

Matty's Story

It was no surprise to me on one rainy late June morning in 2010 that my only son Matthew of 21 months was diagnosed with autism by his pediatric neurologist. I remember specifically after she had observed Matthew, she asked me and my husband what did we want from our visit with her. I told her "tell us that Matty is just a little behind and" At that point she stopped me mid-sentence, shook her head. "We will be diagnosing Matthew with autism today". My first thoughts to her words by which I exclaimed were "I suspected it but did not want it to be true." She then began to provide us with places to contact to give Matty the help he needed. One place was a learning resource center called "The Uncommon Thread" located in Stirling NJ. "Stirling?" I questioned, I did not even know Stirling existed never mind where it was. However, soon I would get to know the area well as I proceed with my story.

Not knowing the rocky and unsteady road ahead, I first proceeded to contact Early Intervention. Due to the length of time that passed to get Matty his services, I proceeded to contact The Uncommon Thread. They quickly responded back to me for an appointment to meet. The center was an hour away from our home. I thought what long ride. This would be impossible to travel every day. Upon our first visit, I remember fair and blonde haired Matty standing there with his big blue eyes that showed no contact with anyone nor did he say a word for he had no speech. Although there were many toys there, he was not able to play with any of them appropriately. He was just interested in ripping the paper flowers off the windows. Emily asked many questions as Matty just stood there lost, without emotion, just wander around. Toward the end of our visit Matty had one of his usual meltdowns.

Emily had quickly set up a schedule for August to begin services with The Uncommon Thread at the daycare center where Matty was currently attending. There, Melanie, one of the center's instructors, began to work with Matty. Within a quick week's time Matty began to use a fork and spoon to feed himself. Even by 23 months, my son was not feeding himself due to his tactile defensiveness. In addition, he would only eat soft foods. Typical toddler snacks, such as cereal and goldfish, were never touched. Also he insisted on only drinking from a bottle. Matty also had a difficult time sitting with the other children and continuously wandered around the room especially during mealtimes. He never joined in circle-time. Melanie patiently worked with Matty and he gradually was able to sit for longer and longer periods of time. These were just small accomplishments, but were big to our family, for we almost believed these were accomplishments that would never happen.

The month passed by fast and September came. Matty's services with Early Intervention soon began. At the same time Matty continued with his services at The Uncommon Thread, where he was required to go to the center at least two days a week to continue with his program there. Although I had much pressure by people not to send Matty for center base learning with ABA therapy, I sent him anyway. I could not see to stop what had the biggest impact on Matty's progress and it was also somewhere that his doctor recommended. I was more inclined to listen to the advice of a doctor than other people that did not have experience with autism or even a therapist that did have experience with autism. These people discouraged and even scared me about ABA therapy. These people's point of view was that it is better to keep autistic children with other typical children to learn the habits of typical children. Looking back, that stance did not work for Matty. Autistic children do not learn that way. The decision I made to

continue with the center based ABA course was the best for us. Early Intervention was just not as effective as The Uncommon Thread and its floor play approach also seemed to create more anxiety for Matty. Where Early Intervention from late August through late November was still just beginning to understand Matty and exactly what to do for his disabilities, it seemed the Uncommon Thread knew exactly where to begin to making changes with Matty's behavior immediately. I read constantly about autism and every source tells you that ABA therapy is the most important to treating autism, especially when diagnosed earlier than 2 years old. . Please keep in mind that I pushed so hard to get Matty diagnosed early when we saw his behaviors glaring at us as early as when he was 18 months old. I am very grateful that the Uncommon Thread acted so quickly.

In late September I had lost my job, on my son's second birthday to be exact. I had started a new job in May and did not have the most understanding managers when my son was first diagnosed. My immediate manager did not sympathize to my situation and became quite aggressive while I scheduled various meetings with Early Intervention during my lunch time. My first reaction to this news was a relief to know that I could have the time to concentrate on my son and to solve this "autism" thing, although this would create a huge financial burden. At this time, I made the decision to bring to the center from 8am to 12pm Monday through Friday. He would then continue his services at the daycare with Early Intervention from 3pm- 5pm each day, to keep him with typical children. I also made the decision to sit with the early intervention therapists at the daycare to learn how to work and interact with Matty. I would think to myself during these sessions, "Why Matty?" All the children around Matty were typical children. The parents here have no problems to know their child and know how they learn. Anyone can just show them what to do. They were all able to imitate actions and words. They spoke. Matty did not. They understood. Matty did not.

Matty's favorite past time at daycare (which was all the time) was to carry two puzzle pieces, and when that phase ended was to carry two trucks around. He often turned these trucks over and would just fixate on the truck's wheels. He would just spin the wheels until someone stopped him. When anyone interrupted this pervasive behavior he became aggressive, throw temper tantrums, and bit. He bit 3 children when they took his toys away and he bit the teaching assistant when she changed his diaper. In addition, he did not nap on the schedule with the other children. He insisted to wander around. The director of the daycare forced us with an option to keep Matty at the daycare all day or he would need to leave the daycare. She said she did not have the staff to walk and watch Matty during naptime and she felt that we could work with Matty on our own. She had not infringed on the disability act in anyway, but did not give me a choice. I could not stop Matty's progress at The Uncommon Thread.

Late November Matty began his services at the Uncommon Thread full time from 8am – 4pm. At the same time I began parent training with Melanie. At this point Matty's progress had picked up and his improved behaviors became very obvious, so much that no one could deny his progress. It is now March and Matty has great eye contact, he responds to his name, he is able to eat independently, he drinks from a sippy cup, and he is able to sit in circle-time for about a ½ hour each time. He actually enjoys circle-time. He can do the hand movements to "Hurry, Hurry, and Drive the Fire Truck". He can throw a ball, walk up and down stairs, and is the biggest babbler at the Uncommon Thread. He even said "dad- dee" and "mom" a few times. I cannot explain the emotions as a parent to hear my son's

voice, something I thought I never would hear. My heart just melted. Like I said, it was a rough road, and we have much yet to travel. But we found the right path to take. The parent training meetings are very valuable to me. They have taught me about my son and given me new ways to maintain my son's progress. Most people take for granted teaching their children life skills, however these opportunities that I am grateful for. For me there is no bigger accomplishment than to teach him just one life skill. It beats graduating from a reputable college or even passing the CPA exam (which everyone always compliments me about). I could pass all those accomplishments and say that teaching my autistic son just one skill is my biggest accomplishment.

There should be more support and centers like The Uncommon Thread available to parents. Each day I drive 4hrs. I drive one hour there and one hour back home. Then there is the return trip to pick him up. There have been times that other parents stop me to comment on Matty when they compare their children to him, but I am getting accustomed to it. From the times dining at restaurants when Matty was still drinking a bottle to the time a parent compared her daughter that was exactly 2 weeks older than Matty, and asked if he was in a preschool program. Melanie always had something to say to make me realized that my family is one of the lucky ones to helping Matty along. I don't think anyone can understand until you live with autism. The life from what I knew is not over. It is just very different. I hope I was able to provide you with just a taste of my experience and see my point of view to understand.