

## But the Music Speaks

Lynn Siegel

Mother of Jeremy, age 13

A voice like an angel, there's no doubt about that. He may not be the best at telling a joke, and certainly has to concentrate just to stay on subject during a conversation, but when he sings, my heart melts. I know how hard he works at everything because I have been there with him. Working as his interpreter and advocate for so long, I get very emotional when I watch my son, the son who nobody understood until he was four, bring tears to the eyes of his listeners as he sings what is in his heart.

My son was born in 1985 after a scheduled induced delivery. My pregnancy had not gone too badly until Storm Gloria swept through Connecticut causing me to begin having contractions about 2 months before I should have. After a few days in the hospital and 7 weeks on terbutaline, it all paid off when I was handed the most perfectly formed, chubby baby boy.

The first couple years of life with Jeremy were so normal it is hard to describe. Jeremy's older brother (by 19 months) was pretty much the focus of much of our lives since he was born with a condition known as Microsomia. This condition caused him to be born without a full mandible on one side and an undersized respiratory system. Aside from a slight asymmetry and frequent sinus infections, he was cruising along just fine, however we kept very close tabs on his growth and development. Which brings me back to Jeremy. At 19 months David was able to tell nurses at the hospital that he had a new "butter", but here we were at two years old still waiting for signs that Jeremy would find a language we understood.

It's funny what you choose to notice in life, and what you seem to ignore. Yes, I knew that our son was not very verbal, yet, neither were a lot of the little boys we met. Boys just seemed to be a bit slower with these things so I let it go, but now he had my attention. The town offered early speech evaluation and therapy through the school system to children who were at least two and a half. When Jeremy hit two and a half, we registered. I sat with him during his sessions interpreting much of what he said for the therapist. She noticed immediately that he had no bilabial sounds. For example, Milk was Nilk. He did not seem to like what he had to do to make those sounds, yet he was a very cooperative child and worked at pleasing everyone. Enrollment in a local nursery school worked fine when we was two, however by three he was just not fitting in. When shopping in our local market one day, I met a mom of a little boy who had been in Jeremy's class the first year of nursery school. She told me about a program that our town had known as Early Intervention. Her son had been evaluated and accepted into the program. It sounded too good to be true. One of the teachers accompanied me to Jeremy's nursery school for an observation session. After 15 minutes we had already seen Jeremy lose toys to children who knew how easy it was to take them from him and heard his name called by the teacher so many times it wasn't worth counting. "Pull him," was what she said. He started in his new class the following Monday. Once in EIP, Jeremy's strengths and weaknesses could be evaluated. Eye contact was not easy for him, but he learned that it was a necessary part of interacting with people, and so he tried it. Sometimes it was a glance, sometimes just a few words, but slowly building. At EIP, his tactile defensiveness was challenged and he learned a lot through structure.

When the program was being reviewed by the Board of Education, it was not hard to find parents like myself who came to the microphone to sing the praises of the program and especially the teachers. We had children who, because of the respect with which they were treated and the respect that they learned for each other, were honestly happy. To the teachers and advocates of EIP, I say thanks because I feel that much of what Jeremy is today is a product of the encouragement that he got from that wonderful program.

Before Jeremy left EIP to go on to Kindergarten, we had a test known as a PEDAL done. This test took months to complete and included multiple trips to the local Children's Hospital to visit neurologists, psychologists, occupational therapists, physical therapists, and many I probably have forgotten. The results left us as confused as before we had started. While he was found to have problems, specifically pragmatic speech and sensory integration, they were unable to give us a clear diagnosis. Pervasive Development Disorder and Autism were thrown at us during the final presentation but ruled out because of certain behaviors that Jeremy either exhibited or lacked. The final line of our evaluation stated

that Jeremy had a neurological impairment. They provided us with lists of what he may not be able to do, but nothing tangible. It told us nothing, but gave us what we needed to keep him covered by special services for the years that were to follow.

Those years brought many highs and lows as Jeremy matured. The PEDAL suggested that reading might be beyond Jeremy for a while, yet he was only four when he decided it was time to memorize as many words as he could. He discovered all by himself that the Sit and Spin made him feel more calm. Watching him was enough to make me nauseous, but as was explained later, his vestibular system needed that stimulation. Even after he outgrew the Sit and Spin, his dad hung a tire swing in the back yard which pretty much does the same thing. We joined a music play group when Jeremy was about four. It wasn't hard to see that he had a talent when it came to the world of music. He was probably two when he walked over to the piano and figured out how to play a couple songs. Not that long after he was figuring out the left hand. I remember being in a music store once and he asked if he could play the piano. The store owner asked that I watch him carefully because they didn't like young children banging on the keys. I told him I'd watch but I thought he'd be OK since banging on keys hurt his ears. Jeremy sat and played what he had figured out of a Minuet by Bach. The piano teacher came out of the back room and asked if we already had a teacher for him, because he would love to teach him. The problem was that Jeremy did not want to be taught. He wanted to figure it out himself. So we only lasted a short time in the music play group and have dropped in and out of piano with many patient teachers. As the school music teacher once said about him as a second grader, "Jeremy has very special ears and he can hear music in a way not everyone can". I believe that she was right.

From Kindergarten through third grade we moved along. A personal aide was provided to keep him on task and services were provided in OT, PT, and speech. By fourth grade, we decided to discontinue the use of an aide. Homework was always a problem because he basically saw no reason for it. He is a very bright boy and he learns everything very quickly. Having to "practice" at home just made him miserable, and didn't do much for those of us who had to listen to him. He was always one to have one "favorite" thing in life. Some call that an obsession, but for us it was our way to reach him. When he was into anything French, he read about France and listened to tapes on how to teach yourself to speak French. I was sure that he'd be well fed by giving everything a French name. He even sat for a haircut without being held tightly just because the barber told him he knew how to cut French haircuts. We've endured the Mortal Kombat phase, the roller coaster phase, and we now live with lots of Coca-Cola items. Karate helped him learn focus, gain strength, and become more accepting of close interaction. The Black Belt that hangs on his wall reminds us all of what can be accomplished when one tries hard enough. He's always had a friend or two who've been there for him. Not always invited into a game, he's been content just watching. That is, until the dreaded year of fifth grade.

Some teachers learn as much as they can about an incoming special education student before they reach the classroom, and others choose to see how it goes. In our case, fifth grade was our first exposure to a cold start. Having missed the PPT in the spring, the teacher had only Jeremy's records as a resource, and even those did not get read until it was too late. After only three weeks into school I was confronted by a frustrated teacher who told me my son was rude. Rude is definitely not a word that anyone would use for Jeremy. He has been carefully taught what is proper and what is not, and life to him is very literal. This behavior is what his new teacher found to be rude. When asked to look around the room and relate what he saw, he did not respond with "everyone has their books out but me", instead he saw chairs, desks, and students. His hearing was also much more acute than most and he was distracted by the sounds he heard coming through the windows just behind his desk. After 11 years of carefully guiding Jeremy through the real world without knowing exactly what was wrong with him, the time had come to revisit the diagnosis of neurological impairment and find out why he was suddenly unable to make it in the mainstream classroom. If Jeremy was to survive where he belonged academically, we had to know why he was having so much trouble socially.

We visited a psychologist with the intention of trying to rebuild a self esteem that had been shattered so quickly. By the second visit we were given a list of personality traits and asked if they sounded like Jeremy. Except for one or two traits, I could have written the list myself. The diagnosis, Asperger's Syndrome, was the best thing that had happened since the days of early intervention. After surfing the net for anything I could find on the subject, I discovered that people with Asperger's syndrome can be very successful and until recently were not diagnosed with anything but were seen as brilliant, eccentric, absent minded, socially inept, and a little awkward physically. Like Jeremy, an "Aspie" may have a wonderful vocabulary but not truly understand the nuances of language and have difficulty with language pragmatics.

Social pragmatics also tend to be weak, leading the person to appear to be walking to the beat of a "different drum". They must learn social skills much like you or I would learn to play an instrument. There is a general perception that Asperger's syndrome carries with it superior intelligence and a tendency to become very interested in and preoccupied with a particular subject. One might see the child being a bit more rigid and apprehensive about changes or about adhering to routines.

Now that we know what we are working with, we know that our lives will be a bit easier. Many of the weaknesses that have been identified can be remedied with specific types of therapy. Anxiety can be also treated both medically and through weekly visits with our psychologist. And school? Well, once we got the diagnosis, everyone stopped looking at who was not doing their job and we began working as the team we should be. The works of two people, Carruthers and Skilbeck, are presented on the net. In one article they state "Work closely with the parents and listen to them - they have already had much experience coping with the child" and "Don't judge atypical parenting as odd - it is often a coping reaction to the child's behavior rather than the cause of the behavior". We know that our son may have the tendency to disrupt the class due to lack of ability to focus, confusion, literal interpretation of instructions, inability to read social rules and cues, overloading of the 'senses' (too much noise, visual stimulation or physical stimulation), inability to explain feelings plus other factors. His biggest desire in life is to fit in. He is very open to behavior modification providing that clear and simple instructions are given.

We now prepare to move into the middle school years. The challenges alone are unnerving, but I think he'll do fine. I've learned that I must insist more vehemently that teachers be more prepared for the arrival of a child with such special needs. Since Jeremy's started playing guitar, he has a new way to express his wonderful gift of music. I am not the only one who marvels at his strength of character or the sincerity that is heard when he shares a song. He leaves everyone who meets him with a warm feeling that can only be shared by someone who never masks their feelings. With Jeremy, his smile is a genuine display of the wonderful person that he is.