport experience

My wife Marlene and I participated in a volunteer program called "Wings for Autism." The concept was to create a social story (see page 25) that simulated an airport experience, alleviating some of the stress of flying for individuals with autism. The event was held at an actual airport.

Our role was to greet the families of the person who was being supported. The family would walk in the airport as if they were getting ready to depart on a trip (picking up a ticket, going through security including removing items and putting them on a conveyor belt, walking through a scanner, etc.). The family would then proceed to the gate for embarking on the plane for a ride (a short taxi on the runway).

When the families were assembled in the staging area prior to entering the plane, I saw that some of the autistic individuals were a little uptight. However, they were coping by lying on the floor, jumping, and touching things. In doing so, they were dealing very well with the new stimuli.

Their parents, in contrast, were very stressed out. They made remarks such as "I wish my son (or daughter) would not do that." I consoled the families and told them that I was so happy that they had come to the airport. I said, "Your loved one is doing a good job dealing with a new environment

in a place that they do not know very well. Look, they are keeping to themselves and not wandering around.”

I also shared my own identity as an individual with profound autism. This statement was usually met with some disbelief. I then described my issues with new situations as a child. Bombardment of too much sensory stimuli made it very difficult for me to sit still.

After hearing about my childhood experiences, the family seemed to take some comfort because I could relate to their world.

My closing remark to those families was this: “As hard as it is, you need to think of your child. Who they are and what they are doing well. Your child is doing a great job and so are you. Appreciate where they are.”